RECOGNITION WITHOUT COERCION: NAVIGATING NEED, OBSTACLES AND ETHICAL DILEMMAS IN CAREGIVER RECOGNITION AND SELF-RECOGNITION

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Author

Camille Girard-Marcil, MSc
Planning, Programming and Research Officer,
Quebec Observatory on Caregiving

Review, validation and discussion

OBSERVATORY TEAM

Margaux Reiss, MSc
Team Leader,
Quebec Observatory on Caregiving

Mélanie M. Gagnon, PhD
Head of Knowledge Transfer Services,
Quebec Observatory on Caregiving

Revision

Révision AM

Translation

Lesley McCubbin

Layout

Julie Brière

Grahic designer

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TABLE OF CONTENTS

SUMMARY

Caregiver recognition and self-recognition are often considered the entry point for accessing support services,[1] since they legitimize and highlight the challenges and needs of family or informal caregivers.[2,3,4] In this way, they help foster a sense of belonging and community.[5]

The Quebec Observatory on Caregiving's 2023 report, Caregiver Recognition and Self-Recognition: Challenges and Practices, defines "recognition" as **an action performed by external stakeholders to characterize or designate certain individuals as 'caregivers' based on various criteria or characteristics**, and "self-recognition" as **the action through which someone sees and describes themselves as a caregiver**.

The criteria and characteristics leading to recognition or self-recognition are influenced by the social perception of caregiving and may vary based on the historical, legislative and/or cultural contexts. For example, caregiving is often socially understood as being limited to a child caring for an ageing parent — a view that remains deeply ingrained. While various organizations are working to shift this perspective, it continues to impact the recognition and self-recognition of caregivers who provide support in other contexts.[6] The social definition of caregiving can thus prevent certain groups from identifying as caregivers.[7]

The literature review that informed the above report identified several obstacles and negative effects related to caregiver recognition and self-recognition. Following the publication of these findings, some health and social services professionals expressed interest in exploring the more negative aspects or barriers associated with these concepts. For example, why might some individuals be disinclined to identify as caregivers? Is it always to the caregiver's benefit to be recognized or to self-identify as such? Does promoting self-recognition increase a caregiver's sense of obligation?

tivated by these ethical questions, the present document aims to deepen the discussion by drawing on a review of both grey and scientific literature, together with the perspectives of key stakeholders in the field and insights from the caregivers themselves.

1

REVIEW METHODOLOGY

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Our literature review aimed primarily to enhance understanding of certain ethical issues related to caregiver recognition and self-recognition.

Grey and scientific literature review – data collection

To assess the current state of knowledge, a total of 91 documents from both scientific and grey literature were consulted. Some scientific articles were identified through a keyword search in the Medline, Google Scholar and Érudit databases; the rest were found by consulting the reference lists of the articles retrieved from the keyword search (snowball method). The grey literature consulted included research reports, master's theses, and dissertations published as part of the consultations on Bill 56, proposed legislation in Quebec focused on caregiver recognition and support. These documents were identified through a Google keyword search as well as through previous publications from the Observatory,[a] including Caregiver Recognition and Self-Recognition: Challenges and Practices (2023) and What is a caregiver? Would you know one to see one? (2023).

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a For more details, refer to the methodology section.

ENGLISH AND FRENCH KEYWORDS IN THE LITERATURE REVIEW

Ethics	Recognition	Self-recognition	Caregivers
Ethic(s) Challenge(s) Forced (identity) Imposed (identity) Consequences Obligation	Recognition Recognized Appreciation Acknowledgment Identification Identity Identifying Awareness	Self-recognition Self-identification Self-identity Self-identifying Self-awareness	Caregiver(s) Carer(s) Family(ies) (?) Spouse(s)
Éthique(s) Enjeu(x) (identité) forcée (identité) imposée Conséquence(s) Obligation	Acceptation Identification Officialisation Identité Sensibilisation	Auto-identification (?) Identité Acceptation	Aidant(s)(es) Famille(s) (?) Aidant(s)(es) naturel(s)(les) Époux(se) Conjoint(s)(es) Partenaire(s) (?)

