Mistreatment of older caregivers (ECG) and caregivers for the elderly (CGE): recognition, heightening awareness and prevention

RESEARCH REPORT

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Research Chair on Mistreatment of Older Adults

With the contribution of :
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Notes for readers

In this research, the acronym **ECG** (elderly caregiver) denotes an older person who is **50 years of age or older who cares for a disabled person of any age**. For example, this may be a 74-year-old man who is the caregiver for his wife of the same age, or a 53-year-old woman who cares for her adult child who suffers from a mental illness. The age of 50 was chosen by organizations for older adults who collaborated in the research, because their clientele includes people 50 years of age and older. This allows a larger number of caregivers to be targeted.

The acronym CGE (caregiver for the elderly) no matter their age, refers to a person who **cares for someone aged 65 years and older** with a disability. This may be a 74-year-old man who is the caregiver for his wife of the same age, or a 19-year-old granddaughter caring for her 77-year-old grandfather. The age of 65 was chosen as it is considered the official threshold for old age in Canada (old-age pension) and in Québec (services offered to older adults).

While the research was funded by the program *Québec amis des aînés* (QADA) developed by the *Secrétariat aux aînés*, the end tools were designed to be adapted to all caregivers, not only to ECGs and CGEs. In effect, since the adoption of Bill 56 (2020) and the *Politique nationale pour les personnes proches aidantes* (2021), the Québec government no longer makes a distinction between a caregivers according to their age (ECG) and one caring for an older person (CGE). Thus in this text, we are using the acronyms ECG and CGE in the sections dealing with reviews of the literature and with data collection, because these individuals are the participants in our sample. In other sections, we are using CG instead to denote all caregivers.

Highlights

This action research, which addresses mistreatment of elderly caregivers (ECGs) and caregivers for the elderly (CGEs), was carried out in 11 regions of Québec with 433 ECGs, CGEs and caseworkers.

The findings show that actions, words or the absence of action all qualify as mistreatment of ECGs and CGEs by the entourage, institutions and healthcare providers, by the care recipient and by the CGs themselves, and manifests itself in seven different forms.

Based on the official definition of mistreatment of older adults by the Québec government (Ministère de la Famille – Secrétariat aux aînés, 2017), the findings of the action research offer suggestions for definitions of mistreatment and wellness care for caregivers (CGs).

Objectives of the action research

1. Document the phenomenon (its forms, its manifestations, its consequences and the contexts in which it occurs).
2. Develop awareness and prevention tools.
3. Offer recommendations to promote wellness care for caregivers.

Apart from this research report, several awareness tools for mistreatment that can be used by caseworkers in the community or clinical setting are being offered: a poster accompanied by a facilitation guide, three leaflets, and narrated PowerPoint presentations. These tools are available online and can be downloaded at: procheaidance.quebec/recherche-maltraitance-proche-aidant

Definition of wellness care	Wellness care for caregivers is an overall accompaniment approach. Its aim is to offer support, foster listening to their needs, and value their input, their experiences and their expertise in their daily lives, in order to prevent mistreatment.
Definition of mistreatment of caregivers (CGs)	Carrying out the role of a CG involves a risk of mistreatment that impacts the CG. This mistreatment comes from institutions, the entourage, the care recipients or the CGs themselves. Whether intentional of not, it manifests itself by the absence of appropriate action, or by an attitude or gesture that occurs once or is repeated. Mistreatment of CGs may take one or more of these forms and will evolve over time: ▪ Imposition of the CG role and over-accountability ▪ Normalization of the CG role and the mistreatment experienced in carrying out this role ▪ Judgments about the way the CG performs their role ▪ Denigrating the CG’s expertise and their family and social contribution ▪ Denial of the CG’s needs ▪ Use of psychological, physical or sexual abuse against the CG ▪ Contribution to the impoverishment of the CG

1. Presentation of the development context for the action research

While we reviewed very few Canadian studies on mistreatment of caregivers (CGs), there was some reflection on the question in April 2017 in Québec, among caseworkers, researchers and students. Using the World Café conversation methodology, the aim of this reflective activity was to define mistreatment of CGs and focus on awareness measures for this phenomenon (Éthier & Côté, 2018). Although the findings cannot be generalized, they suggest that mistreatment of CGs exists and occurs in both relational and organizational contexts. Effectively, it can be linked to a loss of autonomy in the care recipient, or a history of conjugal or family relationships marked by violence. However, it may also be associated with the non-acknowledgement of the needs of the CG, or with a lack of services or help to adequately support the CG in their role (Éthier & Côté, 2018). Based on the results of this refection, the *Regroupement des aidants naturels du Québec* (RANQ) and Professor Sophie Éthier at Université Laval wished to continue this partnership and look at deepening the knowledge about this phenomenon with an awareness and prevention action research funded by the program *Québec ami des aînés* (QADA).

1.1 Objectives of the action research

The action research proposes an approach based on the experiential knowledge of the main actors in relation to an issue that constitutes the subject of the research. These actors are organizations and groups of organizations involved in caregiving, CGs and caseworkers who were solicited to participate in this research. The guiding questions for this approach are the following: *how can we best recognize mistreatment of elderly caregivers (ECGs) and caregivers for the elderly (CGEs) in Québec, and how can we heighten awareness in individuals and communities to prevent it*?

In response to these questions, a comprehensive objective was chosen: *promote awareness of mistreatment of ECGs and CGEs by mobilizing knowledge and from the perspective of local and regional communities.* This general objective produces specific objectives:

1. Deepen the theoretical and empirical knowledge about mistreatment of ECGs and CGEs in order to determine the forms, manifestations and contexts in which this phenomenon occurs;
2. Draw up a list of recommendations for decision-makers, healthcare organizations, social services, groups that deal with mistreatment within CISSS and CIUSSS, and community organizations that work to prevent mistreatment and promote wellness care of ECGs and CGEs;
3. Design a facilitation tool that addresses all CGs, for use in an intervention context. The purpose of this tool would be to heighten their awareness of the phenomenon of mistreatment, provide them with better knowledge of how to protect themselves from it and present resources for assistance in this context.

1.2 Situation regarding mistreatment of ECGs and CGEs: narrative review

A narrative review based on systematic techniques aimed at deepening the theoretical knowledge about mistreatment of ECGs and CGEs was carried out in 2018. Fifteen computerized documentary databases in the fields of healthcare and social sciences[1] from the period between 2000 and 2018 were searched. Pertinent articles from the literature were selected using predetermined criteria[2]. In total, 53 documents[3] were studied. The literature review allowed the forms, manifestations, consequences and contexts in which mistreatment of ECGs and CGEs occurs to be determined. It also identified measures for preventing mistreatment and promoting wellness care.

In the review of the literature, the many interpretations of the concept of mistreatment to describe the experience of ECGs and CGEs are striking. First, the term "mistreatment" is rarely used. Authors often use terms like "abuse", "aggressiveness" or "violence" instead. Second, mistreatment is not well defined. In fact, certain authors refer only to the different forms and manifestations of mistreatment, without providing a clear definition (Hsu *et al.,* 2014; Kosberg & MacNeil, 2003). Others focus only on one or other type of mistreatment, which is often physical aggression (Ahn *et al.*, 2012; Kageyama *et al.*, 2015; Weerd & Paveza, 2006), while most authors offer no particular definition. Some works use a wider definition of mistreatment, such as that proposed by the World Health Organization (WHO)[4] (Band-Winterstein *et al.*, 2016; Band-Winterstein *et al.*, 2014; Özcan *et al.*, 2017), or that of the American Medical Association (AMA)[5] (Bullock & Thomas, 2007). Other research reveals that authors combine several existing definitions (Ayres & Woodtli, 2001; Duxbury *et al.*, 2013).

Only 20 articles in the review offer definitions for mistreatment of ECGs and CGEs. These definitions, similar to those found for mistreatment of the elderly, can be grouped into six main categories representing types of mistreatment. The first category defines mistreatment as **physical abuse** (Ayres & Woodtli, 2001; Brownell & Berman, 2000; Bullock & Thomas, 2007; Elbogen *et al.*, 2005; Kageyama *et al.*, 2015; Kunik *et al.*, 2010; Labrum *et al.*, 2015; Nadien, 2006; Wharton & Ford, 2014), for example: kicking, pushing, which can lead to parricide, even going as far as the murder of the CG in the latter case (Ahn *et al.*, 2012) and sexual abuse (Nadien, 2006), such as unwanted touching. The second category is associated more with mistreatment involving **psychological abuse** (Brownell & Berman, 2000; Labrum *et al.*, 2015; Nadien, 2006) or **verbal abuse** (Ayres & Woodtli, 2001; Elbogen *et al.*, 2005; Kunik *et al.*, 2010; Weerd & Paveza, 2006; Wharton & Ford, 2014), which includes screaming, insults and threats, that undermines the identity, dignity or self esteem of the ECG or CGE. The third category refers to mistreatment as **financial or material exploitation** (Bullock & Thomas, 2007; Labrum *et al.*, 2015; Nadien, 2006), or the use or appropriation of personal or financial assets belonging to the ECG or CGE, without their consent. The fourth category involves **negligence** (Bullock & Thomas, 2007), which can be passive (not informing the ECG or CGE or not offering them the necessary resources) or active (restricting access to services or treatments for their loved one, thus abandoning the ECG or CGE). The fifth category makes reference to **discrimination** (Agyarko *et al.*, 2002), which includes ageism, stigmatization and exclusion of the ECG or CGE. Finally, the sixth category associates mistreatment with **structural abuse** (Herron &

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[1] CAIRN, Canadian Periodical Index (CPI.Q), ProQuest Dissertations & Theses Global, Repère, AgeLine, CINAHL Plus with Full Text, Medline, PsycArticles, Psychology & Behavioral Sciences Collection, PsycINFO, Social Services Abstracts, Social work Abstracts, BANQ, Érudit, Santécom.

[2] Each of the databases underwent a systematic documentary search (Vézina & Sévigny, 2000) using documentary search chains composed of key words in English and French. In total, 2049 documents were reviewed. All non-pertinent literature (that not dealing with mistreatment of ECGs and CGEs), any not in an appropriate format (newspapers, statements, work documents), or published in languages other than French or English, and duplications, were then removed.

[3] The articles come from studies carried out in other countries. The great majority of studies (45) were carried out in English-speaking countries (United States, Canada, United Kingdom, Australia). There are three articles published in Israel, and five articles come from Turkey, Zimbabwe, Japan, South Korea and Taiwan. In the research proposals, there are three mixed studies (quantitative and qualitative), 23 quantitative proposals, 19 qualitative proposals, 6 knowledge syntheses, 1 book chapter and 1 research report.

[4] "There is mistreatment when a single or repetitive gesture, or an absence of appropriate action, whether intentional or not, occurs in a relationship where there should be trust, and when this causes an elderly person harm or distress" (Ministère de la Famille - Secrétariat aux ainés, 2017, p. 15).

[5] "An act of omission involving a prejudice against, or a threat to harm the health or wellbeing of, an elderly person" (cited by Stiles *et al.*, 2002, p. 34).

Rosenberg, 2017b; Herron & Wrathall, 2018; Killick *et al.*, 2014), which stems from laws, regulations, standards or practices of a structure or institution, and which contributes to adversely affecting the CG in the course of their duties.

1.2.1 Mistreatment by the care recipient

The studies reviewed in the literature reveal that CGs are often the target of mistreatment inflicted by the care recipient, during the period of accompaniment/assistance. Four portraits of care recipients who mistreat are identified:

1. Care recipients are adult children or adolescent grandchildren with mental illness and dependency issues (drugs, alcohol, psychotropic substances);
2. Care recipients have cognitive issues;
3. Care recipients have displayed conjugal violence in the past, which is continuing or re-occurs;
4. Care recipients had parents who mistreated their children and who continue to mistreat their adult child, who is now their caregiver.

The contexts for mistreatment of ECGs and CGEs in the studies reviewed, along with the types of mistreatment experienced and their consequences, are thus extremely different, making comparisons, and especially interpreting statistics on their extent, difficult. In fact, considering the contexts and types of mistreatment all together, the studies suggest that **in the performance of their role**, between 6**% and 81% of CGs would have experienced mistreatment by the care recipient.** This major difference does not allow the extent of the phenomenon to be determined accurately. Nevertheless, it is possible to describe certain characteristics of the types of mistreatment.

Although verbal aggression is the most frequent form (between 21% and 81%, according to the research) (Kunik *et al.*, 2010; Phillips *et al.*, 2001; Weerd et Paveza, 2006), ECGs and CGEs are also the target of economic abuse (44%) (Özcan *et al.*, 2017), physical attacks (between 6% and 46%) (Chan, 2008; Cooper *et al.*, 2010; Elbogen *et al.*, 2005; Kunik *et al.*, 2010; Labrum *et al.*, 2015; O'Leary *et al.*, 2005; Özcan *et al.*, 2017; Phillips *et al.*, 2001; Vaddadi *et al.*, 2002), psychological abuse (between 11% and 67%) (Chan, 2008; Cooper *et al.*, 2010; Özcan *et al.*, 2017; Phillips *et al.*, 2001; Vaddadi *et al.*, 2002) and sexual abuse (15%) (Kunik *et al.*, 2010) from the care recipient.

In addition, several types of mistreatment are interdependent, for example: verbal abuse is often linked to physical abuse (Vaddadi *et al.*, 2002). In cases where the care recipient suffers from Alzheimer's, the risk that the care recipient will physically and verbally abuse their caregiver increases as the illness progresses (O'Leary *et al.*, 2005; Weerd & Paveza, 2006; Wilks *et al.*, 2011), due in particular to agnosia (where the care recipient has difficulty recognizing their loved ones) and the loss of social filters (Weerd & Paveza, 2006).

