Self-Neglect in Older Adults

A Global, Evidence-Based Resource for Nurses and Other Health Care Providers

Mary Rose Day
Geraldine McCarthy
Joyce J. Fitzpatrick
Editors
Self-Neglect in Older Adults
Mary Rose Day, DN, MA, PHN, RPHN, RM, RGN, is a nurse consultant in public health nursing and older adult care. Prior to this, she was a lecturer at the Catherine McAuley School of Nursing and Midwifery, University College Cork (UCC), Cork, Ireland. She has also held a range of nursing and management posts in acute care, long-term care, and community settings. She has DN, MA, and BSc degrees in nursing from UCC; a certificate in teaching from Harvard University; and a diploma in management from the Royal College of Surgeons, Dublin, Ireland. She has authored several journal articles, book chapters, and reports, and she continually contributes to nursing/social care and medical publications. Dr. Day has contributed to conferences and symposia on older people and community nursing nationally and internationally. She is a member of the Institute of Community Health Nursing and coordinated the Ageing Research Cluster of the Institute for Social Sciences in the 21st Century from April 2014 to January 2015 and is a committee member of the All Ireland Gerontological Nurses Association.

Geraldine McCarthy, PhD, MSN, MEd, RNT, RGN, Fellow RCSI, is emeritus professor at the Catherine McAuley School of Nursing and Midwifery, University County Cork (UCC), Cork, Ireland, and chair of the South/South West Hospital Group, which comprises nine hospitals in the South of Ireland. Prior to this, she held positions as founding professor and dean of the Nursing and Midwifery School at UCC, and head of the College of Medicine and Health, providing strategic leadership in research and education programs in medicine, dentistry, therapies, pharmacy, and nursing and midwifery. Dr. McCarthy holds an MEd degree from Trinity College, Dublin, and MSN and PhD degrees in nursing from Case Western Reserve University, Cleveland, Ohio. She has held a number of health care posts in Ireland, the United Kingdom, the United States, and Canada, and has been a member of a number of national and international bodies, including the Fulbright Commission. She has been an editor/author of a number of books and continually contributes to nursing publications.

Joyce J. Fitzpatrick, PhD, MBA, RN, FAAN, FNAP, is Elizabeth Brooks Ford Professor of Nursing, Frances Payne Bolton School of Nursing, Case Western Reserve University (CWRU) in Cleveland, Ohio, where she was dean from 1982 through 1997. She is also an adjunct professor, Department of Geriatrics, Ichan School of Medicine, Mount Sinai Hospital, New York, New York. With more than 300 publications, Dr. Fitzpatrick’s work is widely published in nursing and health care literature, including more than 80 authored/edited books. She served as a coeditor of the Annual Review of Nursing Research series, volumes 1 to 26, and she currently edits the journals Applied Nursing Research, Archives of Psychiatric Nursing, and Nursing Education Perspectives, the official journal of the National League for Nursing.
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CONTRIBUTORS

Sharon Abada, BS  Research Assistant, School of Public Health, University of Texas, Houston, Texas

Julie Bach, PhD, MSG, MSW, LCSW  Assistant Professor, Coordinator of the Gerontology Certificate, Graduate School of Social Work, Dominican University, River Forest, Illinois

Toya Band-Winterstein, PhD  Senior Lecturer and Fellow, Center for Research and Study of Aging, Department of Gerontology, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel

Eleanor Bantry White, DPhil (Oxon), MPhil (Oxon), MSW (NUI), BSocSc (NUI), PCTLHE (NUI)  College Lecturer in Social Work, School of Applied Social Studies, University College Cork, Cork, Ireland

Suzy Braye, BA, CQSW, MSc  Independent Consultant and Emerita Professor of Social Work, School of Education and Social Work, University of Sussex, Brighton, United Kingdom

Jason Burnett, PhD  Assistant Professor, Houston-McGovern Medical School, University of Texas and Texas Elder Abuse and Mistreatment Institute (TEAM), Houston, Texas

Leslie E. Clark, BSN  Research Nurse, Houston-McGovern Medical School, University of Texas and Texas Elder Abuse and Mistreatment Institute (TEAM), Houston, Texas

Barbara Cohen, PhD, JD, RN  Professor, Health Services Management, Berkeley College, New York, New York; Section Instructor, Nursing Simmons, Simmons College, Boston, Massachusetts

Mary Rose Day, DN, MA, RPHN, RM, RGN  Nurse Consultant/College Lecturer, Catherine McAuley School of Nursing and Midwifery, University College Cork, Cork, Ireland

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Joan McCarthy, PhD, MA, BA  Lecturer, Healthcare Ethics, Catherine McAuley School of Nursing and Midwifery, University College Cork, Cork, Ireland

Graham J. McDougall, PhD, RN, FAAN, FGSA  Martha Saxon Endowed Chair and Professor, Capstone College of Nursing, University of Alabama, Tuscaloosa, Alabama

Kelly Melekis, PhD, MSW  Assistant Professor, Department of Social Work, Skidmore College, Saratoga Springs, New York

Whitney L. Mills, PhD  Assistant Professor, Department of Medicine—Section of Health Services Research, Baylor College of Medicine; Investigator, Center for Quality, Effectiveness, and Safety, Michael E. DeBakey Veterans Affairs Medical Center, Houston, Texas

Helen Mulcahy, DN, Msc (Research), RGN, RM, RPHN  Catherine McAuley School of Nursing and Midwifery, University College Cork, Cork, Ireland

Aanand D. Naik, MD  Associate Professor, Department of Medicine—Section of Health Services Research, Baylor College of Medicine; Investigator, Center for Quality, Effectiveness, and Safety, Michael E. DeBakey Veterans Affairs Medical Center, Houston, Texas

Sigal Naim, MA  Doctoral Student, Department of Communication Studies, Ben Gurion University of the Negev, Be’er-Sheva, Israel; Lecturer, Department of Human Services, Max Stern Ye’ezreel Valley Academic College, Jezreel, Israel

James G. O’Brien, MD, FRCPI  Professor Emeritus, Geriatrics Institute Scholar, University of Louisville, Louisville, Kentucky

Kieran A. O’Connor, MSc, MB, FRCPI  Consultant Physician in Geriatric Medicine, Mercy University Hospital, Cork, Ireland

Joan O’Leary

David Orr, PhD, MSc  Lecturer in Social Work, School of Education and Social Work, University of Sussex, Brighton, United Kingdom

Kathleen Pace-Murphy, PhD  Assistant Professor in the Division of Geriatric and Palliative Medicine, Houston–McGovern Medical School, University of Texas, Houston, Texas; Medical and Regulatory Affairs, Novartis Pharmaceutical Corporation, East Hanover, New Jersey

Kimberlee Parker, MPH  Research Assistant, School of Public Health, University of Texas, Houston, Texas

1Pseudonym.
Michael Preston-Shoot, PhD, CQSW, PGDip SW, PGDip Psychot  Professor of Social Work and Executive Dean, Faculty of Health and Social Sciences, University of Bedfordshire, Luton, United Kingdom

Katharine Slover, MNM  Director of Community Outreach Services, Marillac St. Vincent Family Services, Chicago, Illinois

John Snowden, MD, MPhil, FRANZCP, FRCPsych, FRACP  Clinical Professor of Psychiatry, Sydney Medical School, Old Age Psychiatrist, Sydney Local Health District, Concord Hospital, New South Wales, Australia

Marietta P. Stanton, PhD, RN, FAAN  Professor of Nursing, Capstone College of Nursing, University of Alabama, Tuscaloosa, Alabama

Bronwen Williams, MSc, BSc, PGCHE (NMC Teacher), RMN  Mental Health Training Team Leader, 2gether NHS Foundation Trust, Collingwood House, Collingwood House Education and Training Centre, Horton Road, Gloucester, Gloucestershire, United Kingdom

Sheila R. Woody, PhD, RPsych  Professor and Associate Head, Graduate Affairs/Professor of Psychology, Department of Psychology, University of British Columbia, Vancouver, Canada
One of the greatest success stories of the 20th century is the extension of human life expectancy. At the turn of the previous century, the average life expectancy was about 47 years of age. Today, that number is much closer to 80 years of age. Certainly, there is some variation around the globe, but, in general, owing to extraordinary strides in public health, nutrition, and health care, we can expect to live long and productive lives. However, with the advent of longer lives comes the responsibility for societies to ensure that their members live longer lives of high quality. This book underscores all the ways in which longer lives can, in fact, become entangled with a number of serious and potentially fatal situations and conditions, such as self-neglect. Congratulations to Drs. Day, McCarthy, and Fitzpatrick for taking on this momentous project, which will help provide evidence-based guidance for all of us who are struggling with enhancing the quality of life and care for older individuals in the context of self-neglect. It makes great sense that nurses have taken a lead with this book. Although its content is certainly not specific solely to the practice of nursing, we are all reminded that 90% or more of health care provided globally is provided by nurses.

When we think about the continuum of nursing practice from home care to critical care to hospice care, it is evident that the profession is well positioned to assess and intervene when there is evidence of self-neglect. The process of ensuring that effective, person-centered interventions are in place to reverse and ameliorate the tragic sequelae that go with this phenomenon is crucial. My career has been dedicated to the eradication of elder mistreatment of all types, and certainly self-neglect is a leading subtype within the broader continuum of elder mistreatment. I am so excited about the momentum building in the field, particularly the contributions of nursing and of this important textbook. This book is unique. It is the first global, evidence-based resource that targets self-neglect and the important evidence-based interventions available to help older people in need.

All of us are aware that older people have the right to self-determination and, if they make a conscious decision to be in the state of self-neglect, that is their right; none of us should use our power or paternalism to intervene in ways we would never intervene with younger individuals. I am reminded of an older patient I cared for who lived under a bridge—that was his home. When he turned 65, it was suggested that adult protective services be called in to have him institutionalized, which, in fact,
happened. He protested and died shortly after. The lesson is that there is no one approach to care for those who are in a state of self-neglect, which is made clear in the pages that follow.

This book is a road map for all clinicians and health care providers who come upon the complex and often heartbreaking phenomenon of self-neglect. There is hope; there is action; and this textbook provides a guiding light.

