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EMOTIONAL SOCIALIZATION AND AGENCY: REPRESENTATIONS OF COPING WITH OLD AGE DEMENTIA AND ALZHEIMER'S IN GRAPHIC NOVELS

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EMOTIONAL SOCIALIZATION AND AGENCY: REPRESENTATIONS OF COPING WITH OLD AGE DEMENTIA AND ALZHEIMER'S IN GRAPHIC NOVELS

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Abstract

This research investigates representations of emotion work and emotional labor in caregiving, in the medium of graphic novels. The study is based on a collection of six contemporary graphic novels that discuss the relationships between older adults who are suffering from dementia or Alzheimer's and their family caregivers and professional caretakers. Family caregivers are caught in a complicated web of family relationships and new, emerging caregiving roles. We rely on thematic content analysis to identify the main forms of emotional agency, structural constraints and trade-offs in family and professional situations. Emotional agency in caregiving is portrayed as situated, though emerging from divergent definitions of the situations for caretakers and patients; it is embedded in the family system, which is contrastively portrayed with the procedural, less empathic medical institution, and also with the general mass media portrayal of old age. Graphic novels contribute to the emotional socialization of people anticipating situations of suffering, or caring for mental disorders associated with old age.

Keywords: caregiving, emotion work, emotional labor, emotional socialization, graphic media, dementia, Alzheimer's, feeling rules, family systems.

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Introduction

This paper investigates how emotional agency is represented in graphic novels that discuss caregiving in the context of old age dementia and Alzheimer's. The study will rely on the conceptualization of emotion work and emotional labor by Hochschild (1979), namely, that emotional management individuals perform in producing and managing self and others' emotions in informal interactions as well as professional interactions. We discuss emotional socialization through the medium of graphic novels, examining 1) representations about how emotional management is performed in both elders and elders suffering from mental conditions, as well as their caregivers, either professional or members of the family, and 2) how is agency represented in patients and their caregivers.

We have chosen graphic novels because they are an increasingly popular medium for people of all ages and for content in multiple genres, from children's literature to the public communication of science. Serious graphic novels combine images and texts to immerse the reader in a rich emotional experience. This is why graphic novels are a good case study to observe the emotional socialization for the challenging situation of caregiving for people affected by old age dementia or by Alzheimer's.

In what follows we introduce serious graphic novels and we discuss their significance for the study of emotional socialization, as well as the social problems of ageism and stigmatization of neurodegenerative disease and mental conditions associated to ageing, which the studied graphic novels aim to mitigate. We then present our methodology.

Serious graphic novels as objects of scientific study

Graphic novels consist of an alternation of messages, both textual and visual, which engage the reader to consume the delivered information considering the tension and connection between the two forms of messages. Graphic novels are not strictly defined, however a definition of The Buffalo & Erie County Public Library (2020) states that "graphic novels are similar to comic books because they use sequential art to tell a story. Unlike comic books, graphic novels are generally stand-alone stories with more complex plots. Collections of short stories that have been previously published as individual comic books are also considered graphic novels." (The Buffalo & Erie County Public Library, 2020).

Graphic novels are categorized based on narrative and appearance. The major categories of graphic novels are Manga, Superhero stories, Personal Narratives and Non-Fiction. Manga is the Japanese word for comics, and it is internationally referred to as a visual style of graphic novels. Manga novels are printed in black and white for time, artistic and financial reasons, even if colored Manga exists as

well. This style also differs from other styles with the fact that it reads from top to bottom and right to left, in the Japanese reading mode (Kordic *et al.*, 2016). Superhero stories became popular in 1938 with the introduction of *Superman*. They are fictional stories about the main hero or heroes and their adventures (Benton, 1991). Personal Narratives and Non-Fiction both address stories from the perspective of the author, based on his own experience of the outside world, the difference is that Non-Fiction graphic novels make use of the author's personal opinions and beliefs to address a greater social issue (The Buffalo & Erie County Public Library, 2020).

In their work *Feeling your pain: empathy in comics,* Sinervo & Freedman (2021) discuss the medium's potential in representing as well as generating empathy. Scott McCloud states in *Understanding Comics: the invisible art* that graphic media makes use of symbols, colors, graphic signs and sequential panels to create tension that focuses on certain messages while ignoring others.

Graphic media has a history in addressing themes that require critical thinking and reflection, such as political violence and war. The most popular example is Pulitzer Prize Special Citations and Awards winner *Maus* by Art Spiegelman, which tells the story of a Holocaust survivor. On the same topic there are also *I Survived the Nazi Invasion, 1944: A Graphic Novel*, by Lauren Tarshis, *White Bird: A Graphic Novel* by R. J. Palacio, *More Than Any Child Should Know: A Kindertransport Story of the Holocaust* by Paul V. Regelbrugge, Julia H. Thompson and Sean Dougherty, *Lily Renee, Escape Artist: from Holocaust Survivor To Comic Book Pioneer* by Trina Robbins, *The Search* by Eric Heuvel, *Survivors of the Holocaust: (A Graphic Novel)* by Kath Shackleton or *We'll Soon Be Home Again* by Jessica Bab Bonde. Also famous among consumers of the medium are the *Persepolis* series by Marjane Satrapi, *The Arab of the Future* series by Riad Sattouf or *Freedom Hospital* by Hamid Sulaiman, which are graphic memoirs and fictional graphic novels that discuss the political tensions in Islamic countries. Death is as well a theme that graphic media addresses in novels such *as Rosalie Lightning: A Graphic Memoir* by Tom Hart, *You Died: An Anthology of the Afterlife* by Kel McDonald and Andrea Purcell*, Last Things: A Graphic Memoir of Loss and Love* by Marissa Moss, or *When David Lost His Voice* by Judith Vanistendael.

The graphic novel ecosystem contains a variety of novels that discuss mental health. A few examples of novels that address mental illness such as obsessive-compulsive disorder are *Everything Is an Emergency: An OCD Story in Words & Pictures* by Jason Adam Katzenstein, *Turtles All the Way Down* by John Green, *The Bad Doctor* by Ian Williams. Depression is discussed in *Look Straight Ahead* by Elaine M. Will, *Marbles: Mania, Depression, Michelangelo, & Me* by Ellen Forney, *Kinds of Blue: An Anthology of Comics about Depression* by Karen Beilharz. Anxiety is addressed in *Just Peachy* by Holly Chisholm, *Super Chill: A Year of Living Anxiously* by Adam Ellis or *The Fire Never Goes Out* by Noelle Stevenson.

Old age and neurodegenerative conditions associated to ageing, such as dementia or Alzheimer's disease, are themes that are scarcely addressed in the graphic media culture. Still, there are some notable works that address these topics, either under the form of graphic memoirs such as *Let's talk about something more pleasant* by Roz Chast, *Aliceheimer's* by Dana Walrath, *Bird in a Cage* by Rebecca Roher or *Tangles* by Sarah Leavitt, or fictional novels such as *Demented* by Jackie Flemming or *Wrinkles* by Paco Roca.

Given the increase in popularity among young readers, teachers and educators are beginning to employ visual media as teaching materials, according to the International Association of Professional Writers & Editors (2009). Scholars such as Basinger (2014) state that graphic novels play an important role in the popular culture, becoming more and more appreciated among readers, especially young readers. They underline the medium's unique ability in addressing themes such as isolation and loneliness because it engages the authors reflective thinking regarding the emotional content of the reading. Arnold (2017) is one of the academics who uses graphic novels in the school environment for the following reasons: simplified wording is more accurate for emergent readers, images help to comprehend complex stories, visuals improve memorization, consuming graphic media allows students to interact in multiple learning modalities (visual and written), storyboarding helps to organize narrative content, graphical images help to decipher meaning, and the experience overall helps in developing the readers' artistic sense.

Authors like Green, & Myers (2010) argue that graphic novels are a valuable tool for medicine, for both patients and doctors and caregivers. The Graphic Medicine online platform is a resource that "explores the interaction between the medium of comics and the discourse of healthcare" (Williams, 2022). Patients who wish to learn more about their disease and connect with others who are experiencing similar symptoms find this platform useful. Graphic media also gives clinicians fresh insights into patients' personal experiences with sickness (particularly worries that patients would not express in a clinical context) as well as misunderstandings about disease and therapy that may impact compliance and prognosis.