However, several authors state that the statistics do not accurately represent the situation experienced by ECGs and CGEs (Bullock & Thomas, 2007; Hsu *et al.*, 2014; Kosberg & MacNeil, 2003; Phillips *et al.*, 2001; Solomon *et al.*, 2005). For example, a study among female caregivers shows that the frequency of mistreatment is lower when it is self-reported rather than disclosed by others (29% compared to 39%) (Phillips *et al.*, 2001). This statistic suggests that some caregivers normalize mistreatment, considering it to be habitual behaviour within the relationship. Moreover, elderly caregivers would be more reticent to report incidents for a variety of reasons, such as fear, embarrassment and shame (Bullock & Thomas, 2007).

1.2.2 Mistreatment by the healthcare and social services system (RSSS)

Although more difficult to find in the literature reviewed, because the issues raised are not clearly defined, mistreatment may also come from within the RSSS, and manifest itself as organizational or structural mistreatment. A consensus is emerging concerning the importance of causes and effects of this type of mistreatment on ECGs and CGEs (Herron & Rosenberg, 2017a, 2017b; Herron & Wrathall, 2018; Kersten *et al.*, 2001; Li *et al.*, 2012; Lilly *et al*., 2012; Soothill *et al.*, 2001; Wiles, 2003). In particular, the findings of the studies show the negative consequences of policies related to home care, from which the service offer results, and which imposes the caregiver role on close family and friends (Herron & Rosenberg, 2017a; Lilly *et al.*, 2012). For example, in Québec, the 2003 policy on homecare services states that “ With a respect for the choices of individuals, the home will always be seen as the first option, at the start of an intervention as well as through all its stages” (Ministry of Health and Social Services, 2003, p. 5). Thus, while most CGs and the people they care for wish to remain at home, the choice is not unanimous. Many CGs are not in a position to meet this objective without incurring higher costs, whether at the emotional, physical or financial level (Herron & Rosenberg, 2017a). Moreover, the complex structuring of the RSSS means that CGs and the people they care for are no longer able to fully understand how these resources work: the legislation and the provision of care seem to them to be fragmented and arbitrary (Wiles, 2003).

Paradoxically, although they sometimes impose the role of caregiver, institutions do not always offer adequate support, either to the CG or to the care recipient. Some studies reveal that 43% of CGs have major needs associated with accomplishing their role, and these needs are not being met by the RSSS (Soothill *et al.*, 2001):

- Support in activities related to daily living (*activités de la vie quotidienne* (AVQ)) and activities instrumental for daily living (*activités instrumentales de la vie quotidienne*) (AIVQ)) (Herron & Rosenberg, 2017a; Kersten *et al.*, 2001; Li *et al.*, 2012; Soothill *et al.*, 2001);
- Short- and long-term respite (Herron & Rosenberg, 2017a; Kersten *et al.*, 2001);
- Psychological support (Herron & Wrathall, 2018; Soothill *et al.*, 2001);
- Social support (Herron & Rosenberg, 2017a; Soothill *et al.*, 2001).

More than one out of four CGs (28%) have at least three major unmet needs (Soothill *et al.*, 2001). The needs of the care recipients, for their part, are not being met either (Turcotte, 2014). One study established a connection between the level of the functional impairment of the care recipient and the unmet needs in services (Li *et al.*, 2012). As a result, when care recipients require more services than those that are offered to them, it falls on the CG to make up for this lack of services, without them receiving support themselves. In fact it is acknowledged that there are few measures aimed at supporting CGs in their role (Herron & Rosenberg, 2017a; Herron & Wrathall, 2018; Lilly *et al.*, 2012; Wiles, 2003), and the lack of resources in rural areas and small towns is even more striking (Herron & Rosenberg, 2017a; Li *et al.*, 2012).

As a consequences of this lack of support, the research shows that the RSSS leave the CGs to fend for themselves (Herron & Rosenberg, 2017a; Herron & Wrathall, 2018) and become exhausted (Lilly *et al.*, 2012). And the actual needs of the CGs in terms of their health are not acknowledged only in terms of their exhaustion (Lilly *et al.*, 2012). In addition, a large number of CGs, who use the services funded by public funds, are often frustrated by the apparent disconnect between the services listed and the reality in term of their flexibility, their criteria for eligibility, and their availability (Wiles, 2003). Thus CGs create strategies to deal with the healthcare system, such as storing numerous documents (as proof), constantly negotiating with healthcare providers or carrying out certain tasks that should be done by the latter. For many, this all comes at a major economic cost: leaving their job, reducing their work hours or significantly reorganizing their work schedule (Wiles, 2003).

Not only is the support insufficient, but according to the authors, there is not enough room given to CGs in discussions about the situation and the health status of the people they care for (Herron & Rosenberg, 2017b).

1.2.3 Findings emerging from the narrative review

Several findings have emerged from this narrative review. **First finding:** the situations of mistreatment of CGs documented in the studies are most often inflicted by the care recipients, notwithstanding their health status and their relationship, which is consistent with the idea that the mistreatment occurs in a context in which a trusting relationship between the protagonists should exist. This however raises several avenues for reflection. On the one hand, certain factors likely to lead to mistreatment inflicted by the care recipients are modifiable and may be subject to intervention, for example: providing the CG with better information about the illness of the person they are caring for and the ways in which to deal with it (Ahn *et al.*, 2012; Wilks *et al.*, 2011); intervening in the current relationship between the CG and the care recipient (Cooper *et al.*, 2010; Hsu *et al.*, 2014; Killick *et al.*, 2014; Smith, 2012); taking into account their previous relationship (Kong, 2018; Kong & Moorman, 2015); and acknowledging, and heightening awareness of, the risk that CGs will be mistreated by the people they care for. This acknowledgement of the phenomenon requires that real measures for support (such as respite services) and appropriate, adapted, psychosocial interventions, in particular in terms of gender, age and culture, must be put in place.

On the other hand, when this mistreatment occurs in a relationship between a caregiver and a care recipient, the intention behind the gesture made by the latter remains a major challenge for CGs. In fact, CGs may find it difficult to name or recognize the situation as being mistreatment and to ask for help when the gestures are made and the words are spoken by those with cognitive or mental health issues, because it raises doubts about their motivations (Hsu *et al.*, 2014). Specific research and interventions into these situations could be developed, in particular to help CGs recognize the mistreatment, so as to avoid them mistreating the care recipient in return, and in order to limit the risk of stigmatizing the care recipient who made the unintentional gestures of mistreatment.

In addition, as the findings of the literature review show that the risks of mistreatment, and even homicide, are greater for female caregivers (Ahn *et al.*, 2012), other research and interventions may provide an opportunity for a cross analysis with the current knowledge concerning violence towards women, principally in the conjugal or intrafamilial context. This merging of knowledge, drawn from two related issues, would allow the caregiving situation to be included as a risk factor for mistreatment and recognized by organizations working to counter violence against women, and thus increase the number of awareness interventions.

Second finding: developing a more comprehensive understanding of mistreatment requires that attention be paid to the characteristics of the care recipients who mistreat their CGs, their relationships and interactions with their CGs, and the wider familial and environmental context (Labrum & Solomon, 2015). In effect, another form of mistreatment related to caregiving, but not addressed in the literature reviewed, is that perpetrated by members of the CG's entourage, which is composed mainly of family members, and sometimes friends and neighbours. The interrelation among institutional mistreatment, mistreatment within the caregiver/care recipient dyad, and mistreatment by members of the entourage does not yet seem to have been documented (Éthier & Côté, 2018). Developing research designs that document the types of mistreatment specific to CGs and the interrelationships among them would provide an opportunity to put in place preventive practices that are more holistic and better adapted. The fragmented knowledge about mistreatment experienced by CGs hinders the development of an integrated awareness or prevention strategy that would involve individuals, their entourage and the structures in which they are evolving.

1.3 Data collection process for the action research

Data collection for our research was done via individual interviews, discussion groups and regional forums. Fifteen semi-directed individual interviews, conducted as part of a related study among mistreated CGs, were added to this data collection. Fifteen discussion groups were held: five groups composed of 43 caseworkers working in the field of caregiving, mostly in the community environment, and ten groups of CGs and older adults, numbering 95 in total. Thus, 138 people were involved in the discussion groups, in 11 administrative regions in Québec[6]. The three regional forums offered the opportunity to consult 280 CGs and caseworkers. Thus in total, 433 CGs and caseworkers participated in this action research. The following figure summarizes the data collection tools and the numbers of participants.

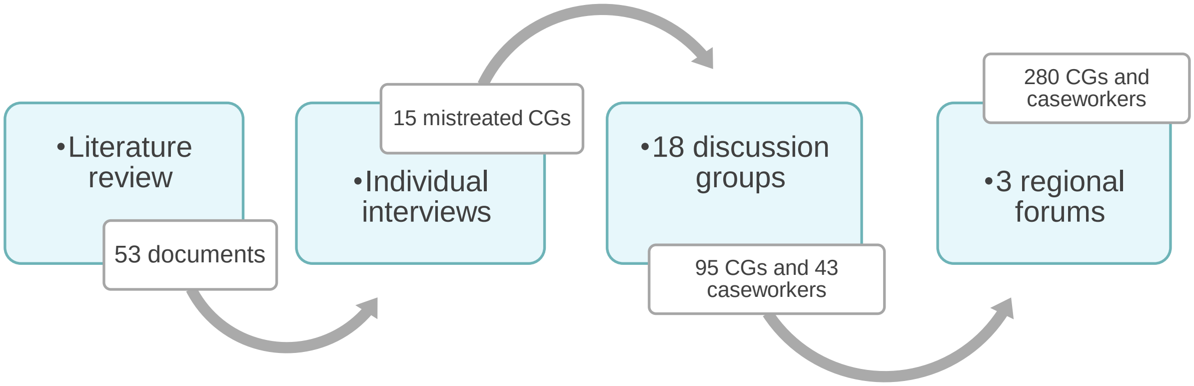

Figure 1: Data collection tools used and numbers of participants.

The themes that emerged from the analysis of the individual interviews helped document, in greater depth and for the first time in Québec, mistreatment experienced by CGs. The interview guide is presented in Appendix 1.

The discussion groups with the CGs and caseworkers were structured in three parts. The discussion began with the mistreatment of CGs, the types of mistreatment, their manifestations and their sources. The differences between men and women were discussed, in terms of the types of mistreatment experienced and the sources. The second part of the discussion dealt with ways to heighten awareness of, and prevent, mistreatment of CGs. The third part looked at wellness care, and more specifically at its definition and measures to promote it. The discussion plan for the groups is presented in Appendix 2.

Although experience with an episode of mistreatment was not a criterion for inclusion in the study for participants (except for participants in the individual interviews), we were surprised to find that several CGs talked about their own experience with mistreatment and/or those of CGs who they knew. In addition, most caseworkers reported regular encounters with mistreated CGs. Thus the quotes gathered are not anecdotal or the result of a single opinion on the subject. They have emerged from thoughts about real and current experiences related to mistreatment.

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[6] Bas-St-Laurent (01), Capitale-Nationale (03), Mauricie (04), Estrie (05), Montréal (06), Outaouais (07), Abitibi-Témiscamingue (08), Chaudière-Appalaches (12), Laval (13), Montérégie (16) and Centre-du-Québec (17).

2. Findings: description of the participants

2.1 Individual interviews

Eleven of the fifteen participants in the individual interviews were women aged between 31 and 84 years, and their average age was 61. Seven participants worked full-time, one worked part-time and seven were retired. Most (9 out of 15) were part of a couple. The level of education of the CGs interviewed individually was relatively high: nine of them had a university degree. One of the probable explanations was that part of the recruitment was done through the list of staff at the Université Laval. In contrast, the annual family income level was not very high considering the education level.

The people who participated in the individual interviews were experiencing or had experienced several types of mistreatment while carrying out their role: physical, psychological, institutional or organizational, violation of rights, material and financial. The mistreatment was inflicted by the care recipient (father, mother, spouse), by the family (uncle, brother, cousin, son) or by caseworkers or healthcare providers (social worker, nurse, physician, client care attendants, police officers, or staff members at the CDPDJ[7], in residential care homes[8], from intermediary resources[9], in an educational institution or at the Public Curator's office). Appendix 3 presents the types of mistreatment and their sources.

2.2 Caseworker discussion groups

Groups of 8 to 10 caseworkers were met with in 5 administrative regions of Québec (Montréal, Centre-du-Québec, Outaouais, Capitale-Nationale and Mauricie) and comprised 43 people in total, of whom 6 were men and 37 were women. Among these 43 caseworkers, the majority (24) had completed a Bachelor's degree, and most had 1 to 5 years of experience working with caregivers. The job positions occupied by discussion group members in their organizations that support CGs were varied. 17 occupied a caseworker position, 11 were coordinators, seven were project leaders, five were managers and three were CG counsellors. It should also be noted that 98% of these discussion group members mentioned getting to know mistreated CGs in the course of their work. The graphics presented in Appendix 5 provide more details.

2.3 Caregiver discussion groups

The 95 caregivers who participated in the 13 discussion groups came from 9 different administrative regions. The groups were composed of 4 to 11 people (7 on average), and 79 out of the 95 CGs were women.

The ECGs and CGEs were aged between 35 and 93, with an average age of 69. In terms of the annual family income of the CGs, most earned less than $60,000 per year. We noted a variation in the education level because some had

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[7] Commission des droits de la personne et des droits de la jeunesse.

[8] Private seniors' residence.

[9] Intermediary resource.

only completed a primary school certificate while others had Bachelor and Master university degrees. However, the largest proportion, 32 out of the 95, had a high school diploma.

As the role of CG is constraining, and many do not have the time to participate in a research study, we chose to include former CGs in the discussion groups. Thus, 72% were active CGs at the time the data were collected, and 24% had been CGs within the last five years. Interestingly, eight participants stated they were currently CGs but at the same time were also former CGs for someone else. Finally, the participants also provided the numbers of years of experience as CGs. We can state that 39 out of 95 participants had over 5 years of experience. Appendix 6 presents more details about the characteristics of the CG participants.

3. Findings: description of the phenomenon of mistreatment of CGs

The participants talked about several aspects of mistreatment. Touched on in this section are: reasons for the silence around the question; manifestations and sources of mistreatment; consequences of mistreatment; measures for prevention.