Terry Fulmer, PhD, RN, FAAN
President
The John A. Hartford Foundation
New York, New York
Self-neglect is a global phenomenon and a serious public health issue. It is a poorly defined concept, which leads to challenges in identifying self-neglecting individuals as well as practical challenges in implementing interventions among health professionals, family members, and friends. Self-neglect can be intentional or unintentional and the difference depends on the individual's mental capacity.

This book is the first to deal exclusively with the subject of self-neglect. It is divided into six sections: Practical and Theoretical Perspectives, Issues Concerning the Self-Neglecting Individual, The Service Responds, Research Evidence, Assessment and Measurement of Self-Neglect, and Ethical and Educational Issues. The authors are from six countries: Australia, Canada, Israel, Ireland, the United Kingdom, and the United States. Many chapters include case studies or vignettes detailing what it is like to live with individuals who self-neglect or to work with them as health care professionals. Each chapter ends with a section on implications for practice and research.

Chapter 1 begins with a daughter profiling the progression of her mother's condition over time to self-neglect from personal, social, and environmental perspectives. The burden and challenges placed on all family members and the difficulty in trying to intervene and to obtain help from social and health care professionals are detailed. The frustration felt by family members who perceive that help is necessary while the mother refuses help is explained. In Chapter 2, Day describes self-neglect as the person's inability or unwillingness to provide goods and services necessary to care for life's needs. She asserts that there is no common understanding of the term and no overarching self-neglect theory and suggests that continued research and theory development are required so that professionals have a common understanding of the phenomenon.

In Section II, the singular or multiple issues that either lead to or are a consequence of self-neglect are presented. Cohen (Chapter 3) informs us of the mental health issues that may be present. McDougall and Stanton (Chapter 4) explain how delirium may sometimes be attributed to self-neglect without an understanding of the causes of the delirium itself and the relationship between delirium and impaired cognitive functioning. Hoarding is profiled in three chapters. Luu and Woody (Chapter 5) describe features, assessment, and intervention strategies that may be used in hoarding situations. Williams (Chapter 6) maintains that animal hoarding
is poorly understood and underrecognized. This type of hoarding creates a risk to adults and the animals themselves and to those who try to deal with the issue. Devitt and Hanlon (Chapter 7) describe neglect issues found in farm animals and farmers themselves. The authors explore the relationship between human problems and farm animal neglect.

Snowdon and Halliday (Chapter 8) write about environmental neglect or the personal behavior and failure to protect one's environment. The authors discuss how best to assess and intervene in such cases and focus attention on the rights of individuals, their capacity to attend to their own welfare, and the rights of others in their environment. This section of the book ends with Lee writing on self-neglect and decision making (Chapter 9). In this chapter, the results of 19 studies are described. Included is a section on assessment of decision-making capacity and a case study in which the client is referred for capacity evaluation.

Section III details the response by health and social care professionals and agencies. It discusses self-neglect as a health care and environmental issue and outlines the fact that self-neglect is often brought to the attention of health care professionals by members of the public. However, self-neglect can be identified initially in acute care settings. O’Connor (Chapter 10) explains the paucity of research evidence for managing self-neglect of individuals who often present with complex medical, social, and psychological conditions. Case vignettes in acute hospital settings illustrate the types of issues encountered. Gomes and O’Brien present a medical perspective on self-neglect (Chapter 11). They address mental health, cognition, and social issues within the medical cases encountered. They present a case study and note that medical care has become so specialized that the services have been diversified. As a result, difficulties and confusion arise for individuals who need a more comprehensive interdisciplinary program for assessment and continuing management. In Chapter 12, Johnson reports on an investigation of home care nurses’ perceptions of elder self-neglect in the United States. Facilitators, such as engaging family members on the health care team, specific focused education, protecting client choice, and lack of resources, are discussed. In a related study, Mulcahy and colleagues (Chapter 13) explore the perceptions of Irish public health nurses, community nurses, and social workers regarding self-neglect. Findings reveal the complexity of and personal responses to self-neglect, and challenges in managing cases. Recommendations include knowing and understanding the client, relationship-building skills, a multidisciplinary team approach, support, and training.

Lessons learned from England are profiled by Braye and colleagues (Chapter 14). These researchers draw on two studies conducted in the English context, including serious case reviews and interviews with managers, practitioners, and service users. They identify approaches that produced positive outcomes. Relationships built around the lived experience of self-neglect, together with the integration of knowledge and professional judgment regarding risk taking, are recommended as best practice.

In Chapter 15, Band-Winterstein and colleagues explore the meaning attributed to elder self-neglect by social workers in Israel using in-depth semistructured interviews. They report on intervention strategies developed by social workers that recognize individual autonomy without compromising client safety. Dowling and Slover (Chapter 16) explain how the city of Chicago addresses the issue of self-neglect among seniors. These authors describe a city-wide approach to addressing the issue.
through the Intensive Case Advocacy and Support Program (ICAS), outlining the historical development of the program together with research on outcomes.

In Section IV, three chapters profile research evidence and delineate many lessons for health care professionals. These chapters are different in relation to evidence for practice, and they profile perspectives from three different countries and from service providers. Melekis (Chapter 17) describes research that used a mixed-methods design to investigate service providers’ perspective on their experience regarding existing resources and service needs in Vermont. Study findings point to the need for innovative, interprofessional, and interagency community responses addressing the challenging experiences, particularly as there is no formal accepted definition of self-neglect in Vermont. Chapter 18 is focused on research conducted by Burnett and colleagues regarding medication use and polypharmacy and the effects on self-neglect. Using a case study that profiles multiple comorbidities and polypharmacy, the authors conclude that a comprehensive review of medications is necessary in cases of individuals deemed as self-neglecting. In Chapter 19, McCann reports on research that was inspired through his student placement on a social care degree program in a community organization in Ireland. He studied health and social care professionals’ perspectives on self-neglect and found, among other things, that self-neglect was considered with respect to prevalence and contributing factors, referral pathways and service interventions, and professional challenges and outcomes.

In Section V, methods of collecting and managing data on neglect and associated factors are presented. These deal with the construction of instruments for use by health and social care professionals and researchers to identify, measure, and potentially respond to self-neglect. In Chapter 20, Iris describes the development of the Short-Form Elder Self-Neglect Assessment Instrument. This includes 12 indicators related to physical and psychosocial aspects and 13 relating to environmental and personal living conditions. The findings of research based on the use of the instruments by practitioners are also presented. In Chapter 21, Mills and Naik contend that few tools exist to help health and social care professionals screen for everyday competence. They describe a screening tool, titled Making and Executing Decisions for Safe and Independent Living (MEDSAIL), which they developed. Furthermore, they review the literature on assessment and competence in self-neglect and describe the development, validation, and refinement of MEDSAIL. They also provide case vignettes demonstrating how the tool can be used in practice. In Chapter 22, Day and McCarthy describe the development and evaluation of a self-neglect measurement instrument (SN-37). Generation of the item pool, validity and reliability, and factor analysis are presented. Environment, social networks, emotional and behavioral liability, health avoidance, and self-determination are the factors that emerged from the factor analysis. Overall, these three chapters provide options for practitioners regarding the use of instruments for screening purposes. Chapter 22 also provides information for researchers embarking on studies of self-neglect.

Section VI comprises two chapters. Bantry White and Bach (Chapter 23) outline the pedagogical demands placed on professional educators by the complex nature of self-neglect. Specific attention is paid to reflective models of teaching and learning that center on active experiential approaches. Day and McCarthy (Chapter 24) apply an ethical decision-making tool to a self-neglecting case. This provides a step-by-step framework of actions and responsibilities to help critically reflect on and respond to an ethically challenging self-neglecting individual.
In Chapter 25, the authors summarize the major components of the text. In addition, they draw conclusions regarding implications for practice and research. We expect that all readers will find this work informative and that many new clinical and organizational changes and initiatives and research projects will emerge as a result of this publication.

Mary Rose Day
Geraldine McCarthy
Joyce J. Fitzpatrick
CHAPTER 17

SELF-NEGLECT: A STATEWIDE ASSESSMENT IN VERMONT

Kelly Melekis

There is no unified, comprehensive definition for self-neglect in the United States. In an effort to enhance understanding and establish a coordinated community response to the issue of self-neglect in the state of Vermont, a statewide mixed-methods study was conducted. This study highlights the importance of definitional clarity to accurately assess the scope and severity of self-neglect, strategies for addressing the challenges to serving adults who are self-neglecting, such as refusal/lack of desire for services, inadequate access to and funding of services, cognitive and mental health issues, limited family and community connectivity, and lack of clarity on self-neglect/capacity determination. The study findings point to the need for innovative interprofessional and interagency collaboration to ensure a coordinated community response through a combination of expanding understanding of self-neglect, addressing systemic challenges, and implementing strategies to enhance the response to self-neglect.

Despite being the most commonly reported form of elder abuse and neglect in the United States, there is no unified, comprehensive definition for the concept of self-neglect. Medical and mental health practitioners have attempted to define self-neglect using specific diagnoses, including Diogenes syndrome and hoarding disorder, which is now included in the Diagnostic and Statistical Manual of Mental Disorders (5th ed., DSM-5; American Psychiatric Association, 2013), but ultimately have failed to achieve consensus or to incorporate the wide array of individual, social, and environmental factors often involved in self-neglect cases in their definition (Brandl et al., 2006; Kutame, 2007). Definitions are often laden with judgment-based principles and conceptualized solely through cultural and societal standards for self-care (Gibbons, Lauder, & Ludwick, 2006; Iris, Ridings, & Conrad, 2010). Gibbons et al. (2006) defined self-neglect as “the inability (intentional or nonintentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecter and perhaps even to their community” (p. 16). The definitions of self-neglect are typically characterized as the refusal or failure of an older adult to provide themselves with basic necessities such as food, water, shelter, medication, or basic hygiene. Self-neglect accounts for the largest percentage of reports to adult protective services (APS). Fulmer (2008) and O’Brien (2011) estimated that there are over 1 million cases per year in the United States.
Generally considered a geriatric phenomenon, the concept of self-neglect is rarely applied to individuals younger than the age of 60 in the United States. As a geriatric phenomenon, self-neglect is generally subsumed within the broad category of elder abuse and neglect. There are many arguments that self-neglect is not a form of abuse and “the immediate challenge with this classification is that with self-neglect there is no perpetrator and the classification does not fit the legal perpetrator/victim paradigm” (Vermont Department of Disabilities, Aging, and Independent Living [DAIL] Self-Neglect Task Force, 2012, p. 4).

