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COMPULSIVE HOARDING – RESEARCH, SOCIAL AND PERSONAL PROBLEM

ABSTRACT

The paper discusses the syndrome of compulsive hoarding in three aspects: difficulties in defining the phenomenon, features characterising those affected, and auxiliary guidelines in working with hoarders, aimed at taking control over the urge to collect and hoard unnecessary items. The analysis focuses on the problems related to the diagnosis of affected people, the process of support for those affected and the scale of the problem. On the basis of estimates, state that there are between 1% and 2% of people in the entire population suffering from compulsive hoarding which can directly threaten their lives. This amounts to between 3 and 6 million people in the United States, between 4 and 9 million people in the European Union, and between 64 and 129 million around the world. Solutions used in Western European countries towards dysfunctional people with the use of the organisation plan showed only minimal improvement of their living conditions. Aid programmes and day care centres show that effectiveness thereof in combating hoarding is low due to the lack of the hoarder's engagement.

KEYWORDS: *social support, compulsive hoarding, syllogomania, Diogenes syndrome, compulsive hoarder*

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THE PHENOMENON OF COMPULSIVE HOARDING – DIAGNOSIS, SCALE OF THE PROBLEM, SUPPORT PROCESS

The paper discusses the phenomenon of compulsive hoarding, focusing on the problems related to the diagnosis of affected people, the process of support for those affected and the scale of the problem.

DIFFICULTIES IN DEFINING THE PHENOMENON

If it attracts the interests of researchers at all, compulsive hoarding is studied predominantly by psychiatrists and neurologists, as well as geriatricians. In social sciences, only psychology studies the phenomenon of hoarding, whereas, in pedagogy and social work this type of research is absent despite the fact that this issue causes many family and neighbourhood conflicts and is primarily the reason for social exclusion, deepening the isolation of dysfunctional people.

In Western countries a series of studies and surveys have been conducted, descriptions of individual cases of compulsive hoarding have been published, although no systemic and comprehensive view on the phenomenon has been established. In Polish literature, works describing individual cases of compulsive hoarding (Majczak, Marmurowska-Michałowska 1974; Giziński 1984; Książopolska, Kotapka-Minc 2005) also have been published, and several publications based on non-Polish literature have also been issued. While analysing terminology provided in the non-Polish literature, Agnieszka Smrokowska-Reichmann (2008) reports that in English literature the term ‘compulsive hoarding’ is used most frequently, while in German literature the term *Vermüllungssyndrom* is used. Furthermore, in the United States, the colloquial name of this disorder, rarely used by specialists, yet, recognised and popular also in Western Europe, is used: *messie syndrome*.

The first researcher, who created the concept of ‘senile squalor’ was Dr Ducan MacMillan (1966). In his research he drew attention to not following the generally adopted norms of cleanliness, personality traits (quarrelsomeness, imperiousness), as well as the parsimony of people suffering from this illness (Pitt 1986, p. 11). Overtime, elderly people living in filth began to be described by the term ‘Diogenes syndrome’ which came from the name of Diogenes

of Sinope, the representative of the Cynics, who lived alone in the fourth century BC, rejected all comforts, adopted a pauper's lifestyle and lived in a barrel. Over the years many authors expressed doubts regarding the accuracy of this term. Some described this disorder as a 'social breakdown syndrome', others as 'senile recluse syndrome' or 'garbage hoarding syndrome'. Others indicated the relation of this syndrome with obsessive-compulsive disorder. They stated that Diogenes chose his lifestyle himself and there is no sufficient evidence to state that diagnosed people make the same choice.

Due to the ambiguous criteria and insufficient research on the phenomenon of compulsive hoarding, currently, there are many definitions of various semantic scope. Agnieszka Książopolska and Sławomira Kotapka-Minc (2005, p. 108) describe the disorder as: 'acquiring unnecessary items and difficulties in getting rid of items perceived by other people as having little value. This activity impairs, or completely obstructs, professional and social functioning, and limits living space. In consequence, a hoarder cannot use living compartments in the way they are intended. Compulsive hoarding is one of other symptoms that include difficulties in making decisions, achieving goals, perfectionism and avoidance behaviours.' American researchers extend the entire spectrum of hoarded items (from plastic yoghurt cups, clothes and newspapers, to electric and electronic devices) with the adoption of large numbers of animals. Hoarding various items can contribute to an increase risk of fire when such items block emergency exits or when flammable materials such as newspapers and journals are kept near stoves and heaters. The size of these items can make it difficult to control a fire (Frost et al. 2000, pp. 229-230).