3.1 Reasons for the silence around mistreatment of CGs

The reasons for the silence around the question of mistreatment of CGs emerged from the data collected from the 153 participants in our research study. They needed to be identified from the perspective of awareness and prevention of the phenomenon. A misconception of the phenomenon proved to be common in the responses. CGs reported that they ignored the existence of the phenomenon or did not know how to distinguish what is considered mistreatment from what is not. The participants also stated that the phenomenon is not covered by the media, which renders it socially invisible. Moreover, in a context in which some CGs are not acknowledged in this role, it was difficult for them to recognize the mistreatment to which they were subjected when performing their role.

Certain beliefs or values also contribute to normalizing mistreatment. The CG often refuses to talk about what they are subjected to, so as not to feel weak or have the feeling that they have broken their promise to assist the care recipient until the end. “When you help someone you love, it’s hard, and you mustn’t show it so as not to lose your morale. […] You need to keep your mouth shut about it.” (CG Group 5).

The silence around this mistreatment is sometimes explained by a desire not to displease: older CGs will very often continue a difficult conjugal relationship so as not to upset the children or because they feel they are abandoning or betraying the care recipient if they speak out. The shame of confessing that they are experiencing mistreatment and social pressure are other factors that explain the silence around this question: “The social pressure too: How will it look if I abandon him now?” (Caseworker Group 3). In certain cases, CGs also see it in relation to the gravity of the situation: “Two or three slaps, that doesn’t bother me.” (CG 3).

In addition, participants say that the silence is sometimes attributable to a fear of the consequences. Thus the CG does not denounce the abusive behaviour of the care recipient due to a fear of being sent to a home or perhaps because of a fear of the legal process that could ensue. Financial insecurity, fears about their own aging process or finding themselves alone may also prevent this denunciation or recourse to resources for assistance in the case of mistreatment.

One participant raised an important issue: community organizations and public institutions lack the human or financial resources to intervene in a context of mistreatment of CGs, so that it proves ethically dangerous to identify an issue for which few resources are offered to remedy it.

Although a certain silence does reign around this phenomenon, and it is even seen as a taboo subject, it must be stated that according to the caseworkers and the CGs, mistreatment exists. However, it does not perhaps come from the source we really expect, as we will now see.

3.2 Sources and manifestations of mistreatment of CGs

Similar to that documented in the literature, the participants in our study reported being subjected to or aware of mistreatment by the care recipient. So it was clear that mistreatment of CGs manifests itself in other ways, sometime insidiously. In fact, qualified actions, words or absence of any action by abusers of CGs come from the entourage, institutions and healthcare providers, the care recipient and the caregivers themselves. While the sources of mistreatment may be different, it was possible to group its manifestations into seven categories: (1) Imposing the role of CG and over-accountability; (2) Judging the ways CGs carry out their work; (3) Normalizing the role of the CG and the mistreatment experienced while performing this role; (4) Denigrating the expertise of the CG and their familial and social contribution; (5) Denying the needs of the CG; (6) Psychologically, physically or sexually abusing the CG; and (7) Contributing to the impoverishment of the CG. Figure 2 illustrates the manifestations of mistreatment of CG and its sources.

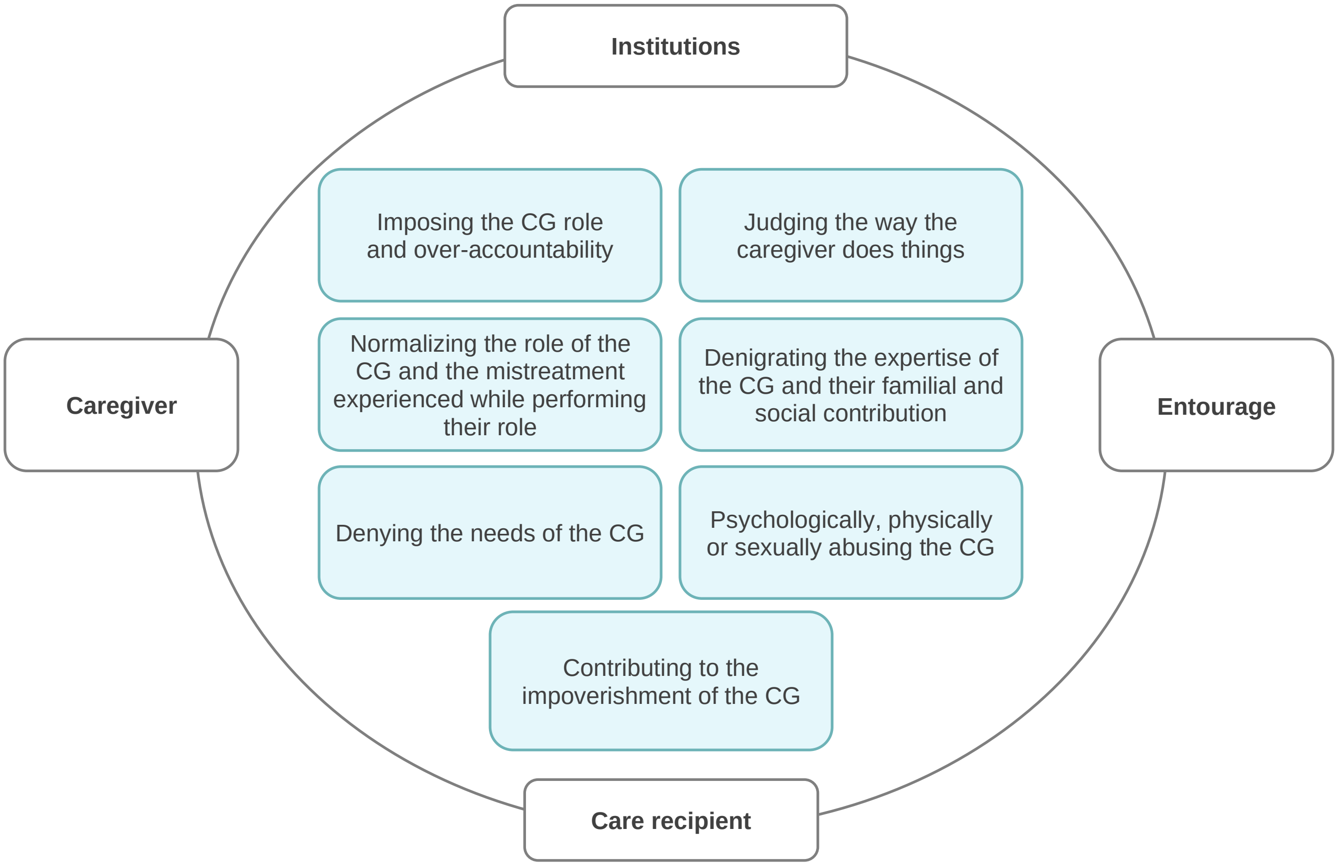

Figure 2: Manifestations of mistreatment of CGs and their sources.

3.2.1 Imposing the role of CG and over-accountability

The imposition of the CG role occurs most often when pressure by the entourage, the RSSS, the care recipient or the caregivers themselves is applied to take on the role. First and foremost, CGs talk about familial pressure. The family often imposes this role on a single person, justifying this imposition by saying, “It’s their turn”, as if that person is the only one able to carry out the role, thus making withdrawing from this role more difficult.

> *Because my family reminded me that I said yes at the start, so there’s no room to negotiate this role now. (Caseworker Group 4)*

Moreover, in the case of couples, extra social pressure is added by the entourage: expectations. In effect, it is expected that one will take care of the sick spouse or partner. These familial and social pressures, sometimes unjustified, are directly but insidiously related to the withdrawal by the entourage from supporting the CGs. In some situations, such as when there is no one else to take care of the loved one or because of pressure from the entourage, the CG feels obliged to take on the role. As a consequence, other members do not participate in assisting the care recipient, because the CG is there, and this justifies their withdrawal and increases the CG’s obligation to carry out the role. Some CGs even talk about being “abandoned” by their siblings. Other situations described show that family members frequently refuse requests for sharing the responsibility for care, by saying they are busy or not in a position to help. Thus by applying pressure on the CG to take on the role or refusing to help, the members of the entourage isolate them. This isolation increases the pressure and the obligation on the CG to take on the role.

> *Sometimes […], I have an errand to run or an appointment to go to with a parent, and I ask my brothers and sisters, “Could you go?” “Oh no, I’m busy, oh no, I have too much to do.” “And me? Don’t you think I’m busy too?” “OK, I’ll do it.” […]. It’s almost like I have to object, I have to assert myself, otherwise I would be doing everything in this family. (CG Group 12)*

The entourage not only imposes the role of CG on a member of the family, but also the conditions for, or ways of, performing the role. For example, the entourage may make negative comments about the chosen place of accommodation, or about the timing of the choice. Thus the family is not respectful of the choice made by the CG to keep the care recipient at home. Similarly, caseworkers reinforce this obligation felt by the CG to care for a member of their family by also imposing this role on them.

> *[The caseworker said to her,] “You’re still capable of looking after him, so just get it done!” (CG Group 3)*

The imposition of the role by caseworkers often results from the inability of the RSSS to meet the demand for assistance, such as that related to accommodation. Caseworkers then take it for granted that the CGs will make up for the lack of accommodation resources. This imposition of the role can sometimes be exacerbated, as one CG mentioned, by the impression that the social worker wants to close the file quickly. This imposition even manifests itself through comments from caseworkers, saying that they would find themselves at an impasse if the CG no longer performed their role. Some CGs have even reported being “told” that they were obligated to care for the person needing care, otherwise they would be put in prison, according to the law! (This is not the case in Québec).

> *I told the doctor, “Don’t send him back home right away. I’m not able to take care of him, with all the tubes and everything. Send him to a convalescent home […]”. I asked him, “Please, don’t send him home, I am not capable. I can’t care for him, I’m not capable.” (CG 4)*
>
> *[The social worker] told me, “If you quit, he’ll be in trouble.” I said, “That’s heavy.” (CG 15)*

Not providing enough care to the care recipient, providing it far too late or imposing unreasonable deadlines for obtaining assistance are other examples that contribute to increasing the burden of responsibility for the CG and that oblige them to assume the role in some way, often beyond their limits. Caseworkers say that CGs have to take all this on as a consequence of the cuts at, and disfunctionality of, the RSSS.

Ironically, CGs may sometimes impose the role of CG on themselves. In effect, they may sometimes believe strongly that they are indispensable because they feel that no one else can perform the role as well as they do. This far too great requirement of themselves is often accompanied by guilt if they reduce the amount of care time or they take rest periods. In general, CGs sometimes impose this role on themselves by not considering the possibility of not doing it, or their capacity for doing it, or not putting in place the optimal conditions for doing it.

3.2.2 Judging the way things are done

The CGs and caseworkers involved offered several examples of situations that they associated with judgments in regard to CGs, especially about the way they performed their role, and which took the form of intimidation and verbal abuse. For example, the siblings of a CG, who judge and encourage a move to a care home.

> *For him, it was suddenly, "We've found a place, time to go! […]." I feel bad about all this business, but their mother never knew anything about it. She never knew. I didn't talk to her about it, but me, I feel bad." (CG1)*
>
> *The others don't help you, they criticize everything you do, they put you down. It gets painful. (CG Group 11)*

Family members do not always accept the illness, insofar as they may deny there is a problem, thus creating consequences for the CG. As a result, some family members question the actions of the CG. The care recipient also makes judgments about the CG by criticizing them. No matter what the CG does, the care recipient feels it is never enough.

> *"You don't know anything. You don't know about my life, you don't understand me. That's not right. It's never right for you to do that, never, never, never." My translation might be, no matter what we do, it's a bottomless pit and whatever we do is never right. I might say it has always been like that. (CG 16)*

Judgments by caseworkers are also numerous. For example, some caseworkers do not agree with the way caregivers perform their tasks or do not take into account the reality (financial or health status) of the CG or the care recipients: a nutritionist judges a caregiver because they do not follow their recommendations, which do not take into account the care recipient's allergies or the CG's budget. When the care recipient is then in crisis mode in hospital, it is the CG and their care that are judged.

3.2.3 Normalizing the CG's role or the mistreatment experienced

The entourage, the care recipient, caseworkers from the RSSS and the CGs themselves tend to normalize the caregiver role and the mistreatment that may occur. Normalizing the CG role implies that we imagine that the CG requires no support, information or acknowledgement in order to perform this role and that it is normal for them to do it. Thus we find it normal that children sacrifice themselves for their parents, and no one takes a CG seriously when they say they are finding the role difficult or that they need help.

> *In non-acknowledgement, there are also loved ones, family members of the care recipient. I'm thinking of one case in particular where the caregiver inherited, was given, the family home, and then, the other family members said, " So you were given the house, so it's normal." That's like zero acknowledgement. (Caseworker Group 2)*

> *On occasion, we minimize our role, they [members of the entourage] don't think that we might need help. Or when we ask for it, they don't see the use. (CG Group 2)*
>
> *They [members of the entourage] should be thanking me because I take care of Mom, but they put roadblocks in my way. (CG Group 9)*

Normalizing the role of the CG means that it is difficult to access information. For example, a social worker provides information about services in dribs and drabs, so that the CG must use a lot of energy to obtain the necessary information. Inversely, in other cases, they bombard an already deprived, exhausted CG with information and references, and the latter is "expected" to be able to assimilate all this information.

Not taking into account the impacts on the CG of certain decisions also normalizes their role. For example, service changes with no prior warning, services that are reduced or simply withdrawn that mean that a 90-year-old man must give his wife the required injection himself. Some participants said that when caseworkers find out that there is a CG for the care recipient, services are automatically reduced and the caseworkers step back.

> *We see it a lot in the system, I think; They rely on the fact that the caregiver is in the house. […] As long as the caregiver is there, it's almost like saying to them, " Leave the house, then they'll go there." (Caseworker Group 5)*

If the role of CG is perceived as normal, it is possible to believe that mistreatment experienced when performing this role is not. However, CGs report that family members tolerate bad behaviour towards the CG by the care recipient. Moreover, family members do not acknowledge the symptoms or problems of the care recipient or do not consider them to be mistreated. In fact, the entourage, caseworkers and CGs themselves tend to excuse the mistreatment and explain it as the illness or the age of the care recipient. Normalizing mistreatment is also rationalized by feelings of guilt: the CG feels guilty about the illness, not doing enough, being in good health themselves, so that they tolerate attitudes or behaviours related to their mistreatment.