The sociological relevance of the graphic media is linked to the importance of the representations and their connection to social institutions. Zorbaugh (1944) states that graphic media acts as a social force, because representation of characters as well as language go beyond the entertainment purposes and engage the reader to reflect upon the message. Because of its potential to represent cultural norms and resonate within certain social settings, we understand graphic media as a product of a social organization (Dobbins, 2016). This implies a deeper understanding of the signals conveyed to viewers and how these messages affect individuals in their everyday lives. Scholars such as Brienza (2010) argue that all artistic production, including comics, is the result of collaborative, frequently systematized human action. Consequently, simply studying the text and/or the artist to whom the work

is explicitly credited is insufficient. To truly comprehend any creative work, one must first examine the wider social and organizational environment in which it was created and disseminated.

Addressing ageism and stigmatization of mental Conditions

Alzheimer's disease and other kinds of dementia cause people's mental capacities to deteriorate over time. Dementia impairs a person's memory, thinking speed and conduct, as well as their capacity to perform everyday tasks. Because these qualities are frequently associated with natural ageing, two out of three individuals believe Alzheimer's is a stage of ageing rather than a neurogenerative condition. This is one of the findings of the *2019 World Alzheimer's Report*, based on answers from 70,000 individuals in 155 countries (Alzheimer's Disease International, 2019). The analysis revealed a significant deficit of knowledge on ageing, mental issues, and neurogenerative diseases, as well as the variations between them. Dementia patients, caregivers, healthcare workers, and other interested parties were among those who responded. Alzheimer's disease is thought to be a natural part of the ageing process by 62 percent of caretakers. Dementia is attributed to "poor luck" by 20% of respondents, destiny by almost 10%, and spells by 2%.

People who are affected by these conditions and their families and communities suffer from stigmatization. Emile Durkheim originally introduced the concept of stigma in 1895 as part of his deviance theory, in which he said that every community has the ability to judge and punish people who violate societal standards by defining their activities as criminal (or deviant) and treating them as such. Stigma is also defined as a phenomenon in which a person with a heavily discredited characteristic is rejected as a consequence of that characteristic (Goffman, 1963), or stereotyping or attributing negative judgment to a person's or a group's attributes or behaviours perceived as different from or inferior to society norms (Dudley, 2000). According to Goffman, there are three types of stigmas: stigma connected with mental illness, stigma associated with physical deformities, and stigma associated with affinity for a certain race, ethnicity, religion, philosophy, or other groups. In present day societies, increasingly driven by a valorisation of youth, old age acquires aspects of stigma. Stigma linked to the elderly can be seen in a variety of settings, such as healthcare facilities, or in the workplace, where older employees may suffer from a devaluation of their abilities.

Through a phenomenon known as stigmatization by association, stigma impacts not only patients but also their communities (Weiss *et al.*, 2006). Shame, anxiety, animosity, low self-esteem, indifference and a lack of support can all impact caregivers and family members of the patients. In a study involving schizophrenic patients, the results revealed that the stigma placed on their caregivers resulted in the patient's isolation and a reduction in their quality of life. Furthermore, medical personnel's stigma resulted in a reluctance to adequately diagnose the

unwell and, as a result, a delay in delivering effective treatment (Rewerska-Juko, & Rejdak, 2020).

Stigmatization of the people affected by dementia and Alzheimer's is amplified by widespread stereotyping and discrimination against the elderly. Through ageism, people invoke individuals' physical characteristics, such as hair and face appearance, as well as the verbal and nonverbal aspects of their interactions, to infer personality and ability profiles (Bieman-Copland, & Ryan, 2001). According to Richeson and Shelton (2006), people tend to associate negative traits with older people in compared to younger people, and they also prefer to generalize these attributes by viewing older people as members of a homogeneous group rather than as distinct individuals. Elders are represented as "older citizens" who are physically and psychologically disadvantaged, powerless, lonely, and old-fashioned by some of these negative characteristics (Brewer *et al.*, 1981).

Media has a significant contribution on stereotyping spreading given the expansion of the culture where one needs to stay young as much as possible on the condition that they consume certain products that are advertised as "miracle makers" in slowing the process of ageing (Richeson, & Shelton, 2006). In his book *The Obsolete Self: Philosophical Dimensions of Ageing*, Esposito (1987) claims that American culture is actively supporting a multibillion-dollar industry by pressuring elders to consume medication and beauty products in order to stay young, emphasizing the benefits of these products over the negative effects of natural ageing.

Stigma attached to mental illness refrains those suffering from a mental condition to admit it, much less confess to others, that they have such a difficulty (U.S. Department of Health and Human Services, 1999). The impact of stigma on people with mental illnesses or neurodegenerative disorders is extensively discussed in the literature (Hinshaw, & Stier, 2008). Despite the efforts of stigma advocates, stigma concerning dementia patients is widespread.

Currently, literature shows a gap in representations of Alzheimer's and dementia in graphic novels. Authors like Medina (2018) argue that the public attention over the social discourses of Alzheimer's is relatively recent, given the fact that for a long period it was discussed in the media from an unrealistic point of view. Such an example would be the consideration of Alzheimer's Disease as an epidemic, presented in an article from the Spanish newspaper, *El Pais*, published in 1994.

Thum (2021) discusses media representations and audience reception by stating that most popular media stereotypes portray Alzheimer's disease as an illness that affects exclusively those over the age of 60 and is characterized by a lengthy and painful course toward death. Ngatcha-Ribert (2004) argues that Alzheimer's arrival into the medical field, owing to scientific progress, allowed patients to become re-culturalized, as well as create a general overview over the condition. The media responded, resulting in the rise of positive depictions. However, as long as negative and menacing ideas persist and are grabbed in the common

imagination, this growth remains insufficient, as Alzheimer's disease became, in the public imagination, synonymous with a journey towards senility.

Medina considers that individuals are not aged by their biological traits but by the culture they belong to, which results in the necessity of challenging the social discourses of ageing in the media and a great deal of attention on how stories about mental conditions associated with ageing, such as dementia and Alzheimer's, are told to the wide public. The evidence of the tendency of cultural materials such as news, movies, fiction and non-fiction books, speeches, and so on, to show dementia as an epidemic or a quiet catastrophe, is provided by Zeilig's (2014) research of the cultural metaphors of dementia and Alzheimer's disease. These metaphors instill dread and shame in those living with the condition, resulting in discrimination.

In Medina's research, in most of the analyzed films, selected from a cross-cultural perspective, individuals suffering from dementia and Alzheimer's are portrayed as main characters, and the audience focuses on their persona, what they do and how they feel within each experience. This approach allows the audience to identify themselves with the character and opens new perspectives in challenging the social representations of old age and conditions assimilated to old age in the world of cross-cultural cinema.

In another study, Segers (2007) concludes that dementia has only been the topic of a few films, due to the fact that it primarily affects the elderly, and the poor prognosis is unlikely to inspire joyful films with happy endings. Representations in his study show that Alzheimer's is mentioned in only 10 of the 23 movies in his database. The main present theme is the constant wandering of the characters, because it helps the filmmakers create a more dynamic story line. Activity disturbances and aggressiveness are both also very often represented. Medical care is less represented, as only two individuals use acetylcholinesterase inhibitors, and 5 of the 11 patients who are relevant do not receive follow-up. Importantly, the author argues that the way in which screenwriters and actors represent dementia and Alzheimer's is primarily intended to serve a dramatic, rather than an educational purpose.

Published magazines were analysed by scholars such as Clarke (2006), who concluded that one of the most significant observations is the lack of the Alzheimer's patient as a person with a voice, interests, and aspirations, while the disease itself is represented as powerful, unforgiving, and violent. Print media studied by Peel in 2014 showed that dementia was portrayed as a *tsunami* and *worse than death*, in contrast to written narratives of personal behavioural change and mindset suggestions to *avoid* the disorder, attaching individual responsibility, blaming and agency. Representations of Alzheimer's in news industry showed that individuals suffering from Alzheimer's disease are shown as both victims of the disease and victims of the health-care system. Negative complaints of care exceed positive reports of care, with rest centres in particular being the target of narratives of maltreatment (Kirkman, 2006).