A. Smrokowska-Reichmann (2008, p. 3; Książopolska, Kotapka-Minc 2005, p. 108) distinguishes the phenomenon of syillogomania (also referred to as: compulsive hoarding) from Diogenes syndrome. Syillogomania concerns people at any age, who unreservedly overfill their homes with unnecessary items. Whereas, Diogenes syndrome concerns only the elderly; in this case the individual not only compulsively hoards items, but also neglects their personal hygiene and does not follow any sanitary rules at their home. Due to the lack of sufficient research and analysis of the phenomenon, all of the aforementioned terms are imprecise and do not extend the semantic scope of the term compulsive hoarding.

THE SCALE OF THE PROBLEM

Randy O. Frost, Gail Stakette and Lauren Williams (2000, pp. 229-335) describe the first, and so far the only, detailed research on compulsive hoarding conducted at the end of the 20th century in the United States, in Massachusetts by the Department of Psychology in collaboration with Boston university and school of social work (as far as the author of this paper is aware, no such research has been conducted in Poland). Survey questionnaires were sent electronically to 325 healthcare representatives in Massachusetts. The survey questions were divided into two parts. The first referred to information on the number of people serviced (questions regarding the number of hoarding cases reported in 1992-1997, recurring and new cases). The second part concerned the detailed circumstances of given cases (who reported the case, the type of housing, the level of clutter, various institutions' contribution in providing assistance, the final outcome of the case). On the grounds of the research, it was stated that based on the number of 1,790,000 citizens covered with healthcare provided by the institutions participating in the research, the general number of cases amounted to 26.3 per 100,000 citizens in the period of a 5-year research. 48% of respondents reported new cases of hoarding in the surveyed period of time. However, 32% of respondents mentioned the recurrence of the problem.

Hoarding reports were usually submitted by neighbours (52%), or a fire brigade or the police (47%), whereas a small number of cases were reported by social and support organisations. The complaints usually drew attention to bad sanitary conditions and collecting clutter (88%), threat of fire (67%), odour and strange behaviour (53%). Officials reported that in 52% of households, the mess was so significant that it also spread outside the house. 79% of resolved cases required the engagement of services other than health care, and at least half of the cases involved more than one service. Usually: fire brigade, mental health facilities, animal care centres, aid organisations.

Regarding how compulsive hoarding is resolved, the results varied significantly. 32% of dysfunctional people willingly agreed to cooperate in order to get rid of unnecessary items, 28% reluctantly agreed to cooperate, and 40% of discussed cases rejected cooperation, as a result of which their items were removed by the public utilities against their will.

Almost half of the houses were earmarked for demolition and the residents were evicted. Significantly, more reluctance to cooperate in solving the problem was expressed by people with numerous animals (57%). It is worth adding that in the majority of cases, the Department for the Elderly dealt with the problems, which suggests that this issue may affect this group of citizens more severely.

The above research implies that the most frequently collected items included newspapers, magazines and waste paper mainly hoarded in living rooms, kitchens and bedrooms. Almost one third of respondents collected animals. In these cases, the sanitary conditions were worse, thus causing a higher health risk and involving more aid organisations. Also, the behaviour of city authorities was emphasised, since they often took partial responsibility for the situation and covered the costs of cleaning homes against the dysfunctional person's will. In the majority of cases, this effort and incurred costs came to nothing, since the hoarders resumed hoarding as soon as the house had been emptied.

On the basis of estimates, David F. Tolin, Randy O. Frost, Gail Stakettee (2007, p. 16) (at the end of the 20th century) state that there are between 1% and 2% of people in the entire population suffering from compulsive hoarding which can directly threaten their lives. This amounts to between 3 and 6 million people in the United States, between 4 and 9 million people in the European Union, and between 64 and 129 million around the world.

A PERSON WITH A COMPULSIVE HOARDING SYNDROME

According to psychiatrists and neurologists, difficulties with defining the problem of compulsive hoarding stem from the fact that the disorder does not depend on one causative factor. A combination of several factors would seem to constitute the most probable reason for hoarding behaviours. According to American scientists, between one third and half of patients with diagnosed Diogenes syndrome do not have any co-existent mental diagnosis. Therefore, it can be assumed that these people suffer from an old age related crisis, reflecting their personality issues. The other half have some basic, and pronounced, mental issues, mainly dementia (Ammanullach et al. 2013). Compulsive hoarding

very often coexists with other diseases. The following disorders are primarily listed: obsessive-compulsive, mysophobia, nosophobia, perfectionism and precision, compulsive cleaning, aggressive obsession and superstitions, personality disorders, cognitive processing disorders, psychotic disorders, hypochondriacal disorders, eating disorders (Książopolska, Kotapka-Minc 2005, pp. 107-110).

