



# Building mental health capacity with older people who compulsively hoard

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## Abstract

People who are compulsive hoarders (CH), “cannot achieve their fullest health potential unless they are able to take control of those things which determine their health” (Ottawa Charter for Health Promotion, 1986, p.1).

Today there is a need to shift away from a model of stress to one of health seeking behaviours that has the potential to promote and empower hoarders and their family members to develop effective coping styles.

The Population Health Model approach (1996) is a tool that can be used to assess conditions of CH and the wider community,

moving away from a victim-blaming approach to a more comprehensive determination of factors that contribute to ill health and injury. Strategies need to incorporate a broad range of services, therapies, and systems that work together within <local> communities to build mental health capacity, improve public health outcomes, and quality of life for CH and their families.

Much more research is needed, beginning with the development of more effective instruments that fully capture the complex phenomenology of the disorder.

## Introduction

The etymology of the words “hoard” and “hoarding” brings a historical perspective to a modern day mental health problem. Hoard comes from the Old English word ‘hord’ meaning treasure and secret place while hoarding is described as a temporary fence made of boards (Hoad, 1986). Today, the commonly accepted definition of hoarding is, “a debilitating disorder characterized

by the acquisition of a large volume of possessions that clutter living areas to such a degree that living spaces cannot be used for their intended purpose" (Steketee, Frost, & Kim, 2001). In this article the authors present strategies to build mental health capacity with older people who compulsively hoard.

For many people who hoard their home becomes a secret place; a place that others are not permitted to enter. Ever heightening fences cut their yards off from the rest of the world. This secret life leads to loneliness, social exclusion, and unhappiness (Frost & Steketee, 2010; Nedelisky & Steele, 2009). Hoarding has been described as a spectrum disorder of obsessive compulsive disorder but recently may be viewed as a disorder in its own right (Frost & Steketee, 2010; Tolin, Frost, & Steketee). Hoarding in older people may have begun as early as childhood, but remained a secret until later in life. Diogenes hoarding in contrast does not commence until later in life and is accompanied by self-neglect and squalor. Cognitive deficits are not sufficient to explain the self-neglect (Murray, 2008).

Images portrayed to the public about people who hoard often depict them in negative terms, such as aloof, lazy, difficult and resistant. These images, whether they are based on reality or not, seem to prevent the development of a therapeutic relationship (Chapin, McKenzie, Landry, Reynolds, Rachlin, & Koenig, 2007). In order to promote a therapeutic relationship and build mental health capacity, there is a need to move towards a model of promoting health with the individual and family, strengthening community action and enhancing their need to control their life.

### **The role of environmental health officers**

One of the major roles of environmental health officers (EHOs) is to protect the health, well-being, and safety of Albertans, as directed by the Alberta Public Health Act (Statutes of Alberta, Chapter P-37, RSA 2000).

In Alberta, EHOs are appointed executive officers under the Public Health Act (Chapter P-37, RSA 2000, Section 1), and have the right of entry into all public places, including rental accommodation facilities. Where a public health nuisance exists in a private place, an EHO may enter with the permission of the owner, or may apply to the Court of Queen's Bench if necessary (Chapter P-37, RSA 2000 Section 1(hh)(hh)(ii) Section 60, 61).

EHOs accept referrals and also respond to complaints related to housing conditions. Investigation of referrals and complaints may lead to the discovery of a hoarding situation. In some cases, the accumulation of 'stuff' prevents access to the bathroom, the kitchen, and even to a safe place to sleep, and may present a fire hazard or obstruct emergency egress. Pest infestations, plumbing problems, lack of running water, and other maintenance issues may not be evident until they reach a crisis.

An EHO who finds conditions that are obviously unsafe and unsanitary is obliged to take steps to ensure that these conditions are corrected to protect the health and safety of the public. When hoarding is extreme, monitoring the environment can become a challenge for EHOs.

Unfortunately, extreme measures, including mandatory cleaning of the environment may be necessary to ensure the health, well-being, and safety of those living in the home. The conditions in the home may also affect neighbours; for example, a bed bug infestation may not be successfully treated in a multi-family building where the suite of the hoarder harbours these pests.