Data selection and analysis	The sole data selection criterion was the relevance of the information to the review's objectives. Document relevance was assessed alongside data collection by reading abstracts and conducting a keyword search within each text. This process yielded a final selection of 82 documents. The documents were then classified and analyzed based on pre-determined themes drawn from the review's objectives, such as the negative aspects of caregiver recognition and self-recognition, invisibility, instrumentalization, stigmatization, formalization and the sense of obligation. These themes were established by consulting the Observatory's previous publications and its expert advisory committee, as well as conducting a brief review of the literature. The themes were also further refined as the documents were reviewed.
Methodological limitations	→ The selected publications were limited to those written in English or French, which restricted the selection to documents from certain geographic regions. → The reviews conducted as part of this state of knowledge report were non-systematic. The goal was to identify certain documents rather than attempting to generate an exhaustive list. Furthermore, no assessment of the quality of the listed documents was carried out.
Stakeholder consultations	We also sought to understand how the ethical aspects of recognition and self-recognition manifested within certain caregiver groups. The literature we reviewed yielded little information regarding caregivers from the 2SLGBTQIA+ communities or about First Nations and Inuit (FNI) caregivers. To address this gap, the Observatory first reached out to Julien Rougerie, a trainer and content specialist at Fondation Émergence.[b] In the subsequent meeting held on August 19, 2024, discussions focused on the sense of obligation to assume the caregiving role and on the barriers to self-recognition among caregivers from the 2SLGBTQIA+ communities. The Observatory then contacted three coordinators who worked with FNI caregivers. An email exchange with one of them centred on the factors that might influence the sense of obligation among FNI community members regarding taking on a caring role.
Testimonies	The Observatory had collected caregiver testimonies under a previous initiative. Participants had been recruited online through an invitation shared on the Observatory's social media channels. The interviews took place during the summer and fall of 2024. Some of these testimonies have been included to support the findings presented in this knowledge review.

[b] Fondation Émergence is a non-profit organization dedicated to combating homophobia and transphobia through a range of initiatives, including training, knowledge transfer and awareness programs.

2

CAREGIVER SELF-RECOGNITION

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2.1 - Why might some individuals be disinclined to identify as caregivers?

There are several benefits to recognizing oneself as a caregiver. As well as fostering a sense of community, self-recognition helps individuals become more aware of their role and responsibilities, thereby legitimizing their own needs.[5] This awareness often serves as a crucial first step in seeking help and support services.[1, 8] However, despite these advantages, many caregivers are reluctant to identify as such. The following section will discuss the various conscious and unconscious reasons that may prevent someone from identifying as a caregiver, with the goal of better understanding these barriers and facilitating more effective intervention. This section will also address the potential negative aspects of self-recognition to encourage reflection on the ethical considerations involved, thus offering a more holistic view of the issue.

Accepting a loved one's diagnosis or changes to their physical or mental state is not always easy. Recognizing oneself as a caregiver essentially affirms that the condition of the person needing care is no longer what it once was. In contrast, not identifying as a caregiver can signify a struggle to accept the deterioration of a loved one's condition. In such a context, refusing to identify as a caregiver may serve as a way of refuting the loved one's diagnosis or their physical or mental incapacity.[9]

For many, the role of caregiver involves being available at any time of day or night. Consequently, not identifying as a caregiver can be a way of creating distance from what may be perceived as excessive demands. This can be an attempt to limit the associated tasks and obligations, particularly when the burden of care is heavy and the caregiver receives little support.[9] Conversely, some individuals may feel that they are not "doing enough" to be considered a caregiver[10] — for example, when the person they care for resides in an institutional setting such as a long-term care centre or community-based residential support.

There is very often a strong emotional bond between caregiver and care recipient. In this context, many individuals may resist identifying as a caregiver in an effort to preserve the original relationship. Doing so serves multiple purposes: it helps avoid the anxiety associated with a shift in the relationship's dynamic, mitigates the fear of introducing an imbalance[9,11] and preserves the dignity of the person receiving care.[9,11,12,13] Furthermore, for some, acknowledging their role as carer can add a sense of burden to the relationship and risk devaluing it.[11] Not identifying as a caregiver is therefore seen as a way to protect the care recipient from the dehumanization that can occur when someone is defined solely by their incapacity.[5]

Many people **prefer to focus solely on the initial relationship**, as it is within that relationship that they **find meaning in their role and responsibilities**.[11,13,14] For these individuals, caregiving is an extension of their duties as spouse, daughter, son, parent and so on. When the responsibilities of caregiving exceed the boundaries of the original relationship, they engage in assimilation — **absorbing caregiving into their original role** in an attempt to preserve the status quo. However, care-related responsibilities can also become overwhelming, leading some to engage in accommodation, where their personal identity becomes subsumed by their role as carer.[2] Being aware of this shift can be difficult; indeed, some individuals who care for a loved one never reach the stage of self-recognition.[2,15]

In a study on spousal caregiving, Morgan and al. showed that disengagement from the caregiver identity was often a **strategy aimed at protecting oneself or one's partner**.[10] Indeed, failing or refusing to identify as a caregiver can mitigate the loss of personal or relational identity brought on by increased responsibilities.[10,16]