Although there are no federal laws, rules, or regulations regarding the investigation and management of self-neglect reports, the 2006 amendments to the Older Americans Act (OAA) of 1965 provide the following definition 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, or general safety, or (c) managing one’s own financial affairs (p. 10).

In the United States, it is estimated that 13 states (including Vermont) do not explicitly include self-neglect within elder abuse and neglect statutes (Brandl et al., 2006). For those that do, definitions vary widely, including and excluding various clarifying elements such as the mental or physical capacity of the person considered to be self-neglecting, the presence and/or actions of a caregiver, and the severity of the impact of the self-neglect (Kutame, 2007; Rathborn-McCuan & Fabian, 1992). The use of these clarifiers not only speaks volumes to the complexity of defining self-neglect but also provides an important level of consistency for local service providers.

In Vermont, state statutes do not address the issue of self-neglect. Vermont State Statute, Title 33, Chapter 69, addresses reports of abuse, neglect, and exploitation of vulnerable adults, but does not include self-neglect. In 1996, a Memorandum from the Commissioner of Vermont’s Department of Disabilities, Aging and Independent Living (DAIL) mandated that referrals for cases of suspected self-neglect among those older than 60 be directed to the Area Agencies on Aging (AAA) and those younger than 60 be directed to the APS (Flood, 1996). It was also directed that the APS would not provide case management, but would make referrals for such services. This position was restated in a 2005 communication from DAIL commissioner Patrick Flood to State Senator Richard Sears. It stated: “For persons over 60, that case management properly belonged to the AAA, which were already providing much of the case management. Unfortunately, there was no obvious party to provide those services for adults with physical disabilities younger than 60, so when those cases arise, APS is still directly involved” (as cited by DAIL Self-Neglect Task Force, 2012, p. 6). A review of state definitions and jurisdictions for self-neglect indicates that Vermont is one of only four states where self-neglect does not legally fall under the purview of the state’s APS system.

In 2012, Vermont convened the Self-Neglect Task Force to address the problem of effectively helping people identified as self-neglecting. The task force expressed unanimous support for not recommending statutory requirements due to the sentiment that those engaging in self-neglect are in need of human services and support, not investigatory or legal approaches. Establishing an effective response to self-neglect requires an understanding of how the concept is defined. The Self-Neglect Task
Force (2012) adopted the OAA definition noted previously, with the addition of a clarifier: This definition excludes people who make a conscious and voluntary choice not to provide for certain basic needs as a matter of lifestyle, personal preference, or religious belief and who understand the consequences of their decision. In an effort to enhance understanding and establish a coordinated community response to the issue of self-neglect in Vermont, DAIL conducted a statewide mixed-methods study (Melekis, 2014a).

**METHODS**

The mixed-methods study of self-neglect reported in this chapter was part of a larger statewide assessment of the needs of and community resources for older adults and their caregivers in Vermont (Melekis, 2014b). Using a concurrent approach, a nonexperimental survey was used to investigate the service providers’ perspectives, and key stakeholder interviews were utilized to gather in-depth information on the experiences of the respondents regarding existing resources and needs in disability and aging services.

Strategies for sampling and data collection were discussed in collaboration with the administrators and the staff from the DAIL Division of Disabilities and Aging Services (DDAS) and the five AAAs. Decisions were based on appropriateness, adequacy, and access, with particular attention paid to the costs and benefits of different strategies for various stakeholders. Both the survey instrument and key stakeholder interview protocols were designed by the researchers in conjunction with DAIL DDAS staff and AAA directors. In addition to the existing measures related to the community/state assessment of needs and resources among the older adults and self-neglect assessment, prior tools utilized by DAIL and the AAA were reviewed for item inclusion as appropriate.

Providers and key stakeholders were recruited via purposive and snowball sampling, with DAIL and each AAA recommending local providers and stakeholders for study inclusion. The survey was distributed via direct email that included a weblink to the survey for providers to complete and share with colleagues. A survey weblink was also included on several provider websites and social media tools, such as Facebook pages, and distributed via provider and partner lists at several agencies. For providers who were unable or did not wish to complete an online survey, there was an option to receive a paper version. The service provider survey was distributed for 1 month (mid-September to mid-October, 2013), with reminder emails sent weekly to encourage completion.

Descriptive statistics were utilized to summarize the data and analyze respondents’ perspectives on the scope and severity of self-neglect cases, warning signs and symptoms, reporting processes, and recommendations for a community-based response.

The qualitative data analysis (QDA) software program Atlas.ti was utilized to assist with data management and analysis of the interviews. All interviews were transcribed verbatim by one transcriptionist. The researcher reviewed all transcriptions by simultaneously listening to the recording and reading the transcript. Errors in transcription or unclear words and passages were edited and clarified where necessary. One of the first steps in the analysis involved a close and careful reading of the transcripts “using filters and analytic axes to organize the process as it unfolds” (Padgett, 2008, p. 140). Repeated readings allowed for a search of meaning units.
that were descriptively labeled. Initially, the data were analyzed using an inductive approach, so that possible categories and themes could emerge from the data (Lincoln & Guba, 1985). The coding process occurred like a funnel, starting at a descriptive level and moving upward, reflecting greater selectivity and synthesis (Charmaz, 2006). The coding strategy utilized in this study followed Saldaña's first and second cycle coding, where the first cycle involved an open coding process and the second cycle was more focused, similar to the coding approach used in grounded theory (Charmaz, 2006). First-cycle coding methods included the use of descriptive, structural, and simultaneous coding (Saldaña, 2009). Descriptive coding was used to summarize the primary topic of excerpts. The descriptive codes and subcodes were helpful in categorizing and laying the groundwork for second-cycle coding and thematic analysis (Miles & Huberman, 1994; Saldaña, 2009). During the second cycle of coding, the goal was “to develop a sense of categorical, thematic, conceptual, and/or theoretical organization” from first-cycle codes (Saldaña, 2009, p. 149). Where appropriate, codes and subcodes were clarified and revised, similar codes were merged, and more advanced, detailed structural coding was applied. The primary method used during this time was focused coding to develop the major themes from the data (Saldaña, 2009). Coding and categorization are an iterative process used to identify patterns, themes, and interactions in the data (Patton, 2002). In order to reflect the voice of the participants, quotes are presented verbatim in the results and represented in italics.

FINDINGS

There were 137 survey respondents representing all areas of the state with a proportional distribution. For the stakeholder interviews, 10 to 15 individuals in each of the five areas were recruited for participation in a 1-hour interview in person or by phone. A total of 36 stakeholders throughout the state were interviewed, out of 68 who were invited to participate. Study participants represent entities conducting programs that receive assistance under the OAA, those conducting other federal programs for older individuals, as well as programs that serve a much broader community population, of which older adults and caregivers are included. Providers/programs represented include AAA, senior centers, health care and home health service providers, mental health practitioners, housing and residential services, community meals programs, and volunteer and employment programs.

Defining Self-Neglect

Although Vermont’s definition of self-neglect includes adults of all ages, this study reveals provider experiences and perspectives that parallel the national distinction of self-neglect as a geriatric phenomenon. Indeed, survey and interview responses indicate that the term self-neglect is generally not utilized for those younger than 60, but that the same characteristics or behaviors are categorized under the realm of another descriptor. As one participant noted, “those people show up . . . they’re not labeled as self-neglect, they’re labeled as having developmental issues, or mental health issues . . . substance abuse issues.” Further, when asked to distinguish between the needs of and resources for those older and younger than 60, there were fewer responses regarding those younger than 60. Some respondents indicated that
they “don’t have the experience with [the] younger-than-60 population to make an informed response,” whereas others identified that there are “no specific services for [the] under 60 population, [they] fall into a crack.”

It is important to note that several study participants noted the role of economics in our identification and categorization of self-neglect. As one respondent noted, “wealth can buy you a lot of leeway, so people who are self-neglecting who are really wealthy are just seen as eccentric.” This raises some important questions about the role of poverty in self-neglect identification and intervention.

**Scope and Severity**

Although one of the study goals was to assess the scope of self-neglect in Vermont, it was extremely difficult to accurately estimate the number of individuals who could be described as self-neglecting, particularly those younger than the age of 60. Survey responses indicate that each year providers were involved in an average of 23 cases involving older adults (60+) and 10 cases involving adults younger than 60. However, estimates of the number of such cases ranged from 0 to 300, and there was no way of assessing how many of the cases are duplicative across sites and providers. Varying estimates and missing data make this data difficult to interpret.

**Warning Signs and Symptoms**

Respondents identified the common warning signs and symptoms in suspected cases of self-neglect for those younger than 60 and for those 60 and older. Warning signs and symptoms included inadequate nutrition, hygiene, home appliances and utilities, living conditions, management of financial affairs, utilization of necessary medical care, inadequate utilization of other services to maintain health and safety. In addition, inappropriate clothing, abuse, neglect, or exploitation by others were considered warning signs.

In addition, the majority of the respondents (59%) either strongly agreed (13%) or agreed (46%) that individuals identified as self-neglecting usually have underlying, untreated mental health problems, or cognitive impairment. Although it can be helpful to acknowledge the potential causes, common warning signs and symptoms, one participant clearly articulates the importance of individualized assessment and response: “Although most self-neglect cases have common denominators, each case is unique to the individual involved and there cannot be a blanket formula to address the needs of these unique folks who come to our attention.”

**Challenges in Responding to Self-Neglect**

In addition to myriad challenges in their individual work with persons identified as self-neglecting, such as lack of desire for/refusal of services and cognitive/mental health issues, providers noted a number of systemic challenges, including (a) capacity determination and assessment, (b) reporting and referral process, and (c) the time-intensive nature of response to self-neglect in Vermont.

**Capacity Determination and Assessment**

The vast majority of the respondents (90%) strongly agreed (41%) or agreed (49%) self-neglect cases inherently present ethical challenges/dilemmas. These center mostly
around the issue of capacity determination, with participants articulating a range of concerns on both ends of the spectrum such as “we too often use the right to self-determination to excuse our doing nothing” and “no one seems to remember the parts of that language that says ‘due to diminished capacity.’” Indeed, the multilayered nature of capacity and the significant implications of capacity determination demand adequate resources for assessment.

