

**IDENTIFICATION AND CARE OF ACCUMULATION DISORDER****IDENTIFICAÇÃO E CUIDADOS NO TRANSTORNO DE ACUMULAÇÃO****IDENTIFICACIÓN Y CUIDADOS EN EL TRANSTORNO DE ACUMULACIÓN**

Mariangelli Souza Gargiulo<sup>1</sup>, Dayane de Aguiar Cicoella<sup>2</sup>, Karina Amadori Stroschein Normann<sup>3</sup>, Ana Paula Hössel Garcia<sup>4</sup>

**ABSTRACT**

**Objective:** to review the national and international scientific literature on identification and care in Accumulation Disorder after inclusion in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). **Method:** integrative review, performed in the LILACS, MEDLINE and Science Direct databases, using the descriptors Therapeutic, Accumulation Disorder, Signs and Symptoms and the keyword Compulsive Accumulation. **Results:** 754 articles published between May 2013 and June 2016. Following the criteria and reading in full, 11 articles were selected, giving rise to three categories of analysis. **Conclusion:** the studies analyzed presented doubts about the criteria and failures in the social identification of accumulating individuals. A closer approximation, with an expanded conception, is necessary in order to contemplate the reception in the healthcare network, due to the lack of knowledge of the disease. **Descriptors:** Hoarding Disorder; Signs and Symptoms; Therapeutics; Nursing Care; Nursing; Obsessive-Compulsive Disorder.

**RESUMO**

**Objetivo:** revisar a literatura científica, nacional e internacional, sobre a identificação e os cuidados no Transtorno de Acumulação, após a inclusão no Manual Diagnóstico e Estatístico de Transtornos Mentais (DSM-5). **Método:** revisão integrativa, realizada nas bases de dados LILACS, MEDLINE e Science Direct, mediante os descritores Terapêutica, Transtorno de Acumulação, Sinais e Sintomas e a palavra-chave Acumulação Compulsiva. **Resultados:** 754 artigos publicados entre maio de 2013 e junho de 2016. Após critérios e leitura na íntegra, foram selecionados 11 artigos, dando origem a três categorias de análise. **Conclusão:** os estudos analisados apresentaram dúvidas quanto aos critérios e falhas na identificação social de indivíduos acumuladores. Faz-se necessária uma maior aproximação, com concepção ampliada, de forma a contemplar o acolhimento na rede de atenção em saúde, em virtude do desconhecimento da doença. **Descritores:** Transtorno de Acumulação; Sinais e Sintomas; Terapêuticas; Cuidados de Enfermagem; Enfermagem; Transtorno Obsessivo-Compulsivo.

**RESUMEN**

**Objetivo:** revisar la literatura científica, nacional e internacional, sobre la identificación y los cuidados en el Trastorno de Acumulación, tras su inclusión en el Manual Diagnóstico y Estadístico de Trastornos Mentales (DSM-5). **Método:** revisión integrativa, realizada en las bases de datos LILACS, MEDLINE y Science Direct, mediante los descriptores Terapéutica, Trastorno de Acumulación, Signos y Síntomas y la palabra clave Acumulación Compulsiva. **Resultados:** 754 artículos publicados entre mayo de 2013 y junio de 2016. Tras criterios y lectura íntegra, se seleccionaron 11 artículos, dando origen a tres categorías de análisis. **Conclusión:** los estudios analizados presentaron dudas en cuanto a los criterios y fallas en la identificación social de individuos acumuladores. Se hace necesaria una mayor aproximación, con concepción ampliada, para contemplar la acogida en la red de atención en salud, en virtud del desconocimiento de la enfermedad. **Descriptores:** Terapéutica; Trastorno de Acumulación; Signos y Síntomas; Atención de Enfermería; Enfermería; Trastorno Obsesivo Compulsivo.

<sup>1</sup>Nurse, Methodist University Center/IPA. Porto Alegre (RS), Brazil. E-mail: [gargiulo.mari@gmail.com](mailto:gargiulo.mari@gmail.com); <sup>2</sup>Nurse, Master, Professor, Methodist University Center/IPA. Porto Alegre (RS), Brazil. E-mail: [dayane.cicoella@gmail.com](mailto:dayane.cicoella@gmail.com); <sup>3</sup>Nurse, Master, Professor, Methodist University Center/IPA. Porto Alegre (RS), Brazil. E-mail: [karina.stroschein@metodistadosul.edu.br](mailto:karina.stroschein@metodistadosul.edu.br); <sup>4</sup>Professional of Physical Education, Methodist University Center/IPA. Porto Alegre (RS), Brazil. E-mail: [anapaulahosselgarcia@gmail.com](mailto:anapaulahosselgarcia@gmail.com)