When hoarding cases are identified, dealing with the related mental health issues is out of the scope of training of EHOs. A

multidisciplinary approach which focuses on early intervention; establishment of a trusting, caring, and therapeutic relationship; promotion of individual and family strengths/promotion of mental health; and on-going support to enable prevention of a relapse are integral to development of successful treatment for hoarding.

### **Seniors Association of Greater Edmonton (SAGE) This Full House Program**

This Full House, a program operated by SAGE (Seniors Association of Greater Edmonton) has been helping individuals 55+ living in the community, not only addressing the complexity of dealing with years of accumulated 'stuff,' specifically compulsive hoarders, but also facilitates a process whereby older people seek positive ways for exploring life changing opportunities. The program provides education about the behaviours associated with compulsive hoarding, teaches new methods of dealing with the accumulation of 'stuff' and assists older people in reaching out to others to share their triumphs. The program works in partnership with the This Full House Advisory Committee which is comprised of community agencies with an interest or experience in the area and a research team at the University of Alberta.

Every client who is referred receives a comprehensive in-home hoarding assessment. From there, the client collaborates with a multidisciplinary team to develop an action plan, which is client-centered and focuses on the values, needs, and wishes of the client. A personal assistant, works together with each client in implementing and evaluating their action plan. During the action planning process and afterward, a social worker continues to provide ongoing support to the individual. In addition, individuals have the opportunity to attend a monthly support group, where they meet others who also live with compulsive hoarding.

Outcomes that clients have achieved include:

1. Prevented homelessness: 100% of client referrals who received an eviction notice have remained in their home.
2. Increased senior's connection to other community services such as Home Care, meal delivery services, and medical services.
3. Increased client referrals to the program as a result of heightened community awareness initiatives (e.g. media interviews, articles and publications etc.).
4. The older person's quality of life improved. Clients reported a gain in confidence in facing challenges, a willingness to explore their hoarding behaviours, and the opportunity to socialize more.

Doneka Simmons, a social worker who has worked as the program lead since the beginning, says, "each and every one of these individuals are inspiring to me because of their courage and how they show that even though change is hard, they are doing it and reaping the rewards of doing something different to make positive changes in their life."

### **A call to action: promoting health and empowering older people who hoard**

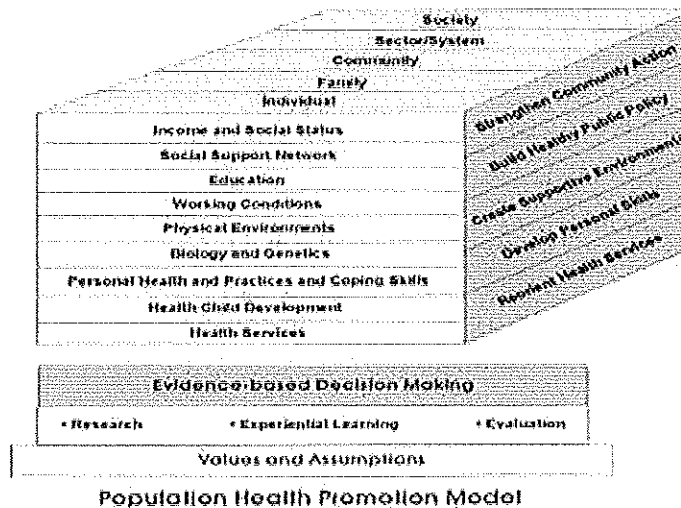
Strategies for the treatment for compulsive hoarders (CH) are extremely difficult, because they have a complex range of symptoms, and often success requires the person to have a high degree of motivation for treatment (Saxena & Maidment, 2004).

Approaches may include: intensive treatment programs (Saxena & Maidment, 2004); modification of faulty beliefs, assistance with organizing, examination of emotional attachments (Steketee, Frost, & Kim, 2001); cognitive-behavioral therapy (Rodriguez, 2010); and therapeutic and support groups

(Haase, Coulson, & Watkins, 2011). While medications may be used, “no pharmacotherapeutic study has specifically targeted the compulsive hoarding syndrome” (Saxena & Maidment, 2004, p. 1146).