Dementia, Alzheimer's and old age are represented in other forms of media as well, such as video games. Rughiniș *et al.* (2011) observed the narrative of ageing in art games, stating that in art games, disabled old characters are commonly used as rhetorical resources to induce players to ponder on serious subjects like loss, loneliness, or de-personalization. There is little discussion of the benefits of age, such as knowledge and valuable life experience. There are also few elderly characters with a voice and a purpose in art games: old people in art games mostly remember past experiences and wait for death.

Agency in emotional management

Agency

The debate over whether instrumental rationality or moral and norm-based conduct is the highest manifestation of human freedom may be traced back to the Enlightenment period, according to Emirbayer and Mische (1998). The idea of agency evolved, recognizing humans' capability to influence their living circumstances. This idea maintained a long series of social philosophers, grounding agency in an individualist and calculative conception of action, following John Stuart Mill, Adam Smith, and Jeremy Bentham (Emirbayer, & Mische, 1998). The principle of agency is based on Emile Durkheim's social structure theory. Structure can relate to both material (often known as economic) and cultural (which includes norms, traditions, and ideas) components. According to Durkheim (1893), established patterns of behaving, thinking, and feeling exist across a society and function as external limitations on its individuals. Structure refers to individual capacity to act despite certain rules, whereas agency is explored from the opposite perspective. Lopez and Scott (2000) established two fundamental methods to conceptualizing structure based on Durkheim's work. The logical concept of structure relates to how individuals are connected in social groups and networks, and how they are generally divided into specialized social connections sectors such as familial bonds, religion, the economy, and the state, among others. The institutional is the second sort of structure, and it refers to the shared beliefs, values, symbols, ideas, and expectations that allow members of a community to interact and engage meaningfully. To find a pattern, both methods to structure are applied.

Agency and emotions are discussed by various scholars including Slaby (2014), who argues that emotions and feelings are better defined as deliberate encounters with the social environment, rather as passively endured experiences. They are not simple feelings that happen to people, but emotions that people feel as part of a social context. This idea explains how the dynamic form of emotion provides insight on the relationship between emotion and value. Emotional involvement

is what allows value to materialize and solidify. It is believed that emotional interactions are both constituted and detected by value.

Individuals' values are tied to how they choose to follow specific norms that have been created within the social environment in which they live. Taking into account social standards, established rules and personal or group values, individuals perform emotion work when unveiling their emotions.

Emotion work

Emotion work is the synergy of actions one undertakes when experiencing and displaying certain emotions in accordance with what they are expected to act. The concept was theorized by Arlie Russell Hochschild (1979), who states that the experiencing and display of emotions is an act of management that we perform with the objective of complying to feeling rules. Feeling rules are socially accepted conventions that guide people's attempts to feel emotions in certain social situations (Tatsuya, 2000). Hochschild used Goffman's (1959) work to claim that individuals play roles and strive to produce specific perceptions in almost all social encounters. The expression of normatively suitable emotions in accordance with specified display standards constitutes an impression. Even if some authors consider that emotions cannot be controlled and therefore, cannot be normalized, according to Hochschild, emotion work is highly linked to social structure and norms, because rules "seem to govern how people try or try not to feel in ways appropriate to the situation" (Hochschild, 1979, 552). To better understand how emotion work functions, we must look either into the social factors that induce the emotions, or into the emotions determined by the social factors.

Relationship management considers the effort that individuals perform in order to adapt their emotional responses to other individuals' actions, as to maintain a good relationship. Some authors state that emotional management is gendered. Serry & Crowley (2000) conducted a qualitative research based on family observations and semi-structured interviews with 23 women, and the results showed that 18 women perform emotion work in order to maintain a healthy father-child relationship in their family. Giving recommendations for mutual father-child activities, giving information about positive emotions, endorsing fathers for their active participation with children, administering the family program, and creating or maintaining positive images of fathers were all identified as strategies to encourage desired father-child involvement. Various peace-keeping strategies designed to mediate angry or hurtful feelings were noted when fathers and children were assumed to be frustrated with one another: recognizing and trying to prevent uncomfortable feelings, separating fathers and children during disagreements, and collecting and communicating to encourage rapprochement and family harmony. Strazdins, & Broom (2004) also discuss the gender imbalance in emotion work. By stating that even if both men and women have equal access to emotional resources, in a household where all family members work together to support

people's emotional needs, promote their health, and keep the peace, the gender imbalance influenced women's feeling of love and conflict in their marriage, but not men's, according to qualitative research collecting data from a sample of 102 couples. Furthermore, the gender imbalance created a health risk to women and helped explain gender variations in psychological anguish as a result of the breakdown of marriage. Couples maintained a feeling of mutuality by explaining the gender imbalance as something beyond men's choice or control, or as a result of women's excessive emotional demands, so entrenching gender inequalities in the performance and outcomes of emotion work. Scholars such as Mirowsky (1996) argue that an explanation for this inequality is that men experience lower levels of psychological suffering than women starting in early adulthood. He links the disparity in distress between men and women to distinct social connections, duties, and obligations, particularly the uneven allocation of paid and household labor.

Some authors argue that emotion work is performed as a coping mechanism, in the case of individuals who must recover from a traumatic experience. Whittle *et al.* (2012) discuss about the emotional management adults and children went through during their recovery period following floods that took place in June 2007 in Hull, UK. Farnia *et al.* (2018) discuss the emotional management linked to trauma-focused cognitive behavioral therapy in the case of physically abused children.

Emotional labour

Hochschild distinguishes emotion work from emotional labour, where the latter is considered to be the expression of emotions adapted to a certain context where the performer is showing specific emotions in accordance with a formal agreement and in exchange for a wage. Emotional labour is directly linked to the workplace, and it involves that individuals perform activities that require emotional management for which they are paid, which translates into the fact that they are indirectly paid to manage and produce feelings. This applies to individuals who have to manage people relationships as part of their job, usually people working in the public sectors, hospitals, schools, restaurants, events masters of ceremony, and, at an extreme side, actors. According to Zapf (2002) emotional labour is the quality of relationships between employees and clients. Any individual who interacts with an employee, such as patients, children, consumers, travellers, or visitors, is referred to as a "client". Many employees are needed to display acceptable emotions during face-to-face or voice-to-voice encounters as a job requirement. Managing one's emotions, as a job requirement, suggests that the desired emotions are necessary under any circumstances. Flight attendants are supposed to be nice even to arrogant or belligerent clients, nurses or instructors are required to exhibit empathy for patients or youngsters, and bank staff are required to put on a kind but sober expression to communicate trustworthiness, according to Zapf (2002). Morris and Feldman (1996, 987) defined emotional labour as

"the work, preparation, and control required to exhibit organizationally desirable emotions during interpersonal exchanges".

Morris & Feldman (1996) argue that emotional labour has the following characteristics: (i) it occurs in face-to-face or voice-to-voice interactions with clients; (ii) emotions are displayed to meet other people's emotions, attitudes, and behaviours; and (iii) the display of emotions must adhere to certain rules.

According to Hochschild, both emotion work as well as emotional labour have in common the idea of performing tasks that require emotional effort from the performer. Basic daily task performance is just labour or work in the absence of the emotional struggle one goes through in order to perform that task. In the case of emotional labour, where the individual performs a task for the exchange of a wage, the person must take into consideration all official requirements of the job itself.

Emotional management and caregiving

Strauss *et al.* define emotional labour as "sentimental work". They claim that emotional labour is a secondary effort that must be carried out with careful attention to the reactions of the person to whom the work is directed and who does another major task (Rice, 1963).

Simson and Acton (2013) state that literature shows that emotion work is conventional as part of family work and that the positive or negative outcomes are determined by this specific type of emotion work. Hochschild argues that family is generally considered a safe place and relief zone, where members of the family feel comfortable enough to share their emotions regardless of the feeling rules, and where they are requested to perform less emotion work. However, the author also states that the deeper the connection between two individuals, the more emotion work they perform and are less aware of it. Therefore, going deeper in understanding how emotion work is performed in caregiving plays an important role.