Approximately 68% of respondents indicated that they (or someone else in their organization) conducted an assessment of self-neglect, which appeared to be happening in a myriad of ways, frequently on an informal, observational basis. Respondents included no references to formal or standardized measures and no standard measures were identified as being used across providers/sites in the state. It was repeatedly acknowledged that an essential part of the assessment was an opportunity to observe the individual in his or her home environment. One participant noted, “We do not have a formal system to assess self-neglect, however, I am in their homes on a regular basis and we can see [the warning signs]. I would not see it if they were coming to my office for appointments.”

Although there were several indications of assessment of cognitive ability or decision-making capacity, it was unclear who was conducting the assessment of cognitive ability and decision-making capacity. While some respondents indicated they were comfortable conducting the assessment and consulting with mental health providers in questionable or challenging cases, others indicated that they felt this type of assessment was beyond the scope of their roles and responsibilities. Only one survey respondent noted the use of a specific tool for measuring cognitive status, the Mini-Mental State Examination (MMSE), which does not measure executive functioning.

Although the majority of the respondents (59%) either strongly agreed (13%) or agreed (46%) that individuals identified as self-neglecting usually have underlying, untreated mental health problems or cognitive impairment, there was widespread concern that “there is a serious lack of mental health services, and those we do have are not always easily accessible to the people who need them.” Another fundamental concern was the role of dementia and cognitive impairment. One participant noted that the definition of self-neglect is “in a nutshell, what happens to somebody who has dementia . . . because it is by virtue of the disease process and trajectory going to happen if someone does not step in.” Participants articulated a need for mental health professionals in terms of both determining capacity and helping to address issues underlying the presenting concern of self-neglect.

**Reporting and Referral Process**

Findings clearly indicate a lack of clarity regarding self-neglect reporting, with providers reporting cases of suspected self-neglect to a wide variety of organizations, programs, and providers (Figure 17.1). Providers most commonly reported to the APS (37%), with 15% of the respondents reporting to the AAA, and an equal number (15%) noting that they make reports to the APS and/or the AAA.

Respondent comments reflect the potential complexity of these situations, as well as confusion about where reports should be made. One clearly stated, “I don’t know where to report this.” The challenge in reporting cases of self-neglect for those younger than 60 was highlighted: “For people 60 or older, reports are made to the Area Agency on Aging providing services in the region where the person who is self-neglecting resides. For persons under 60 years old, referrals may vary. There is
no one place/source to make a referral for self-neglecting younger adults.” To address this issue the following suggestion was made: “A single point of entry would help curb some of the community confusion and allow that agency to help clients while educating the community about the greater issues.” However, it was acknowledged that regardless of age, it is a challenge that “there is no mandate to intervene in cases of self-neglect . . . so if someone refuses treatment no follow-up occurs.”

**Time-Intensive Nature of Self-Neglect Cases**

As a result of the complex combination of contributing factors and challenges in assessment, service providers overwhelmingly reported that compared with the average workload, cases of self-neglect take more time. The important yet time-intensive nature of building rapport was evidenced in the following: “Building relationships that enable change takes time and repeat visits . . . often with little visible sign of success.” The vast majority (85%) of the respondents reported that self-neglect cases take more time (33%) or much more time (52%) than their average cases/workload. This was often due to the emotional elements and common ethical dilemmas experienced. One participant commented, “Self-neglect is just that, a crisis waiting to happen most of the time and that’s when change will happen or could happen” and several referred to the cyclical nature of such cases, in which a crisis is abated and there is a lull until the next anticipated crisis occurs. As one respondent stated, “even if this behavior is identified and addressed, it will most likely resurface.”

Several provider respondents indicated that the concerns of community members can be difficult to manage. One participant said “a lot of time spent listening to community members’ concerns . . . getting yelled at by community members that no one is helping the person [or] dealing with other agencies and individuals calling about the client [asking] why aren’t you doing something . . . without understanding issues around working with someone who is self-neglecting.” Those participants,
particularly those on the frontlines of responding to self-neglect cases, expressed the difficulty of being on the receiving end of frequent frustrations and helping other service providers and community members understand the nature of confidentiality and the limits of intervention. The time and effort required on self-neglect cases points to the need for what one provider called perseverance, and another referred to as consistent presence and compassion. One participant articulately noted:

Self-neglect is often very gray. Frequently, the person who is self-neglecting in our eyes, doesn't think there is a problem. Developing the necessary skills to meet the person on their own turf, and help them through the situation is essential. Approaching with respect, understanding what it is the person may want or need, is essential and often may not jive [be aligned] with what his/her family or community find acceptable. There are no quick fixes, and it is not easy to know what the “right thing” is, or to avoid placing our own values on the person/the choices they’ve made. . . . Figuring out what can be done, should be done, what the individual wants or will accept, is not an easy task.

Responding to Self-Neglect

Participant responses offered a number of strategies and recommendations for enhancing the response to self-neglect. Common strategies included (a) training and education, (b) care management and collaboration, (c) and community involvement and support. Embedded throughout the recommendations was an acknowledgement of the need for financial resources and organizational leadership to ensure the effectiveness of a coordinated community response to self-neglect.

Training and Education

Participants expressed a strong need for specialized training and education about how to respond in cases of self-neglect. It was noted that this training was needed “across the continuum of health care providers.” Participants articulated a need for trained providers to conduct assessments for self-neglect, particularly in terms of assessing decision-making capacity, mental health, and cognitive impairment. Furthermore, many frontline providers acknowledged that responding to cases of self-neglect requires unique expertise in establishing trust, building rapport, respecting self-determination, and assessing risk and capacity. Although many providers “really want to help,” they often need training and resources to do so. Public awareness on self-neglect is also needed.

Care Management and Collaboration

Nearly 95% of the survey respondents reported the importance of engaging in interdisciplinary collaboration with colleagues and providers from other organizations. The following participant comment articulates the need for such collaboration: “Individuals respond uniquely to different types of intervention; someone might take the animal control officer’s recommendation very differently than one with the same ends by the town health officer. For this reason, self-neglect needs to be approached in a customized way, which requires collaboration across a variety of sectors.”

Many study participants articulated a desire for increased involvement from town health officers, animal control, and zoning authorities, as well as family members.
and community faith-based organizations. Many respondents identified a need for collaborative outreach and assessment, and specifically noted the prerequisite of adequate funding of mental health services and availability of geriatric mental health providers, in particular. Accessibility of mental health services was noted frequently, indicating that there was a need for “more accessible mental health services and supports, which are not only office based but community based” and “more access to mental health information, services, and support for self-neglect clients and the community partners who need guidance in how to help them.” Although Vermont’s Elder Care Clinician program was frequently highlighted as a valuable resource, significant variability in accessibility and utilization was noted throughout the state. Concerns were raised regarding inadequate funding of the program, inaccessibility to providers due to long wait lists, or inability to respond to crisis situations. Several respondents noted concerns that mental health providers were unwilling or unable to address cooccurring mental health issues and cognitive impairment, and that there is a serious need for mental health providers, particularly emergency/crisis responders, who can adequately conduct differential diagnostic assessments.

Community Involvement and Support

Generally, cases of suspected self-neglect come to the attention of service providers following a report or referral by the concerned family, community members, or providers. Although this often reflects a value of community and care for fellow community members, it also raises important questions and concerns reflecting the spectrum of perspectives regarding the role of personal choice and the balance of safety and risk. The majority of the survey respondents strongly agreed (12%) or agreed (43%) individuals of all ages should be able to do what they wish with their lives and their property. This result reflects the potential limits to personal choice perceived by some providers and community members. Comments illustrate the range of expectations regarding community involvement and impact from: “More community empathy for folks who may be different. . . . Less judgmental attitude to folks who are different” to “For many people it is a long-standing habit and lifestyle. . . . It should not be tolerated because it adversely affects the entire community.”

Study participants offered several innovative strategies for a true community-based response to self-neglect, including community spaces, outreach, and the utilization of peer support networks consisting of volunteers and senior companions. It was suggested that we “need to have spaces in the community that are safe, community-centered spaces that are open cradle to grave.” Local communities might “lead the community in frank discussions about the ethics and realities of those who might be self-neglecting and educate [about] available resources” and/or “establish strong volunteer networks for home visits and local companions.” However, some respondents also noted a potential barrier in terms of “getting community partners or members to participate in helping the self-neglecting person.”

Several participants indicated that since the nature of self-neglect cases is that people “don’t want services” it is important to provide information and options via volunteers or a peer support network. However, some were clear that it would be important to utilize paid peers rather than unpaid volunteers, due to the nature of the work. Also, several expressed a significant concern that such a model would require extensive training, as well as ongoing support and supervision. It was noted that some individuals might be open to informal peer support—but perhaps only from
a known neighbor or true peer (i.e., farmer to farmer), but might react negatively
to perceived intervention via a network of community volunteers representing local
teens, business people, or town leaders, for example.

Overall, many study participants reflected the sentiment that there was a significant
need for providing family support and establishing a network of community volunteers
to help when needed: “It is an issue that impacts not only the individual and their [sic] family but the community as a whole. If we can find ways to assist individuals with the underlying causes of self-neglect we will enhance the overall health and well-being of all.”

**DISCUSSION**

The rapid aging of the U.S. population will likely exacerbate the problem of elder self-neglect (Dong, Simon, Fulmer, et al., 2010; Dong, Simon, Wilson, et al., 2010; Pavlou & Lachs, 2006). It is expected that by 2030, one in five Americans will be 65 years of age or older (U.S. Census Bureau, 2011). As a state with one of the oldest populations in the United States, Vermont must be prepared for a potential growth in self-neglect cases. The complex and challenging nature of self-neglect requires a locally informed strategy to ensure individuals and families receive support in a manner that maximizes safety, health, and well-being with respect to autonomy and individual/family decision making. A coordinated community response would involve collaboration among multiple systems and services at the local level. Based on the study findings presented in this chapter, a coordinated community response to self-neglect should involve a combination of (a) an expanded understanding self-neglect, (b) addressing systemic challenges, and (c) implementing strategies to enhance the response to self-neglect.