> *When you're halfway through your day, no one is there to care for the carers. A little, yes, but they're not there. If you complain a bit, or if you make any remarks, they're going to tell you the same thing as I heard from my children or anyone else, "Oh well, it's the illness. "I mentioned that in a meeting I had with a social worker, that just because he's ill, he shouldn't allow himself to say he's done with me. (CG 15)*

3.2.4 Denigrating the CG's expertise and familial and social contribution

While we rely on the CG to make up for the lack of resources, paradoxically, we tend not to acknowledge their expertise, skills and abilities to understand and manage situations when required. The lack of information is a good example: a healthcare provider who will not divulge a diagnosis, does not inform the CG about the health status of the care recipient, does not provide information about the medication prescribed or sends the wrong information. CGs then feel excluded, not considered, and caseworkers frequently doubt their observations.

> *We feel we are being held hostage because we want to suggest things, we want things done in a certain way, but they don't agree, and you can't cry about it too much either. Because you don't want your mother to feel the impact of that. (CG Group 9)*

Denigration of the expertise of the CG is seen at home and in care home and hospital settings. For example, the point of view of a caregiver who had been listened to by staff at the intermediary resource when the care recipient was first admitted to the home, but who was quietly ignored thereafter insofar as the staff took over care of the medication. The CG can also be excluded from any decision-making, especially in regard to changes in medication for the care recipient. Finally, there is the denigration of expertise when the healthcare providers do not take into consideration that the CG needs to be present to translate or hear what is being said whenever the care recipient has cognitive issues or language problems.

> *As for me, I've seen that the more progress I made, the more I was pushed aside, the more my mother was medicated so that she would stay quiet. She was not bothersome, she was not aggressive, the proof: she no longer took up their time. It's as I said, "I think that if you keep my mother busy, it's going to work well." And I offered ideas to keep her busy and we were all there, the family, we made ourselves very available to help. I was not the only one who went to see her. And I felt that at times when they had difficulty doing something, and I tried, yes I am a close relative, it went well and I said, "For me, when I do it in that way, it works well." I didn't threaten them, but it was unwelcome. (CG12)*

In another case, a healthcare provider asked the CG to leave the office during the consultation with the care recipient. When the caregiver asked questions afterwards, the caseworkers told them that this information had already been given to the care recipient. The attitude of healthcare providers, the sighs when they see CGs arrive and comments like "What are you doing here?" show that CGs are excluded from decision-making and that their involvement is not always wanted.

Another example involves a caregiver who was deprived of their right to see their spouse in the CHSLD. They were given no information about the spouse's health status. The law is not always clear and the structures are not always flexible, especially when family dynamics are complex. Some caregivers would like to have access to more information and have more latitude, even when they are not mandataries: "This is why we are married and why I take care of him/her!" (CG Group 12)

Furthermore, complaints made by CGs are not always considered, or are judged as not saying anything important or not worthy of a reply or follow-up. Some CGs interpret this attitude as indifference in their regard by the caseworkers.

> *The nurse who called me for a geriatric evaluation said to me, when I explained my father's symptoms, "Your view of your father is biased". I find this statement to be a form of mistreatment because it puts my observations in doubt. (CG 4)*
>
> *First of all, it's about not being listened to when you talk about symptoms. Not being listened to when you have a discussion with the family doctor or another caseworker. Normally, it's supposed be a discussion, right? And so, when you answer, no one is listening to you, the conversation immediately goes to another subject. So we have to bring the conversation back to the previous subject and it's a struggle. (CG 13)*

3.2.5 Denying the needs of the CG

According to the participants, the needs of CGs are not evaluated formally in the current RSSS. The services they are offered do not necessarily take into consideration their specific needs: their first goal is to support the care recipient, and eventually offer respite to the CGs so that they can continue in their roles as CGs as long as possible. Disturbing testimony from a CG shows at what point the needs of a caregiver were denied, even while they were incapable of movement and the ability to care for their own basic needs.

> *I was truly paralyzed, I couldn't even move about in my own bed. And when I asked for help at the CLSC, believe it or not, it happened this fall, I got this response: "But you're the caregiver! We cannot help you. I would need to open another file." A caseworker came to the house to help my husband. I was in my bed, she didn't help me, didn't give me anything to eat. It was two days before I had anything to eat. My husband was going to offer me a coffee but he*

> *forgot, he didn't bring it to me. She said to me, "Call Jean Coutu [pharmacy], have them bring you something to eat." I couldn't even get out of bed to use the phone! (CG Group 1)*

<u>The needs of the care recipient takes precedence over those of the CG</u>. As an example: respect for the decision by a care recipient to die at home is at the expense of the choice of the CG who is not consulted and for whom the emotional and physical burden of this decision (which is not their own) is far too high.

> *I have a flagrant example in my family. The government seeks to keep the care recipient at home for as long as possible […], but this exceeds the caregiver's capacities. It is not deemed necessary to consider that. In the end the caregiver gets sick. I'm talking about an end-of-life situation here. We have a lot of work to do to meet the needs of the caregiver rather than using them as a tool. (CG Group 11)*

In this sense, the rules for access to services are applied to the letter, rather than in terms of taking into account the real needs of the CGs. As an example of this, a surgical procedure was planned for the care recipient 140 km from their home. It was the CG who had to drive, pay for gas and use their own time to make the journey. We may also see a significant period of time between the needs expressed by the CG and the response they receive.

> *There was one [social worker] who called me in February 2016. First thing they said to me was, "I'm following up on your call last September." I just couldn't help myself in replying, " Wow, you have some service there, don't you?" […] He called me in February to say, "Following your call in September." […]. There have been 10-12 social workers since then. (CG 5)*

The denial of needs also manifests itself when the participants feel that <u>services are technically offered and available</u> to support CGs in their roles, but in actuality, this is not the case.

> *Some organizations act just like bait, it's a load of hot air in my opinion. Getting access, guardianship. […] My file was open and no one did anything. (CG Group 13)*
>
> *It's their way of inserting "chocks" for cases, they don't tackle problems. They look the other way. The social worker is subject to hierarchy and the hierarchy doesn't want us to stir things up. (CG Group 13)*

<u>The hierarchization of caregivers according to the situation of the care recipient, and by consequence the prioritization of the response to their needs</u>, are also manifestations of this denial of needs. In more concrete terms, if the care recipient has Alzheimer's, the CG will receive more services than a CG whose loved one has a different illness, such as Parkinson's. In addition, certain conditions, such as chronic neuropathic pain in the care recipient, makes their access to homecare support more difficult because the pain is more difficult to measure. Even support and empathy for the CG from the entourage and the family are affected, depending on the care recipient's diagnosis.

> *If she had cancer, it would be easier. You say to the person in front of you, "Yes I've just learned I have cancer," and the person is like, "Oh my God!." And they are full of empathy and want to help you. They know the journey you're going on, and my God, it's terrible! For us to get this [level of empathy], we almost never get there, we would need another person to believe, someone who understands. It's really the crux of the matter for us. As for me, my experience with society hasn't been good in this regard, because I am not a caregiver for someone with cancer, I'm a caregiver for someone with chronic pain, which is invisible. (CG 11)*

The care recipient can also contribute to this denial of needs for the CG: "It's my spouse who needs to look after me. No one else." (Caseworker Group 4). By refusing the help offered them, by refusing to allow their caregiver to take respite time or by refusing to be admitted to a care home, the care recipient contributes, sometimes completely unconsciously, to the mistreatment of their caregiver. For example, a caregiver has to fight hard so that the care recipient will agree to treatments, because they reject anything that comes from a biomedical setting. Or the care recipient is in denial of their physical or cognitive decline and the deterioration in their health status, and uses inappropriate behaviour towards others', with the result that the caregiver/care recipient dyad isolates to avoid difficult situations.

> *I often hear it said, I call this a form of mistreatment, it's when respite is offered to a caregiver, but they can't take it because the care recipient won't accept it. They won't have anyone in the house except for their spouse or children. No outsiders. [The caregiver says]: "I tried it, but I had to put up with a whole week of his bad mood afterwards!" This plays on the emotions. We become isolated, trapped (CG Group 3)*
>
> *I have a husband who has been partially blind for 11 years, he is stubborn, he is very obstinate. For him, as he manages fairly well by himself, I am not a caregiver at all, I don't help him. What am I doing going to a caregiver group? I'm being asked this all day, every day. He's now just starting to understand. (CG Group 2)*
>
> *Up until just before he died, he never stopped saying to me, "You, you're never happy. You're always in a bad mood." He never saw that for me, right through his illness, I was there and I had needs too. He would scold me, "Oh yes, you, you're never happy." It wasn't about hearing nice comments, it wasn't about the never-ending arguments, but still… (CG15)*

This denial of needs can also come from CGs themselves. <u>CGs deny their own needs, keep silent about their difficult situations, do not want them "widely known"</u> and therefore will not seek help.

> *All of us mistreat ourselves. We don't take proper care of ourselves, our finances even worse. We give up. We hardly have a life, few clothes, I don't have permission to go to the hairdresser [in case] I need 20 bucks for a ride to the hospital, in the middle of the night. And even if I'm tired, I'll make a detour, I'll get gas just in case… We put ourselves in extreme conditions, we don't look after ourselves, it's almost as if we're mistreating ourselves. (CG Group 4)*

3.2.6 Using verbal, psychological, physical and sexual abuse

In the words of the participants, verbal abuse, which manifests itself through insults, false accusations about stealing or defamation that damages someone's reputation, is rampant. It consists of <u>hurtful, offensive, cruel words spoken by the care recipient</u>, and which the CG justifies because of the illness.

> *We hear it every single day, it's always verbal, of course it's the illness [tears]. But it stays here [she points to her chest]. Not talking about it makes us ill. That's what I'm scared about, that I'll become ill. (CG Group 12)*

Participants also talked about psychological abuse, which takes the form of <u>harassment, manipulation or lack of consideration</u>. This most often comes from the care recipient, but can also come from the entourage and the caseworkers. Here are two testimonials about psychological abuse from the care recipient and from the entourage:

> *My own experience, it's denigration. I'm the only one caring for my mother. It's a trait of her personality. For me, it's a form of abuse […] every week she says to me, "You're so fat, you need to look after yourself! Your teeth are crooked, you don't have much hair on your head, your scalp is showing […]." I've been looking after her for 40 years. I'm there to help someone who belittles me, who is incapable of thanking me (CG Group 6)*
>
> *I experienced it again today from my ex [the caregiver] [tears]. It's very emotional. That's why I am no longer there. He is destroying me, and my sisters too. It's not easy. Hurtful words, it's like you don't exist for these other people. Since September, lots of things have happened, it's getting worse, he called me a whore [tears] […]. Two of my children told me I would no longer exist as a mother… It's not easy. (CG Group 10)*

The psychological abuse carried out by the care recipient often takes the form of control. One participant described how a care recipient in their entourage is very self-centred and they deny that others have problems or needs, such as that of the CG to take a rest. The CG feels obliged to meet the many requirements and feels they are being controlled psychologically in terms of their time off. One caseworker gave an example of a care recipient who did not like it when their caregiver attended a support group. The control exercised by the care recipient is sometimes accompanied by threats of suicide when the CG wants to perform personal activities:

> *"[The care recipient said]: "You'll never be able to put me there [temporary accommodation] because I'll kill myself […]." They had taken a bottle of Tylenol." (CG3).*

Other examples also reveal the control exercised by care recipients: the care recipient feels isolated and corners the CG, refusing to allow them to leave the house; they monitor the way meals are prepared; the CG has to hide in the garage in order to call an aid agency.

> *We also see another form, which is abuse that involves social isolation. The caregiver, who is no longer allowed to leave the house because the other person doesn't want them to, because the other person whines, "Great, you're going out again! You're leaving me all on my own?" So it's a case of assigning guilt so the caregiver will no longer have a social network. So that they will focus just on the care recipient. (Caseworker Group 2)*
>
> *As for me, I had caregivers who hid in the garage so as to be able to call us because all of a sudden [the care recipient] would know they were calling. Then there are others who will call us because the care recipient always answers the phone. So the care recipient really has control over the caregiver! (Caseworker Group 4)*

The attitudes of, and comments from, some caseworkers are also perceived as psychological abuse for CGs. For example, one CG said they experienced psychological abuse during repeated calls from nurses or attendants at the care home of the care recipient asking the CG to come. There were even rebukes and accusations made. Some caseworkers might use a caustic tone when speaking to CGs or make inappropriate remarks. Others lacked empathy and consideration for the CGs.

> *[The caseworker said to them], "Why are you still doing that? Didn't you understand? Your husband won't recover." And using the same tone, "You need to look after yourself, you can see for yourself you're not accepting the reality." Well no, I'm fighting hard and I want him to get back to the way he was, and I think that with rehabilitation we could gain some ground. They would be very surprised to see what state he's in today! (CG10)*

It is no surprise that participants also mention physical abuse. It is not however the most frequent type of mistreatment. This abuse is expressed in different ways and comes mainly from the care recipient: throwing objects, slapping, biting, scratching, hitting with a cane, holding tightly onto arms. On occasion the care recipient also refuses the help offered by pushing their caregiver or using their physical strength to restrain them. The participants explain this abuse as a result of the illness and attribute it in some cases to cognitive issues. Nevertheless, it remains unacceptable in their eyes:

> *Once, he held me tight in his arms, saying ... […] I said, "Touch me again and I'll call 911." (CG 8)*
>
> *We had a [CG] here, her husband lives in the CHSLD. When he is abusive towards her, we ask her to leave. She returns. Sometimes he's violent, sometimes he becomes abusive. The last time it happened, he was abusive, and she left the room. (Caseworker Group 2).*

Finally, although cited to a lesser extent, CGs are also likely to experience sexual abuse.