PhD. Murray Bowen proposed in the late 1960 the family systems theory, which states that people cannot be understood in isolation from one another, but rather as members of a family, like in an emotional unit. Families are complex systems of interrelated and interdependent individuals, none of whom can be comprehended in isolation. Bowen argued that nuclear family emotional system explains patterns that cause an emotional disfunction within a family, and the disfunction must be seen within the family system as a whole, not the problem of an individual. Bowen considered that the nuclear family is the emotional unit, and whatever affects one individual, has an influence on other members of the system, like transferring anxiety from one individual to another. In a high-anxiety environment, the manifestation of the symptom indicates the action of the reciprocal mechanism. Maintaining the symptom over time, on the other hand, might lead to new responsibilities for family members, which can help to reduce family conflict (Kerr, 1981). The caretaking and nursing postures that emerge in

reaction to the dysfunctional individual, for example, might actually help to reduce conflict within the family. The end result is a fascinating contradiction. Although the symptom indicates increased anxiety in the family and can lead to a higher degree of chronic anxiety, it also gives additional mechanisms that assist to control the anxiety and allow others in the family to operate normally.

Caregiving is a complicated process that necessitates a great amount of effort, stress and a variety of tasks. Hochschild separates the concepts of work and labour from the concepts of emotion work and emotional labour by linking the latter to stress, anxiety-provoking or fear-evoking processes, where the individual goes through an internal emotional struggle caused by a gap between their emotions and the feeling rules. According to Rae (1998) caregiving must take into consideration all dimensions, including physical, financial, social as well as emotional. The focus on the emotional work underlines the intensive emotional management of informal caregiving as well (Abel, 1991). In order to highlight the dual character of caregiving as a job, scholars claimed that it entails not just caring for someone in the sense of meeting their needs, but also caring about them in the sense of feeling compassion for them (Ungerson, 1983). Therefore, the act of caregiving involves not only an instrumental dimension of work, performing tasks, servicing needs, but also an emotional dimension that consists of caring for the person and showing empathy. According to Rae (1998), most caregiving activities take place within the family and the majority of emotional performers are women. In the context of informal caregiving, where emotion workers do not receive a wage for their activity, following Hochschild's framework, Rae used the term on emotion work rather than emotional labour.

In Rae's work, the focus is on caregiving work that individuals perform when caring for members of the family who were diagnosed with Alzheimer's disease. The fatality of the condition, determined by the fact that it has no cure, as well as with the subjective perspective of the process as a whole, generates an enormous amount of stress as the affected person becomes more and more dependent on other people who become their caregivers. Caregivers undergo a great deal of frustration caused by stress and enormous burden. This amount of stress is usually generated not only by the effort that is required by the work itself but, also by the fact that caregivers are perfectly aware of the caring rules and thus, they must perform the caregiving as to view themselves as well as be seen by others as loving family members and generally good caregivers. Feeling rules, according to Hochschild, guide emotional management and give the caregiving a social pattern, so that the caregivers can control their feelings and act appropriate to a specific situation. Pearlin *et al.* (1990) argue that caregiving for someone who is cognitively impaired is additionally challenging. In the case of caregiving for patients suffering from Alzheimer's, there is a wide range of emotions involved, overwhelming and demanding, leading the caregiver to experience anxiety, guilt, frustration, love, grief, sadness, resentment, fear and anger. Apart from the emotional management that caregivers perform in order to control their own feelings, they also face

the challenge of dealing with the patient's inability to manage their own, as people who suffer from dementia or Alzheimer also experience fear, anger and frustration, but they lack the ability of managing these emotions. According to Hochschild, caregivers find themselves in a situation of unbalanced emotional exchange, where the feeling rules are not shared by both parties, the patients and caretakers. Therefore, the reciprocity expectations fade and new patterns take place. Rae's study resulted in various examples of how caretakers helped patients with Alzheimer's cope with their emotions only after they learned to manage theirs, and admitted that the hardest part of the process was controlling their own feelings.

Among the feelings caregivers experience there is also the mourning resulting from loss of the relationship they had with the person suffering from dementia or Alzheimer's. One of the respondents of a study performed by Coughlan mentioned "a sadness that you say farewell in little bits and pieces" (1993, 76). Guilt was also reported by many respondents in Rae's study as well as Coughlan. Hochschild explains that guilt happens when caretakers experience emotions that they should be not experiencing according to the feeling rules. But because those feelings are real, they feel guilty for experiencing those emotions. Given this context, caregivers must learn how to control their emotions when loved ones' act in ways that cause caregivers to instinctively react with anger. Rae mentions a few of these situations such as when their loved ones accuse them of things, they did not do, such as stealing or cheating. This dynamic causes personal caretakers to feel anger and resentment, as well as shame and guilt. One must practice an intense emotional control and patience. Whitbourne (1986) argues that self-evaluations in the fields of family and job embody all other aspects of identities, which is why most respondents in her study consider that loving a family member is part of what represents them, part of their identities. When failing to control emotions, expressing anger instead of love, respondents felt that part of their identity is compromised.

When discussing emotional management in her work, Hochschild states that in order to adapt to the reactions of others and control one's personal feelings, individuals must learn to adapt certain techniques to display emotions in accordance with the feeling rules. She offers an example of how flight attendants keep their instinctual feelings under control when a passenger is rude or expresses irritation. In that specific moment, flight attendants consider that passengers act similar to children who want to attract attention and whose needs come first, therefore this action of emotional labour helps flight attendants to show patience and tolerance. So, as similar as adults would react when a child throws a tantrum, by prioritizing their emotional needs before anything else, in the same way the flight attendants would put the passengers' needs first. In caregiving, one thought that helps caregivers do their job with empathy and love is to always remember that the misconduct is not a result of malicious intentions, but the effect of a disease that is affecting their loved ones in ways beyond their control. So, they blame the disease and not the patient (Gubrium, 1986).

Findings in Rae's study showed that respondents found it very hard to be both caregivers of their parents as well as their children. They would state that if they were to be taking care of someone else to whom they would not have an emotional connection, they would just ignore the things that patients would do and say, but since they are their children, the uncontrolled actions of their ill parents would trigger their emotions and determine them to feel anger and further, guilt and frustration. While they cannot separate the caregiver feelings and the personal feelings, the situation is different in the case of people suffering from Alzheimer's because they no longer are aware of the personal relation they have with their caregivers. Respondents in Rae's work stated that trying to comfort their parents in ways a child would comfort a parent, by offering him a hug for example, is not efficient. Patients would react in a negative mode to such a display of emotions, because they lack the conscience over the emotional bond, they have with their caretaker who is also their child.

Suppressing one's feelings is also an act of emotional management, according to Hochschild, because emotion has a signal function, and people use emotion to communicate with each other. Respondents would claim that, in the absence of reciprocity in the communication process, they would see no use of expressing emotion and thus, they would stop the display of anger and other similar feelings. As a result, they would try to keep calm and do what is necessary in order to reach the emotional state they were in before they got angry. Such examples would consist in leaving the room or taking a short walk.

The enormous amount of stress that results in the process of caregiving for a family member comes not only from the interaction with the person who suffers from the condition, but with other members as well. Rae discusses the idea that conflicts arise when the family deals with the new situation, but these conflicts are usually latent conflicts caused by unresolved issues along the years between the members of the family, which affect their ability to communicate under stress pressure. Caregivers would often come in conflict with other members of the family who are either in denial, or less involved in the caregiving process, or simply share a different opinion. They report the need of support from their family and often must face criticism, which adds to the stress they experience while caring for their loved ones. The logistics of the caregiving experience are also linked to emotion work, as caregivers report that they must take decisions that go against their feelings, such as admitting that they can no longer take care of their loved ones and must seek help in an institutionalized environment.

In conclusion, even if caregivers would try to convince themselves that the person suffering from Alzheimer's is not to blame for her behaviour, even if they would try to adopt an attitude where they would avoid their loved ones on a short term to control their anger, they consider that trying to reason with the patient suffering from Alzheimer's would lead to no result (Rae, 1998). Hochschild thus states that emotion work as well as emotional labour is not an optional response in displaying emotions, but a necessity performance in the caretaking process as

respondents would state that the only way to reason with the Alzheimer's patients is to agree with them in everything they say or do.

Methodology

In this research we relied on thematic content analysis of a corpus of graphic novels that deal with caregiving and mental conditions associated to ageing such as Alzheimer's and dementia.

Thematic analysis is a method used to identify and analyse specific patterns of meaning in a set of data (Braun, & Clarke, 2006), delineating the main themes that are present in the corpus under study (Daly *et al.*, 1997). We followed Braun and Clarke's guidelines and phases of thematic analysis, as follows: 1. Becoming familiar with the data; 2. Creating initial codes; 3. Identifying themes; 4. Reviewing the previously identified themes; 5. Explaining themes; 6. Presenting the results in a produced report.