**Understanding Self-Neglect**

As demonstrated in the literature and illustrated in the study findings, the scope of self-neglect is particularly challenging to ascertain. Due to the aforementioned categorization of this issue as a geriatric syndrome, self-neglect estimates are generally embedded within estimates of the incidence and prevalence of elder abuse and neglect overall, which are considered to be underreported nationally and internationally. Furthermore, states and localities have varying definitions of self-neglect and reporting processes, adding to the difficulty of obtaining clear numbers of confirmed cases and accurate estimates (Teaster, 2003). Vermont faces perhaps a unique challenge given the structure of self-neglect reporting (younger-than-age 60 cases to the APS and older-than-age 60 cases to the AAA) and the lack of inclusion of self-neglect in state statutes. Although the aging service network (most notably the AAA) provides essential care and response in cases of self-neglect and has a fundamental role in supporting the overall health and well-being of the older adults and caregivers, the definition of self-neglect indicates that systems of care involved in addressing the physical or mental impairment, or diminished capacity, should be active collaborative partners, not peripheral responders. The apparent difficulty in defining self-neglect stems from both the ambiguous nature of the concept itself, the limited research on the topic, and a lack of consensus among national, state, and local service providers. It is also important that we enhance the understanding of self-neglect from the clients’ perspective (Band-Winterstein, Doron, & Naim, 2012). Furthermore, although often vital for the provision of services, the connection of self-neglect to elder abuse and
neglect may exacerbate the difficulty of defining and conceptualizing both the term and its response (Rathborn-McCuan & Fabian, 1992). The need for definitional clarity, more accurate reporting of self-neglect, and consistent documentation is not only important for the development and provision of services but also vital to the health and well-being of those involved.

Though many studies have shed light on the potential risk factors and causes for self-neglect, it is still unclear exactly how these aspects inform, influence, and compound one another to cause and perpetuate self-neglect. Mental health issues and cognitive impairment are among the most commonly cited causes or risk factors for self-neglect and weigh heavily on discussions of capacity and competence. Those who self-neglect are likely to have some form of mental illness or cognitive impairment (Dong, Simon, Wilson, et al., 2010; Dong, Wilson, Mendes de Leon, & Evans, 2010), with dementia and depressive symptoms being the most common (Abrams, Lachs, & McAvay, 2002; Bartley, Knight, O’Neill, & O’Brien, 2011; Burnett et al., 2006; Dyer, Pavlik, & Murphy, 2000). Likewise, cognitive impairment and declines in executive functioning are often found in conjunction with self-neglect (Abrams et al., 2002; Dong, Simon, Fulmer, et al., 2010). Study findings are aligned with the existing literature, with the vast majority of the respondents reporting underlying, untreated mental health problems, or cognitive impairment among individuals identified as self-neglecting. It is important to recall that Vermont’s definition of self-neglect includes a clarifier that “excludes people who make a conscious and voluntary choice not to provide for certain basic needs as a matter of lifestyle, personal preference, or religious belief and who understand the consequences of their decision.” Perhaps inherent in this definition is an assumption that anyone identified as self-neglecting has some mental health problem or cognitive impairment that results in a lack of understanding of consequences of their decisions. Regardless, there is a clear call for effective assessments of decisional capacity, access to mental health services, and interprofessional collaboration.

### Addressing Systemic Challenges

As illustrated in the study findings, frontline responders are often in the center of the inherent conflict between society’s desire to protect vulnerable adults from harm and respect for individual autonomy. An essential element of cases in which services are refused is deciding whether someone has the capacity to make that decision. Determining capacity and competence are extremely difficult tasks, and often prove to be a gray area for most practitioners, who have very few specific guidelines for such determinations. As White (2014) stated, “the tension between an adult person’s right to make [his or her] own decisions and the responsibility of society to protect the individual from harm has made defining, researching, and addressing self-neglect an arduous and often debated process” (p. 134). One of the biggest difficulties for practitioners is that they often lack the tools or resources to determine capacity (Braye, Orr, & Preston-Shoot, 2011). Usually, capacity determinations can only officially be made by a geriatrician or psychiatrist (Day, 2010), which often requires an office visit. For individuals who are homebound or wary of office visits, obtaining an official determination can prove difficult.

In addition to the challenge of obtaining a capacity determination, there are few accurate or official measurements for the assessment of self-neglect. This is due in part to the lack of a universal definition and the limited research on effective self-neglect assessment tools (Brandl et al., 2006; Kelly, Dyer, Pavlik, Doody, & Jogerst, 2008).
As illustrated in the study findings, there is no standardized measure or even common/shared assessment method being used throughout Vermont. Most often, individual judgments of APS field workers, AAA case managers, or health professionals are used to initially determine cases of self-neglect. There are an increasing number of measures for determining capacity (Naik, Lai, Kunik, & Dyer, 2008; Parmar, Bremault-Phillips, & Charles, 2015; Skelton, Kunik, Regev, & Naik, 2010) and assessing for self-neglect (Day & McCarthy, 2016; Kelly et al., 2008; Pickens et al., 2013), which could inform a more universal and coordinated process for assessment. “Building therapeutic relationship with self-neglecting clients and sensitive comprehensive assessment are key to evaluating situations” (Day, Mulcahy, Leahy-Warren, & Downey, 2015, p. 114).

Given that one of the defining features of self-neglect is the failure to obtain goods and services necessary to maintain health and safety, those considered to be self-neglecting rarely present for services. This points to the need for an efficient reporting and referral process. Study findings indicate notable confusion about this process in Vermont and point to the need for clarity among both providers and the public. Research indicates significant gaps between expert and public views of elder abuse in that “many experts and organizations that deal with elder abuse treat self-neglect as a form of elder abuse, yet the public excludes self-neglect from the concept and assumes that the term ‘elder abuse’ refers only to cases in which one person abuses another” (Volmert & Lindland, 2016, p. 5). In order to put self-neglect on the map and/or raise public awareness, “strategies are needed to bring self-neglect into the conversation, under the heading of ‘elder abuse’ or as a twin concept” (Volmert & Lindland, 2016, p. 7). Furthermore, in Vermont, there is a need to raise public awareness and provider understanding about where to report suspected cases of self-neglect.

Findings indicate that self-neglect cases are among the most time-consuming of provider caseloads. Given that one of the defining features of self-neglect is the failure to obtain goods and services necessary to maintain health and safety, those considered to be self-neglecting rarely present for services. Those on the frontlines of response face a challenging situation in engaging individuals who frequently do not desire involvement with formal service providers, and in working on high-risk, high-demand cases with diminishing resources. Outreach and engagement are essential for assessment and service provision, however, they are frequently time-consuming and demanding. Although this may require resources at the front end, it could help to distinguish between those cases that qualify as self-neglect or not, so that services can be referred, utilized, and coordinated most appropriately and efficiently. This could help to avoid allocation of provider time and resources to inaccurately categorized cases/situations, potentially reducing costs in the long term. Through outreach efforts and adequate time invested in establishing trust, service providers can assess for self-neglect and either provide or connect individuals to essential case management and health/mental health services as appropriate.

Implementing Strategies

Clarification of the reporting and referral process, and the establishment of this process via formal policy is fundamental to an effective response to self-neglect. Study findings point to a vital need for clarity around the reporting and referral process for suspected cases of self-neglect. The reporting process in Vermont may benefit from review and modification to establish a single point of entry and reflect the most
appropriate location for coordinating the response to cases of self-neglect. Service providers across the continuum of health and social services are in need of training to enhance the recognition of and response to self-neglect. Nearly 75% of respondents reported that training on self-neglect was an extremely important component of responding to it. Not only did providers express a need for more training and education for themselves, but for their families and community members as well. Given the role of community concern and involvement in reporting/referring suspected cases of self-neglect, public education is essential in terms of raising awareness about warning signs, resources, and referral options. Of particular concern is raising public awareness regarding self-determination and the limits to intervention.

Study findings point to the need for specialized training and/or access to expertise via consultation when responding to cases of self-neglect. Several respondents indicated a desire for the designated staff to respond to self-neglect cases. Although some indicated a preference for a specially trained and/or experienced staff to be hired/assigned to address self-neglect cases, given the high need and expectations for engagement and unique characteristics of these cases, others suggested having all staff trained and/or having a specialist available for consultation so that all staff are able to respond accordingly. Another option is teaming case managers and mental health providers together for a response. Ultimately, there is a significant need for expertise in this area and resources to support the provision of specialized services for complex self-neglect cases.

Study findings illustrate that care management services are an essential component of the response to cases of suspected self-neglect. Case managers play a crucial role in coordinating care and facilitating interdisciplinary collaboration. Unfortunately, in a time of financial constraints and increasingly limited resources, service agencies and providers face challenges to collaboration, including time and competition. Findings indicate that although collaboration is perceived as key to an effective response to self-neglect, there is limited time for additional team meetings. Local areas may prefer to utilize existing interagency meetings or collaborate on a one-on-one, case-by-case basis. It was also noted that although agencies need to work together, and often have a long history of doing so, they are simultaneously vying for limited resources, creating a competitive rather than collaborative environment. Whether through existing teams and collaborative meetings, the development of new partnerships, or individual provider relationships, it is clear that interprofessional, interagency collaboration is essential to accessing expertise, maximizing resources, and providing a comprehensive response to self-neglect.

Given the role of concerned community members in bringing suspected cases of self-neglect to the attention of providers, there are several ways that community support and involvement could enhance the response to self-neglect. It is of primary importance that the public is informed regarding the nature of self-neglect and process for report, referrals, and response. Related to the recommendation provided under training and education, a public awareness campaign may be useful in providing information and education about elder self-neglect to the concerned community members and families. There is a clear need for additional support for families and caregivers, specifically for individuals suspected to be self-neglecting. Of particular concern and worthy of further investigation is the issue of caregivers who may be neglecting to address their own needs in the process of caring for a loved one. As long-term care services are increasingly home and community based, family caregivers will likely need additional supports to help reduce cases of self-neglect as well as
potential abuse and neglect resulting from caregiver stress. Ultimately, the movement toward a coordinated community response to self-neglect could be strengthened by an effort to involve community members through an organized volunteer/peer/companion network. As community members are generally the concerned party who brings self-neglect to the attention to others, they may be well positioned to be an active part of the response. Providers can partner with communities to engage in both prevention and intervention efforts, however, it is clear that significant attention to and resources for training and support will be essential to success.