Furthermore, much like caregiving relationships, family relationships and those characterized by emotional bonds are generally based on mutual help and reciprocity, making it **difficult to draw a clear line between the roles of caregiver and care recipient**. A person may also be reluctant to identify as a caregiver if they receive some form of support from the care recipient.[10,11]

A caregiver interviewed by the Observatory commented on her unwillingness to self-identify:

> I don't like that term [caregiver] because it's used everywhere, for all kinds of situations. . . . I see it all the time on social media, often from the two or three organizations I follow. It's always "oh, take care of yourself, blah blah blah." Because the word is out there, but what does it actually mean in real life? Calling myself a caregiver, what good would that do me? A label — that's all it is, a label. (Élisabeth)

Any identify must have meaning for someone to adopt it; however, that person must also **feel that adopting the identity brings certain benefits**. If someone sees nothing to be gained from being labelled a caregiver, they may simply forego the label.[10]

Finally, **certain groups are less apt to self-identify as caregivers**. For instance, young people rarely recognize themselves as such, not only for fear of intervention by youth protection services, but also to avoid stigma and shame — supporting one's parents is largely perceived as abnormal for children — or simply due to a lack of information.[17] Women are also less likely to self-identify as caregivers, owing to culturally normative expectations that frame caregiving as simply part of being a wife, daughter or mother.[18,19] Lastly, people from the 2SLGBTQIA+ community may not identify as caregivers because they are more likely to support a friend, neighbour, partner or expartner: a situation that contradicts the lingering social perception is that caregiving only occurs within biological family relationships.[6]

2.1.1 - NEGATIVE IMPACTS OF IMPOSING THE CARER IDENTITY

Along with the finding that many individuals who provide care to a loved one choose not to identify as caregivers, the literature we consulted makes it clear that **self-identification should not be a requirement**. This is because it may **give rise to negative emotions**[10] and impose **additional emotional labour.**[5] Furthermore, requiring people to identify as caregivers could **conflict with the coping strategies** that partners have developed to preserve the reciprocity of the original relationship or maintain the dignity of their family member.[10,11]

For all of these reasons, **a personal reluctance to adopt the caregiver identity should not create a barrier to accessing the available support** — for instance, in cases where identifying as a caregiver is required to qualify for a given program or service.[10]

Lastly, self-recognition does not always guarantee universal access to dedicated support services. For some individuals, their identify becomes entirely wrapped up in their caring role, **leading them to subordinate their own needs to those of the person they care for**. As a result, they fail to recognize that they, too, have needs and may distance themselves from the support services intended for them.[10,20]

Guidelines for professionals

One approach that professionals can take with individuals who do not self-recognize as caregivers is to **focus on the original relationship, adapting to relational realities** rather than reducing the relationship to a simple care recipient/care provider dyad. This means **emphasizing mutuality, viewing those involved as a unit as opposed to considering each person's needs in isolation**. The point is not to assume that both parties will have identical needs, but rather to recognize that their needs are interconnected. Without such acknowledgement, the caregiver may feel disengaged and refrain from seeking support.[10,11,21]

In research as in practice, **using language that emphasizes caregiving responsibilities rather than the term carer or caregiver** is more likely to resonate with a larger number of people, making them easier to reach them.[8,10]

3

CAREGIVER RECOGNITION

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At times, **caregivers may remain unrecognized by those around them**, even when they wish to be. In some cases, the care recipient may refuse to acknowledge their caregiver, and for various reasons. For example, parents supported by a child who is still a minor may be hesitant to recognize that child as a caregiver, out of fear of retaliation from child protection services or concern over the stigma their child may face[17,22] Tensions often arise when the caregiver's role or status is not equally recognized by both parties in the dyad. [12,15]

In Quebec, caregivers who support someone with a mental health disorder are less likely to be recognized as such by the Réseau de la santé et des services sociaux (RSSS, health and social services system).[23] **Confidentiality issues are a significant barrier** to changing practices in a way **that would better integrate family members** into the care process and **acknowledge their contributions to the care and services provided to individuals with mental health disorders**.[23,24]

Guidelines for professionals

It is still possible to involve caregivers in the care continuum, even without the consent of the person receiving the care. Professionals can listen to the concerns of family members without confirming or validating confidential information, focus discussions on their needs or perceptions of the situation, and refer them to the appropriate services. These approaches can help promote the inclusion of family members in a mental health context.[23]

3.1 - The normalization and invisibilization of caregiving

Caregiver invisibilization and the normalization of the provision of support occurs when the contribution of carers is taken for granted, and this can constitute **a form of non-recognition**.