> *Thus the loss of sexual inhibitions puts pressure on the caregiver to make love, or have sexual relations much more frequently. This may also be… In any case, I think it should be considered as mistreatment of caregivers. (Caseworker Group 1)*
>
> *What happened was, that particular time, I go to his home, it's Father's Day, and he abuses me sexually. He pats my leg and makes sexual advances. So I didn't really like that. Especially as I was really not expecting that, and I was suddenly glued to the spot. I was like, "Hey, why are you doing that?" Then his wife said to him, "Let go of your daughter's legs!". So I had a witness. (CG9)*

3.2.7 Contributing to impoverishment

It is certain that caregiving has a financial impact at several levels (increased expenditures and/or reduction in income), which can contribute to impoverishing CGs. Certain gestures or actions by the care recipient, by the entourage and by the RSSS can effectively be categorized as financial mistreatment. It first manifests itself when the care recipient refuses to repay a loan made by the CG or to reimburse the CG for certain expenses that the CG must pay for on their behalf. In other cases, the CG does not have access to the spouse's money, because they are in denial about their illness and they refuse to provide them with the necessary information to better manage their assets. One participant pointed out that financial mistreatment of the CG is even present at the moment of death. The CG receives the same share of the inheritance as all the other children. Other cases are even more explicit: a care recipient promises money and threatens blackmail if the CG does not collaborate. Another care recipient threatens to cut off the CG's financial support or relieves them of their legal responsibilities on their behalf.

> *I have a fireproof safe in the basement in which I keep the wills. We made wills in 2012 and he wanted to give the combination to my son. I don't know what pretext my son gave him for getting the combination of the safe. He took his mother's will, he went to the notary to change the will to become the mandatary in place of me[10]. (CG 5)*

Certain other situations show that it is the CGs themselves who contributes to their own impoverishment: They voluntarily give money to the care recipient and pay their rent from time to time.

According to the participants, institutions contribute to the impoverishment of CGs when the latter have to personally assume the costs for obtaining services or equipment to ensure the safety of the care recipient, such as purchasing bed railings. CGs also have financial problems that prevent them from accessing certain resources, such as difficulty paying the required $60 to obtain a medical form giving access to other services such as home adaptations.

In other circumstances, CGs seem to have difficulties getting good financial advice that would allow them to make good decisions, for example, a caregiver who is unable to use all the tax credits available due to a lack of information at the opportune time.

Finally, participants stated that the loss of income related to work days missed in order to help a loved one constitutes a type of financial mistreatment that contributes to their impoverishment.

The table presented in Appendix 7 summarizes the various manifestations of mistreatment according to the source, with concrete examples.

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[10] Here, the words of the CG are not clear. If they are talking about a will, they should say, "executor" and not "mandatary". If they really mean mandatary, it should say "power of attorney" and not "will".

3.3 Definition of mistreatment of CGs

Based on the review of the literature and the findings from the data collection above, we are suggesting a definition of mistreatment of CGs:

> *Performing the role of CG involves the risk of mistreatment. Mistreatment of a CG may manifest itself through attitude or a single or repetitive gesture, or an absence of appropriate action, whether intentional or not, by institutions, the entourage, the care recipient or the CG themself, and impacting the CG. It manifests itself by: imposing the CG role and over-accountability; judgments about the way things are done; normalizing the role of the CG and the mistreatment experienced while carrying out this role; denigrating the CG's expertise and their familial and social contribution; denying the needs of a CG; being verbally, psychologically, physically or sexually abusive towards the CG; and contributing to their impoverishment.*

3.4 Consequences of mistreatment

The participants highlighted several impacts and consequences of mistreatment of CGs. In talking to the participants, there seemed to be ongoing confusion between the consequences of mistreatment and those of caregiving. Several consequences of mistreatment identified by the participants are already known and well documented for caregiving (exhaustion, problems with physical health, pain, etc.). Are these consequences actually the consequences of the mistreatment? Or are they instead the consequences of caregiving? If the consequences of caregiving and those of mistreatment are the same, what can we learn from that? Here we are trying to shed light on what the direct consequences of mistreatment are in the context of caregiving. But this interdependence of consequences should remain a consideration.

Psychological consequences of mistreatment experienced were identified by the CGs and the caseworkers who participated. There was much talk of emotional exhaustion, sadness, depression, guilt, lowering of self-esteem, feelings of helplessness and distress.

> *It prevented us from turning the page and being happy doing other things. Because there was always something hammering away. We never had any peace. (CG Group 10)*
>
> *You've got nothing left to give. (CG Group 8)*

Anxiety, worry, fear and distrust can also materialize: the CG is careful about what they say to the care recipient and the gestures made to them so as not to create problems and exacerbate the situation. Some CGs fear for their safety, even for their lives.

> *I'm scared that he'll suffocate me while I'm sleeping. I put a chair under [the handle of the door]. I was scared, really scared. (CG 6)*
>
> *We had a woman who slept close to the door so as to be able to leave if the man had an outburst. (Caseworker Group 2)*

The burden in terms of the caregiving role, along with judgments to which they are subjected means that CGs live in great distress, which sometimes leads to them becoming angry, and makes them feel inadequate, even violent towards the care recipient:

> *This one time, I raised my hand. I'd reached the end of my tether. (CG 3)*

This physical violence towards the care recipient may be in response to abusive behaviour towards the CG. One participant said that violent behaviour suffered by the CG was then inflicted on their spouse, which led to feelings of guilt. Distrust of the healthcare system or its healthcare providers can also occur:

> *You get the impression that they wait until you give up the fight. (CG Group 8).*

Another caregiver said that she was frightened for he own old age because she had seen that the healthcare system was dysfunctional.

> *As for me, I've lost confidence in the healthcare system. I'm getting old and see what's happening, and it scares me. What am I going to do? They'll put me there [in a care home] and I won't have anyone. Those that govern have no respect for the elderly. I feel like a piece of garbage in the system. They have no respect. (CG Group 8)*

CGs are also excluded from their entourage on occasion because of abuse by the care recipient: neighbours stay away, no longer visit; activities and outings must be cancelled. In some cases, the entourage is the source of the mistreatment; one CG said they had cut ties with the other members of the family to protect themself:

> *They would help me, but they can't at the moment because it will bring it on (the abuse). (CG3).*

As a consequence, CGs feel alone and isolated when they are mistreated, and feel that no one understands them.

> *My children are angry with me, they blame me. (CG Group 8)*
>
> *In these crises, 100% of the time, I'm alone. No one can understand me. You do it, you're immersed in it, but you're unable to call anyone. (CG 3)*

The following table lists the direct consequences of mistreatment experienced by CGs while carrying out their role; these consequences were identified by the participants. They refer only to caregiving. Those for which we could not make a determination about whether they were consequences of caregiving or of mistreatment are not included.

TABLE I: Consequences of mistreatment of CGs

Psychological level	▪ Emotional exhaustion ▪ Sadness ▪ Depression ▪ Lowering of self-esteem ▪ Feeling of helplessness	▪ Distress ▪ Anxiety ▪ Worry ▪ Fear and distrust
Social level	▪ Social isolation	
Familial level	▪ Broken relationship with children ▪ Tensions within the family	

3.5 Measures for preventing mistreatment and promoting wellness care

The discussion groups and interviews provided us with the opportunity to look at measures to prevent mistreatment and promote wellness care for CGs. It would seem that the measures suggested by the participants impact the CG, their entourage, institutions, social policies and the community. This is logical and in line with the types of sources that had been identified. Thus it would appear important that action be taken at all these levels in order to prevent mistreatment. Figure 3 presents the systems in which there are measures for preventing mistreatment of CGs. In the next section, suggestions and comments from the participants are listed according to the different sub-systems in the bio-ecological approach put forward by Bronfenbrenner (1979, 2005).

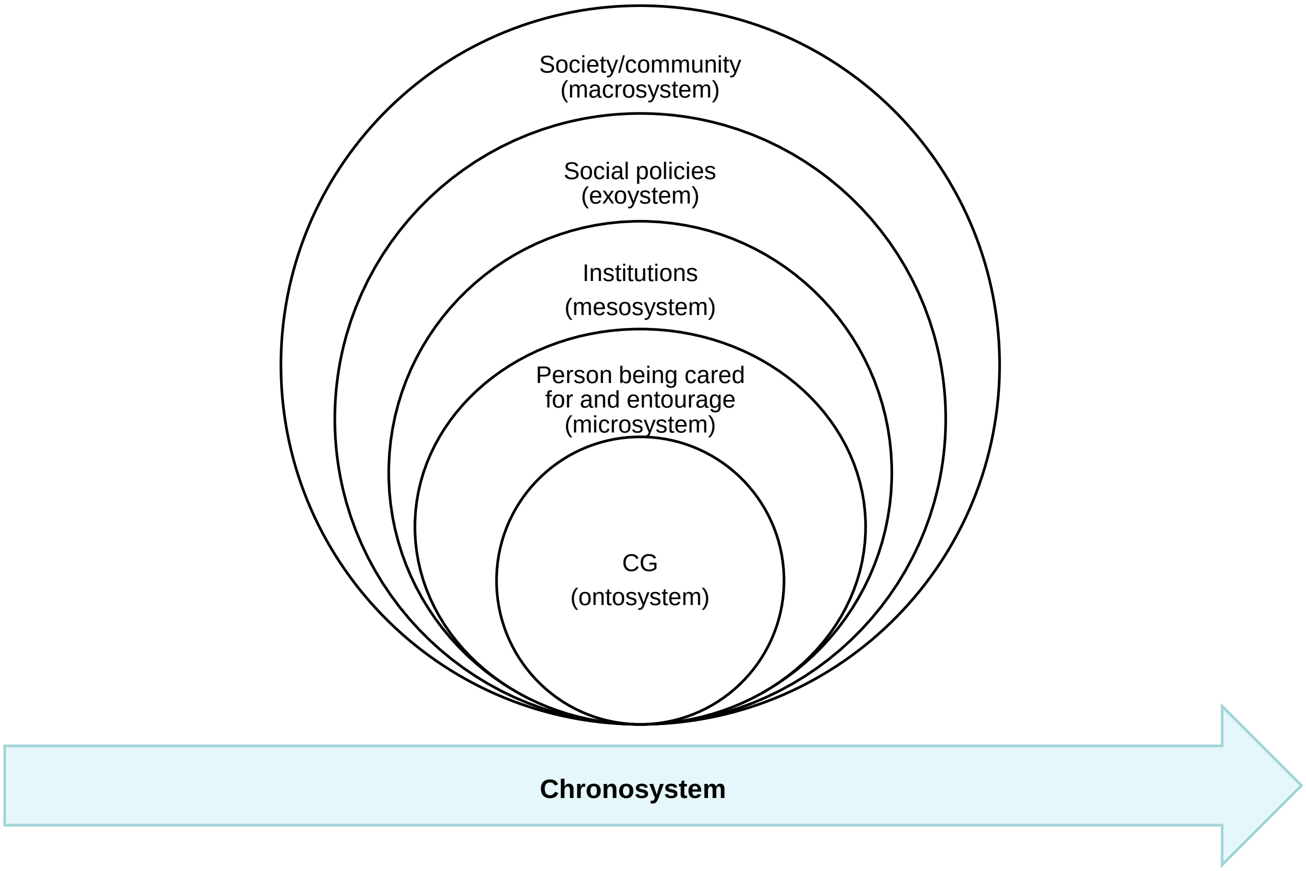

Figure 3: Systems in which there are measures for preventing mistreatment of CGs.

3.5.1 Measures meant for the general public, the community (macrosystem)

According to the participants, it is essential for measures for the prevention of mistreatment of CGs to be developed in the community, in order to heighten awareness in more of the general public who would not necessarily feel strongly that the services offered for CGs affect them. We have talked a lot here about changing values and culture (macrosystem), which requires time and must be done at an opportune moment (chronosystem). The reputation caregiving once had must be restored so that one day, mistreatment experienced while providing care becomes unacceptable. The participants suggested a public acknowledgement that caregivers deserve to have resources and support. Various tools, such as a wellness care chart, could be developed. This social change involves:

- Promoting the role of CG;
- Encouraging intergenerational humanist values for mutual aid and solidarity;
- Promoting the spirit of good neighbourliness: knowing who the caregivers are and helping them;
- Prioritizing the importance of living in dignity;
- De-stigmatizing the illness, aging or the handicap, to reduce isolation;
- Talking about quality of life rather than longevity;
- Enhancing the lives of older adults to counter ageism towards ECGs and CGEs.

These changes in culture social values, which may appear to be utopian, start with concrete actions:

- Organizing coffee meetings, breakfast meetings and public lectures on the theme of mistreatment of CGs in places they are likely to frequent (Fédération de l’âge d’or du Québec [FADOQ], Cercle de Fermières du Québec, Chevaliers de Colomb, libraries, etc.);
- Distribute leaflets and attend meetings with people in specific locations such as vaccination clinics;
- Nominate a lead agency for the mission of wellness care for CGs;
- Make caregiving and mistreatment of CGs visible by showing realistic, varied and non-stereotypical situations of mistreatment of CGs (news stories, advertisements, documentaries, investigative journalism, plays, videos, short films, television programs for the general public, books, TV series) and offer them more widely;
- Heighten awareness in cultural communities that are less associated with caregiving agencies and for which the definitions and forms of mistreatment and caregiving may be different.

In all the discussion groups, the importance of also talking to young people was discussed:

- Make students aware, starting in the primary grades, of ageism, ableism, caregiving, mistreatment, and familial support;
- Initiate intergenerational projects to make young people aware of the importance of caring for the elderly and thus encourage them to volunteer.

The need to heighten awareness in the workplace and union circles was also touched on:

- Make employers aware of the measures favourable to balancing work with caregiving;
- Review the employee assistance program so as to provide better information about caregiving and preventing mistreatment;
- Train peer helpers in the workplace.