When dealing with themes, we followed Braun and Clarke and we addressed the patterns that are found in the data, patterns that are present in the manifest content on the data, the directly observably pieces of information, as well as in the latent content, the indirect references that can be noted.

The graphic novels in our collection are the following:

1) Aliceheimer's: Alzheimer's Through the Looking Glass (2013) by Dana Walrath.

Dana Walrath's novel "Aliceheimer's: Alzheimer's Through the Looking Glass" depicts the narrative of woman whose mother, Alice, has Alzheimer's disease - hence the play on words between her mother's name and the name of the neurodegenerative condition. The author uses shredded pieces of paper from Lewis Carol's novel *Alice in Wonderland* to form visual images that suggest the diminishment of identity elements as Alice becomes less and less Alice. The narrative revolves around Alice's conversation with her daughter Dana.

2) Bird in a Cage (2016) by Rebecca Roher.

"Bird in a Cage" by Rebecca Roher is a memoir of her grandmother's dementia, which develops following a car accident, told from the writer's point of view. The author provides examples of her grandmother and highlights the changes in her family's lives following the accident, when her grandmother began performing things, she was unaware of.

3) Can't We Talk about Something More Pleasant?: A Memoir by Roz Chast (2016).

Roz Chast's memoir covers the narrative of the author's parents' ageing process. The author depicts the ageing process, which ends in the death of both of her parents, in a vivid graphic technique, and how it is experienced by the three of them. We discover that the title is inspired by her parents' aversion to addressing

sensitive topics like death, but it can also be seen as a metaphor for the fact that, in general, ageing is not a comfortable subject to discuss.

4) Special Exits (2001) by Joyce Farmer.

Joice Farmer's "Special Exits" is a fictional graphic novel that depicts a family struggling to maintain emotional equilibrium while caring for an elderly relative. While describing her parents' hobbies and specific actions, the author emphasizes their incapacity or lack of will when it comes to making important or difficult decisions in their daily lives, which motivates their daughter to gradually take on this responsibility with full dedication, while balancing it with her personal life.

5) Tangles (2012) by Sarah Leavitt.

"Tangles", a graphic memoir by Sarah Leavitt, describes the life and death of an Alzheimer's patient through the eyes of the author's mother. She embraces the medium of comics to emphasize little but essential aspects, particularly when describing her mother's memories and her shift from a strong to a vulnerable woman. The word "tangles" creates the image of a twisted mind.

6) Wrinkles (2016) by Paco Roca.

Paco Roca's "Wrinkles" is a fictional graphic novel that tells the narrative of Ernest, a former bank manager who suffers from Alzheimer's disease. The action takes place in a nursing home, which sets it apart from the other books. Ernest's son and daughter-in-law are unable to care for him properly, so they accommodate him in a nursing home without informing him of the diagnosis, which he discovers by mistake while in the facility.

All of the graphic media in our selection depict life situations set in major, fast-paced cities throughout the globe, including Toronto and Vancouver in Canada, Vermont, New York, and Los Angeles in the United States, London in the United Kingdom, and Valencia in Spain. They were included in the dataset due to their temporal similarities, and to the fact that they depict ageing and neurodegenerative disorders, while their narratives focus on interactions between patients and their families as well as professional caretakers.

Because the topic of graphic media that focuses on seniors and patients who suffer from mental conditions associated to ageing is still underdeveloped, there is a limited range of graphic novels suitable to serve as data for our work. At the time of this writing, the graphic novel audience appeared to be increasingly interested in graphic novels that cover mental illnesses such as depression, anxiety, and stress, which are linked to adults' and young adults' fast-paced lifestyles. In addition, we discovered a large number of graphic novels that address mental diseases that are categorized as psychiatric, such as schizophrenia, but the characters were not elderly, so we did not include them in our work. In addition, only graphic novels with a realistic point of view were included in the dataset (either autobiographies or fictional stories that relate usual actions). As a result, fantasy books (including magic and time travel, such as Tom Zahler's *Time and Vine*) were not included in the sample, and we focused solely on autobiographies and realistic novels, as

our objective was to investigate the representation of elders and patients suffering from Alzheimer's in a world of realistic happenings.

We are looking at how emotional agency and emotional management of the dynamics between older adults, patients suffering from Alzheimer's or dementia and their caregivers are represented. Graphic novels play a role in the emotional socialization of readers, concerning feeling rules and practices of emotion work and labour. By iteratively reading and coding the graphic novels, we identified the following patterns, that we detail in the sections below:

1. Situated rules of feeling: emotions emerge from tasks and situations related to caregiving;
2. Agency in emotion work – producing and managing feelings in an informal environment;
3. Agency in emotional labour – producing and managing feelings as a profession requirement;
4. Characters' reactions to mediated feeling rules and norms, which contrast with the emotions they feel in their new roles;
5. Emotional agency in family systems;
6. The emotion work of acceptance.

We focused on three categories of characters: 1) older seniors and patients suffering from dementia or Alzheimer's were investigated in the same category as individuals that are being taken care of, 2) family caretakers and 3) professional caretakers.

Results

Situated rules of feeling: emotions emerge from tasks and situations related to caregiving

We investigated representations of tasks related to caregiving and the emotions resulted in them. Most of the tasks are performed by caregivers, the older adults or patients are the passive receivers of the results of the tasks performed by their caregivers. In the case of family caregivers, they perform these tasks as extra work, which creates a tension caused by both emotional involvement as well as task overload.

Helping with or taking over the housekeeping work is one of the elements identified in the dataset regarding caretaking. This action is either appreciated, or it receives the opposite reaction, because elders or patients are having a difficult time in transferring agency to their caregivers, of they simply want to have things done in their own way.

We can observe in the image below Roz Chast trying to help her mother on the cleaning of the house. The house needs cleaning but since it is unsolicited by

her old aged mother, performing this task results in Roz feeling not necessarily helpful, and her mother feeling insulted or embarrassed.

Figure 1. Chast, R. (2014). Can't We Talk about Something More Pleasant? A Memoir. New York. Bloomsbury, page 23

In *Special Exits,* at page 19, we observe a similar discomfort that is highlighted in the text boxes, where the daughter observes that there are too many pieces of clothing in the room, and her mother specifically asks her not to throw anything away.

Personal care is another activity that older adults and patients suffering from dementia or Alzheimer's can no longer perform for their selves, so it is transferred to their caregivers. Though it is an uncomfortable situation for both parties, caregivers perform it with love and empathy, in order to help their loved ones to have a decent experience even if they are aware of it or not. In the image below, Sarah Leavitt kindly gives her mother a massage and tries to untangle her hair, and while she is performing a task, what she really feels is the need to get as much of her mother as possible. This activity is both technical, it gets the job done, as well as emotional, as it comforts the caretakers and reinforces their compliance to the feeling rule.

Figure 2. Leavitt, S. (2012) Tangles, Freehand Books, page 114

In *Special Exits,* at page 86, we observe the same pattern. The daughter gives her mother Rachel a bath while kindly explaining to her the process, as well as the fact that she may need a haircut because of her tangled hair.

Helping an Alzheimer's patient have dinner is also a caregiving task that sometimes can generate tension between the two parties. In the image below, Ernest's son is trying to make sure his father eats his dinner but because of a memory black-out, Ernest doesn't realise he is supposed to have dinner, which causes his son to lose his patience and have an anger moment. The anger displayed by Ernest's son soon transfers to Ernest, determining him to throw his food in his son's face.

Figure 3. Roca, P. (2015). Wrinkles, Knockabout Publishing, London, page 8

In Bird In a Cage, at page 39, Rebecca tries to feed her grandmother and receives the same treatment as the characters in the previous images. These representations reinforce the idea explained the literature section, that caregivers have one way only to reach their caregiving objective, that is to put the patient on the first place, similar to how one would do with a child in a tantrum moment, and keep their calm and control their anger, because the opposite would only make the patients angry as well.