CONCLUSION

Findings from this study and related recommendations should be considered in light of several limitations. First, this study represents the perspectives of service providers and stakeholders in Vermont. The purpose of this study was a statewide assessment, and although results may be applicable to other areas, there is no guarantee that findings would be replicated across other state, national, and/or international regions. In addition, use of alternative methods, such as the inclusion of elders and caregivers, could have resulted in different findings and recommendations to inform a community response. That said, study findings point to several implications for research and practice.

IMPLICATIONS FOR RESEARCH AND PRACTICE

- Further research is needed to better understand the relationship between self-neglect and mental health/cognitive impairment, and the utilization and impact of different capacity-determination and self-neglect assessment measures.
- There is a paucity of research on the outcomes of various self-neglect interventions, indicating a need for comparative, longitudinal studies.
- There is a need for practitioners trained in capacity determination and assessment of self-neglect.
- Care management and coordination services are essential to a coordinated community response. Interprofessional and interagency collaboration will require practitioner education and systemic support for interprofessional practice.
- Increasingly, innovative peer, family, and community support models may serve as a valuable resource in a coordinated community response to self-neglect.

REFERENCES


Self-neglect is a hidden and undeniably complex problem that presents a serious public health issue. It is associated with multiple issues, including serious adverse health outcomes, hospitalization, institutionalization, and ill health. Health and social care professionals are often faced with a multiplicity of ethical challenges related to refusal of services, mental capacity, and whether to intervene. The research presented in this chapter was inspired by my experiences as a student on a social care work placement at a community organization for older people. The aim of the pilot study was to explore the perspectives of a public health nurse (n = 1) and a senior caseworker (n = 1) on self-neglect. A qualitative methodology that used semi-structured interviews was employed. Data were analyzed using content analysis. The findings of the study identified four themes: prevalence and contributing factors, current referral pathways and service interventions, professional challenges, and outcomes in cases of self-neglect. Despite the small sample size, the study highlights the significance of self-neglect for health and social care professionals.

Although the needs of older people can be varied and complex, self-neglect, as a serious public health issue, presents multifaceted problems for family members, communities, as well as health and social care professionals. As part of my undergraduate bachelor degree program, I spent 12 weeks in a work placement at a multidisciplinary agency and research center in Ireland. This research center is dedicated to improving the lives of older people and is funded by a number of agencies. During this work placement, I encountered several instances of self-neglect for the first time and saw firsthand the multiplicity of issues that encompass self-neglect work. I attended several multidisciplinary case conferences and witnessed discussions on processes and approaches used by team members to work with people engaging in self-neglecting behavior. After my 12-week placement, I remained as a volunteer on a day-visiting program. These experiences motivated me to pursue research on self-neglect, the aim of which was to investigate the perspectives of a public health nurse and a senior caseworker on self-neglect. This chapter describes the results of that research.
BACKGROUND LITERATURE

Defining Self-Neglect

As a starting point, a clear definition of self-neglect is paramount. Given the Irish context of this research, the following definition by Day (2010, p. 74) is perhaps the most pertinent:

Self-neglect can present along a continuum of severity ranging from failure to attend to self-care, leaving bills unattended, noncompliance with treatment regimens, not eating or drinking, service refusal with evidence of self-neglect; to dilapidated homes and environments, faulty electrics, hoarding of rubbish, squalor, and hoarding of animals.

This definition illustrates and describes a whole range of diverse behaviors, which can manifest among individuals who self-neglect, from personal idiosyncrasies to severe environmental hazards. Much of the literature offers similar definitions, as well as outlines myriad consequences such behaviors have on the health and well-being of older persons. Although Dong and Simon (2013) assert that there are some significant gaps in current knowledge regarding the exact consequences of self-neglect, they concur that the available evidence identified an increased rate of mortality (Dong & Simon, 2015), high rate of health care utilization (Franzini & Dyer, 2008), increased risk for nursing home placement (Lachs, Williams, O’Brien, & Pillemer, 2002), all-cause mortality (Lachs, Williams, O’Brien, Pillemer, & Charlson, 1998), a 15-fold increase in cancer, and a tenfold increase in nutritional- and endocrine-related mortality (Dong, 2005). Self-neglect is also associated with a high rate of hospitalization, in addition to longer stays in hospitals (Dong, Simon, & Evans, 2012a). Furthermore, in instances of extreme self-neglect and squalor, where hygiene and environmental conditions are very poor, such circumstances pose not only a threat to the health and safety of the individual but also to those surrounding them, such as neighbors and community members (Dong, Simon, Mosqueda, & Evans, 2012).

Although it can vary in its presentation and degree of severity, self-neglect is predominantly characterized by extensive environmental neglect and aggregate diverse behaviors and deficits, which can have devastating consequences for the person’s health, safety, and well-being (Day, Leahy-Warren, & McCarthy, 2016). Self-neglect is often associated with other conditions, sometimes labeled “risk factors,” such as depression, dementia, cognitive and/or physical impairments, poor social networks, living alone, economic decline, old age, and alcohol or substance abuse (Gibbons, 2009; Pickens, Ostwald, & Pace, 2013). Although self-neglect behaviors can occur among the young and old, research has primarily focused on older people (Lauder, Roxburgh, Harris, & Law, 2009). This is largely due to the overwhelming absence of age-related morbidities among younger people, suggesting that it may be a somewhat different phenomenon in this particular age group (Iris, Ridings, & Conrad, 2010).

Prevalence and Policy Context

Although self-neglect behaviors are more often associated with older people, in particular older men (Dong et al., 2012), determining its prevalence has been very difficult given that it is often hidden and under-reported (Day, Mulcahy, Leahy-Warren, &
Downey, 2015). Moreover, there is a divergence of self-neglect classifications across the literature, as some countries, particularly Canada and the United States, and even different states/provinces within those countries, choose to include self-neglect under the definition of elder abuse (Day, 2010). This is not the case in Ireland, where self-neglect is excluded from the definition of elder abuse because it does not occur within a relationship (Health Service Executive [HSE], 2014). Some argue that inclusion is necessary (O’Brien, 2011), yet others maintain that exclusion is appropriate to avoid ambiguity and confusion (Doron, Band-Winterstein, & Naim, 2013). This does not rule out the possibility that in some instances self-neglect can occur simultaneously with elder abuse (Bartley, O’Brien, & O’Neill, 2010; HSE, 2014). Arguably, these divergent definitions have contributed to the underdeveloped epidemiology of self-neglect (Day et al., 2015).

In Ireland, cases of self-neglect account for approximately 21% (or 631) of the referrals received by senior caseworkers who specifically deal with cases concerning elder abuse (HSE, 2014). However, current policy dictates that senior caseworkers may only take on a referral if the criterion of extreme self-neglect is present, a concept not very well defined. Of the 21% of individuals referred to senior caseworkers, 53% have come from public health nurses, with 15% comprising hospital staff and 13% family members (HSE, 2014). In a recent study, Day and McCarthy (2015) revealed that 89% of public health nurses and other health and social care professionals had come into contact with cases of self-neglect in the previous 12-month period. Nevertheless, these statistics may only be the tip of the iceberg, as individuals who self-neglect are difficult to profile, with under-reporting and nonengagement issues obscuring the true scope of the phenomenon (Day, Mulcahy, & Leahy-Warren, 2016).

At present, older persons (65 and older) represent less than 10% of Ireland’s population based on the 2011 census (Central Statistics Office [CSO], 2012). But population predictions by the CSO suggest that by the year 2036 older people could account for 20% to 23% of the country’s total population (Gallagher, 2013). The implication, then, is that the prevalence of self-neglect will increase and create myriad challenges for health and social care professionals and for society in general (Day, Leahy-Warren, & McCarthy, 2013). Consider that in 94% of the cases referred to senior caseworkers the older person lived alone. This elucidates how the behavior can potentially go unnoticed, and possibly become deep-seated for a long period of time before ever coming to the attention of health and social care professionals (HSE, 2014).

**Self-Neglect: Geriatric Syndrome or Sociocultural Phenomenon?**

Numerous theories have been postulated as to why self-neglect typically occurs from biological causes, such as cognitive or physical impairments, to more social and environmental factors, like poverty and social isolation brought about by bereavement or dwindling social networks (Braye, Orr, & Preston-Shoot, 2011). However, although some correlations have been uncovered, there is no one absolute explanatory model for self-neglect, and a complex interaction of these factors is said to be the best interpretation for why the behavior takes place. Diogenes syndrome, also known as senile squalor syndrome, is described as a behavioral disorder of the elderly, typically associated with frontotemporal dementia, characterized by an extremely neglected physical and environmental state, social isolation, lack of shame, and a tendency to hoard excessively (Capriani, Lucetti, Vedovello, & Nuti, 2012). Similar theories
have been described, which emphasize the role that dementia, depression, or other cognitive changes in the frontal lobe area of the brain may play in bringing about a functional decline that can lead to self-neglect behaviors (Dong et al., 2010). This type of cognitive impairment, coupled with physical dysfunction and exacerbated further by a lack of financial or social support, could easily aggravate the overall condition, resulting in a plethora of self-neglecting behaviors (Dong, Simon, & Evans, 2012b). In contrast, others maintain that poor self-care could be the result of society's failure to ensure adequate quality care for the elderly in general (Choi, Kim, & Asseff, 2009; Gill, 2009). Another theoretical model attempts to distinguish between older people who self-neglect by choice and those struggling to cope due to cognitive, functional, and financial constraints (Iris et al., 2010).

The belief that self-neglect is solely attributable to biological dysfunction is quite pervasive, despite limited empirical evidence for this claim, with literature being self-referential and comprising reviews and case studies opposed to actual original research (Lauder et al., 2009). McDermott (2010) uses critical theory to highlight how the prominence of biomedical explanations in the literature can obscure the influence of professional judgments in shaping understandings of and responses to self-neglect among older people. There is a gray area between what is considered living a “nonconformist” lifestyle and a pathological state (Lauder et al., 2009). Perception of self-neglect, then, becomes an identifiable theme and the literature reveals that cultural attitudes toward the elderly and perceptions of self-neglecting behaviors play a role in the detection of the phenomenon. For instance, San Filippo, Reiboldt, White, and Hails (2007) found that self-neglect is viewed differently by various cultures and cohorts, which can inhibit the ability of professionals to intervene in a timely manner. However, Snowdon, Shah, and Halliday (2007, p. 48) argue that “some people live in conditions so filthy and unhygienic that almost all observers, in whatever culture, would consider them unacceptable.” And yet, one only has to consider that throughout history human beings have managed to live in all sorts of diverse environmental conditions that would be in stark contrast to contemporary standards of domestic living.