The literature also offers the thesis that elements of compulsion as well as addiction can be distinguished with regard to the hoarding syndrome. Giving up hoarding items is often felt by the dysfunctional person as a resignation from their own identity. In their subjective opinion, items, which are often completely valueless, are of great value. Similarly as in the addiction process, in this case a loss of control over their own actions can be observed (Smrokowska-Reichman 2008, p. 7).

People suffering from compulsive hoarding are easily distracted and have difficulties in focusing on a specific task. Stimuli distracting people with the hoarding syndrome usually come internally (from themselves) rather than externally (Tolin et al. 2007, p. 32). Important factors are psychosocial and specific events in the biography of the afflicted person. Hoarding syndrome can occur in depressed and reclusive people. Therefore, people who are especially prone to this syndrome are the elderly in a difficult life situation. They replace a lack of interpersonal relationships with relations with tangible items. The more a lonely elderly feels socially isolated, the more they focus on collecting items that cause clutter, resulting in growing shame and thus leading to avoiding contact with others. A vicious cycle is established. Hoarding seems to intensify when an afflicted person experiences a loss—perhaps of a job, when their living situation worsens, or when they lose a loved one – or in a situation of overwhelming stress (Smorkowska-Raichman 2008, p. 7). The hostile approach and rejection by the community they live in both contribute to the intensification of destructive behaviours of the elderly.

D. F. Tolin, R. O. Frost, G. Steketee (2007, p. 11) also draw attention to civilisational factors which can encourage behaviours of people obsessed with hoarding. Contemporarily, civilisation is based on consumerism, saving and acquiring. For some people the will to possess an irrational number of things becomes stronger than the upsetting consequences of an extremely cluttered home.

Summarising the description and analysis of the case, A. Księżopolska and S. Kotapka-Minc (2005, p. 109) conclude that in the case of hoarding, a hypothesis can be proposed that is based on multiple factors. Both neurobiological and psychosocial factors play a significant role. However, the question regarding the relative importance of various factors in developing this disorder remains unanswered.

People suffering from hoarding cannot refrain from collecting unnecessary items. This disorder may intensify from a minor to a life threatening degree. The literature gives three criteria that help diagnose 'a compulsive hoarder' (Tolin et al. 2007, pp. 12-14).

A person hoards various items and has a significant problem getting rid of anything, although, objectively, the majority of people consider those things useless or of little value. A hoarder views the usefulness of such items differently. They perceive items that others consider valueless as offering a range of possibilities. They believe that getting rid of them would be uneconomic, and having such items makes them feel safe. As a result, the clutter continuously grows.

The mess is onerous, significantly limiting the living space. Often the space is cluttered to the point of preventing them from preparing meals, using the home's amenities or moving around in a safe manner. This factor differentiates syillogomania from healthy collecting. Affected individuals stop letting others enter their space.

Mess, hoarding or difficulty getting rid of items causes weakness and stress. Particular rooms transform into storage spaces. Hindered functioning causes deterioration of the quality of life. At the same time, the sufferer does not know how to deal with this situation, feels ashamed and does not know where to seek help. The problem can be especially dangerous for elderly people suffering from various health problems^[1].

A typical hoarder can be characterised as someone who does not get rid of damaged items that are beyond repair or that are of no use. This person purchases items in quantities that are impossible to consume (e.g. washing liquids and detergents), purchases useful items but never uses them and instead keeps them 'just in case'. A hoarder is afraid to throw anything away, because it may turn out that such items are important. They are particular

interested in collecting newspapers, magazines, leaflets. Such a person often hoards items ‘not for themselves’, but to be allegedly used by others, motivated by social or ecological purposes (e.g. clothes for the homeless, waste paper for recycling) (Smrokowska-Reichman 2008, p. 4).

Furthermore, D. F. Tolin, R. O. Frost, G. Steketee (2007, pp. 35-37) draw attention to other traits characterising hoarders such as perfectionism and fear of making mistakes, the sense of responsibility for items in their possession, the feeling of being attached to these items, perceiving things as sources of their belonging and self-identification, underestimating their own memory capacity – i.e. leaving everything ‘within reach’, to remind them of their duties (bills, laundry, etc.), which ensures a sense of safety and control over their lives.

In the sparse literature on the subject, two classifications of people suffering from syillogomania are given (Smrokowska-Reichman 2008, p. 6). The first one refers to dysfunctional people and concerns tendencies that can occur as early as in their childhood. These are:

- ‘hamsters’ – unable to deal with the items they collect in alarming quantities;
- ‘individuals chaotic in terms of time’ – they do not have a sense of time, are always late, neglect deadlines, which results in losing their jobs and friends;
- ‘individuals chaotic in terms of work’ – start many various jobs at the same time and never finish any;
- ‘individuals chaotic in terms of ideas’ – they are familiar with everything and interested to a certain degree, jump around various topics, ideas and trends, but do not stay with any for longer.