Another task that involved emotional distress is taking over the administrative aspects such as expenses management, interacting with the personnel in the nursing home, taking decisions on behalf of their loved ones. These activities are often represented in Can't We Talk about Something More Pleasant? A Memoir. Pages 89 and 146 show representations of Roz Chast making financial calculations, being worried that the money will not be enough for the process, and feeling, as she states in the text as well, "like a disgusting person".

Agency and emotion work: producing and managing feelings in an informal environment

In a variety of moments, caregivers as well as older adults and patients feel, express, or contain anger, anxiety, and other negative emotions. A significant part of caregiving is trying to keep their loved ones in a safe emotional space, regardless of those negative emotions, so caregivers would often perform activities that influence how they display emotions as well as how they manage the emotions of the older adults or patients.

In figure 4 we see a representation of Rebeca Roher and her cousins performing a ritual of singing for their grandmother, with the objective of cheering her up. The scene takes place at their grandmother's house, where her nieces meet, and even if they are concerned and tired as one of them mentions, they are smiling and enjoying the time with their grandmother, manipulating their feelings from tiredness and concern to serenity and joy.

In *Tangles,* at page 67, the panels illustrate the emotional effort Sarah goes through during a phone call with her mother, caused by an outbreak of her mother. The mother is angry and scared because she knows she has Alzheimer's and her condition will get worse, so she feels she is not a real person anymore and she does not want to be married anymore. Not being used to being her confident on marriage problems, but her daughter, Sarah explicitly states that she has to pretend in the moment of the conversation that her mother is not her mother, in order to be able to listen and comfort her. After hanging up the phone, she comes back to her real feelings, of anger and helplessness.

Figure 4. Roher, R. (2006). Bird in a Cage, Conundrum Press, Wolfville, Nova Scotia, Canada, page 77

Another example of manipulating one's emotions comes from *Wrinkles,* where, at page 36, a couple is represented, holding each other, and the image also shows a man sitting in front of them. We learn that the woman's husband is not the man that she is leaning on, but the one in front of her. Because of Alzheimer's, the woman believes her real husband is someone else, so the real husband comes and visits her even if she doesn't remember him. Such an occurrence, according to the feeling rules, would make a person angry and jealous. But in this case, he expresses care and love, demonstrated by the fact that he visits her every day. Though sources in the literature state that emotion work is what people perform to keep their relationships, the panel below shows that the character represented as the woman's husband is not performing emotion work to save a relationship itself, but the memory of the relationship and what the relationship means to him.

The analysed graphic novels aligned with the observation from studies of caregiving (Rae, 1998), where caregivers reported that one way to cope with the

new situation is to accept it. This implies that they would often perform activities or adopt mindsets where they would stop fighting back and expressing anger and frustration, given the fact that fighting back would lead to no change in the situation.

Figure 5. Chast, R. (2014). Can't We Talk about Something More Pleasant? A Memoir. World the Curiously Abstract Concept of Agency. Sociological Theory, page 179

Caregivers also worked on their emotions to make their loved ones feel comforted and calm. The panels presented at page 111 in *Special Exits* show how Rachel is about to become anxious because she is starting a sentence and is not able to finish it. Her daughter and husband look for a way to comfort her, so her husband gives her his Teddy bear that she likes. Even if we learn from other sections of the book that her husband is hoarding objects and doesn't like when other people use his things, we notice him offering a valuable object for him, which makes him feel good because his wife is comforted.

Agreeing with someone when having of different opinions is also an element of emotion work. In the image below, the woman in the wheelchair who suffers from dementia believes that she is travelling to Istanbul on the Orient Express to meet her husband. The other woman, represented in the first two panels, has a conversation with her as if they were both traveling together. Even if the other woman is aware that they are not in the train, she complies to the imaginative story of the woman in the wheelchair, to keep her calm and comfortable.

Figure 6. Roca, P. (2015). Wrinkles, Knockabout Publishing, London, page 97

In *Aliceheimer's*, Dana states that her mother, Alice, "escapes the captivity of Alzheimer's through story" (Walrath, 2016, 29). Most of the novel is populated by stories from Alices' imagination, where Dana plays the role of companion and often confident. Alice's mind wonders in different time zones, recalling memories or creating new stories, and Dana maintains a vivid dialogue along each story, playing a different role each time, according to her mother's needs. As she underlines in the novel, the reason of this emotional management is that she wants her mother to feel loved in all her moments.

Agency and emotional labour – producing and managing feelings as a profession requirement

Emotional labour, as defined in the literature review, considers all emotional management individuals perform as a profession. In our research, we investigated emotional labour in the emotional management performed by professional caretakers.

In contrast to family caregivers, in the studied graphic novels professional caretakers were represented as characters that showed fewer negative emotions such as anger, anxiety or stress. They were portrayed as performing tasks as part of their job without the emotional involvement specific to family members. Therefore, the professional caretaker characters serve to highlight the emotional challenges and work of the family members.

Page 17 from *Tangles* illustrates a representation of a caretaker who is following the feeling rules of their profession by displaying a positive, friendly emotional state while meeting and accommodating Sarah's mother, as she moves into Pine Grove, a nursing home her family takes her to. The positive expression of the caretaker is represented in contrast with the representations of Sarah's mother and her family, who all show sad faces in the common panel, as well as in the following ones.

Figure 7. Leavitt, S. (2012) Tangles, Freehand Books, page 117

Professional caretakers can be interpreted as being more procedurally driven and less empathic on performing emotional labor, compared to family caregivers, such as in the images represented at page 79 in *Bird in a cage,* where the caretaker follows the rules of recommending a feeding tube for a 93-year-old patient who can no longer feed themselves. Even if, according to the procedures, the suggestion could help the patient get nourished, and the caretaker is just doing their job by presenting this option to the family, judging by their reaction of disapproval, represented both graphically as well as with their statement "can you believe that?", the suggestion hurts their feelings. So, the caretaker decides to walk away and come back later.

Compared to family caretakers, professionals were represented as being less attentive to the patients. In the image below Laura informs the facility manager that her mother was affected by the personnel's bad treatment, as they did not feed her even if there was a sign next to her bed saying that she cannot feed herself, and they left her bed rail down, even if she could have fallen.

Figure 8. Farmer J. (2010). Special Exits, Fantagraphics Books, page 146

The lack of attention that results in representation of a less emphatic reaction can be observed in the image below where Ernest's caretaker gives him by mistake the medicine of a different patient, who was suffering from Alzheimer's. Following this action, the caretaker states that it does not matter, since they both are following the same treatment. This reveals the moment when Ernest finds out that by following the same treatment as an Alzheimer's patient, he suffers from the condition as well. Since the caretaker did not know that Ernest was unaware of his condition and gives him this sensitive information simply my mistake, he is not performing emotional labour, but just a task.