## INTRODUCTION

The inclusion of Accumulation Disorder (AD) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013, prepared by the American Psychiatric Association (APA), elucidates a psychopathology previously presented with diagnostic variation of other mental disorders.<sup>1-2</sup> It is characterized by the difficulty of disposing of belongings, as a consequence of a strong perception of the need to conserve them and the suffering associated with their disposal.<sup>2</sup>

It was formerly seen as a symptom of Obsessive-Compulsive Disorder (OCD), not being better explained by the presence of symptoms characteristic of other mental disorders.<sup>3</sup> In the DSM-5 manual, it is presented in the chapter on OCD and Related Disorders (RD), with important differences in diagnostic criteria and therapeutic approaches. OCD is characterized by the presence of obsessions and / or compulsions. Obsessions are recurrent, persistent thoughts, impulses or images, while compulsions are repetitive behaviors or mental acts that an individual feels obligated to fulfill in response to an obsession. In AD, the perception is of the necessity of guard and suffering in the discard.<sup>2</sup>

Individuals affected by AD are generally not recognized as "sick" by the community and are referred to public health services, often years after the phenomenon is detected. The functional consequences are the impairment of basic activities such as transiting and cleaning the house, doing personal hygiene and even sleeping.<sup>4</sup> Various health risks due to poor sanitary conditions can be observed. There is social damage because it is incapacitating, threatening the health and public safety of the accumulator itself and other people, such as neighbors and relatives.<sup>5</sup>

It is worth noting that it is a poorly explored disease, since in the past accumulation was not considered as pathological behavior.<sup>4</sup> This fact possibly occurs to the detriment of the knowledge of the pathology by professionals and the population in general. There are many cases of identification when environmental urgency or degradation has already occurred, such as odor, infestation or even the discovery of corpses, signaled by

prolonged absence of individuals or body odor.

Due to the increased demand in public services to support people in psychological distress, it is important to evaluate the knowledge of health professionals regarding this pathology, since studies of nationally representative prevalence of AD are not available.<sup>2</sup> Because follow-up is indicated of an interdisciplinary team, it is important to verify how they perceive the subjects compromised by this pathology, since these individuals often live isolated from society.<sup>5</sup>

In the case of an as yet little known disorder, it is important to evaluate the triggering factors. In the last 30 years, there has been an increase in urbanization, stressful working conditions, violence, abuse of psychoactive substances, consumerism, among other situations that promote psychic illness.<sup>6</sup> The Psychiatric Reform, through the Antimanicomial Struggle, begun in the years 70, proposes the reformulation of public policies of mental health, in order to abandon the asylum model, in which deprivation of liberty occurs and the exercise of singularity and citizenship. There is a need for a networked logic of open and community services that must guarantee the person with mental disorder the necessary care to live safely, in freedom, in family and social life.<sup>7</sup>

In order to contribute to a better investigation of the subject, it is intended, with this study, to review the current national and international scientific literature on issues related to identification and care in Accumulation Disorder after inclusion in DSM-5.

## OBJECTIVE

- To review the national and international scientific literature on identification and care in Accumulation Disorder after inclusion in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

## METHOD

Integrative review is used prominently in evidence-based practice. Integrative research includes the analysis of relevant research that supports decision making and improvement of clinical practice. It allows to summarize previous researches and to obtain general conclusions to analyze the

scientific knowledge about the subject to be investigated.

In order to make this review operational, the six stages of the integrative review process were used. The first step was to establish the hypothesis or question of research, making the choice and definition of the theme, objectives, keywords and the topic related to clinical practice. In this phase, the literature review was guided by the following question: How to identify and care for the individual with Accumulation Disorder?

The second stage consisted of sampling or searching in the literature, establishing the inclusion and exclusion criteria, the use of database and the selection of studies. Advanced search brought together two descriptors, or descriptors and keywords simultaneously. Inclusion criteria were: health research, published in the selected period for research, in the Portuguese, English and Spanish languages. The initial search period is justified, due to the fact that, in May 2013, the 5th edition of DSM-5 was released, which presents the AD, for the first time, separately from another disorder. Regarding the exclusion criteria, were considered: review studies, in duplicate, without abstracts available and those that, despite presenting the selected descriptors, did not directly address the proposed theme.