The second classification refers to the elderly diagnosed with Diogenes syndrome.

Dysfunctional people are divided into three types (Amanullah et al. 2008):

- dissocial – individuals who belong to this group cannot stand anyone trying to help them, they openly reject such help. Close family members occasionally manage to participate in the life of such a person. One of the possibilities is to help in cleaning, although this requires the

participation of a larger group of family members. The patient's reluctance to engage other family members can prevent from implementing this plan;

- antisocial – they actively object to accepting help and the suffer may end up being placed in a hospital against their will, on the basis of a court order. These people protest against any form of help;
- the group that 'litters and abandons' is the rarest. These people do not have a problem with proper perception of reality. They move from cluttered space to a cleaner and healthier space, making consecutive rooms useless.

Specialists prove that the hoarding phenomenon must be considered in multidimensional terms, taking into account various perspectives. Currently, treating the disorder as comprising many symptoms allows more flexibility in dealing with such cases. Typical disorders related to the hoarding mechanism enumerated by D. F. Tolin, R. O. Frost, G. Steketee (2007, pp. 17-20) are disorders in the *awareness sphere of the dysfunctional person*. Many individuals suffering from sylogomania are bothered by their problem. They know that their mess is not 'normal'. They feel ashamed and would like to do something about it. Some of them show a complete lack of awareness of how serious this problem is. This is proven by statements given by people with advanced hoarding: 'What is all the fuss about? It is not that messy!', or 'There is nothing unnecessary at my home.' Sometimes people who acknowledge they have a problem change their minds and claim that everything is fine. In many cases it is a family member who turns for help, because their loved ones cannot admit that they cannot cope with the mess.

Authors also distinguished the disorder in the *life organisation sphere*. Despite the problem with continuous hoarding and difficulties with getting rid of things, people suffering from compulsive hoarding often have a problem keeping their collections in order. For many, order and space organisation are something natural. For people suffering from compulsive hoarding it does not matter where they place their items. Therefore, it is difficult for them to specify where something is located.

A dysfunctional individual believes that each item is useful, puts it somewhere and quickly forgets where.

Another possible disorder occurs in the *sphere of living conditions*. For some people, compulsive hoarding is something more than a mess. It means unhygienic living conditions. Rotten food, dust and fungus on the walls, animal and sometimes even human faces. Sometimes these people are unkempt and simply smell bad, although this is not a rule, because there are clean and neat individuals among them. More frequently, the neglect concerns the elderly suffering from Diogenes syndrome.

A particular problem occurs in the case of *hoarding animals*. Animals living in a household of a compulsive hoarder cause a drastic deterioration in living conditions. Sometimes animals are collected together with other things, or instead of them. There are well-known cases of (often popular) people who lived with 30, 80 or even 100 cats or dogs. In such situations, health and safety of both the animals and their owners, as well as the immediate surroundings, are threatened.

MEANS OF COUNTERACTING COMPULSIVE HOARDING

Problems with defining and classifying compulsive hoarding cause difficulties in effective prevention of this phenomenon. Researchers underline that this is a serious disorder that requires long-term professional help. Providing individuals with support is important, since hoarding causes highly negative consequences for those afflicted and their surroundings, including the following: deteriorating social networks, family conflicts, complete social isolation, losing jobs, risk of poverty. In extreme cases, a person manifesting hoarding behaviours is evicted from their place of residence.

In Western European countries, people suffering from syillogomania are taken care of not only by psychiatrists and psychologists, but also properly trained ergotherapists and social workers. Direct cooperation with the sufferer is possible only when the hoarder's condition does not require hospitalisation.

Intervention in the hoarder's environment involves several stages (Smrokowska-Reichmann 2008, p. 10). During the first step, during a house visit, a specialist diagnoses the scale of the problem. Next, they specify

the order of activities and motivate the client to undertake action in their presence. The lead conducts an entire educational programs assess the value and usefulness of particular items.

A specialist working with a dysfunctional person should pay short, yet, regular visits at a home of the person under their care, which provide an opportunity to set consecutive 'assignments' for the hoarder (e.g. until the next meeting they have to organise one shelf on their own). Experience shows that initially a person may not comply, although getting used to the thought that it is enough to organise one fragment of their home gives them courage and increases motivation. Cleaning the entire flat for the person under specialist care is not a solution, since the flat will return to its previous state in a short period of time. An individual undertaking measures in order to clean their home must be praised for each success. Experience in offering support to dysfunctional people from Western Europe shows that as a result of long-term therapy (and support of self-help groups and cooperation of various institutions), many people can successfully cope with their compulsive hoarding problem.

