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GREY MATTERS

A GUIDE TO COLLABORATIVE RESEARCH WITH SENIORS

Nancy Marlett and Claudia Emes

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Appendix 12

Elder Self-Neglect: Project Description

Nancy Marlett

This is an example of a formal research proposal written with an aging studies orientation. It was not funded and so can be used for discussion purposes.

Elder Self-Neglect (ESN) has been called by many names: Diogenes syndrome, hoarding syndrome, social breakdown, or even squalor or messy house syndrome. ESN is defined as “the inability or unwillingness to provide for oneself the goods and services needed to live safely and independently” (Murphy, 1994). It occurs in vulnerable older adults who have multiple deficits in various social, functional and physical domains, and who often live in extreme conditions such as squalor (Pavlou and Lachs, 2006). They are socially isolated with poor health, disheveled or unkempt appearance. “These persons habitually hoard.... Yet, alarmingly, these persons are often comfortable in their

surroundings, refuse intervention, and believe nothing is wrong (*italics added*).” (Dyer and Prati, 2006) Only 30–50 per cent of reported cases in the United States are associated with mental illness or cognitive impairment (Burnett et al., 2006). Under all the descriptions is a fundamental failure to care for one’s self.

As a “syndrome,” ESN collects many of the problems faced by very old, poor, isolated, and fearful seniors losing physical capacities and without adequate access to primary care or in-home support. But as a medical syndrome, pathology is accentuated, and most research looks at those who have been institutionalized due to medical and psychiatric crises (Burnett et al., 2006). However, Interviewing persons prior to a crisis presents a serious challenge. Researchers can unintentionally pose a threat to a person’s self control (Heisler and Bolton, 2006). How the condition manifests or why it occurs is complex, and understanding this failure to maintain functional autonomy is indeed a priority for Canada as our population ages and our service infrastructures fail.

The language used to describe health problems affects how professionals see themselves in relation to those who are labelled. Most of the professional language about ESN has been held by nurses and homecare workers and has had little influence in the public sphere. However, this situation is changing. There has been a move, primarily in the United States, to link elder self-neglect with elder abuse. This transforms ESN from a private or professional issue to a public concern (Pavlou and Lachs, 2006) and this, in turn, brings into play protective and legal systems. Claims have been made in USA that ESN as the most commonly reported form of elder abuse (Dyer and Pati 2006). This leads to fear among seniors that this trend is bound to affect Canadian thought and our commitment to values of tolerance and support in contrast to protection and control. The exclusive use of medical frameworks may be too narrow (Lauder, 1999b) and there is a pressing need for a fresh look at ESN in the context of prevention and health promotion (Lauder, (1999a)

What We Want to Accomplish: The Questions and Objectives

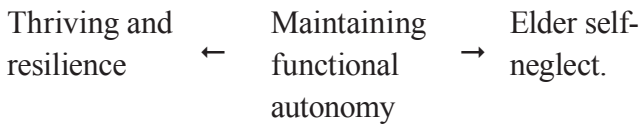
The study is presented in a logic model (Figure 1), with the goals represented by intermediate outcomes and objectives as short-term outcomes. In the interest of space, these will not be discussed here. The overall goal is to take a new look at the language, concerns, research trends, and priorities through the eyes of seniors who befriend and support other seniors who are not looking after themselves. This information, along with reports on research trends related to ESN, will be taken to public guardians, health care professionals, and service providers to add their input. All data and reports will be compiled as study material for a two-day forum to discuss priorities, strategies, and partnerships for a Canadian ESN research agenda with strategies on how to manage the ethics involved in proposed research directions.

In the long term we hope that this fresh, open, and grounded look at ESN will contribute to research that will increase the quality of life for seniors who struggle to care for themselves and remain independent. Equally important is the opportunity to make a place at the Canadian research table for seniors as full and capable partners.

Why Is This a Reasonable Thing to Do: The Rationale

There is considerable confusion and concern about ESN among professional, academics, and seniors (Lauder, 1999a; Lauder et al., 2002). The voices of the seniors have been profoundly silent, and yet, this topic is very relevant to seniors because most seniors fear losing their ability to look after themselves. The treatment of those labelled ESN influences everyone who could lose their independence. All seniors will, to some extent, bear the stigma of the discourse of self-neglect as abuse, and seniors and service providers share concerns that this emerging discourse will impact service options and debates about intergenerational conflict.

ESN might more effectively be located within the CIHR–IA priority area of maintaining functional autonomy.



To one side are the hopes of seniors that they will continue to thrive and be resilient in the face of the challenges of aging. On the other side there is the fear that they will lose autonomy because they are seen as incapable of looking after themselves. Previous research work on resilience conducted by seniors has provided insights into the nature of resilience from the seniors' perspectives (see Appendix 1 in this book). Seniors locate resilience as social capital to be earned and shared, in stark contrast to medical and psychological theories, and we would hope that their input would provide an opportunity to take a fresh look at ESN. The following four aspects of health discourse will frame our initial investigations into related research trends (Marlett and Shklarov, 2008) and will guide our focus groups and interviews:

Biomedical: health risks that come with advanced age, disability, health and mental health conditions, and pain;

Functioning: daily living and health routines and habits that interfere with functional autonomy;

Social and societal aspects including social and economic determinants of health; and

Personal autonomy: motivation and the strategies that enhance control and choice.

