

Older adults and hoarding: Challenging medical and ageist constructions

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Abstract

The purpose of this article is to critically analyse the dominant discourses surrounding older adults who are labelled with a diagnosis of hoarding disorder. Hoarding has increasingly attracted social interest in recent decades, with a growing number of television shows, books and media dedicated to unpacking the explanations, implications and treatments of hoarding behaviour. The article seeks to disrupt deficit frameworks, applying critical social work perspectives to create new meanings, policy and practice directions for Social Workers. Informed by a postmodern and critical social work approach the article seeks to analyse how power is socially and systemically constructed, questioning universal grand narratives. It seeks to highlight how our understanding of hoarding is informed by Western, ageist and gender discourses. This theoretical platform recognises the diversity of human experiences, and the many ways in which people construct meaning throughout their lives. The article concludes with recommendations for future research.

Keywords

Hoarding; discourse; gender; ageing; social work practice

Introduction

Hoarding has increasingly attracted social interest in recent decades, with a growing number of television shows, books and media dedicated to unpacking the explanations, implications and treatments of hoarding behaviour (Orr et al., 2019). While the number of academic studies have similarly accelerated, few have specifically looked at the experiences of older adults who collect and keep items (Eckfield et al., 2013). Given that the rate of hoarding in older adults is said to be significantly higher than that of the general population (Ryninks et al., 2019), this represents a gap in current literature and policy.

The purpose of this article is to critically analyse the dominant discourses surrounding older adults who are labelled with a diagnosis of hoarding disorder. *Section 1* of the article will deconstruct the prevailing medical and ageist understandings of hoarding, drawing on recent studies and policy examples in Australia. *Section 2* seeks to disrupt these deficit frameworks, applying critical social work perspectives to create new meanings, policy and practice directions for Social Workers. The article concludes with recommendations for future research.

The article is informed by a postmodern and critical social work approach which is concerned with analysing how power is socially and systemically constructed, questioning universal grand narratives (Harms & Connolly, 2012; Morley, 2003; Fook, 2002). This theoretical platform seeks to practice in ways that do not perpetuate domination and oppression. Instead, it recognises the diversity of human experiences, and the many ways in which people construct meaning throughout their lives.

Section 1: Dominant discourses

The most common definition of hoarding applied across policy and academia is by Frost & Hartl (1996), who sought to differentiate clinical compulsive hoarding from generalised hoarding behaviours. Their definition characterised clinical hoarding as “the acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value” (Frost & Hartl, 1996, p.342), with a resulting preclusion from usable living spaces and significant personal distress or impairment. The formation of this definition coincided with

broader societal moves to medicalise hoarding from the 1990's, whereby hoarding behaviours were viewed as a deviation from psychosocial, ethical or legal norms (Shaeffer, 2017).

Medicalisation of hoarding culminated in its classification as a unique disorder in the DSM-5, released in 2013 (Orr et al., 2019). Since then, dominant cultural and clinical understandings of hoarding have been shaped by the prominence and power of the DSM (Orr et al., 2019; Macfarlane, 2009). This is strengthened by the dominant White Western narratives of wellbeing that prioritise individual rights and self-actualisation (Quinn, 2009) and locate the 'problem' in the mind of the individual, rather than within society (Orr et al., 2019; Fitzpatrick, 2018). Here, a messy home is perceived to mirror an individual's chaotic inner life (Lepselter, 2014). This is a gendered issue, as the domestic failure to maintain a "clean" home is loaded with moral judgement against women who continue to be placed as the proprietors of this domain. A women's neglect of home is not just emblematic of her neglect of self, but also of her family (Lepselter, 2014). Ageism intersects with these discourses by attributing older person's health challenges to the normal process of ageing, silencing or undermining their voices and concerns (Airth & Oelke, 2020). The Australian Human Rights Commission (2019) submission to the *Royal Commission into Aged Care Quality and Safety* affirmed the impact of ageism and sexism in Australia's healthcare system. It argues that ageist discrimination manifests in deficit views of older adults as "less deserving, incapacitated, burdensome and needing protection" (Australian Human Rights Commission, 2019, p.17) and that "the impact of gender inequality throughout a woman's lifespan is exacerbated in old age" (p. 22). Recent literature has warned that the current construction of 'hoarding disorder' might similarly end up generating more stigma, overriding any benefit gained (Orr et al., 2019).

