



Review

Functioning and quality of life in hoarding: A systematic review



Clarissa Ong*, Shirlene Pang, Vathsala Sagayadevan, Siow Ann Chong, Mythily Subramaniam

Research Division, Institute of Mental Health, 10 Buangkok View, Singapore 539747, Singapore

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ABSTRACT

Hoarding, the acquisition and inability to let go of a large number of possessions, has been found to be associated with high levels of impairment that can compromise functioning and quality of life (QoL). Yet few studies have specifically investigated the relationship between hoarding and functioning/QoL. The present review aimed to summarize the current status of research on functioning and QoL in hoarding as well as identify knowledge gaps in the extant literature. We conducted systematic searches in ProQuest, PsycINFO, PubMed and ScienceDirect, and identified 37 relevant articles for inclusion. There was much evidence to indicate that hoarding has a significant impact on various aspects of functioning and that functioning can improve with treatment, though findings on the relationship between hoarding and QoL were more tenuous. The limitations of previous studies and implications of our findings are discussed.

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1. Introduction

Hoarding is defined as the acquisition and inability to let go of a large number of possessions, resulting in clutter that precludes the use of living spaces for their intended purposes (Frost & Hartl, 1996). Compulsive hoarding was originally conceptualized as a subtype of obsessive-compulsive disorder (OCD), but is currently classified as a distinct disorder – hoarding disorder (HD) – under

the chapter on obsessive-compulsive and related disorders in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; American Psychiatric Association [APA], 2013). HD has its own diagnostic criteria in the DSM-5, which diverges slightly from the proposed tripartite model of hoarding that highlights difficulty discarding, excessive acquisition, and excessive clutter as salient features of the pathological syndrome (Frost & Hartl, 1996; Frost, Steketee, & Grisham, 2004). For example, excessive acquisition is listed as a specifier – not a symptom – in the DSM-5 definition of HD (APA, 2013), even though studies indicate that the overwhelming majority of individuals who hoard (86–100%) have acquisition problems (Frost, Rosenfield, Steketee, & Tolin, 2013; Frost, Tolin, Steketee, Fitch, & Selbo-Bruns, 2009; Mataix-Cols, Billotti, Fernández de la Cruz, & Nordsletten, 2013).

* Corresponding author. Tel.: +65 6389 2573; fax: +65 6343 7962.

E-mail addresses: wei.yi.ong@imh.com.sg (C. Ong), shirlene_pang@imh.com.sg (S. Pang), vathsala.sagayadevan@imh.com.sg (V. Sagayadevan), siow_ann_chong@imh.com.sg (S.A. Chong), mythily@imh.com.sg (M. Subramaniam).

Epidemiological studies have estimated the prevalence of clinically significant hoarding to be between 2 and 6% (Iervolino et al., 2009; Nordsletten, Reichenberg, et al., 2013; Samuels et al., 2008; Timpano et al., 2011), indicating that it is a relatively common condition in the community. Furthermore, the consequences of hoarding may extend beyond the individual concerned, affecting family members, neighbors, and even the wider society (Tolin, Frost, Steketee, & Fitch, 2008; Tolin, Frost, Steketee, Gray, & Fitch, 2008). The present review, however, focused on the impact of hoarding on the individual's functioning and quality of life (QoL).

There is currently no universal or comprehensive definition of QoL. The World Health Organization (1997) conceptualizes QoL as “[the perception of individuals] of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.” QoL is an overarching construct that depends on individuals' “physical health, psychological state, level of independence, social relationships, personal beliefs, and . . . relationship to salient features of their environment” (WHO, 1997). In other words, QoL is a highly subjective concept contingent on people's view of their current status relative to their surroundings as well as personal standards. Functioning, on the other hand, broadly refers to the ability to perform specified actions or activities (Ayers et al., 2013), such as completing tasks at work (occupational functioning) or interacting with friends (social functioning). Compared to QoL, it is a more objective construct since it does not necessarily depend on personal needs or desires. Moreover, little subjective judgment is required to determine whether one is able to carry out a particular task. Nonetheless, although functioning and QoL are two distinct constructs, they are closely related and there is expectedly some overlap between the two.