One caveat to consider in light of these findings is that people who self-neglect, especially those who live in squalor, may differ from the “nonconformists” in that they can recognize what others should do in instances when their health is at risk because of self-neglecting behaviors but not actually do it themselves (Naik, Pickens, Burnett, Lai, & Dyer, 2006). This corresponds with further research, which reveals that older people living in environmentally hazardous conditions who possess emotional processing can recognize pictures of other filthy homes but also exhibit executive dysfunction (or lack of capacity), which might explain why they do not consider their own homes to be filthy (Gregory, Halliday, Hodges, & Snowdon, 2011). Hildebrand, Taylor, and Bradway (2013) suggest that proper self-care may require the person’s recognition of both societal expectations of hygiene as well as having the capacity and problem-solving ability to execute these particular standards. In a study with individuals who self-neglect, Kutame (2007) found that participants did not interpret their behavior as self-neglect and, instead, portrayed the problems as being outside of their control. Band-Winterstein et al. (2012) report similar self-perceptions among self-neglecting individuals, who largely dissociate themselves from any responsibility or agency.

Identification of self-neglect by health and social care professionals is a highly subjective matter, hindered more so by the lack of any validated self-neglect
instruments, suggesting that professional judgments are not standardized but rather susceptible to individual interpretation (Day, McCarthy, & Leahy-Warren, 2012). Although severe cases of self-neglect more often than not are referred to specialist services such as senior caseworkers, other instances that present challenges and ethical dilemmas may not be classified as extreme and could subsequently lose service intervention prioritization because of demanding caseloads among professionals (O’Donnell et al., 2012).

Capacity and Ethical Considerations

Throughout the literature, one major theme emerges concerning how cases of self-neglect can present challenges and ethical dilemmas for professionals mandated with responsibility for safeguarding the older person (Blagodatny, Skudlarska, & Tocchi, 2007). Such challenges include legal frameworks for intervention and the nature of the older person's decision-making capacity and autonomy (Braye et al., 2011). Torke and Sachs (2008) state that trying to establish a safe living environment for the older person who is self-neglecting can be extremely difficult if they are at risk and simultaneously resist any kind of help. The ideal of respecting self-determination and achieving a person-centered approach in many cases of extreme self-neglect poses a considerable challenge to practitioners, especially for senior caseworkers and public health nurses (Day, 2010; Day, Leahy-Warren, et al., 2016).

Hurley, Scallan, Johnson, and De La Harpe (2000) describe those who self-neglect as “service refusers,” highlighting the general unwillingness to accept treatment or services as being one of the defining features of the phenomenon. Naturally, such an inclination of service refusal can become a key issue and impede service providers from building a therapeutic relationship of trust, as the older person either outright rejects or merely tolerates myriad interventions, which they deem as unnecessary and intrusive (Lauder, Anderson, & Barclay, 2005). Perhaps the most difficult issue for professionals working with older persons who self-neglect is recognizing the kind of extreme situations that merit overriding the person's wishes to be left alone and the ramifications of such actions. In many instances, it is the lack of capacity as a result of physical illness, mental illness, or cognitive impairment that is the primary characteristic that health professionals cite as the justification for making such judgments (McDermott, 2010). Capacity is defined as the ability to understand the consequences of decisions as well as being able to execute decisions (Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly, 2007). Yet, capacity is not always completely present or totally absent, but rather, it appears on a gradient or sliding scale (Dong & Simon, 2013).

In Ireland, when a person is deemed mentally incapacitated to the extent that he or she is unable to manage his or her person and/or property, an application to have the individual legally deemed a ward of court can be made (O’Neill, 2006). This specific action substitutes the legal decision-making capacity of the person, who is brought into state wardship concerning his or her property and person, with the court appointing a substitute decision maker. This entire process can involve the forced removal of the person to an institutional facility (i.e., a nursing home), which although intended to safeguard the person, may cause psychological harm rather than physical good (Mauk, 2011). In essence, appropriate consideration is needed and community health teams and other social care professionals should be well trained in self-neglect and risk assessments (Day, Leahy-Warren, et al., 2016).
Conversely, the wardship system is currently being phased out, soon to be supplanted by the Assisted Decision-Making (Capacity) Act 2015, which will repeal the Lunacy Regulation (Ireland) Act 1871. Thus, adults with diminished mental capacity can no longer become a ward of court and, instead, they will have an assistant decision maker, codecision-maker, or attorney appointed based on the extent of his or her capacity (Griffen, 2015). However, at the time of writing, the legislation is not fully operational. It is difficult to predict how it will impact the practice of health and social care professionals.

Day, Mulcahy, et al. (2016), along with Braye, Orr, and Preston-Shoot (2014), draw particular attention to the more complex and challenging cases of self-neglect in which people choose to self-neglect and have capacity while, at the same, remain steadfast in their refusal of services. Bergeron (2006) implies that accepting service refusal could be construed as client abandonment. Yet, trespassing without permission can infringe the property rights of owners and home surveillance visits without any clear purpose can have the effect of stigmatizing individuals who self-neglect (Ballard, 2010). As such, the most frequent dilemma raised by professionals appears to be not whether to intervene in cases of self-neglect, but how to intervene (McDermott, 2010).

Effective Practice in Responding to Self-Neglect

The primary role for all health and social care professionals is to take a coordinated interagency approach to cases of self-neglect and establish a holistic assessment to inform what, if any, intervention should take place (Braye et al., 2011). Good governance structures and procedural guidelines are recommended (Braye, Orr, & Preston-Shoot, 2015). Dong and Gorbien (2006) state that a comprehensive geriatric assessment should take place. Murray and Upshall (2009) underscore the benefits of global assessments in determining how best to proceed. Understandably, the early detection of self-neglect is identified as being of paramount importance as, in doing so, it can prevent the behavior from becoming too entrenched and, thus, it is much easier to put early intervention supports in place (Day & Leahy-Warren, 2008; Snowdon & Halliday, 2009).

Maintaining positive relationships and regular contact with older people who self-neglect is, perhaps, the greatest responsibility health care professionals have and Lauder et al. (2005) recommend that any ongoing monitoring plans should be shared across various agencies to be sustainable and effective. This is because outcomes of self-neglect are generally poor and associated with high rates of relapse and mortality (Dong, Simon, et al., 2009). A key area for intervention is assistance with activities of daily living (ADL), which is provided for by various agencies (i.e., home help services) as self-neglect is often linked to disability and poor functioning (Dong, Mendes de Leon, & Evans, 2009; Naik, Pickens, Burnett, & Dyer, 2007; Pickens et al., 2007; Poythress, Burnett, Naik, Pickens, & Dyer, 2007). Focusing on ADL can yield substantial improvements in cases of self-neglect (Griebling, 2010).

In summary, the literature encompasses the broad scope of self-neglect behaviors and manifestations, from its prevalence and diverse contributory factors to the means in which health and social care professionals can be multifarious in their attempts to address the behavior. What should be apparent is that self-neglect is far from being a straightforward phenomenon with simplistic solutions, and, as the population grows policy makers and other stakeholders will need to pay greater attention to this public health issue.
METHODS

Participants and Sample

A qualitative research approach was chosen to provide a detailed perspective on how cases of self-neglect can be identified and how they are managed by health and social care professionals. Two professionals from the HSE were selected to comprise the research sample: a public health nurse ($n = 1$) and a senior caseworker ($n = 1$). The justification for choosing these particular individuals was made on the grounds of purpose-based, nonprobability sampling, given that both possessed, by virtue of their job descriptions, extensive knowledge and firsthand experience of encountering self-neglect in their line of work.

Data Collection

Semistructured interviews were conducted using open questions to elicit a series of in-depth responses. The interview questions were informed by the myriad themes uncovered in the literature review, representing a more deductively orientated strategy intended to answer focused questions in relation to professionals’ experience of self-neglect. The interviews began with basic questions that were relatively easy to answer before progressing toward a more detailed line of inquiry designed to illicit more intricate responses, as recommended by Berg and Lune (2012). Furthermore, each question was centered on a single topic or concept. Although the degree of control over interview proceedings may vary, there is, nevertheless, a tacit agreement embedded within the whole process of being interviewed that the agenda for discussion will be at the sole discretion of the researcher (Denscombe, 2010). Notwithstanding, both participants were given the opportunity at the end of their respective interviews to add anything further that they deemed relevant to the topic of research that had not been covered in the preceding set of questions put to them. In doing so, the researcher was satisfied that the participants’ freedom to openly discuss the topic of self-neglect had not disproportionately limited.

Both participants were provided with an information sheet and consent form on the day of their respective interviews and the consent forms were signed. Participants were also advised that they were under no obligation to answer all or any of the questions and that they could “pass” on any given question if they so wished. Upon completion of the interviews, the audio data was transcribed and stored as two password-protected text files. All personal data and identifying locations were made private, shielded under the protection of anonymity with each of the participants being assigned a pseudonym and any references made to their geographical location of work removed to uphold the participants’ sense of privacy (Christians, 2000).

Data Analysis

The interviews were processed using content analysis, which is a systematic examination and interpretation of the raw data by the researcher to identify any patterns, themes, biases, or meanings (Berg & Lune, 2012). Familiarization with the interview transcripts was the first step undertaken through a process of immersion in the data by reading it over several times, taking memos of anything deemed noteworthy, and employing theoretical sensitivity, a specific type of researcher insight.
and self-awareness (Corbin & Strauss, 2008). The second stage involved minutely coding the data in order to help identify any concepts and themes. At this early stage, the open code names were rough and involved labeling chunks of data with either a word or a phrase that described said data sufficiently (Rivas, 2012). This was then followed by axial coding, in which the researcher searched for relationships among the codes, establishing links and associations that allowed certain codes to be incorporated into larger headings or categories, as well as particular codes being perceived as more frequent or crucial than others in relation to the research questions (Denscombe, 2010).