The stigmatising impact of medical and ageist responses to hoarding in older populations can be seen across academia, policy, and social dialogue. In the literature, hoarding has been labelled in as a "debilitating mental illness" (Wheaton et al., 2015, p.208), a "disabling psychiatric disorder" (Kings et al, 2017, p.51), where by a person is said to have "poor insight" (Postlethwaite et al., 2019, p. 315), potential genetic deficits (Hirschtritt & Mathews, 2014) or neuropsychological impairment (Tolin & Slyne, 2014). Other literature links elders who hoard with deviant personality traits such as "stubborn, aloof, independent, domineering, quarrelsome, and unfriendly" (Roane et al., 2017, p. 1083). In Australian government policy documents, hoarding is "associated with physical and/or mental incapacity" (Government of

South Australia, 2013, p.7), and “the result of a number of psychiatric disorders” (City of Sydney, 2021a, para.1). The Western Australian Department of Health (2013) hoarding toolkit goes on to frame people who hoard as having potential “behaviour management or poor self-management issues” (p.8). This framework has also pervaded television and popular media, such as the *Hoarders* docuseries which seeks to “give them the tools they need to keep their behaviour in check” (SBS on Demand, para.1). These reductionist and homogenising narratives of what it means to live and experience hoarding deny the agency of people who are labelled as disordered (Orr et al., 2019). Diagnostic labelling also affixes seriousness and a sense of permanency to these perceived deficits (Read, 2007; as cited in Briskman et al., 2009). Furthermore, it legitimises interventions to ‘fix’ the problem: with the help of an expert they can become rational choice-makers (Lepselter, 2014). This behavioural-psychological ‘fixing’ extends into medical treatments (Shaeffer, 2017), therapy, or the use of mental health legislation (Orr et al., 2019).

The concept of *self-neglect* is a pervasive label that contributes to these discriminatory and individualised narratives of hoarding amongst older adults. Self-neglect is defined as an individual’s inability, failure or unwillingness to meet basic aspects of their care, health and lifestyle (Roane et al., 2017; Government of South Australia, 2013). While first identified in the 1950’s (Day et al., 2016), the term continues to appear in policy and literature in reference to older person’s wellbeing, as recently as the City of Sydney (2021a) guide for hoarding support. At its most extreme application, a diagnosis of *Diogenes Syndrome* is viewed as a pathological form of self-neglect reserved for older adults, characterised by a “lack of self-respect, social withdrawal, apathy, having a tendency to hoard a willingness to live in domestic squalor, and often a lack of shame” (Day et al., 2018, p. 135). Ironically, these discourses perpetuate the shame with which they attempt to diagnose. Perhaps ‘lack of respect’ and ‘unwillingness to meet basic aspects of care’ is a diagnosis best applied to the medical system, rather than the individual.

Medical problematisations have dictated the types of solutions offered by government and providers. Means (2007) states that policy has shouldered responsibility and cost for older person’s mental health onto local services and families. This trend has been widely linked to Neoliberal ideals, specifically the decline in government spending on welfare and wellbeing of citizens (Fitzpatrick, 2018). As a result, wellbeing has become a commodity rather than a right (Airth & Oelke, 2020). The Neoliberal privatising and localising of mental health

services is concurrent with the steadfast focus on providing individual psychological intervention (Shaeffer, 2017). The cognitive behavioural model has received the most attention in the literature on hoarding, implying that problems wrest with the individual who has an erroneous attachment to objects (Ruby-Granger, 2020). A current example is the *Buried in Treasures* hoarding group support program which is based on the popular self-help book “Buried in Treasures” by Tolin, Frost & Steketee (2013). It uses psychological and CBT principles, characterising hoarding as foremost a problem of an individual’s “emotional, mental, behavioural and social wellbeing” (Tolin et al., 2013, p.65). The program is run by local healthcare providers, predominantly in aged care spaces (City of Sydney, 2021a; Catholic Healthcare, 2020). While access to the program for older adults is government-subsidised under the aged care Commonwealth Home Support Program (CHSP), availability and access to ongoing support is location-based; dependant on whether funding is allocated, and then whether the dedicated government provider offers the service. Furthermore, failure to engage in intervention can result in increasing coercive measures by the State, such as child removal (Tolin et al., 2008), guardianship (Connolly, 2008), eviction (Shaeffer, 2017), and legislative orders including fines amounting to \$2,200 (City of Sydney, 2021b). This highly fragmented and problematised approach to hoarding impacts upon the quality and availability of support, particularly for older populations. It also ensures that dominant narratives remain focused on the individual, rather than the social-political.