Several authors highlight how the normalization of caregiving and support provided by women contributes to carer invisibilization and non-recognition.[20,25,26,27,28,29] In Quebec, women are more likely to be caregivers than men (24.1% vs. 18.1%); they also tend to take on a broader range of care-related tasks which, centred in the domestic sphere, represent a more cumbersome and restrictive workload.[30] Yet their **contribution remains largely overlooked, since, according to social role theory, women are 'responsible' for caregiving tasks**. Qualities such as empathy and kindness that are intrinsic to caregiving are perceived as innate in women, despite the fact that these attributes are largely acquired through socialization.[20,25,31,32,33]

Another **key factor** contributing to the **invisibilization of caregivers is the tendency to view caregiving as part of the private sphere**.[25,26] Under this perspective, caring for individuals with a disability is considered an individual responsibility of the family or loved ones rather than as a collective responsibility, thus rendering their efforts invisible.

One consequence of invisibilization or normalization often cited in the literature is the **difficulty caregivers face in mobilizing as political agents or advocates**.[20,26,27,29,34,35] Viewing their role as 'natural' limits the caregiver's ability to have their rights acknowledged.[27,29] This can lead to caregivers advocating solely for the rights of the person they care for, while neglecting their own needs or rights.[20] Caregiver recognition seeks, in part, to assert that they, too, have rights and should not be seen merely as a means to an end.[34,35,36]

Invisibilization is a process that operates on two levels.[26] The first involves relegating caregiving to the private sphere, as discussed earlier. The second involves the **construction of a flawed belief that a person with a disability is incapable of participating in our social model**. This process reinforces the belief that caregiving is not a matter of political or social justice, but rather a private affair that families and loved ones must manage. It also assumes that caregiving should not affect their participation in society and paid work, particularly since employers often struggle to support and accommodate caregivers in the workforce.[26]

Ultimately, invisibilization of caregivers perpetuates the notion that they **don't need support, recognition or information**, because it is assumed that they will naturally take on the role.[31,37]

3.2 - Stigma

Stigmatization refers to the negative attitudes, beliefs or behaviours directed towards a group of people because of their personal situation. It encompasses discrimination, prejudice, judgment and stereotyping. Those who are its victims are at risk of experiencing isolation and negative impacts on their mental health.[38] Stigmatization can be an unfortunate consequence of being recognized as a caregiver in society, as some studies show that caregivers are vulnerable to stigmatization either through their association with the person they care for, or simply by assuming the role.[39,40,41,42]

In the case of **stigma by association**, caregivers **encounter the same judgments as the person with the disability**.[40,41] Those at greater risk are typically caregivers who support individuals whose disability is already socially or historically stigmatized — for example, people with mental health disorders,[39,40] intellectual disabilities,[25,43,44] autism spectrum disorders41 or issues related to addiction.[42]

The stigma attached to the person receiving care may also be internalized by the caregiver, leading them to **adopt the negative attitudes perpetuated by society or their social circle**. These individuals often conceal or minimize their caregiving role as a result.[39,40] At times, they use denial as a defense mechanism against stigmatization and a way of coping with the associated psychological distress.[43]

The **very role of the caregiver can also become a conduit for stigmatization**. Young people are particularly vulnerable to this form of stigma when other become aware of their role. The perception that they are part of a family dynamic that deviates from societal norms makes them more likely to experience bullying, particularly in school settings.[17,22]

More broadly, stigmatization **undermines the psychological well-being** of caregivers.[44] It also **compounds their burden**, as they tend to withdraw and avoid seeking support services for either themselves or the person they help.[42] Their tendency to conceal the condition of the person they care for — and, in some cases, their very caregiving role — is a response to the prevailing prejudices and the shame they experience as a result.[45]

Peer support[40,44,46], openness[44] (disclosing the disability rather than concealing it) and awareness would appear to be the most effective means of combating stigmatization.[43] For example, one study on young caregivers showed that **peer support groups not only improved their quality of life, but also helped reduce internalized stigma**.[40]

3.3 - Formalizing and professionalizing the caregiving role

In caregiving, *formalization* involves clearly and systematically defining the responsibilities, expectations, tasks and objectives associated with the role.[47]