3.5.2 Measures meant for policy makers (exosystem)

The social changes proposed above require a review of policies and social structures. It would seem to be necessary to speak out in the public sphere in order to:

- Broadcast video lectures about mistreatment of CGs in Regional County Municipalities (MRC);
- Denounce the cuts in social and healthcare services by explaining the consequences;
- Intervene before familial mistreatment evolves into mistreatment of the CG (intervention with the help of Youth Protection [DPJ] is sometimes necessary);
- Fund community organization projects that develop tools or intervention methods for mistreatment of CGs;
- Revise the definition of CG used in the policy on homecare services (2003) in order to include all caregiving situations and incorporate the various policies or measures into them (consistency in criteria, reduction in administrative processes, etc.), and put in place a policy for CGs;
- Clarify the rights of CGs, the rules about finances, the notions of incapacity and the need for protection, timelines and legal steps (publication of documents, hiring resource people);
- Pay or financially compensate all CGs who need it, no matter what their age or the status of the care recipient.

3.5.3 Measures meant for institutions (mesosystem)

Many of the measures for prevention and heightening awareness of mistreatment of CGs that were put forward were directed at institutions, especially the RSSS. First, the need for training was suggested numerous times by the participants:

- Train the healthcare providers and future healthcare providers so that they will pay attention to, and become aware of, signs of mistreatment, among other things, when evaluating family dynamics, and ways to take action when there is mistreatment, without making it a denunciation (in the legal sense of the term);
- Heighten awareness of the fact that CGs may be abusive, but may also experience mistreatment themselves;
- Include the issues of mistreatment of CGs and their right to wellness care in training sessions, lectures and documentation dealing with caregiving or mistreatment;
- In schools, acknowledge and champion (give credit to) volunteers in community organizations working with CGs so that students become aware of this reality;
- Train future caseworkers in life skills and knowing what to say, so that they are better able to talk to CGs (diagnoses, bad news, etc.), so as not to upset CGs, make them feel welcome and as a form of mentoring, talk about case studies and have discussions with them;
- Heighten awareness in caseworkers so that they take into account the expertise of the CGs and their choices.

The caseworkers and healthcare providers involved are usually client care attendants, home help workers, pharmacists, police officers, judges and 911 interveners.

From a structural point of view, several recommendations would prevent mistreatment and promote wellness care:

- Opening files for CGs to evaluate their needs, identify the mistreatment, and develop an accompaniment plan for each CG and then include it in the intervention plan for each person they care for;
- Creating a single window for CGs to identify them quickly, direct them to healthcare providers more efficiently and provide them with tools to prevent mistreatment;

- Designing a tool to track the mistreatment of CGs for first-line caseworkers, in particular family doctors, social workers, pharmacists and stakeholders from community organizations to help them identify problematic situations, then direct their intervention. In place of such a tool, participants suggested incorporating information about mistreatment into intervention tools that already exist in the field of caregiving;
- Modifying the ethics code for physicians and notaries, especially in regard to confidentiality, in order to take the reality experienced by CGs into account.

In terms of organizing services, participants suggested several possible actions:

- Put in place services for CGs who have experienced mistreatment (psychosocial support and sharing groups). This venue for sharing ideas among close friends and family should be maintained, even when few people attend;
- Implement services for defending the rights of CGs (resources that can enlighten CGs about means of recourse and protection when they have suffered mistreatment);
- Increase the number of caseworkers working with care recipients and CGs, encourage the work of the latter and promote interdisciplinary and intersectoral collaboration that includes CGs and other family members;
- Ensure continuity of services and stability in the attribution of files; ideally, assign a caseworker who will navigate for the CGs;
- Enhance care and respite services (healing lodges, hotel rooms at reduced prices in the low season for CGs, flexible schedules for care services, etc.);
- Make hospital parking free for CGs;
- Establish less strict, more flexible rules for inclusion, not based on the situation of the care recipient (illness, diagnosis, age) or the caregiver (cohabitation, connection with the care recipient, etc.);
- Adapter interventions and services better to the needs of the CGs, for example by increasing the number of respite hours per week, by providing a local service and by not separating couples living in care homes;
- Develop affordable or alternative accommodation establishments (intergenerational villages, etc.) that include committees of family members and CGs;
- Enhance home care services;
- Enhance the offer of public transit and adapted transport in each region, and improve snow-clearing in care and service settings;
- Organize exchange services (trade-ins) to provide greater access to medical equipment (rollator, hospital bed, adapted clothing, lift system, etc.);
- Promote funding, consolidation and action for community resources, such as training caseworker to better harmonize services with the RSSS and thus improve collaboration.

Finally, participants stated that caseworkers, healthcare providers and institutions have a duty to speak out publicly to support and defend the cause of CGs, among others, and denounce the cuts that have concrete, direct consequences for CGs.

3.5.4 Measures meant for the care recipient and the entourage (microsystem)

When certain care recipients are in actuality unable to recognize words or gestures of mistreatment that they may say or make to their CGs, especially in cases of mental or cognitive issues, participants stated that several of them were unable to do so. As a consequence, it was suggested that information documents should be created for them too (leaflets, posters) and individual, family or group interventions be implemented, in order to:

- Make the care recipient aware of the exhaustion of their CG so that they will accept the services offered to them;
- Encourage the care recipient to thank their CG and show them kindness and concern.

In addition, participants suggested measures for awareness and prevention using leaflets and interventions meant for the entourage:

- Heighten the awareness of the family to the role of the CG and the needs that this role incurs;
- Encourage the entourage to concern themselves with the wellbeing of the CG;
- Encourage the entourage to act as secondary caregivers to alleviate the burden of the main CG and to take on some of the costs.

For both the care recipient and the entourage, it was suggested that an intervention tool be developed to work on the relationship of the CG and the care recipient/entourage in the context of mistreatment, without assigning blame.

3.5.5 Measures meant for the CG (ontosystem)

CGs must be equipped with the tools to recognize mistreatment, know what their rights are, some of which are associated with wellness care, and know about the services and recourse to their provisions. Some CGs do not believe they deserve to be treated well, hence the importance of psychosocial assistance and information. Through individual meetings or small groups, this involves:

- **Addressing the risks** of mistreatment in order to promote awareness of the phenomenon;
- Assisting CGs in **implementing preventive strategies**: making them aware of the fact of asking for help is not a failure; helping them to develop their ability to set limits; helping them understand their loved one's illness; making them aware of ways to care for themselves and prevent exhaustion;
- Assisting CGs in **implementing intervention strategies**: teaching them to be more wary about behaviour that suggests mistreatment; teaching them to protect themselves, physically, emotionally and morally; help them to plan a safe place to which they can flee in case of a crisis situation;
- Addressing the right to wellness care by all actors;
- Assisting them in learning to see themselves in a good light, to respect themselves, to love themselves, to recognize their skills in this role, without worrying about their performance;
- Helping CGs to recognize themselves, to identify as CGs and to be proud of that;
- Suggesting different activities associated with self-wellness care: taking time for themselves, going to leisure activities adapted to CG situations, allowing themselves respite time.

Participants also suggested creating information documents such as leaflets and posters meant for CGs, with the following objectives:

- Presenting the services available to CGs for assistance, and recourse in the event of mistreatment;
- Describing mistreatment and wellness care (wellness care wheel, etc.) using situations/testimonials illustrating situations that are unacceptable experiences for CGs;
- Providing information about the way to tackle this role: illness, approaches for communication and intervention;
- Creating a personal screening tool for occurrences of mistreatment.

According to the participants, promoting the offer in services is also essential and must be personalized:

- Identify CGs when they begin their caregiving journey so as to offer them preventive and personalized services, and ensure transitions when they occur (home to care home);
- Direct people experiencing mistreatment to the appropriate resources in a better way;
- Promote the services of community organizations in order to provide more support to CGs;
- Promote the tax measures available for CGs, simplify forms and relax the eligibility criteria for financial aid or help resources.

4. Reflections on awareness tools for mistreatment of CGs

The discussions raised the issue that the proper perspective should be chosen for the creation of the awareness tool: countering mistreatment or promoting wellness care? However, it was stated several times that the term “mistreatment” is perhaps not the appropriate word, and that “wellness care” would no doubt be more promising for communicating the message. The participants formulated objectives that our awareness tools should meet:

- Tear down prejudices: Mistreatment concerns CGs as well as the elderly;
- Heighten awareness that wellness care is a right and not a privilege;
- Promote acknowledgement of the CG role.

In addition, they prepared a list of characteristics that should be included in these tools:

- Use a common language that is simple, clear, light-hearted and inclusive, and talk about the subject in a kind way;
- Define and explain what mistreatment is;
- Describe the types of mistreatment that CGs are likely to experience;
- Use means of communication that are accessible to everyone, not only the Internet or complex phone lines;
- Provide information about possible services;
- Exploit feelings: messages that shock, with which the CG can identify (this could be me);
- Launch an illustrated message, with provocative or surprising words, to catch the viewer’s attention, for example: “CGs are tired, give them a hug!” or “Our loved ones need time to breathe!”;
- Use a wide range of examples that are realistic: the person involved in the intervention must be able to put themself in the CG’s shoes or recognize themself;
- Use CG testimonials (written or visual messages);
- Do not treat CGs as victims;
- Suggest tools (or alternatives) to replace behaviour that involves mistreatment.

What form should these tools take? Several concrete suggestions were made: yes/no game/questionnaire, first to identify themself as a CG and then to determine whether there is mistreatment; comic strips; posters; leaflets.

Participants highlighted a few obstacles that could make heightening awareness difficult and should be removed so that the tools created would actually be used:

- CGs do not always recognize themselves in this role: recognizing themselves as mistreated CGs requires an extra step;
- CGs sometimes refuse services or do not ask for them;
- Care recipients sometimes refuse services for themselves or for CGs;
- Cognitive issues and undiagnosed illnesses of care recipients are often a source of behaviour involving mistreatment;
- A lack of resources, a lack of information about resources and difficulty accessing services;
- Lack of knowledge about the reality of CGs in the various settings in which they find themselves (familial, work, education, leisure activities, etc.);
- Normalizing mistreatment;
- Lack of awareness about the existence of mistreatment of CGs.

4.1 Presentation of the awareness poster: *Treating Caregivers Well. A shared responsibility.*

Supported by the findings from the study, a poster was created with the goal of heightening awareness of the phenomenon of mistreatment of caregivers. The overall idea was to portray caregiving as a journey on which mistreatment could occur. This journey may be long or short, and of varying intensity. Thus it is on occasion a marathon, a sprint, an obstacle course or a relay race, and sometimes it is a long march. The situations illustrated on the poster were created with the aim of starting a discussion, with room for different interpretations. Here is our interpretation. Everyone should be able to see themself here. There is one main pathway on the poster. It represents the official path, “specially mapped out” for the caregiver, to which CGs commit themselves. Certain characters are outside this main pathway, while others are attempting to join it. Various characters are shown all along the path: caseworkers, members of the entourage, care recipients, and CGs, all of whom represent the four sources of mistreatment mentioned earlier and by the same token, the potential actors for promoting wellness care for CGs.

The CGs wear different kinds of vests. One CG leaves a CLSC and has difficulty finding their way to the main route; they are running, exhausted and weighed down by the huge amount of information they have been given. A second caregiver seems distressed, alone in the middle of the path, not knowing what to do, or which direction to take. This may represent a loved one suddenly propelled along this journey, with no preparation, with little understanding of their role, their situation or the route to follow. Moreover, they seem to be heading in the opposite direction. Or perhaps they are questioning the proposed path. The third CG belongs to the sandwich generation, caught between her work, the care she must provide to her child and to her mother. In trying to combine all these roles, she is heading straight for a dead end. The CG wearing Vest 4 seems excluded from the discussion that the healthcare providers are having with the care recipient. An elderly couple wear vests 5 and 6: it is difficult to say which of them is the caregiver, because the roles can change depending on the circumstances. The woman looks exhausted and impoverished; she is dragging along heavy bags while the man seems to be grumbling and threatening with his cane. Is this a mistreated care recipient? Is this a mistreated caregiver trying to express his anger? Is this an elderly couple caring for a disabled adult child? Near them is a young caregiver wearing Vest 7 who is pushing a wheelchair in which sits someone who could be his grandmother, and they both seem enthusiastic. However, they are heading towards an obstacle that they seem to want to avoid. Or perhaps they are hurrying towards the aid resources that are being offered to them?

As for the caseworkers, the one in Situation 1 wants to help but gives the CG far too much information without noticing their fatigue or the burden they are carrying. Other caseworkers at bottom right are supportive; they are encouraging the caregiver. One of them is closer to the caregiver and is offering him water (or support along their journey). The other stays at a distance and waits for the CG to ask for help. Close by is a rest area. Is it easy to access?

As for the entourage, we see family members and friends at top right, who are encouraging the CG on their journey: they are offering flowers and make loving gestures. However, others at centre left sit on a bench, make comments from a distance, observe from afar, without intervening. Their conversation could be interpreted differently.

Finally, the route includes various symbols that could also lead to discussions: a stop sign, signs indicating help resources but pointing in different directions, a hole in the path and obstacles.

The poster is accompanied by a facilitation guide in the form of a manual showing a variety of contexts. It can be used for lectures given to groups, by support groups, in coffee meetings or in training sessions. Another use for the poster would be in an individual intervention situation. It is versatile enough to be presented to a diverse audience: CGs, care recipients, caseworkers, employers, the general public, and as suggested by our participants, even by children in schools. This poster is also accompanied by three leaflets: the first is for CGs, the second is for caseworkers and the third is for the entourage (parents and friends), as well as the care recipient. The leaflets repeat the images on the poster, and include definitions (of CG, mistreatment and wellness care) and information (sources of mistreatment, examples of manifestations and help resources) from our data collection.

Finally, narrated presentations are used by caseworkers in their interventions with CGs and also to heighten awareness in a wider audience during training and information sessions.

Treating Caregivers Well

A Shared Responsibility!