Section 2: Critical Social Work Perspectives

Medical supports and intervention have some merit: for some a diagnosis of hoarding disorder can be liberatory, providing a supported pathway for sense-making and change (Orr et al., 2019). However, medical frameworks cannot continue to be privileged at the expense of other ways of knowing (Glasby & Beresford, 2006). The range of ways in which people have come to understand their hoarding experiences are as diverse as the people themselves. Daya et al. (2020) contemplate how to authentically engage consumer-survivor views in mental health settings, stating that all voices must be openly welcomed into the space. This reflective stance is taken throughout this section of the article, which looks towards critical social work perspectives in exploring how the diversity and complexity of hoarding experiences might be embraced.

Centring lived experience

There is emerging qualitative literature which attempts to understand the lived and living experiences of people who hoard (Ruby-Granger, 2020). However, many of these studies focus on third-party informants such as volunteers (see: Ryninks et al., 2019) and family members (see: Neziroglu et al. 2020; Garrett, 2020). Fewer studies directly engage with people experiencing hoarding themselves (Orr et al., 2019). Even fewer still are the voices of older people in the literature on hoarding. Epistemic injustice occurs when a person is wronged in their capacity as a knower (Fricker, 2007). This silence compounds the dominant stigmatising practices surrounding older adults and hoarding described in *Section 1*. It is therefore argued in this article that to gather social power, attention must be paid to the first-hand voice, knowledge and experience (LeBlanc & Kinsella, 2016). Bernard & Scharf (2007) speak of “bringing elders back in” (p.9) as partners in exploring their realities, with the view to work together to promote change. This includes co-creating counterstories that challenge dominant constructions of hoarding (Brown & MacDonald, 2020). However, ageist assumptions are a significant barrier to achieving this change, as they patronise, infantilise and minimise elder’s voices, ultimately excluding them from decisions about their own care (Australian Human Rights Commission, 2019). Compounding this issue is the stigmatised view that people who hoard have ‘poor insight’ or ‘impairment’ that prevents them from participating in decision-making. This is a major area for future Social Work enquiry and disruption.

Shifting language

Orr et al. (2019) observed that, contrary to the binary hoarder/collector discourses, there exists a diverse array of meaning and language used by people to describe their relationships to hoarding. As Sophie, a participant in the Orr et al. (2019) study, aptly stated “All hoarders are individuals with individual reasons” (p. 268). Reflecting on the VMIAC Declaration’s (2021) call to recognise the diversity of mental health experiences through language, perhaps the term ‘hoarding’ needs to sit alongside a spectrum of diverse terminology, as defined by people themselves. A quick internet search of peer-led programs reveals alternate language, including the *Messies Anonymous* support group for “people who are creative, busy and overwhelmed” (Messies Anonymous, 2022, para. 4) and the *Clutterers Anonymous* (2022) support group which addresses physical, mental, emotional and spiritual clutter. Ruby-Granger (2020) recently put forward ‘a struggling to manage’ as alternate language to

hoarding disorder after interviewing 11 adults who self-identified as having challenges with hoarding. However exploration of language and counter-narratives led *by* people, particularly older adults, is limited both within and outside formal systems.

Critical reflexivity

Studies proclaiming to centre lived experience can still privilege the psychological approach. One example is the Subramaniam et al. (2020) study which sought to go beyond the psychological model to acknowledge “that social reality is shaped by lived experiences and social contexts” (p. 458). However, the questions participants were asked, such as how the hoarding behaviour first started and the impairment or consequences associated, falls back on individual behaviour and deficit frameworks. This is reminiscent of ‘lifestyle-drift’ which describes how research and policy can set out with holistic intentions, but ultimately reverts to the individualised behaviourist approach (Fisher et al., 2016a; as cited in Shakespeare et al., 2020). It is no wonder that in their conclusion, Subramaniam et al. (2020) state that the “themes identified in this study mapped well to the DSM-5 criteria of hoarding” (p.464). This demonstrates the sheer power of dominant discourses in shaping research and policy. What is required, but often not accounted for, is reflexive analysis of positionality when conducting research and policy-making. This involves interrogation of the taken-for-granted claims to knowledge that contribute to unequal power relations (LeBlanc & Kinsella, 2016). Without such critical processes in place, the medical and ageist lens on hoarding will continue to be silently centred.