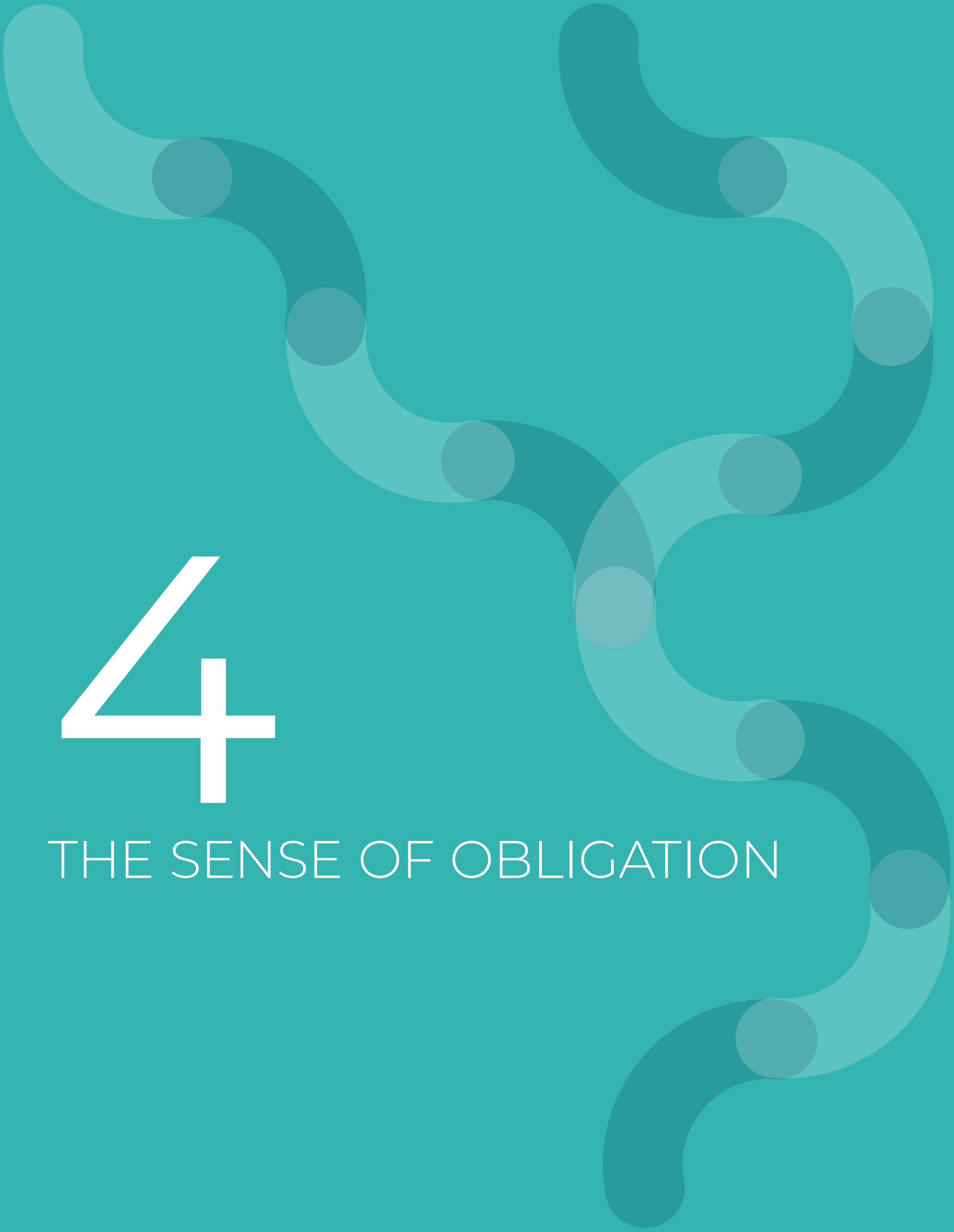
Professionalization, on the other hand, is a process through which an activity evolves to attain professional status. This includes the development of specialized skills and the acquisition of technical and theoretical knowledge, as well as the creation of standards, certified training programs and regulatory frameworks.[48] In Quebec, caregiving is not considered a profession. Nonetheless, caregivers are at risk of becoming part of a professionalization and formalization process, which many scholars argue is an unintended consequence of the growing recognition, increased effectiveness and legitimization of the caregiving role in society.[49]

For example, the Quebec government's 2020 Act to recognize and support caregivers grants legal recognition to caregivers. While this recognition provides **formal rights, it also comes with formal responsibilities**.[29, 50] One risk associated with formalization is that it could restrict caregivers to their role, **without the ability to redefine their responsibilities or level of involvement** as their caregiving journey evolves, even though the Act specifies that this decision must be revocable.[29]