AAA Line (Aide Abus Aînés) **1 888 489 2287**

Caregiver Support Line **1 855 852 7784**

Info-Social Line **8 1 1**

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Research Chair on Mistreatment of Older Adults
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5. Conclusion

5.1 5.1 General recommendations

The data gathered as part of this action research are extremely rich, and not all could be taken into account in this report. And from among those presented, we had to make a choice in preparing a list of general recommendations that emerged from this study and on which we believe it is essential to concentrate to counter mistreatment of CGs.

1. Training and heightening awareness

- Teach healthcare providers about the mistreatment and wellness care of CGs, especially by using the material produced in this study (poster, facilitation guide, leaflets, narrated presentations);
- Make CGs aware of the risks of mistreatment and their right to wellness care, in particular by the use of the material produced in this study (poster, facilitation guide, leaflets, narrated presentations);
- Make the care recipients and the entourage aware of the risks of mistreatment of CGs and their right to wellness care, in particular by the use of the material produced in this study (poster, facilitation guide, leaflets, narrated presentations);
- Develop tools for screening and self-screening for mistreatment.

2. Funding community organizations

- Increase funding for community organizations to allow them to offer more individual and group intervention for CGs, including services devoted to mistreated CGs;
- Increase funding for community organizations to allow them to offer more familial intervention and heighten awareness to encourage the involvement of the entourage, including the care recipient, so as to lessen the risk of mistreatment.

3. Improving the healthcare and social services system and social policies on caregiving

- Enhance the services offered by including acknowledgment of the expertise of CGs and their inclusion in the intervention plans for the care recipient;
- Promote public home care and offer services in sufficient quantities, such as those for CGs;
- Integrate CG committees into long-term care home settings;
- Align policies, measures and eligibility criteria with services at the various government levels to improve access to services for CGs;
- Curb the impoverishment of CGs by implementing financial and tax measures in flexible admission criteria.

4. Changing values and social culture

- Change our society (beliefs, values, ageism, ableism) in the school setting (primary, secondary, university) and in the workplace, in order to raise the level of acknowledgement of the contribution of CGs and the need for them to take care of themselves.

As our narrative review was carried out as part of a study aimed at heightening awareness and preventing mistreatment of CGs, the means proposed for this heightening of awareness and prevention were also identified. They concern CGs who had experienced or were at risk of experiencing mistreatment, their entourage, communities and society in general. The following table presents a summary. All the means identified were also put forward by our participants, and several of them also appeared in our general recommendations. The latter appear in bold font so as to be more easily identified.

TABLE II: Means identified in the studies chosen for the narrative review for preventing mistreatment of CGs

Means for preventing mistreatment	**Authors of the studies**
Quickly identify CGs and present them with the services available	Killick *et al.*, 2014.
Quickly detect early warning signs of mistreatment of CGs	Bullock & Thomas, 2007; Cooper *et al.*, 2010; Kong, 2018; Kong & Moorman, 2015; Kunik *et al.*, 2010; Phillips, 2000; Weerd & Paveza, 2006.
Develop tracking tools that take into account cultural differences in describing mistreatment	Bullock & Thomas, 2007.
Take into account any history of mistreatment in childhood	Kong, 2018; Kong & Moorman, 2015.
Encourage CGs to talk about mistreatment they have experienced	Cooper *et al.*, 2010; Phillips, 2000.
Offer adequate psychological and medical treatment for care recipients who suffer from schizophrenia, mood disorders and behavioural problems	Chan, 2008; Hsu *et al.*, 2014; Weerd & Paveza, 2006.
Heighten awareness in healthcare and social services providers, and offer them training sessions on the issue of mistreatment of CGs	Herron & Rosenberg, 2017b; Kageyama *et al.*, 2015; Özcan *et al.*, 2017; Phillips, 2008; Smith, 2012; Spencer *et al.*, 2018; Walsh *et al.*, 2007; Wilks *et al.*, 2011.

Develop preventive interventions that strengthen emotional ties within the family and community, and that seek to address societal issues	Agyarko *et al.*, 2002; Killick *et al.*, 2014.
Increase funding for community support services using public funds	Wiles, 2003.
Increase access to services and their use, especially in rural settings and small towns	Agyarko *et al.*, 2002; Weerd & Paveza, 2006, Herron & Rosenberg, 2017.
Adopt a provincial policy in favour of CGs that recognizes their status and their rights	Chan, 2008; Herron & Rosenberg, 2017b; Herron & Wrathall, 2018; Kageyama *et al.*, 2015; Labrum & Solomon, 2015b; Lilly *et al.*, 2012.
Carry out awareness campaigns for the general public	Bullock & Thomas, 2007; Kageyama *et al.*, 2015; Killick *et al.*, 2014; Wiles, 2003.

5.2 Avenues for reflection emerging from this action research

Mistreatment of CGs is unfortunately not a new phenomenon. However, for the first time in Québec, this action research has provided an opportunity to document it. Going forward, we can no longer ignore this reality. Nevertheless, research is still needed to add to our knowledge in this field. There are several angles to this phenomenon that remain to be explored. For example, the discussion about the gaps in the healthcare and social services system and its role in the mistreatment of CGs casts a shadow over the factors associated with social culture, family arrangements and social roles. We should also consider the fact that there are causes and contributing factors that are intrinsically, and indiscriminately, associated with caregiving. What can we learn from this?

5.3 Limitations of the action research

As in all research, this study has limitations that need to be mentioned. Here are three such limitations. The most significant is that associated with our inability to derive an analysis of mistreatment of CGs based on gender, despite our explicit questions on this subject that were addressed to the participants. First, our sample was mainly female. Next, whenever the theme was touched on in the discussions, the talk (sometimes stereotypical) dealt more with the differences between men and women in the way they approach caregiving, than on the mistreatment experienced in the role. However, the findings from the study may henceforth be used to document gender differences. For example, the seven manifestations of mistreatment (imposition of the role, making judgments, normalization, denial of needs, etc.) could now be used to look at how they impact men and women differently, using a sample composed of equal numbers of men and women.

The second limitation concerns the scope of the study and relates to the objective of the action research. In order to really prevent this phenomenon, in-depth analyses of the factors leading to mistreatment of CHs and their articulation in terms of the systems (onto, micro, macro, etc.) would need to be carried out. The purpose of this action research was to describe this phenomenon. In future, case studies or again, descriptions of the trajectories that lead to mistreatment, would need to be done in order to have more in-depth knowledge of this phenomenon.

The third limitation we need to mention concerns the sample. Initially, it was composed of almost all women. In addition, although 13 administrative regions in Québec took part, some regions were not represented. It is therefore possible that mistreatment is experienced differently in more remote settings.

5.4 Strengths of the action research

Despite the limitations described above, this study has considerable strengths. Without doubt, the first is that it provided an opportunity to highlight a poorly documented phenomenon, by presenting original, concrete data. Mistreatment of CGs has specific characteristics and does not see itself in the same terms and within the same parameters as mistreatment of older adults. The sources and manifestations of the mistreatment and its definition are unique. In addition, the tools created are already being used in practice.

The second strength is that the study was developed in the context of an action research. The methodology used, based on a consultative process throughout the study, means that the findings are the result of a co-construction with the CGs and the caseworkers. The appropriation in practice settings of the tools created is thus a natural outcome. Finally, the use of an eco-systematic model to study the phenomenon of mistreatment of CGs provided a better understanding of how the different systems involved work together and thus address the complexity. This makes it easier to focus on the overall work that needs to be done to counter this phenomenon. We can no longer believe that a single action will solve the problem. As mistreatment of CGs stems from, and is fed by, all the systems, it is therefore necessary to work on all the systems. And this is the work that still needs to be done!

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Appendix 1 :

Interview guide for CGs who are experiencing mistreatment

The questions for the individual interviews deal with mistreatment experienced by CGs.

- You have agreed to participate in this study, because you have experienced difficulties in carrying out your role as CG. Are you able to tell me a little about this?
- This lasted how long? Did it happen often? How did it begin? How did it end? Was it mainly the result of behaviour, words, attitudes?
- In your opinion, why did this happen to you? What is your explanation for why this happened in the context of your role as CG?
- How and when did you become aware that this situation was unhealthy for you?
- What you're talking about, in the study and in the intervention, you know that it's called mistreatment. Did you know this word before, and what does it mean to you?
- Do you think you were being mistreated in your role as CG?
- What could have been done and by whom, so that you did not find yourself in this situation?
- What do you think that members of your family and your entourage perceived (perceive) and understood (understand) about your role as CG?
- How do you think society (neighbours, strangers who you meet in stores or elsewhere) perceived (perceives) and understood (understands) your role as CG?
- How do you think caseworkers in the healthcare system and community perceived (perceive) and understood (understand) about your role as CG?
- What could or should be done so that mistreatment of CGs is talked about?

Appendix 2 :

Discussion plan for CG groups and caseworker groups

FIRST SECTION

- How would you define the mistreatment of CGs?
- Where does this mistreatment come from?
- What are the consequences of mistreatment for CGs?

SECOND SECTION

- Why don’t we talk about mistreatment of CGs?
- Do you see a connection between heightening awareness (talking about it so that it becomes better known) and prevention (so that it doesn’t happen)?
- In your opinion, will heightening awareness help to prevent it?
- How can we heighten awareness of mistreatment of CGs?
- How can we prevent mistreatment of CGs?

THIRD SECTION

- What does wellness care mean to you?
- What could we do to promote wellness care for CGs?
- In an ideal world, how should CGs be viewed, treated and considered?

Appendix 3 :

Types of Mistreatment experiences by the CGs who participated in individual interviews and their sources

Participants[11]	**Types de maltraitance**	**Auteurs de la maltraitance**
Mario	▪ Physical and psychological	▪ Care recipient
Lisa	▪ Physical and psychological ▪ Violation of rights ▪ Institutional/structural/organizational ▪ Material/financial	▪ Care recipient ▪ Caseworkers/institutions: – Social worker – Nurse – Doctor – Personal care assistant – Police officer – Public Curator ▪ Entourage : – CG’s uncle – CG’s brother – CG’s cousin
Luc	▪ Psychological ▪ Violation of rights ▪ Institutional/structural/organizational ▪ Psychological ▪ Material and financial	▪ Caseworkers/institutions: – CDPDJ employee – RSSS ▪ Entourage : – Son of the care recipient
Claire	▪ Psychological	▪ Care recipient
Gisèle	▪ Psychological ▪ Violation of rights ▪ Institutional/structural/organizational	▪ Caseworkers/institutions: – Manager of the private seniors’ care home

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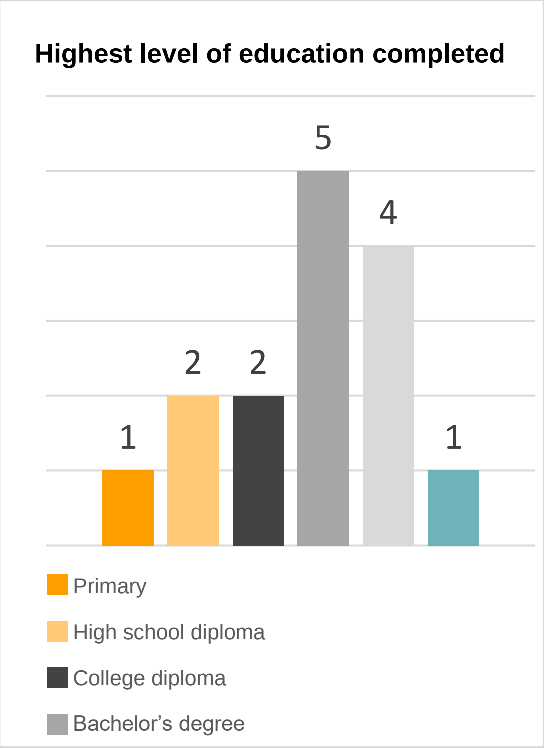
[11] These are fictitious names.

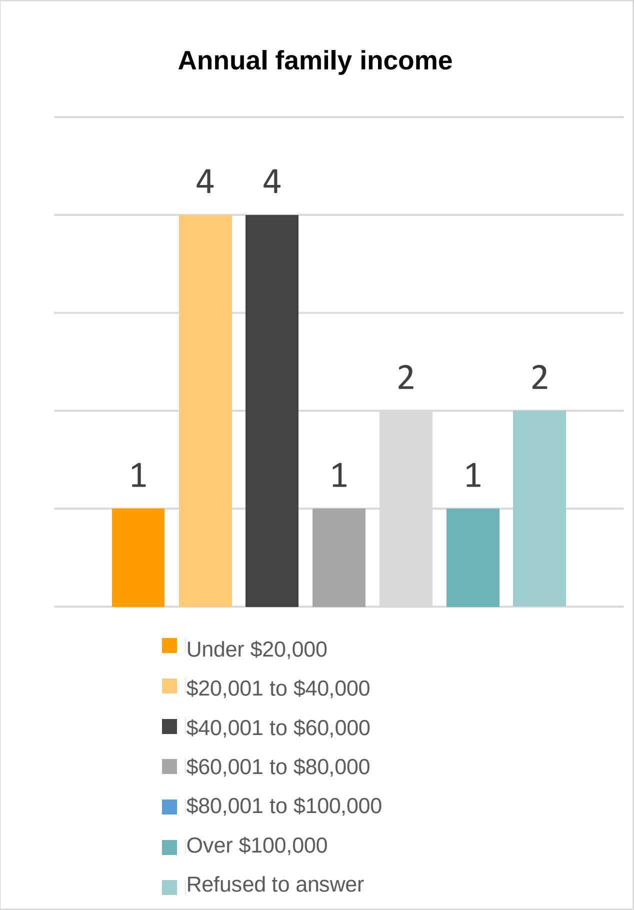
Types of Mistreatment experiences by the CGs who participated in individual interviews and their sources (cont.)