Ecological systems thinking

Medicalisation has the power to frame a person’s skilful adaption to complex societal circumstances as a deficit pathology (Conrad & Schneider, 1992 as cited in Shaeffer, 2017). Ecological systems thinking is one potential antidote to this discourse, respectfully recognising that human behaviour is deeply cultural, social, political, economic and contextual (Harms & Connolly, 2012). This framework also appreciates the varied expressions and meanings attached to mental health across cultural and local settings (Miller et al., 2006 as cited in Quinn, 2009). For people who experience hoarding, instead of seeing their collected objects as “useless or of limited value” (Frost & Hartl, 1996, p.342), an ecological perspective might better understand them as tokens of emotion, symbols of obligation to family, signals of social class, reflections of consumerism, or a person’s

mindfulness of wasteful disposing (Shaeffer, 2017). Some studies have also identified a connection between traumatic life events and hoarding (Cromer et al. 2007 as cited in Ruby-Granger, 2020). For older adults who are survivors of the Second World War, collecting items might have historical meaning, as Bruce who is a participant in the Orr et al. (2019) study explains: “Everything had a value, every bit of wood, nails from packing cases. We would straighten them and collect everything, because everything in my eyes then, and indeed now, has potential use” (p. 269). Hoarding activities might also form part of hobby collecting, which was viewed as a social norm in Western society for many years, particularly amongst retirees in the later stages of life (Shaeffer, 2017). Shaeffer (2017) therefore conceptualises hoarding as “social phenomena with deep historical and social roots” (p.1). This frame has the added benefit of recognising collective experiences of hoarding. It also steps back from the prevailing assumption that hoarding is the core issue to be addressed (Orr et al., 2019). Shaeffer (2017) posited that hoarding behaviours might be better viewed as normal human activities, that are neither unusual nor disordered. Assigning meaning and memories to objects, or collecting furniture and ornaments as symbols of social status, these are very relatable and human ways of being in the world (Shaeffer, 2017). Orr et al. (2019) commented upon the psychiatric over-reach of the DSM, specifically noting its capacity to diagnose otherwise unremarkable human experiences. It is therefore a recommendation of this paper that future hoarding supports recognise multiple aspects of being beyond individual, physical or mental, to include: emotional, familial, cultural, communal, spiritual, and historical. It also requires a critical focus on the broader political and social landscape within which these experiences are nested.

When leaning into this complexity, tensions naturally arise. This includes balancing the rights of an individual with the rights of the community, and the social policies surrounding them. One example is dignity of risk. A person who has dedicated years to collecting newspapers has a right to keep these items and accept the safety risk they may pose. However, a neighbour may be concerned about the volume of combustible materials, and has a right to safety. Government policy may privilege immediate enforcement of public health standards, while a local NGO might have a duty of care to the person and take a psycho-behavioural intervention. Meanwhile, stigmatising and oppressive social norms may play out across these interactions. Adequate time and funding are required for communities to collectively respond to these complexities. However, the lack of resources is an ongoing issue that detracts from appropriate support and service provision.

Recognising resistance

Resistance is often understood as ‘speaking out’ against dominant systems (Gray, 2007). However, speaking out is not the only pathway to advocacy. Resistance also occurs in silent and subversive ways across society, and these collective stories can be found in the literature on hoarding. For example, researchers often lament the unwillingness of people who hoard to acknowledge that they have a mental health problem (Ryninks et al., 2019). People’s choice to disengage from diagnostic labelling might then be better understood as a resistance strategy. Studies also discussed the issue of “high dropout rates, therapy-interfering behaviours, and initial refusal to engage in treatment” (Kings et al., 2017 p.56). This could be reframed as active resistance against ineffective and oppressive interventions. Orr et al. (2019) observed that interviewees in their study both adopted and disputed mental health framings according to their usefulness, a further demonstration of exploring and challenging dominant narratives of the self. LeBlanc & Kinsella (2016) speak of *epistemic resistance* as the fight against injustice that belongs to the collective body of people. This radical collective approach completely strips back the individualised medical lens, and further places collecting items as a normalised human response to complex social contexts.

Conclusion

This article has challenged many of the deeply held assumptions on hoarding and ageing. It has drawn on examples to demonstrate how stigma and discrimination play out across policy, academia and practice settings. It has also called on practitioners to enact change: to embrace diverse ways of knowing about hoarding, and discard unhelpful pathologies. This includes seeing the person in their environment, and their objects as connected to their being in ways that are profoundly human. A major finding of this article is the pressing need for meaningful engagement in policy and literature with people who have themselves lived as collectors, hobbyists and hoarders. Social workers are in a unique position as proponents of this change, obliged by Australian Association of Social Workers (2020) to challenge unjust policy and practice. By undertaking these advocacy practices, Social Workers and other practitioners can push the mental health system to take seriously the social inequities that surrounding hoarding and ageing.

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