Finally, having identified a number of salient themes in the data, the concluding stage of analysis involved integrating the particular findings into the research document through a mixture of summarization and verbatim quotes, for the sake of clarity. Four prominent themes emerged.

**FINDINGS**

**Prevalence and Contributing Factors**

Both the public health nurse (Jane) and the senior caseworker (Aoife) stated that their workloads included cases of self-neglect. Jane reported that these particular cases accounted for 10% of her total caseload, whereas Aoife stated that it comprised 20% but added that elder abuse services only dealt with cases of extreme self-neglect. The major contributing factors to self-neglect were identified as dementia, cognitive deterioration or delirium, in addition to mental health behavioral issues or addiction.

**Current Referral Pathways and Service Interventions**

Instances of self-neglect often come to the attention of public health nurses through a general practitioner (GP), a personal carer, or a neighbor, whereas the senior caseworker was usually contacted by a public health nurse who had made a referral for a case of extreme self-neglect. Jane stated that usually something public had happened with the older person when public health nurses were notified. Similarly, Aoife explained that there would be a crisis in the older person's medical presentation by the time elder abuse services became involved. However, there was a lack of a formal self-neglect assessment procedure among public health nurses for determining the degree of self-neglect. When asked whether there was a comprehensive assessment tool used by her agency Jane stated that:

> There isn’t, no. We’d be just using our own nursing assessments and making our own determinations. I suppose it would be a classification of the type of neglect rather than the degree of it because we don't have a tool that determines degree.

Aoife explained that the closest thing to a comprehensive assessment tool utilized by the elder abuse services was a referral form, which identified the self-neglect behaviors involving environmental and individual characteristics (dirty, matted hair, etc.). These details would inform the referral process for the senior caseworker to make a determination of extreme self-neglect. Service interventions included providing specific services such as home supports. For example, a caregiver who can assist...
the older person with keeping himself or herself and/or the environment clean and tidy. Financial services could also be provided, particularly in instances in which a clean-up of the home environment was deemed necessary. Other interventions included admission for assessment to acute hospitals, or to long-term-care beds in nursing homes. More complex interventions necessitated a GP medical assessment and referral to the psycho-geriatrician.

Professional Challenges

Based on the interviews, a number of distinct challenges were identified. Aoife elucidated some of the main barriers such as gaining access to the older person (i.e., engagement) and the understanding of the older person and his or her perception of the situation, especially when there are other contributing factors. She said:

There could be issues in terms of capacity or there could be issues in terms of mental health or addiction. So, you could have somebody who lacks the insight as to what's happening. So, they're very vulnerable and could be living in total squalor.

Similarly, Jane stated that if the person has dementia or a behavioral problem it can be very difficult because they will not see self-neglect as a problem. She also asserted that family is a problem encountered by public health nurses and not the older person. On the topic of service refusal, Jane went on to say:

Service refusal is often the refusal of the family more than the refusal of the client. The refusal of the client would be from maybe somebody who has dementia or a mental health issue . . . but if they're deeper issues, sometimes it can be the family who doesn't want somebody going into the home. That can be it, more than anything else.

When asked to elaborate upon this point she added:

Well, if it's somebody with dementia the family just haven't come to the point of acceptance. If it's behavioral, then maybe some of the family members have similar behavioral issues and they don't see it as someone else does. Sometimes, they just probably don't want the intrusion and you can have a bit of house politics going on and often the client can be neglected in the middle of it all because there's family dynamics going on.

In terms of service refusal, Aoife highlighted how senior caseworkers ought to try to engage with the older person to build up a level of trust and make incremental changes, but added that any attempts to make considerable progress in a short time are ill-advised:

I don't think you can go into a very squalid situation and completely remove everything because I think that can be quite traumatic, particularly if you’re looking at the whole aspect of hoarding.

Another significant professional challenge identified was the area of accessing the necessary medical assessments in a timely fashion to confirm whether the older
person lacks capacity. Such instances typically come about when professionals have identified the risks as being too high to respect the older person's autonomy. Jane described the current system as being archaic, referring to the laws under which it's governed as being outdated. She also highlighted how public health nurses have no direct referral pathways to old-age psychiatry services. The referral must come from the GP, who may not be aware that the older person is self-neglecting. Indeed, instances of self-neglect, which require a medical determination of capacity, can become very complex, by way of the sheer number of persons involved, as illuminated by Jane in this quote:

There are too many people involved in the decision. We can't do it ourselves so we have to refer to a GP or a social worker or somewhere and then you have to get solicitors on board, you have to get family agreement . . . it's a very complex process, which takes months and months and in the meantime the patient is still refusing care or the patient is getting deeper into a complicated scenario.

From Aoife's perspective, a determination of capacity and any decision to override the older person's autonomy are quite individual and depend on the context of the case.

Hopefully, now with our new assisted decision-making legislation, whilst it's not operational yet, we would hope that would assist us in this because it will give us more focus in trying to ascertain the views of the individual to the very best we can. I think it is very important that we try and do that.

However, she expanded on a number of challenges that still lie ahead in trying to address some of the more progressive concepts given the current state of service provision:

I think there's a lot of discussion around person-centered care and positive risk taking. I think it's wonderful to have such discussions ongoing. I don't actually think, however, that we have been able to marry the discussions around the concepts to what is available on the ground. I think we're talking, and I think the talking is good, but it's not being replicated on the ground because we don't have the options available to us.

**Outcomes in Cases of Self-Neglect**

Outcomes in cases of self-neglect can include both positive and negative aspects, with instances of negative outcomes serving to illustrate the role played by the aforementioned professional challenges. As summarized by Jane:

Good ones are just a matter of getting the appropriate services in place. If somebody has lost the will to keep themselves [sic] clean or tidy and you get in a good carer with a good relationship, good communication skills, I mean it can completely turn the situation around. You get somebody then who accepts social connections and it brings them [sic] into other services because
of that. If it doesn’t work out, then it’s very difficult. You’re hitting off a brick wall all the time and you’re going nowhere and that’s when you end up then having to go through the legal process because nothing is changing and the neglect persists and the danger persists. And you have to keep reminding yourself, once you’re aware of it you have to make sure you close the loop somehow. Pass it on. Keep it and do nothing, you’re in trouble.

This quotation underscores the responsibility and difficulties around engagement with cases of self-neglect as stated by Aoife:

Well, hopefully, we have, in all cases of extreme self-neglect, what you’re trying to achieve is, maintaining the person’s independence whilst minimizing risk. We can’t eliminate the risk and we can’t eliminate behaviors that may lead to the hoarding. But we can minimize it in terms of trying to engage positively.

CONCLUSION

The research described investigated the perspective of two experienced professionals who have firsthand experience of self-neglect. The study findings have deepened the recognition of the multifaceted nature of self-neglect, from manifestations of the behavior and contributing factors, to the potential role played by family members and the myriad challenges faced by health and social care professionals in trying to deal with cases, which can involve both service refusal as well as multidisciplinary impediments.

The prevalence of self-neglect based on both participants’ estimations of their caseloads is corroborated by the literature. Jane approximated that 10% of her public health nursing work involved cases of self-neglect. In a recent study, Day and McCarthy (2015) revealed that 89% of public health nurses, including other health and social care professionals, had come into contact with cases of self-neglect in the previous 12-month period. Aoife stated that cases of self-neglect made up 20% of her workload as a senior caseworker. Cases of self-neglect account for roughly 21% of the referrals received by senior caseworkers for elder abuse (HSE, 2014). However, one must remember that these are just cases that come to the attention of professionals and may not be representative of the true extent of self-neglect within the population.

The absence of a formal self-neglect assessment tool for use by public health nurses and social workers identified in this research means the assessment of self-neglect is subjective and not standardized, a fact recognized by Day et al. (2012). Jane and Aoife indicated that in the absence of such a comprehensive tool they were using their own assessments and making their own determinations. This is a concern given that these health and social care professionals have a key role to play in the identification of vulnerable older people at risk of self-neglect. The results revealed that until a medical determination of capacity is made, health and social care professionals cannot intervene against the older person's wishes, even when there is a huge risk and they are a clear danger to themselves.

Service intervention for self-neglect clearly presented a number of issues causing significant impediments. These included greater access to multidisciplinary services to speed up the process of assessment and intervention and access to a nursing home placement or supervised home support or sheltered accommodation (Mauk, 2011).
The research findings state that putting in the right supports can completely turn the situation around. Going the legal route should be the last resort and acknowledging that the process takes considerable time is paramount. The research findings reveal that professionals are tasked with having to monitor ongoing situations involving deep-seated self-neglecting behaviors while trying to maintain the older person's independence and also minimizing the risk. This approach has been described as “positively engaging” with the older person and, thus, keeping the lines of communication open. According to Day et al. (2015), gradually building up a therapeutic relationship with the older person and including him or her in any decision-making and negotiation processes can be one of the key factors in achieving more positive outcomes. Lauder et al. (2005) recommended that any ongoing monitoring plans should be shared across various agencies to be sustainable and effective.

What may be one of the most significant implications of this pilot study is that self-neglect has no easy solutions. This phenomenon continues to remain a hidden and undeniably complex problem, presenting a serious public health issue. Given the association between self-neglect and dementia or other forms of cognitive deterioration, the numbers of people at risk for self-neglect is expected to increase significantly. Good governance structures, self-neglect policy and legislation, and training and support are required for effective practice. Self-neglect is a burgeoning area of study, that should continue to be researched to add to the existing body of knowledge. This way, policy makers and other stakeholders can be fully informed of its prevalence and how society can try to best minimize its impact for the benefit of both the individuals and communities affected.

### IMPLICATIONS FOR RESEARCH AND PRACTICE

- A comprehensive self-neglect assessment tool will support health and social care professionals in identifying and responding to self-neglect cases in a more objective and standardized way.
- Assessment and intervention in self-neglect cases requires an interdisciplinary team approach as manifestations of self-neglect can present along a diverse spectrum and usually require diverse skill sets and resources to address self-neglect phenomena.
- Research on self-neglect will need to focus on specific interventions and associated outcomes.

### REFERENCES