The following represents a snapshot of the current literature on Elder Self-Neglect in the above four perspectives:

Biomedical. Most of the literature on Elder Self-Neglect to date deals with untreated medical and psychiatric conditions: depression and post-traumatic stress disorder from previous or current mistreatment or abuse (Burnett et al., 2006; Dyer and Pati 2006); cognitive impairments, including memory loss, decreased brain activity, stroke, heart attacks, dementia, Alzheimer's disease, psychiatric illnesses such as schizophrenia, psychosis, alcohol abuse (Aung et al., 2006), Vitamin D deficiency, nutritional deficiency, and defective food intake (Poythress et al., 2006) and general pain or physical decline (e.g., arthritis, hearing loss, loss of eyesight) (Paylou and Lachs, 2006; Naik et al., 2006)

Coping (functioning). A number of studies addressed the impact of health conditions (e.g., falls, stroke, apathy resulting from depression, frailty, incontinence) (Burnett et al., 2006; Naik et al., 2006) on the ability to fulfill daily routines at a general level. There is a need to investigate mechanisms, strategies, and supports that could reframe the diagnosis of ESN and bring a clearer focus to behaviors such as hoarding (Heisler and Bolton, 2006; Poythress et al., 2006).

Social and societal aspects. Research on social aspects of ESN in the United States indicates that those at particular risk are older males living alone on low incomes (Burnett et al., 2006a). Also at risk are those who have fewer contacts with family or neighbours, participate less in religious activities, and in general have less adequate social resources (Burnett et al., 2006a).

Autonomy. Autonomy touches research related to personality, hope, and motivation. The impact of the loss of control on health and mortality is startling (Poythress et al., 2006), with the estimated rate of death after intervention above 50 per cent. Autonomy decreases when power figures intervene (Heisler and Bolton, 2006) and increases with the availability of peers (other seniors) who offer assistance, friendship, and guidance (Lauder, 2001).

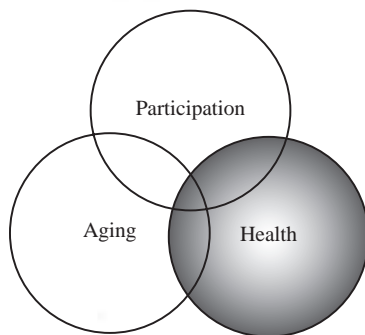
Table 10.1. Logic model of Catalyst grant proposal: Elder Self Neglect: A Canadian Agenda

Situation: the concern surrounding the concept of Elder Self-Neglect (ESN) syndrome as abuse calls Canadian researchers to rethink “maintaining functional autonomy” and to do so in partnership with seniors.

Short Term Outcome Arenas	Intermediate Beneficiaries
<p>Research and development</p> <ul style="list-style-type: none"> -Describe research trends in biomedical, functional, social, and, personal autonomy perspectives that may be relevant to ESN -Describe the lived realities of a small representative sample of those who are at risk of losing functional autonomy. -Describe what seniors providing friendship and support and professionals in home care, public guardians, mental health specialists, and physicians understand about losing functional autonomy and the potential impact of the term ESN. -Negotiate conceptual maps, definitions, language, priorities, partners, and strategies based on above information to create a Canadian research agenda. <p>Capacity Building</p> <ul style="list-style-type: none"> -Attract early career researchers in aging (Doctoral and post Doctoral students) to work with senior researchers and provide support for their research interests. -Train seniors as researchers in setting research agendas. -Provide an opportunity for seniors, academics, and professionals to learn about seniors as researchers. -Create a collaborative Canadian research network related to maintaining functional autonomy. <p>Knowledge and Translation</p> <ul style="list-style-type: none"> - New knowledge related to the socially constructed nature of functional autonomy through the lens of ESN. -Compilation of research trends in plain English to be available for the research participants, on line, as pamphlets and as articles. -A Canadian research agenda and strategy related to the loss of functional autonomy in relation to the construct of ESN syndrome. -Articles on the process of creating a partnered research agenda in academic and lay platforms. 	<ul style="list-style-type: none"> - CIHR-IA and Canadian Researchers in Aging. - Natural and informal supports and service providers for at risk seniors. - Seniors at risk of being “diagnosed with ESN syndrome”. - Health and Guardianship systems.

Contextual Factors: Canadian history of entitlement to health and autonomy, Canadian voluntary and formal health systems, systemic barriers that may arise from re-conceptualizing loss of functional autonomy as elder self neglect.