In her master's thesis on the recognition of caregivers' rights in Quebec (2023), Bruton-Cyr observes a certain formalization of the role in the 2020 Act, which encourages caregivers to selfrecognize so that they may better identify their needs and seek support.[51] However, it is not necessarily aiming to directly reduce their responsibilities or burden, but rather to improve their current quality of life.[29] The author cautions that **self-identification should not be used to foster caregivers' continued involvement in their role**, as it may intensify their burden and sense of obligation to become — and remain — a caregiver.[29] Beyond self-recognition, if caregiving is indeed considered a 'choice,' then the state must establish services and support systems that facilitate that choice.[35]

A further unintended consequence of formalization is the creation of **two distinct categories of political or social agency**: "recognized" caregivers who benefit from the advantages this status confers; and their "unrecognized" counterparts. The latter group includes those who, for the reasons discussed earlier, do not wish to self-identify and thereby forfeit their rights to support or recognition.[50]

Regarding **professionalization**, Bill 90, which amends the Quebec Professional Code, stipulates that a caregiver may engage in **certain professional activities reserved for members of a professional order**[37,52] (e.g., administering an injection or inserting a catheter). This constitutes a recognition of their skills to an extent. However, the risk is that it may **increase their burden and generate stress or anxiety**, particularly if they lack training or feel uncomfortable performing such tasks.[37] Furthermore, like formalization, professionalization can **contribute to the entrenchment of caregivers in their role**: having become essential to the care recipient's support, they may feel guilty about stepping back from their duties.[52]



4

THE SENSE OF OBLIGATION

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We have discussed how recognition or self-recognition can help keep a caregiver in their role through the processes of formalization and professionalization. In some cases, being designated as a caregiver — or encouraged to identify as one — can foster a sense of obligation to assume the role.

In 2018, one in five people in Quebec was a caregiver.[53] For some policymakers and members of the scientific community, the fact that caregivers continue to offer support in such large numbers, despite the numerous documented negative effects on their social, family and financial lives as well as on their physical and mental health, is seen as evidence of a pervasive sense of obligation to take on the role.[27] Yet the Quebec government's *Act to recognize and support caregivers* (2020) asserts that the support must be "provided in a free, enlightened and revocable manner."[51]

The concept of free choice is crucial, since individuals who reported feeling they had no choice in becoming a caregiver experience higher levels of emotional stress, poorer physical and mental health, and a lower quality of life compared to those who felt they had a choice.[54]

The sense of obligation will be the final ethical issue addressed in this report. The literature reviewed highlighted how various factors contribute to this sense of obligation. We will first explore structural and organizational factors like instrumentalization and the partnership paradigm. We will then examine the more individual factors, including the roles played by the caregiver's immediate circle, the professionals with whom they interact, and the attitudes of the caregivers themselves.

4.1 - Instrumentalization

With regard to caregiving, *instrumentalization* refers to the way in which care and services within the health and social services system are organized. The question here is one of how **structural and organizational elements work to heighten the sense of obligation to take on a caring role**.[29,31,55]

Two events in the province's recent health care history — namely, the shift to ambulatory care in the early 1980s, followed by the 2003 policy on home care[56] — reflect an **organizational reform of care and services that many believe has served to intensify the sense of obligation among caregivers**.[35,36,52,57,58]

With the shift to outpatient care, the provincial health and social services system (RSSS) aimed to shorten hospital stays and bring services closer to the user's living environment. The focus thus turned to home care and services. However, in practice, these reforms to long-term care implied a **lower intensity of the available at-home professional care and services** (through the implementation of limits, longer wait times, etc.) along with stricter admission criteria for institutional care.[55,58,59,60] The upshot was to make family members key players in the effort to keep service users at home.

According to a 2012 report from the provincial ombudsman, the Protecteur du citoyen,[60] insufficient public funding for home support services was forcing individuals with disabilities and their primary caregivers to bear an increasing share of care and service costs, often by turning to private agencies or community organizations (e.g., EESAD). A more recent study from the Commissaire sur le bien-être et le soutien à domicile (CSBE, a public body tasked with assessing the performance of Quebec's health and social services system) reached similar conclusions. In its 2024 report,[61] the CSBE identified home support accessibility as the most problematic aspect of the current system, citing the financial unsustainability of home support as a significant factor in the growing imbalance between current service availability and future demand. The report also noted the 30% rise in the number of people waiting for their first service, which had gone from 13,250 on March 31, 2019, to 17,226 on March 31, 2022. Average wait times between new service requests and the first intervention were likewise seen to increase: from the 18 days reported in 2019-2020, they had risen to 19.71 days in 2021-2022.[61]