Strategies to treat and manage CH need to include a shift away from a “model of stress response to health seeking behaviour” (Wilbram, Kellett, & Beal, 2008, p.71) and have the potential to promote and empower hoarders and their family members to develop coping strategies (Haase, Coulson, & Watkins, 2011). MacKian (2005) argues that when this shift occurs, “we will begin to see the value of understanding health seeking behaviours, not as something that resides in the individual, but as a reflection of wider societal processes and something that *is* related to the health system” (p.19). Researchers have therefore begun to explore “the way in which the local dynamics of communities have an influence over the well-being” (MacKian, 2005, p. 3), and health of individuals.

Participants in Haase, Coulson, & Watkin’s (2011) study emphasized how hoarders collaborated with other hoarders in their local community, arranging garage sales, attending educa-



Population Health Promotion Model

tion sessions, joining support groups, and providing motivation and emotional support to each other, which promoted health and strengthened community action.

The “Population Health Promotion Model” (Figure 1) Hamilton and Bhatti (1996) was expanded from the *Ottawa Charter for Health Promotion* (1986) and could be used as a plan for action. The Ottawa Charter supports that health promotion is the process of facilitating people to improve and increase control over their health and environment by building healthy

public policy, creating supportive environments, strengthening community action, education for health and enhancing life skills, and reorienting health services.

Services are then shared among individuals, community groups, health professionals, health institutions, and governments. The Population Health Promotion Model “can be implemented through action on the full range of health determinants by means of health promotion strategies” Hamilton and Bhatti (1996, p. 1) and includes the need for evidenced-based decision-making in developing strategies.

Figure 1: Population Health Promotion Model Public Health

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Agency of Canada, Hamilton, and Bhatti (1996)

Health promotion strategies need to include an analysis of how the determinants of health have an impact on the population of CH and their need to enhance control of their life (e.g. income, physical environment, health services). Strategies that support health promotion could include a co-ordinated-integrated task force consisting of community groups, health professionals, health services, institutions, and governments, to develop shared goals that help families and people who are CH to take control of their environment and health.

Furthermore, organizations need to work together to enable families and people that hoard to feel safe to connect to available community resources. A co-ordinated system that includes CH and their families as partners within the decision-making-process, enables joint action and leads to safer and healthier communities and has the potential to foster community participation (Ottawa Charter for Health Promotion, 1986; Hamilton and Bhatti, 1996; MacKian, 2005).

Co-ordinated systems could include a community multidisciplinary (MD) triage team who meet regularly to collectively share communication, services and education between organizations and identifying evidence-based practice, so that programs can be designed with CHs (Chapin, McKenzie, Landry, Reynolds, Rachlin, & Koenig, 2007). Ideally triage services could be bundled so that professionals are able to provide a range of services for CH and their families; thereby, increasing therapeutic relationships (Haase, Coulson, Watkins, 2011).

### Conclusion

"People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health" (Ottawa Charter for Health Promotion, 1986, p. 1). The Population Health Model provides a tool to analyze and assess conditions and communities that place CH at risk.

This approach facilitates a "move away from a victim-blaming approach to a more comprehensive determination of factors that contribute to ill health and injury" (Vollman, Anderson, & McFarlane, 2004, p. 24).

Strategies need to incorporate a broad range of services, therapies, and systems that work together within local communities to improve mental health, public health outcomes, coping strategies, and quality of life for CH and their families.

In addition, much more research is needed, beginning with the development of more effective instruments that fully "capture the complex phenomenology of the disorder" (Mataix-Cols & Conceicao do Rosario Campos, & Leckman, 2005, p. 235). The International Obsessive-Compulsive Disorder (OCD) Foundation supports that the mission and goal should be to educate the public and professionals, raise awareness, support research, advocate, and lobby for the OCD community and to improve access to resources for those who suffer from an obsessive compulsive disorder ([www.ocdfoundation.org](http://www.ocdfoundation.org)).

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