Intermediate Outcomes	Intended Beneficiaries	Long Term Outcome Arenas	Major Life Domains
<p>Policy</p> <ul style="list-style-type: none"> - Integration of priorities into Canadian research agendas. - Understanding of how the label 'ESN syndrome' might effect access to community supports and services - Clarify the use of the medical terminology in Guardianship processes for at risk seniors. 	<ul style="list-style-type: none"> - Canadian public. - Seniors at risk of losing functional autonomy. - Support and service providers. - Health care providers. - Public Guardians. 	<ul style="list-style-type: none"> - Maximize the potential for seniors to maintain functional autonomy. - Promote public awareness of the obstacles faced by seniors in maintaining their independence. - Promote awareness of the importance of seniors as research partners. 	
<p>Practice</p> <ul style="list-style-type: none"> - Facilitate the role of seniors in negotiating Canadian research agendas. - Promote the potential roles for seniors in collaborative research methods. - Promote the need for ethical procedures and strategies when engaging high risk seniors in situations where harm may be a factor in the research intervention. 			
<p>Behaviours</p> <ul style="list-style-type: none"> - Seniors will become more active partners in setting collaborative research agendas. Their perspectives will be heard and their skills acknowledged. 			



Why Is This Important?

The rapid increase of numbers of very old seniors, the diminishing access to primary care for seniors, and inadequate funding in home care create an incubator for the development of conditions understood as ESN. In order to prepare a proactive Canadian response, we need to review research trends and offer new ways of thinking about functional autonomy and ESN, ground our understanding in survivors, establish new partnerships and directions in research, build the capacity of seniors to be involved in this research, and find ways to involve seniors as participants.

How Do We Plan to Accomplish This?

The purpose of this research is to establish a first Canadian ESN research agenda. The study will follow the “READY: Setting the Agenda for Your Research” chapter of *Grey Matters* (Marlett and Emes, Chapter 7 in this book). Seniors will be trained in facilitating focus groups and interviewing. We will:

1. Gather interest and awareness through a workshop where we will recruit eight to ten seniors willing to be trained as researchers. Others may join working groups related to the topic.

2. Clarify the problem. We intend to accomplish this by: (a) providing awards to PhD and postdoctoral students to look at research trends in biomedical, functional, social, and personal (autonomy) research that could open new lines of inquiry; and (b) interviewing seniors who help and befriend those with ESN to describe lived experiences and create sample vignettes. Note: there will be no direct contact or identifying information gathered during this grant.

3. Attract other players through focus groups with those providing in-home support (Meals on Wheels, shoppers, elder abuse shelter), Public Guardian representatives, and seniors’ health professionals

(mental health, homecare professionals, and physicians). We will explore the topic and language used. For example, “What impact would the term ‘elder self-neglect’ have on your work and communications with other groups and families?” “What research would you like to see done to clarify the issues and challenges you face?”

4. Negotiate a Canadian research agenda. Materials from the above steps will be sent to forty invitees (senior researchers, award winners, representatives from focus groups, stakeholders, and experts identified in the process) to a two-day research forum sponsored by the Kerby Centre of Excellence, the Office of the Public Guardian, and the Community Health Sciences department. Participants will discuss the materials and make recommendations on priorities, partners, and strategies to include seniors as researchers and participants.

5. Prepare research reports and plan submissions to CIHR and related funding sources and facilitate a collaborative grant.

Before commencing any activities, the project will be approved by the appropriate university ethics committees. The project will consider ethical issues related to this type of research.

Why Should We, Seniors and Academics, Do This Research?

The Kerby Centre of Excellence and the University of Calgary have established a good working relationship and KCE holds a unique knowledge and skill set related to seniors as researchers, which has been used in three research projects to date. Kerby staff and volunteers supporting isolated seniors have assisted in the preparation of this proposal and will continue to be involved. The investigators have ongoing and direct contact with health care providers, the Office of the Public Guardian, and Jewish Family Service Calgary.

A Canadian Institutes of Health Research funded project investigated the potential of seniors as researchers this informs the methodology of the current project. The KCE hosted the first National

Senior's Assembly in collaboration with CATALIST (<http://dev.www.uregina.ca/catalist/>), a network of over fifty seniors-led third age learning agencies to discuss seniors-led supports and services, education, research, and policy development. An agreement was reached to create a Canadian network of trained senior researchers to take up issues important to seniors. This research committee will advise the next steps in the creation of a national research proposal.

Seniors and seniors-led services are increasingly providing support and guidance to vulnerable seniors and, as peers, they have the advantage of being trusted and able to promote autonomy. We have chosen to begin the study by listening to elderly volunteers (most in their 70s and 80s) who visit isolated and frail seniors, because they bring an insider perspective to what counts as functional autonomy for the very old. The principle investigator, herself a senior, comes to health research from Community Rehabilitation and Disability Studies. Her research includes: the development of an Adaptive Functioning Index (Marlett, 1971), which is a measure of functional abilities, problem-solving, and cognitive abilities; training of marginalized populations in the use of research; narrative in achieving personal autonomy; and the determination of the need for guardianship.

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