The period delimited for the research was of paramount importance to obtain more conclusive and current studies, which was obtained from the period of 2013. The search of the articles occurred in the months of January to March of 2016. For the phase of data collection, national and internationally produced health surveys were included from May 2013 to June 2016, published in periodicals indexed in the Latin American and Caribbean Literature in Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE) and Science Direct, under the key word: compulsive accumulation and the descriptors: Therapeutics, Accumulation Disorder and Signs and Symptoms. The LILACS and MEDLINE databases were intermediated by access to the Virtual Health Library (VHL). After, using the advanced search for the crossword of keywords and descriptors, the results were filtered through the icons: selected filters, full text, database (LILACS and MEDLINE

separately), type of study, language, year of publication and type of document. In the SCIENCE DIRECT database, access occurred directly on the site. In this database, the filter used was article with free payment access, year and type of article material.

The third step was the categorization of the studies, with the extraction of information, the organization and summarization of information and the formation of the database. For this purpose, a specific data collection instrument was used and elaborated by the authors with title, authors, year of publication, periodical and the study. This reading instrument made it possible to synthesize the thematic, contributing to the exploratory phase of the research. The fourth step consisted of evaluating the studies included in the review, with the application of the statistical analyzes, inclusion / exclusion and critical analysis of the selected studies.

However, in order to critically evaluate the results of the selected studies, the classification of the Evidence Level of the selected studies from the Hierarchical Classification of Evidence for Evaluation of Studies was analyzed: 1 - systematic reviews or meta-analysis of relevant clinical trials; 2 - evidence of, at least, one well-delineated randomized controlled trial; 3 - well-delineated clinical trials without randomization; 4 - well-delineated cohort and case-control studies; 5 - systematic review of descriptive and qualitative studies; 6 - evidence derived from a single descriptive or qualitative study; 7 - opinion of authorities or expert committees, including interpretations of information not based on research.

The publications selected for the analysis were fully and accurately translated and subsequently cataloged in an organization tool to form a database.<sup>10</sup> For data analysis, an instrument was used containing article title, index base, country of origin, objective, methodology, result and conclusion of the studies, in order to organize the selected studies and make feasible the analytical-descriptive phase. In this way, it was possible to synthesize the included articles, facilitating the categorization of the themes found.

The fifth step was the interpretation of the results, from the discussion of the findings, proposals for recommendations

and suggestions for future research. The sixth and last stage resulted in the synthesis of the knowledge and presentation of the review, from the preparation of a summary of available evidence and creation of this document that describes in detail the review.<sup>10</sup>

RESULTS

The research provided a search result of 754 articles in the three databases that

were consulted. After careful analysis, a large number of publications were excluded, which either repeated or did not match the research theme, or, even, met the exclusion criteria.

Table 1 presents the results of the searches in the databases selected for the study.

Table 1. Result of cross-descriptor and keyword cross-checking in selected databases. Porto Alegre (RS), Brazil, 2017.

Descriptors and Key words	LILACS	SCIENCE	MEDLINE	TOTAL
Compulsive hoarding AND Hoarding disorder	3	4	52	59
Compulsive hoarding AND Therapeutics	0	14	0	14
Compulsive hoarding AND Signs and symptoms	0	6	42	48
Hoarding disorder AND Therapeutics	0	0	406	406
Hoarding disorder AND Signs and symptoms	1	6	220	227
Total	4	30	720	754

Source: Prepared by the authors (2017).

In the search for answer to the guiding question, only 11 publications were selected, excluding nine pre-selected studies. As for the year of publication, one can notice numerical expressiveness in the year 2014, with seven published articles, followed by the year 2013, with three publications. In the following years, there was a gradual decrease of the articles: in 2015 only one article is evident and, in 2016, no publications were found that fit the proposed parameters.

During the data collection phase, in the pre-selected studies, it is noteworthy that only two articles were found in the Portuguese language. This situation reinforces the idea that the theme is relatively new in Brazil. In relation to the methodology, there was a predominance of qualitative research.

DISCUSSION

The discussion of the results is divided in three main axes from the categorization of the studies: Epidemiology and impact in Public Health, Identification of the Accumulation Disorder and the Care with the individual accumulator.