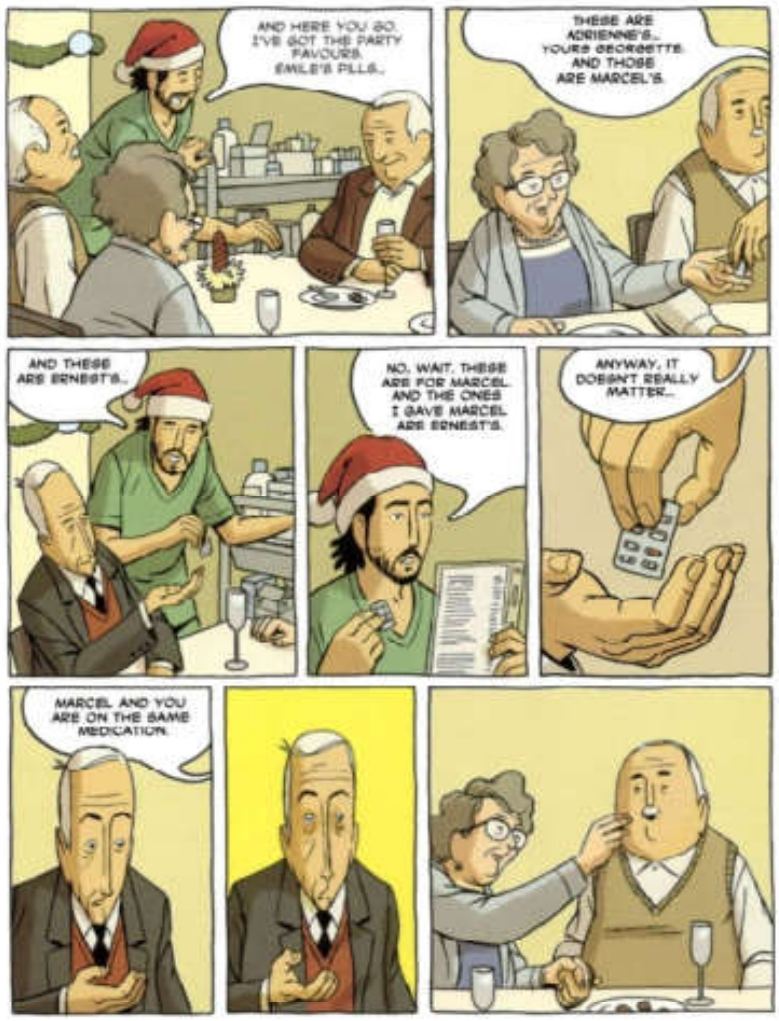

Figure 9. Roca, P. (2015). Wrinkles, Knockabout Publishing, London, page 55

Mediated feeling rules and caretaking roles

The authors of the graphic novels under study have also addressed the emotional socialization that mass media performs, regarding old age. They highlight what they consider to be dominant feeling rules and structures, in an attempt to critique and reformulate them. Roz Chast illustrates the gap between how old age should feel according to what people observe in the media, and how it feels in reality. The panels from page 27 underline the difference between positive expected

emotions, shaped by the media and the beauty industry regarding ageing, and real-life emotions, that we can observe in both image and text from the figure below.

Caretakers believed that they should be "good" caretakers but did not feel that way all the time. In the figure below we see a couple of seniors who are not comfortable being taken care of, so they respond with hostility, which adds pressure on the caregiver, in this case on their daughter Roz Chast. Chast knows it is her responsibility to look after her parents but because they are not cooperating, she feels she is not doing a great job.

Figure 10. Chast, R. (2014). Can't We Talk about Something More Pleasant? A Memoir. New York. Bloomsbury, page 23

Feeling rules also imply that caretakers would do anything to keep their loved ones safe but in the absence of succeeding at this, one might feel guilty and ashamed, as in the example below. Chast illustrates at page 146 a variety of details that a caregiver must take into account and how all the administrative issues are financially conditioned. Because the caregiver has to think about the expenses, she feels "like a disgusting person" (Chast, 2004, 146). While love is unconditional, medical care is an institutional public service that has financial cost, and not being able to cover that cost makes Chast feel like she doesn't love her parents enough, which makes her feel guilty.

Page 147 of the same novel shows with parallel panels how the character fails to adjust to the feeling rules. In the left panels we observe how she considers she should feel, on the right panels we see how she feels. The humorous representation, making use of the angel-demon metaphor shows the enormous difference between expected feelings and reality, as well as the magnitude of the effort she has to perform to be a good daughter, a good caretaker, a good human being.

Managing one's emotions to comply with the expected emotional display is part of an individual's identity, so characters would often act in accordance to what other people expect them to do, not only because of external expectations, but also because they need to act in that specific way as part of who they are.

Figure 26 beautifully illustrates this aspect. The author specifically states that "even though grandma couldn't hear or couldn't remember" (Roher, 2006, 19), her family would still sing and surround her with love, which the author graphically represents by having the grandmother always in the centre of the page, surrounded by her daughters and nieces.

Figure 11. Roher, R. (2006). Bird in a Cage, Conundrum Press, Wolfville, Nova Scotia, Canada, page 19

Emotional agency in family systems

Caregivers and their loved ones share and transfer emotions, and one's actions determines other's reactions as well. In figure 6 (see above) we observe a calm Ernest in the first-row panels, but as the narrative evolves, we see his son losing his temper, which determines Ernest to lose his temper as well. A transfer of anxiety and anger takes place between the two characters, and the use of the word "again" indicates the fact that this moment is not the first of this kind.

In Walrath's *Aliceheimer's*, the author uses text to show, at pages 42-43, how Alzheimer's brought to surface unfinished business in their family. In one of the stories, the mother, Alice, admits that she was not very good to her daughter Dana, in comparison to the other children, and apologizes to her. Dana Walrath realizes and states in the novel that this conversation takes place only because of

her mother's illness, and she tells her mother that she forgives her, because she knows her mother did the best she could as a parent.

Alzheimer's and dementia are conditions that impact not only the person who suffers from the affection, but also the family as a unit. Caregivers add to their daily routines activities that they do for and with their loved ones. They must manage their emotions and the emotions of others to keep the family united, safe and comforted. In the image below, Laura's parents want to see their grandson, but their home is not a suitable place for a new-born, so Laura offers to go to her parents' place a day before the visit of the new-born to clean the house.

Figure 12. Farmer J. (2010). Special Exits, Fantagraphics Books, page 75

In Roz Chast's memoir, she states from the beginning of the narrative that her parents were co-dependent, and this is represented on various occasions along the novel. At page 62, Chast states that her mother was very determined and could not be convinced to do things she did not want to do. Refusing to go to the hospital or even call a doctor, she produces enormous tension in the family. Her father, described as being anxious and with low decision-making capacities, is overwhelmed by the situation and, as Chast states, is "losing it".

The emotion work of acceptance

In all the presented novels, all older adults and patients who needed caretaking die at the end, so the authors reserve a space in the narratives for representations of acceptance of death, along with acceptance of the conditions. As the literature showed, from an emotional perspective, the only effective way to manage a healthy and non-violent relationship with a patient suffering from Alzheimer's or dementia is to put their emotions first and the caregiver's emotions after. Since this action requires intense emotion work and less expressing of agency by trying to change things, caregivers create individual stories, make use of memories, metaphors and their imagination to accept the things they cannot change.

Dana Walrath prefers to see her mother as a superhero.

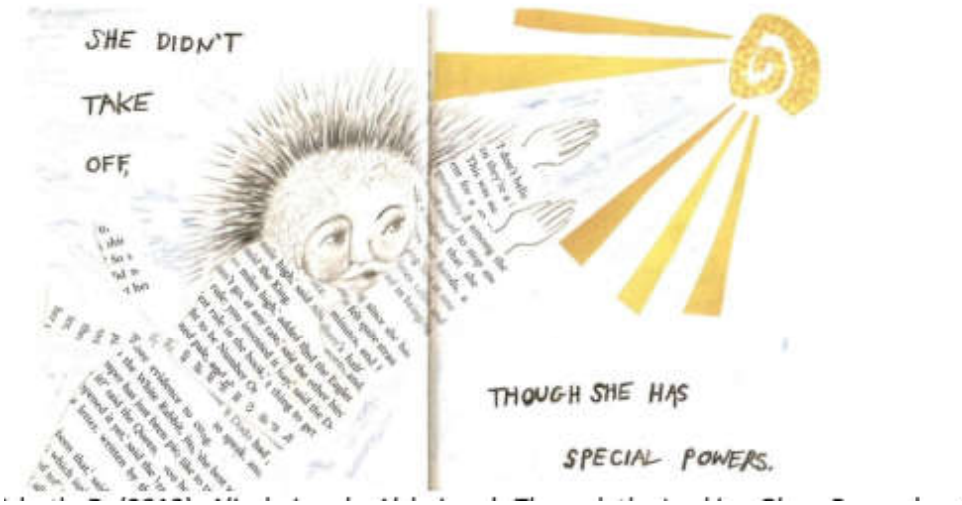

Figure 13. Walrath, D. (2013). Aliceheimer's: Alzheimer's Through the Looking Glass, Pennsylvania State University Press, page 18

Also, she prefers to believe that even if pieces of her mother are disappearing, she is still with her, in a common "here" they both share.

Figure 14. Walrath, D. (2013). Aliceheimer's: Alzheimer's Through the Looking Glass, Pennsylvania State University Press, page 20

Sarah Leavitt prefers to be brutally honest with her mother, and represents a dialogue between the two at page 57, where she tells her mother that she wants to spend as much time as possible with her, because her mother is sick and will die.

Part of the process of accepting the disease is accepting that home care is no longer an option, and her mother needs to go to a nursing home, even if the decision is awfully hard for the family.