Behavioural psychologists (working with hoarders) F. Tolin, R. O. Frost, G. Steketee (2007, pp. 87-105) give practical hints which should be used by hoarders in the cleaning process, among others:

- *sorting and organising strategies.* 'Before starting sorting, choose the basic categories you are going to use. Divide items at the 'basic level' into two categories: 'things to keep' and 'things to throw away'. Divide things to be thrown away into general categories: garbage, things to be recycled, things to be given away (charities, library, friends, family), things to sell (selling off used things, a library, a second-hand shop, online selling). Next, think about categories into which you are going to divide items you want to keep. It is also important to limit the quantity of used categories;
- *selection of a place for each category of kept items.* Decide in advance where you are going to place sorted items. Because of the fact that you are going to sort them in a hurry, it is not necessary to immediately put things away where they belong. At the beginning try to place them close to their destined place. Do not finish sorting without putting previously sorted things in their place;

- *paying particular attention to paper items.* A lot of people who hoard items have trouble deciding what to do with paper items such as correspondence, newspapers and journals, personal documents, etc. As a result, those individuals mix necessary and unnecessary papers: documents and bills with leaflets from grocery stores and newspapers. It is important to develop an archiving system for various types of documents.’

Psychologists also formulate questions that a hoarder has to ask themselves to make proper decisions while organising unnecessary items (ibidem, p. 114):

- How many things do I already have and are they enough?
- Do I have sufficient time to use, look through or read them?
- Have I used them in the past?
- Do I have a specific plan to use these items in the near future?
- Do they match my values and beliefs?
- How can I compare them with items I value a lot?
- Is this item up-to-date (not past the expiration date)?
- Is this object of good quality, accurate or reliable?
- Do I really need it?
- Do I have enough room for it?

The purpose of supporting a person suffering from syllogomania is to restore their ability to properly function in the environment, restore the usefulness of the flat, and education aimed at preventing relapse in addictive hoarding of unnecessary items.

Diogenes syndrome, compulsive hoarding or syllogomania, is a phenomenon which is worth attention and submitting to in-depth analysis, since people who show self-neglect are characterised by a 5.8 times higher rate of annual mortality than other people at the same age (Tsai Wei-Chi et al., 2012, p. 1780).

Currently, common difficulties are encountered in background surveys of individuals suffering from compulsive hoarding. Late detection, non-adherence to the recommended treatment and persistent refusal of help constitute challenges for people providing care/assistance. The problem is often accompanied by dehydration, malnutrition, infections, falls and injuries. Hoarding is considered to

be a life-threatening condition, since in the majority of cases, until the hoarders suffer a sudden worsening of their health, this disorder is not diagnosed due to the resistance to social and emergency services. Repetitive refusals of aid raise ethical and legal doubts: a need to coercively remove the dysfunctional individual from their flat, forced cleaning and the intervention obligation of various services (healthcare, social, emergency, sanitary and animal protection services) arises.

Hoarders' resistance to aid can stem from depression, distrustfulness, alcohol or other substance abuse more than the will to live in filth. A controversial issue is the problem of protecting the individual's rights while simultaneously protecting the right to general safety, since individuals suffering from this syndrome may be a threat to public health. Solutions used in Western European countries towards dysfunctional people with the use of the organisation plan showed only minimal improvement of their living conditions. Aid programmes and day care centres show that effectiveness thereof in combating hoarding is low due to the lack of the hoarder's engagement (Amanullah et al. 2008).

Compulsive hoarding is a difficult personal problem proved by psychiatry publications. It's hard to conduct statistical analysis of compulsive hoarders, because a lot of them do not keep in touch with social workers or health care institutions. Meanwhile, it is a social issue, an issue with which families and neighbors struggle and that's why it is worth looking for effective solutions used by social workers, including family's help, psychiatrists, volunteers. A set of aid models created based on data from social care centers would be helpful in conducting interventions. Compulsive hoarding is one of the challenges for social welfare centers established in communities that aim to help their residents in solving local social problems.

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ENDNOTES

- [1] Compulsive hoarding of items can increase the risk of injury caused by falling down, especially among the elderly. This problem may constitute a medical hazard as it puts individuals at a risk of poisoning by rotten, perishable food. Exposure to dust and bacteria also constitutes a frequent problem in households, which are not thoroughly and systematically cleaned.