◆ Epidemiology and Impact of Public Health

The behavior of collecting and accumulating objects is present in all populations, varying from normal to pathological aspects.<sup>11</sup> Epidemiological

studies suggest that the accumulating people usually live alone, in unemployment, overweight, poor quality of life and with problems in social relationships and housing.<sup>12-3</sup> The profile is of older, unmarried, separated, or divorced individuals who are generally faced with economic difficulties or faced in the course of their lives.<sup>14</sup>

AD affects both genders and is associated with substantial adversities, but, some research suggests a higher incidence in men.<sup>12,15</sup> It can be observed in different cultures and with varying age for onset of signs and symptoms. The estimated prevalence is 2% to 6% in the general population, presenting greater severity in the elderly.<sup>11,13,16</sup> Studies indicate a progressive worsening of the disorder over time and age. Typically, functional disability increases in the fourth or fifth decade of life, becoming more pronounced with the elderly.<sup>13,16-7</sup>

The help of family or friends in the organization of objects can minimize the disability of the spaces in the house and mask the severity of the disorder. The deficiency of the accumulating individual's *insight* and the lack of knowledge by the professionals also leads to an underreporting of the disease.<sup>18</sup> It directly impacts family and neighbors, because, sometimes, the disorganization is so great that it can harm



the surrounding community, becoming a health problem significant public.<sup>11</sup>

Household contamination is one of the most severe markers and the disease can be costly for health surveillance.<sup>18</sup> In addition to all the clinical implications of the disorder, there are occupational problems, such as frequent absences from work due to exacerbated concern with the loss of accumulated items.<sup>19</sup>

#### ◆ Identification of the Accumulation Disorder

Initially, the term accumulation arose as scientific terminology to describe the collecting of food in the behavior of animals, especially in rodents. In 1960, the term was used, for the first time to describe the psychopathological phenomenon in humans. After, accumulation was progressively related to a variety of comorbid psychiatric disorders, such as OCD and Schizophrenia. Subsequently, primary accumulation appeared as a behavior that begins at the beginning of the third decade of life, with decreased *insight*, little interest in receiving treatment, and little attempt to resist compulsion.<sup>18</sup>

The DSM-5 recognizes AD as different from OCD because it is characterized by persistent difficulty of being discarded or separated from possessions, regardless of their actual value, with the perception of the need to store items and distress associated with disposing of them. This results in accumulation of goods in the inhabited areas, which compromises their intended use. Individuals with accumulation symptoms are known to have so much disorder in the household that they are no longer able to perform daily activities such as cooking, cleaning, or moving around.<sup>11,19</sup>

Until recently, the disorder was considered a subtype of OCD, although professionals and research indicate that it occurs separately. However, finally, with inclusion in DSM-5, it was recognized as a clinical syndrome per se.<sup>15,17</sup> In the manual, pathology is presented in the chapter on obsessive-compulsive disorder and related disorders, with the categories of over-acquisition and varied *insight*.<sup>18</sup> The three main commonly identified symptoms, are difficulty in discarding, disorder, and overacting.<sup>11</sup>

It can result from other untreated disorders, since, on average, 1/3 of these people generally do not seek mental health

services. Some relatives indicate that the individuals affected by the disease have weaknesses in self-perception, leading to the possibility of eviction from the home and the loss of custody of dependent children under age.<sup>14</sup>

Its main symptoms refer to the need to intentionally collect objects or animals, with a difficulty in disposing of these possessions. Characteristics of the disorder are highlighted, such as consumerism, desire for organization, lack of impulse control, lack of limits and critical judgment. The three main forms of acquisition of form objects are compulsory buying, free collection and theft.<sup>11</sup>

There may be the presence of some common childhood events in subjects with accumulating behavior, such as the use of physical discipline and the presence of psychiatric disorders on the part of the parents. Evidence indicates that individuals who experienced childhood trauma develop symptoms earlier than those with the same diagnosis without trauma. Usually, the difficulty in disposing of objects and disorganization consists of the first symptoms presented, followed by the need to acquire new objects and, finally, the recognition of the symptom as dysfunctional.<sup>19</sup>

However, the collector accumulator manages to maintain a higher level of organization, related to the environment where it lives. The difference between collectors and accumulators collectors lies in the fact that the former choose specific objects and discard their collections for money or exchange.<sup>12</sup> Compulsive accumulators would be individuals for whom obtaining unnecessary objects becomes repetitive behavior, constituting a form of investment, in an attempt to preserve the underlying affective value of things.