Figure15. Leavitt, S. (2012) Tangles, Freehand Books, page 116

Roz Chast finds it difficult to go through her parents' possessions while they are not living in their home anymore, so she thinks of coping mechanisms to help her accept their ageing and eventually, their death. She touches objects, recalls

events that are linked to the specific objects, takes pictures, decides to keep a few objects and eventually, is ready to let them go, as represented at page 121 and 122. At page 124, the author created the image of her on a beach, waving to a floating platform full of objects, that shows through a metaphor that once she lets go of things by sending them to the sea, she has to let go to her parents as well.

In Rebeca Roher's graphic novel, after the death of her grandmother, the family meets for the Shiva, have dinner together, and go through family photo albums, to honor the grandmother's family because she would have loved this activity.

Figure 16. Roher, R. (2006). Bird in a Cage, Conundrum Press, Wolfville, Nova Scotia, Canada, page 109

Conclusions

In this paper we have investigated representations of emotion work and emotional labour that are linked to dementia and Alzheimer's disease. The focus was on representations of family caregiving, but we observed representations of professional caretaking as well.

Characters from the novels in our dataset that represented seniors and patients suffering from dementia and Alzheimer's showed less emotion work, compared to their family caregivers. They were portrayed in order to highlight, contrastively, the challenging emotion agency required of family caregivers.

The people who were suffering from conditions that affected memory and critical thinking were portrayed as less in control of their emotions in most situations. In some circumstances, they would become angry because they would have difficulties in understanding why certain things are happening to them and how they should react. Their emotional agency consisted, often, in facing and remedying a patchwork, absurd situation, by filling in the blanks with missing information. For example, Alzheimer's patients were portrayed as recalling events from the past or creating new stories, shaping and expressing their emotions as a result of these emerging and often surprising definitions of the situation. This resulted in misalignment with caregivers' actions, since they reacted to different interpretations of the situation, complicating the emotional agency required in the relationship.

Family caregivers were represented as performing challenging feats of emotion work in order to deal with their family situation. They were trying to align their powerful emotions to the feeling rules of previous roles, or the rules they were socialized with in mass media. When they failed to do so, they would get frustrated and feel guilty. Emotion work was also performed on the purpose of coordinating actions and calming their loved ones' emotional outbursts. Caregivers understood that if they become angry, their loved ones might respond in the same way, so they tried to control their own emotions to maintain a stable, actionable environment. Caregivers are portrayed in a constant struggle to make their loved ones feel secure and comfortable. They would take a role in their stories, agree with them at any time, change their daily schedule to adapt to their loved ones' needs. Overall, under the pressure of time, caregivers would put the patients' needs and emotions first, and would do everything that is necessary to make them feel as good as possible and therefore, have a positive impact on their wellbeing.

Emotional labour as part of a professional skill was also observed in professional caretakers presented in the dataset. They were represented as being less focused on the feelings they expressed as well as feelings of others, but not devoid of emotions. They would often come in conflict with the family caregivers, because of their involuntary mistakes caused by lack of attention or by their focus on medical rules. While some of them were performing tasks according to the procedures, they

would not take into consideration the feeling rules of caretaking, since they were not paying attention to how the procedures might feel for patients or stakeholders.

Representations of family caregiving process familiarize the readers with a situation of high stress and anxiety and with the emotional agency required to handle this challenge. Negative emotions resulted from the intersection between taking over tasks that overlap daily activities and taking care of someone from the family. The emotional bond and family relationships between patients and caregivers generates powerful feeling rules, causing caregivers to experience emotions such as guilt, insufficiency, anxiety, or the feeling of not being available enough, prepared enough, financially capable enough or simply, just good enough.

Anger was also frequently represented in all studied graphic novels. Caregivers are portrayed as angry at the situation because they feel that they cannot change it. They also feel angry when their loved ones, for whom they care, do not cooperate, diverging through their interpretation of the situation. Still, once they realize that they are not doing inappropriate things on purpose, but because of the disease they are suffering from, caregivers direct the anger towards themselves, because of the guilt they experience. In the direct relationship between caregivers and patients, anger is mirrored: when caregivers would become angry, this action would only make patients feel angry as well. So, in result, caregivers give up their attempts to influence patients' definitions of the situation and simply put their needs and interpretations first, to alleviate their anxiety or discomfort. Representation of anger in the analysed graphic media contributes to the normalization of this emotion and to the decrease in stigmatization of people who express this feeling when they find themselves in the new role of caregivers or the new role of patients.

As all of the novels presented narratives that evolved around families, part of the attention was focused as the family as a unit, not on observations of separate individuals. Emotional agency is represented as a collective endeavour, a systematic process occurring through family interactions. We could observe that all family members were having their own emotional journey when one of their loved ones would get sick, but they would influence each other in both positive was as well as negative way. When one character would become anxious, other members of the family would feel the same. Or when one of them was having a hard moment, others would try to get him in a better mood. In all cases, they would not ignore each other, but would rely on each other and influence each other, either intentionally or not.

Caregivers were taking over activities, tasks, and decisions for their loved ones, however they were occasionally forced to make decisions they did not want to be responsible for. In most novels, the hardest decision to make was accommodating their loved one to a nursing home. Even if the decision belongs to the caregiver, was not experienced as a decision of the caregiver, but a decision determined by the context in which the caregiver is, so this type of action and others similar to it are not portrayed as a result of agency.

As discussed in the literature review section, other forms of media such as news industry, cinema, printed magazines and video games showed representations of Alzheimer's and dementia as *a tsunami*, *worse than death*, *aggressive* and *an epidemic*. Our results indicate that graphic novel portrayal largely overlaps with these representations, as Alzheimer's in the studied works is the nucleus of the story, and also the reason why the life of those involved in the illness ecosystem change dramatically. The *tsunami* metaphor is used as an environmental framing, where life will be reconstructed for those who survive the disease but will never be the same because of their loss, and it is present in all studied novels. Representations of *aggressivity* are also present in our dataset in both patients and caregivers, but in the case of patients it is attributed by the family to the condition per se, not to the person. As Ernest in *Wrinkles* states that going on the second floor of the nursing home, where the disabled are, is the worst thing that can happen, we might consider that the expression *worse than death* is present as well. The *epidemic* representation was not present in our data. Other forms of media showed that Alzheimer's is linked to blaming and accountability, where individuals can control the condition if they want to. This representation was present in *Wrinkles* where Ernest does not feel blame because he suffers from the disease, but he tries to control its progress by training his memory with intensive reading. While some researchers observed representations of *no voice* and *no control* in characters suffering from dementia and Alzheimer's in movies, and others observed the opposite, our research showed that the studied graphic novels focus on the individuals suffering from this condition, offering them primary roles in the narrative. The dynamics of the plot also focus on their voice and needs which caregivers try to respect while performing emotional management, except for the situation where patients are accommodated in care facilities against their wish.

Medical care was relatively little represented in other forms of media and it was similarly under-represented in our selected graphic novels as well. However, the works in our research focus more on family dynamics and less on institutional care. News articles and written media showed that negligence in facilities is more represented than proper care, and this was also present in several works included in the study, specifically in *Wrinkles, Bird in a Cage, Can't We Talk about Something More Pleasant?* and *Special Exits*.

Previous research on representations of old age and medical conditions related to old age in the art game industry showed that there is little discussion about the benefits of ageing, such as *knowledge* and *valuable life experience*. Conversely in the graphic novels from our dataset, a significant part of the information provided is linked to the evolution of characters as a result of their life experience. Caregivers from their family admit, respect and celebrate their knowledge, traditions and valuable insight.

Given its specificity in depicting Alzheimer's experiences, the graphic novel proves to be a versatile instrument for emotion socialization specific to the challenging situation of caregiving. By combining images and text, feeling rules

and emotion agency become visible and vivid for the public. The narratives as well as visual representations invite the readers to critical thinking and deeper analysis on the process, focusing on details they might not have noticed before. Therefore, serious graphic novels may offer a useful reflection and learning resource for understanding how mental conditions associated with ageing simultaneously affects all characters that deal with this new situation, both patients and caregivers.

The limits of our research are given by the number of graphic novels in the dataset. While other novels addressing the same topic may exist, also in different languages, we could not identify them for inclusion in our corpus. The subject may also be tackled in graphic novels on different topics, which might offer valuable insights, but they were not identified. Another limitation is that we investigated graphic novel representations without inquiry into public reception and impact, which remains a topic for future studies.

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