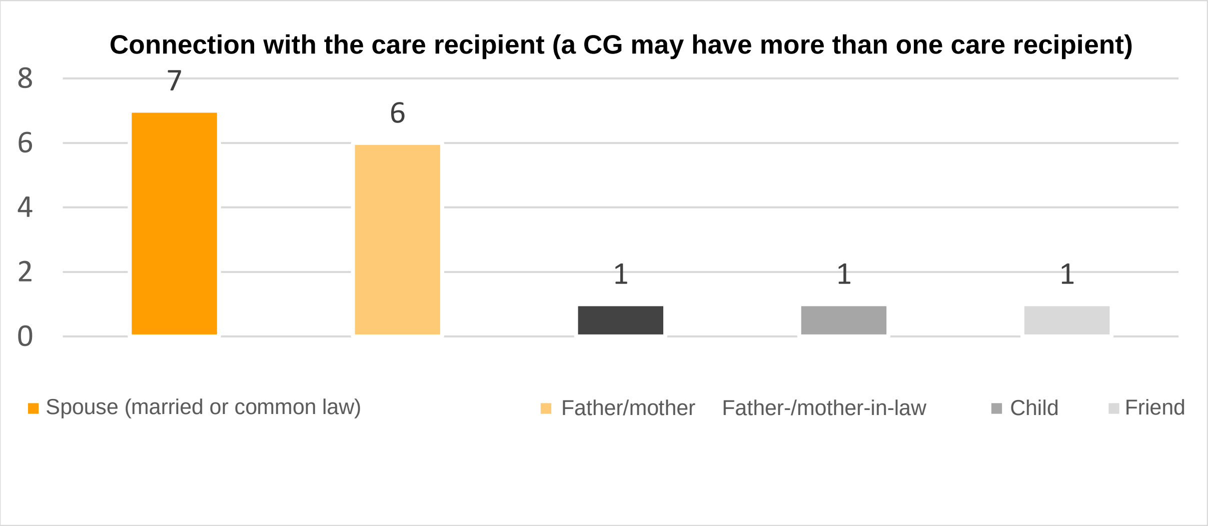
Guylaine	▪ Physical and psychological	▪ Care recipient
Ariane	▪ Psychological, physical and sexual	▪ Care recipient
Anna	▪ Psychological ▪ Violation of rights ▪ Institutional/structural/organizational	▪ Caseworkers/institutions: – Social worker – Nurse – Doctor
Maurice	▪ Institutional/structural/organizational ▪ Psychological	▪ Caseworkers/institutions: – Social worker
Charlotte	▪ Institutional/structural/organizational ▪ Psychological	▪ Caseworkers/institutions: – Intermediary resource staff member
Juliette	▪ Psychological and physical ▪ Psychological and violation of rights ▪ Institutional/structural/organizational	▪ Care recipient ▪ Caseworkers/institutions
Charles	▪ Psychological and materiel/financial ▪ Violation of rights ▪ Institutional/structural/organizational	▪ Care recipient ▪ Caseworkers/institutions: – Caseworker in a school setting
Claudine	▪ Psychological	▪ Care recipient
Virginie	▪ Psychological and physical ▪ Psychological and violation of rights ▪ Institutional/structural/organizational	▪ Care recipient and entourage – CG’s mother – CG’s stepfather ▪ Caseworker/institution – Social worker
Valérie	▪ Psychological and physical	▪ Entourage: – Friend

Appendix 4 :

Profiles of the 15 CGs who participated in individual interviews


Highest level of education completed

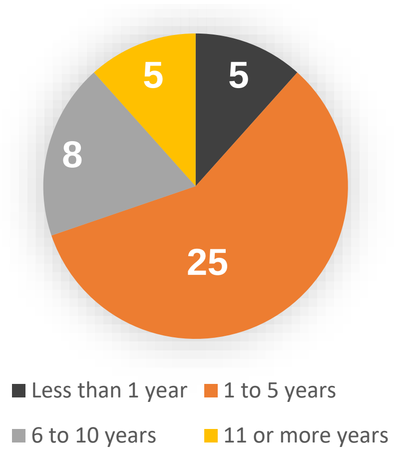

Annual family income


Connection with the care recipient (a CG may have more than one care recipient)

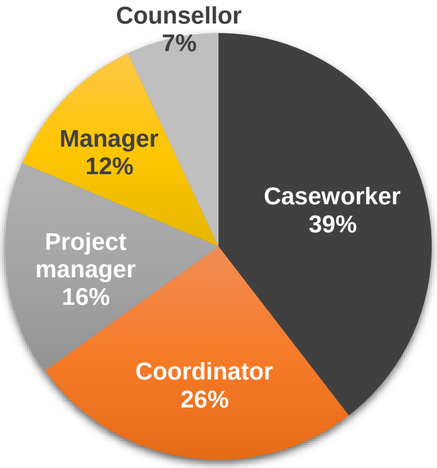
Appendix 5 :

Profiles of the 43 caseworkers who participated in the 5 discussion groups

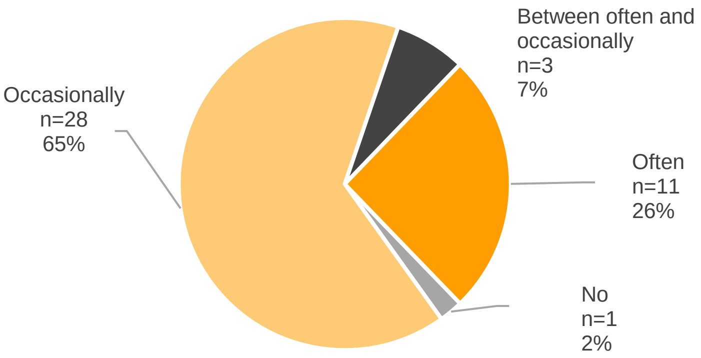
Number of years of experience with CGs of the caseworkers who participated in the discussion group



Positions held by the caseworkers who participated in the discussion groups



Frequency of contact with mistreated CGs for caseworkers who participated in the discussion groups



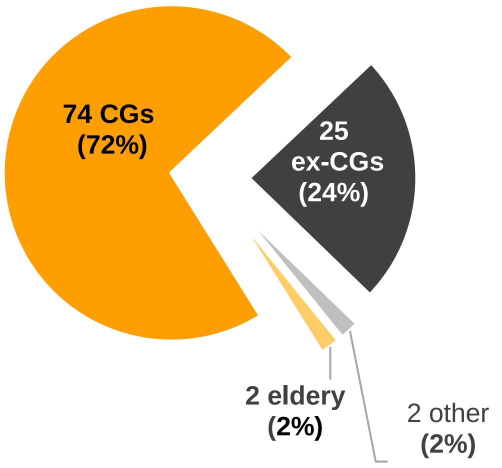
Appendix 6 :

Profiles of the 95 CGs who participated in the 13 discussion groups

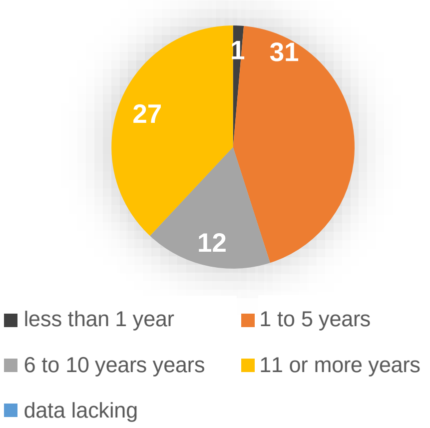
Number of CGs per discussion group according to sex and administrative region

Administrative region		M	F	Total no. of participants
1.	Montérégie	0	6	6
2.	Chaudière-Appalaches	0	6	6
3.	Mauricie	1	10	11
4.	Mauricie	0	6	6
5.	Abitibi-Témiscamingue	3	4	7
6.	Montérégie	2	8	10
7.	Bas-St-Laurent	3	1	4
8.	Montréal	0	8	8
9.	Laval	0	7	7
10.	Estrie	3	5	8
11.	Capitale-Nationale	3	5	8
12.	Capitale-Nationale	1	7	8
13.	Montréal	0	6	6
Total		16	79	95

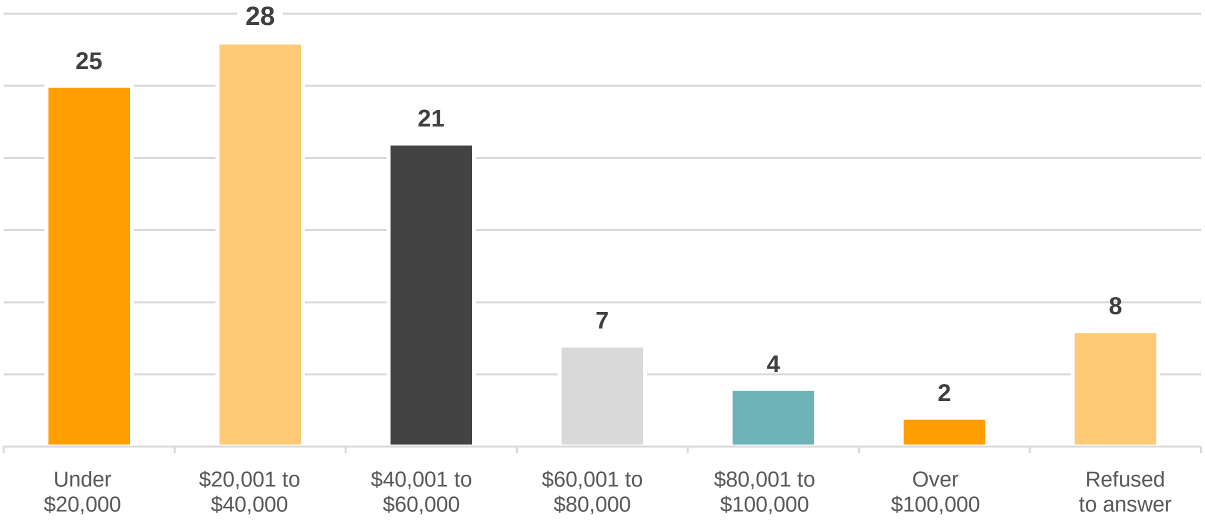
CG status of discussion group participants (a CG may have more than one status)



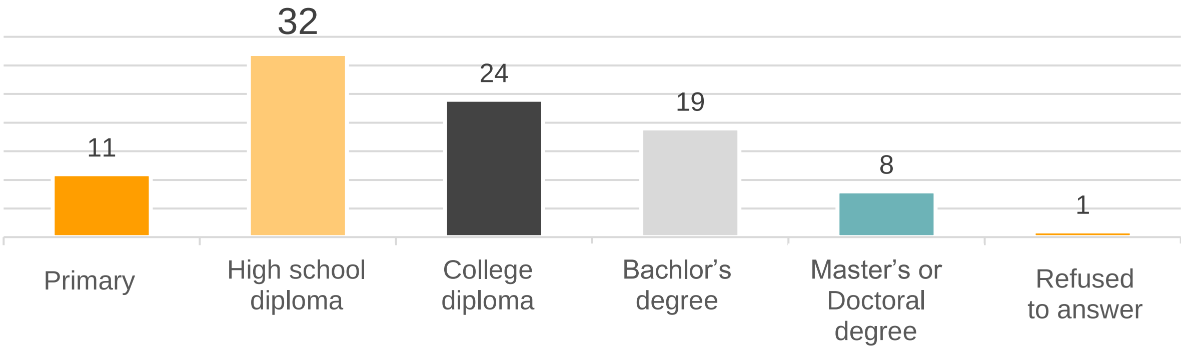
Number of years of experience as caregivers for the discussion group participants



Family income of CGs who participated in the discussion groups



Education level of the CGS who participated in the discussion groups



Appendix 7 :

Examples of manifestations of mistreatment experienced by CGs according to source

Imposition of the role of CG or over-accountability	▪ **Care recipient:** expects the CG to be available at all times, to do everything well, not to make mistakes, etc. ▪ **Entourage:** expectation by the entourage, but rarely questioned, that someone will care for their spouse, their child, their mother, etc. ▪ **Institutions:** expect that someone will act as CG without being asked, do not offer them enough support or offer it too late, unreasonable delays in providing them with help, etc. ▪ **CG:** imposes high or unrealistic standards, etc. on themself
Makes judgments	▪ **Care recipient:** is dissatisfied with, or critical of, the person helping them, etc. ▪ **Entourage:** judges what the CG is doing and their relationship with the care recipient, etc. ▪ **Institutions:** blame or reproach, or make inappropriate remarks, lack of empathy and consideration, etc. ▪ **CG:** feels incompetent in their role, etc.
Normalization of the role and the mistreatment experienced	▪ **Entourage:** tolerates inappropriate behaviour by the care recipient, does not recognize the symptoms or issues, such as mistreatment, etc. ▪ **Entourage, institutions, care recipient and CG:** excuse the mistreatment and explains it as the illness or the age of the care recipient, etc.
Denigration of the CG's expertise and the familial and social contribution	▪ **Entourage, care recipient and CG:** do not acknowledge the extent of the CG's role, its consequences and the diversity of knowledge and skills required to carry out the role, etc. ▪ **Institutions:** minimize the CG's expertise, exclude them from decisions, do not consider them, question their decisions, etc.
Denial of needs	▪ **Institutions:** Dismiss the needs of the CG at the expense of those of the care recipient or by a lack of resources, etc. ▪ **CG:** does not consider their own needs, does not consulter a doctor on their own behalf, stays silent about difficult situations, neglects themself, etc. ▪ **Care recipient:** does not understand the support, respite or other needs of the CG, etc.

Use of verbal, psychological, physical or sexual abuse	▪ **Care recipient:** throws objects, slaps, bites, inflicts pain or injury, forces or withdraws sexual relations, intimidates, insults or threatens the CG, etc. ▪ **Institutions:** intimidate the CG, threaten them, speaks to them in a condescending way, medicate them for sleep problems, anxiety, eating disorders instead of looking at the cause of their problems (exhaustion, mistreatment or other), etc. ▪ **CG:** blames themself, feels responsible for everything, accepts psychological, physical or sexual abuse, etc.
Contribution to impoverishment	▪ **Care recipient, entourage:** do not acknowledge the financial impact of caregiving, do not repay loans made by the caregiver, refuse to pay certain expenses assumed by the CG, etc. ▪ **Institutions:** charge for certain support or respite services in order to continue in a role provided free of charge, etc.

RECOGNIZE, RAISE AWARENESS AND PREVENT