Accumulators with characteristics of compulsive consumerism obtain greater satisfaction in the accumulation itself than in the possibility of enjoying the acquired objects. Some researchers have the idea that compulsive accumulators would necessarily have undergone experiences of material deprivation at some point in their lives. And, above all, it would be related to experiences of emotional deprivation in childhood.<sup>12</sup>

Another category is that of animal accumulators, which are characterized as

individuals who acquire a large amount of animals, tens or hundreds, which can be kept in inadequate spaces or in unsafe and unhealthy conditions. Sometimes they can not meet the basic care an animal needs, but they keep keeping them with it. This accumulation is driven by feelings of compassion and compassion towards animals in situations of neglect and / or ill-treatment. They find it difficult to get rid of them, even after the death of the animals, which causes serious problems of animal infestation.<sup>12,19</sup>

Individuals with AD may be frustrated by their accumulations but do not recognize the cause of such suffering as inherent in the difficulty in discarding or excessive acquisition of unnecessary objects. The presence of poor *insight* or variation in *insight* is a feature that can lead to a reluctance to seek help, that results in worse response to treatments. Neuropsychological studies demonstrate deficits in categorization, memory work, decision making, attention and error in information processing, as well as problems in learning and particularly in the visual domain.<sup>17</sup>

Accumulation is the result of information processing deficits, difficulties in forming emotional attachments, avoidance of social behavior, and erroneous beliefs about the nature of possessions.<sup>18</sup> Concerning the new diagnosis, research suggests that the disorder is included in ICD-11 (International Classification of Diseases) separately from OCD because characteristics such as poor *insight* and the severity of domestic misery are considered to be AD specifiers. Accumulation is generally described as a condition with poor *insight*, as the affected person perceives the accumulated items as an extension of the same.<sup>20</sup>

There is a criticism and a discussion about the severity of the use of the disorder criterion, since some manage to continue using the spaces of the house according to their functions and, others, lose the function of the spaces. Both cases are considered accumulators, but cases of those who manage to organize possessions are rare and do not disable the residences.<sup>18</sup>

Accumulation is especially dangerous for the elderly due to increased risk of falls, fire risks, malnutrition, poor health management and use of medications. To date, standard cognitive behavioral

treatments, for late-age accumulation have not been shown to be effective.<sup>21</sup> Accumulation in old age is a serious psychiatric condition, with significant health implications, since elderly individuals with accumulation demonstrate a greater impairment in daily and high-activity activities number of medical complications.<sup>13</sup>

In moderate accumulators, difficulties have been reported in finding important items in the home and absence of habits such as eating at the table, using the kitchen sink or even sleeping in the house. Individuals with AD feel less satisfied with their overall safety and are more likely to be victims of crime. In the middle age, they lose, on average, seven days of work per month due to the disease.<sup>13</sup> The difficulty in discarding may be associated with psychotic symptoms, rather than the intense feeling for the accumulated object.<sup>11</sup>

Traumatic events and relationship difficulties may be associated with the onset of symptoms. The pattern of excessive consumption of a society, which values the acquisition of goods and accumulation, that is, a modern society in sickness, also contributes to the growing number of individuals with this pathology.<sup>12</sup>

The symptomatology of TA differs from OCD in certain aspects. Although the diagnosis of OCD has similarities with TA, one of the main differences between these two psychopathologies is that the subjects that accumulate do not present intrusive thoughts, rituals or feelings of anxiety when discarding the objects they possess. On the contrary, they feel anger, a symptom that would not be consistent with the clinical characteristics of the obsessions defined by DSM-5.<sup>18</sup>

Research has concluded that the accumulation behavior is a diagnosis whose course may occur concomitantly with other mental disorders, such as Personality Disorder, Generalized Anxiety Disorder, Depression, Dementia, Schizophrenia, OCD, Bipolar Mood Disorder, Social Phobia, among others.<sup>12,15</sup>

Until inclusion in DSM-5, accumulation symptoms were often classified as a spectrum of OCD. The expressed cognitions of many individuals who accumulate could be understood as obsessions characterized by a fear of losing things and compulsions to acquire and store objects. However, a

number of factors suggest that accumulation may be a single variation or even an entirely different disorder of OCD, despite frequent comorbidity.<sup>19</sup> In practice, what occurs is that it may occur concomitantly with OCD, but generally, in 60% to 80% of cases, these disorders occur independently of one another.<sup>17</sup>

Thoughts related to accumulation can still result in feelings of suffering and anger, while in OCD, they result in anxiety. Accumulation behavior is also associated with pleasure and reward, while in OCD, behavior leads to relief of anxiety.<sup>12,19</sup> Accumulation behavior worsens with each decade of life, whereas in OCD it tends to increase and decrease over time.<sup>18</sup>