Hoarding has been linked to high levels of impairment (Frost & Hartl, 1996; Frost, Steketee, & Greene, 2003) and the symptom that appears to be most directly associated with impairment is the accumulation of clutter that results from difficulty discarding and excessive acquisition. Such impairment likely spans across the domains of functioning and QoL, by limiting the capacity of hoarding individuals to carry out various activities as well as by preventing them from accomplishing goals they might have set for themselves. In fact, clutter not only directly compromises functioning (e.g., by restricting ability to navigate and/or utilize living spaces), but can also have other indirect consequences on the individual (e.g., by making him or her too embarrassed to invite others to the home).

Despite this tangible relationship between hoarding and functioning/QoL, few studies thus far have looked at functioning in hoarding – to our knowledge only one study has specifically investigated QoL in hoarding (see Saxena et al., 2011). The lack of research on this topic is of clinical concern because findings on the relationship between hoarding and functioning/QoL could have important treatment implications. For example, a positive association among these variables would suggest that hoarding symptoms cannot be addressed in isolation. Instead, clinicians must consider the myriad ways in which symptoms affect patients' overall well-being and provide more holistic treatment approaches for hoarding that take functioning and QoL into account. Hence, the objective of the present review was to examine the relationship between hoarding and functioning/QoL across a range of contexts, in order to summarize the current status of research on functioning and QoL in hoarding as well as to identify knowledge gaps in the extant literature.

2. Method

The authors conducted systematic literature searches in four databases: ProQuest, PsycINFO, PubMed, and ScienceDirect. The

process was based on an a priori-defined search protocol, which specified the search terms, “hoarding” and “functioning,” “disability,” “impairment,” “quality of life,” “HRQoL,” or “well-being,” producing a total of six search combinations (e.g., “hoarding” AND “disability,” “hoarding” AND “quality of life”). In addition, relevant references from articles were retrieved if they met the pre-determined eligibility criteria, regardless of whether the original article was eventually included in the review. To be included, studies had to (1) involve an assessment of at least one of the three main hoarding symptoms (i.e., difficulty discarding, excessive acquisition, and excessive clutter); (2) report findings specific to the relationship between hoarding and functioning or hoarding and QoL; (3) use an adult human sample; (4) be published in a peer-reviewed journal; (5) be published from 1995 onwards; and (6) be written in English. Case studies, series, and reports as well as articles that evaluated the variables of interest (i.e., hoarding behavior, functioning, and QoL) solely from a secondary perspective (e.g., service providers who work with individuals who hoard) were excluded.

In the first stage, titles and abstracts were carefully screened for relevance, and all potentially eligible articles were accessed for detailed review. Authors were instructed to err on the side of leniency; therefore, articles with any mention of hoarding or functioning/QoL in their titles or abstracts were selected for full-text evaluation. Articles that could not be rejected with certainty were also retrieved and assessed. Each full-length article was then independently evaluated by at least two of the study authors and disagreements were resolved through discussion among the authors until a unanimous consensus was reached. The agreement rate between authors at this stage was 88.7%.

3. Results

3.1. Literature search

Searches in the ProQuest, PsycINFO, PubMed, and ScienceDirect databases yielded a total of 1,929 articles. A review of the references of relevant articles provided an additional three papers. One thousand and eighteen duplicates were removed, leaving 914 distinct papers. Of the 914 abstracts screened, 53 were included. Ultimately, 37 full-length articles were included in the present review (refer to Fig. 1 for an overview of the search process). The most common reason for exclusion was that studies did not directly examine the relationship between hoarding and functioning/QoL, even though the constructs were separately assessed.

3.2. Functioning

Individuals with HD have reported moderate overall impairment (Ayers, Saxena, Golshan, & Wetherell, 2010) as well as greater functional impairment compared to self-identified collectors (Nordsletten, Fernández de la Cruz, Billotti, & Mataix-Cols, 2013). Those with clinically significant hoarding also demonstrated worse overall psychosocial functioning than those without hoarding (Samuels et al., 2008), while patients with hoarding symptoms had worse overall psychosocial functioning than patients with non-hoarding OCD (Chakraborty et al., 2012; Matsunaga, Hayashida, Kiriike, Nagata, & Stein, 2010) despite comparable scores on depression and anxiety scales (Saxena et al., 2011). In the same vein, Matsunaga et al. (2010) found that participants with primary hoarding (i.e., hoarding symptoms were independent of OCD) showed poorer global functioning than those with secondary hoarding (i.e., symptoms were related to OC obsessions). Moreover, individuals who merely had difficulty discarding worn-out or worthless items showed greater disability and functional impairment than those who did not (Rodriguez, Simpson, Liu, Levinson,

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