On average, 40% of patients with OCD have some level of accumulation, however, most individuals with difficulty accumulating do not exhibit other symptoms of OCD, including obsessions and compulsions related to anxiety.<sup>20</sup>

Depression appears to be a triggering factor that influences the severity of accumulation. In this case, it is pointed out the importance in tracking accumulation symptoms among patients with prominent depressive symptoms.<sup>11</sup>

#### ♦ Care of the individual accumulator

In AD the most applied approach is Cognitive Behavioral Therapy (CBT). It is a modality that consists of a brief, focused method with structured sessions, aimed at understanding the restructuring of thinking.<sup>17</sup> The focus of CBT, for accumulating individuals, is to modify their beliefs about their possessions, helping in decision-making and the development of strategies to decrease the frequency of collection habits. It emphasizes the presence of magical, distorted or catastrophic thoughts about getting rid of their possessions.<sup>12</sup>

Motivational Interviewing (MI) and Harm Reduction (HR) are also common to treatment because they focus on cognitive distortions related to fear of discard and strong will to acquire. MI seeks to reduce ambivalence for treatment, by identifying areas of disability. HR, however, reduces the disability caused by symptoms and promotes improvement in quality of life.<sup>17</sup> But for the success of any approach, it is important that the diagnostic criteria be clear, and this is still discussed in relation to AD.<sup>18</sup>

The combination of treatments that is successful for AD is the application of Combined Cognitive Rehabilitation (CCR) with CBT, as both promote habituation to suffering caused by discarding or not acquiring possessions. CCR and disposal reorganization is a viable, acceptable and promising treatment with a significant reduction in the severity of accumulation.<sup>21</sup>

Therefore, it is pointed out the importance of professionals to carry out home visits and clinical interviews to assess the severity of the disorder, since the criterion of disorder and agglomeration should only work when one has access to the home of the individual accumulator.<sup>14</sup> The approaches to be used should include relapse prevention to achieve promising results. It is suggested to formulate a specific cognitive model for AD, with a suitable therapeutic plan for this pathology.<sup>12</sup>

Regarding psychopharmacological interventions, there are those focused on selective serotonin reuptake inhibitors, benzodiazepines and atypical antidepressants, which also produce significant improvements in signs and symptoms. However, pharmacological treatment has been based and modified from the current treatments for OCD since it has recently been recognized the disorder and drug tests are still performed.<sup>17</sup>

It is recommended to establish a network of attention with emphasis on the Unique Therapeutic Project of the individual with AD. It is a challenge for professionals, managers and other actors involved in a qualified health care.<sup>19</sup> It is suggested that working groups be established, with meetings to strengthen the individual in the community. Also, if necessary interventions of the public service of garbage collection, pest control and legal assistance.<sup>12</sup>

## CONCLUSION

This integrative review shows that there are still few conclusive studies regarding the diagnostic and therapeutic criteria in the AD. However, it is possible to observe a need to disclose the pathology in order for the affected individuals to be identified by health professionals.

Without an increase in the care of this disorder, individuals afflicted by the disease will continue to be ignored and labeled as "sloppy". In various realities, there are still



weaknesses in relation to the understanding of the disease, which is highly debilitating and causes suffering.

It should be noted that, for the most part, people with AD are late identified and use the public health system when they are already affected by several associated comorbidities. In addition, the fact that dwellings may be the focus of infestations by rodents and insects, which may potentiate the spread of disease in the community, is present.

Another issue that is observed is that other sectors, related to health, such as the environment, justice, are not aware of the disorder. Such a situation suggests that those affected by accumulation are simply condemned to take action, often, without regard to the singularity and reality of the individual.

In this sense, it is possible to verify that there are insufficient data that emphasize the Brazilian reality of accumulators, being necessary the development of new academic works that identify this specific reality, often, masked by the simple ignorance and stigmatization of the disease.

It is necessary to get closer to the professionals with an extended conception of care to the accumulating individual. Sometimes, there are difficulties of the professionals in performing the care in health that contemplates the reception in the network of attention in health, due to the ignorance of the disease. It is suggested that new studies, aimed at the accumulation, disorder be developed, since they could strengthen the health teams in the management and care to the individuals diagnosed with the pathology.

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#### Corresponding Address

Mariangelli Souza Gargiulo

Rua Landel de Moura, 1081/202

Bairro Tristeza

CEP: 91920-150 – Porto Alegre (RS), Brazil