Clearly, the lack of access to adequate home care services intensifies the burden on caregivers. Families are either forced to pay for private services, if they can afford it, or take on the responsibility of providing the care themselves.[60,62] In Quebec, the shift to ambulatory care has been seen to increase the involvement of family members and loved ones in the provision of care, since **home support services are significantly reduced when a relative is available to provide such care**, often without due consideration as to their consent.[35,60,63]

While the focus on home care has its benefits, there is a problematic downside: the increasing reliance of the health and social services system on family members and/or informal caregivers. In a context **where little support or alternative services are provided**, the burden then disproportionately falls on family members.[36,52,62] Compounding the situation is the belief held by many stakeholders that, all too often, **caregivers are left with little choice but to step in, particularly when formal services are lacking**.[14,28,29,31,35,59,62,64,65,66,67]

In concrete terms, instrumentalization may manifest as the state's tendency to view caregivers as **service suppliers or subcontractors**: an outlook that can only be described as flawed, given that the compensation currently provided for caregivers in Canada and Quebec is well below what it would cost to deliver similar professional services.[68] One caregiver we spoke to attested to this dynamic:

> I know that society asks a lot of [caregivers] because I'm sure I've saved [society] millions of dollars on anything to do with staffing, occupational therapy, pharmacy care, administration, accounting, all of that, because that's what it amounts to: to replace me, to do everything I do to take care of my father, it would take a whole lot of staff.
> (Diane)

Instrumentalization may also manifest as the perception of caregivers as a resource with which to address current staff shortages in the health and social services system.[69] However, **the role played by these individuals cannot be used by the state to disengage from its obligations toward service users**.[57]

Faced with the limited availability of home support services through the health and social services system, families may turn to private agencies or temporary immigration programs like Canada's Temporary Foreign Worker Program (TFWP) as potential solutions to alleviate the caregiver burden. Through these programs, families can hire foreign workers to provide care in private homes for children or elderly individuals. However, it bears pointing out that workers in these services are often racialized women with **precarious immigration status, doing work that is poorly paid and largely unregulated, leaving them vulnerable to various forms of abuse**.[26] To avoid the further instrumentalization of marginalized workers, it is essential to remain aware of these negative consequences when seeking ways to reduce the caregiver's burden.

4.2 - The partnership paradigm

The partnership paradigm that began to emerge in the Quebec government discourse in the late 1980s became more formalized in 2018 with the publication of the *Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux* (reference framework for a partnership approach between patients, their families and health & social services stakeholders).[36,70] The framework defines "partnership" as follows:

> *[Translation]* Partnership is an approach based on the relationship between service users, their families, and stakeholders within the health and social services system. . . . More specifically, the relationship helps build bonds of trust along with a recognition of the value and importance of each person's knowledge, including the experiential knowledge of service users and their families, as well as co-construction.[70 c]

In its discussion paper on caregiving,[36] the Comité national sur le vieillissement (CNEV, national committee on ageing) presents several collateral effects of the paradigm. The way in which the partnership is framed **crystallizes the individual responsibility of families for the rehabilitation and quality of life of service users**. Furthermore, the reliance on individual responsibility risks creating **inequalities in the user's rehabilitation**. Indeed, not everyone has the same financial, social or educational resources, nor the same level of education and literacy, to manage rehabilitation.[36,52]

In practice, it is clear that perspectives on what the 'partnership' consists of can differ between RSSS professionals, service users, and their families and caregivers. The organization of home care services **can sometimes require professionals to delegate certain tasks to family members without necessarily taking into account their limitations**.[36,71] **Caregivers**, for their part, expect **recognition of their role and their decision-making skills, as well as to receive support and guidance in performing their care-related tasks**.[29,65,71] One caregiver we spoke to expressed frustration about being excluded from certain aspects of her mother's care:

> They tell me I can't see the care plan, that I'm not "supposed" to be a partner in care. But I am, because I don't give them the choice. And that's really too bad, because if I could build on what [RSSS professionals and providers] do, it would really help with the continuity of my mom's care and keep us all on the same page. Like what I say to my mom to calm her: they could say the same thing, and vice versa.
> (Brigitte)

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c Original French: *Le partenariat est une approche qui repose sur la relation entre les usagers, leurs proches et les acteurs du système de santé et de services sociaux... Plus précisément, la relation favorise le développement d'un lien de confiance, la reconnaissance de la valeur et de l'importance des savoirs de chacun, incluant le savoir expérientiel des usagers et de leurs proches, ainsi que la co-construction.*

This dynamic in the relationship between professionals and caregivers risks mirroring the structure of Quebec's current care and service model.[36,71] Caregivers are effectively mobilized to support the rehabilitation plan **as stopgaps for any professional time or resource shortages**, since professional services are seen as a last resort to be applied only when there is no family member available.[71] One caregiver remarked on the need to convey 'urgency' in order to access services:

> When they come to check up on my parents, [the CLSC workers] say "They're okay, they have everything they need," but it's only because we [the caregivers] make sure they have everything they need. But sometimes you wonder: maybe I should present things differently, like make the house look unsanitary?
> (Claire)

In sum, **it is not always clear where the responsibilities of the health and social services system end and those of the family or caregiver begin**. Furthermore, there is a risk that the caregiver's burden and sense of obligation will only increase if they feel poorly supported by health system professionals.[24,68,71]

Guidelines for professionals

Professionals, service users and their families often have differing expectations regarding care and services. The initial home visit gives professionals the opportunity to clearly outline their role, responsibilities and expectations, while also allowing caregivers to express their own.[68]

The latest framework from the Quebec health and social services ministry, *Reconnaître les personnes proches aidantes comme partenaires pour mieux les soutenir* (2024),[72] highlights the importance of communication and mutual agreement among all parties. Notably, it outlines two key actions to be taken at the start of each clinical intervention. First, the professional must confirm whether the care recipient consents to the caregiver's involvement, and the care recipient must agree to allow the professional to contact and meet with the caregiver. Second, the professional must ask the caregiver if they wish to participate in supporting the person who receives the care. The information gathered through these actions provides a clearer understanding of the needs and contributions of everyone involved.[72]

4.3 - The role of family

Family can play significantly into the caregiver's sense of obligation. While family members generally do not force the caregiver to assume the role, the latter may be **implicitly designated as such**.[31] Women in general as well as individuals who work or study in the health or social services sectors are particularly likely to be designated as caregivers.[29,73] Obligation may also arise when other family members disengage. If no-one else in the family steps up, then one person may feel they have no other choice but to take on the role.[31]

Familism can intensify the sense of obligation for caregivers.[74,75] *Familism* is a cultural value that emphasizes a deep sense of connection and support among family members. It involves a strong sense of loyalty, commitment, mutual responsibility and emotional bonds with both immediate and extended family.[74]

A further **contributing factor to the sense of obligation** is **filial obligation**.[15] Montgomery and Kosloski (2013) note that the pressure to take on the role of caregiver for an ageing person follows a priority order: namely, partner, children, extended family, friends, neighbours and formal care organizations, with those at the top of the list more likely to feel duty-bound to assume the role.[15] When the caregiver is a parent of a child with a disability, the obligation to take on the role arises from a legal and moral responsibility to protect and support their offspring.[76]

Furthermore, filial obligation is influenced by a gendered dynamic.[30] A 2014 study conducted in the United States showed that for men, having a sister reduced their caregiving responsibilities toward an ageing parent, whereas for women, having a brother served to increase their burden.[77] In general, the literature shows that **the sense of obligation to become a caregiver is more pronounced among women due to traditional gender roles**, whereby caregiving is part of the social expectations of being female.[19,26,28,29,78] A difference has also been observed between male and female caregivers. As discussed earlier, women are more likely to perform a greater range of supportive activities that are centred primarily in the domestic sphere, where the responsibility is the more burdensome.[30] Since it is less "natural" for men to be caregivers, they are better able to set limits and seek professional help, and their requests are also more likely to receive professional attention than those of women.[52]

The parameters of filial obligation can shift somewhat in a migration context. For caregivers from immigrant backgrounds — a situation often characterized by a fragmentation of the family or social network due to migration — there may simply be fewer individuals available to assume caregiving responsibilities. As a result, it is not uncommon for immigrant men to assume the role of primary caregiver, particularly when they or the person they care for are isolated.[58]

4.4 - The role of the caregivers themselves

The **sense of obligation can also be internalized by caregivers**,[31,32] often manifesting through **the concept of reciprocity or a sense of duty, especially when someone feels indebted to the person they care for**.[19,79] For example, adult children may wish to repay their ageing parents for the love, attention, care and support they received as children.[32]

Clearly, **attachment weighs significantly into caregiving motives**. Emotional attachment generally refers to the deep and meaningful bonds between individuals, characterized by feelings of tenderness, affection and mutual concern. For the carer, the **meaning they derive from their relationship** with the person they care for helps them cope with the mental, physical and financial pressures associated with caregiving.[14] Reflecting both harmony within oneself (from a sense of having honoured one's commitments) and harmony with others, this attachment makes the caregiver's journey meaningful. Still, a caregiver's emotional bond with the person they care for **does not erase the structural constraints that contribute to the sense of obligation**.[14,58,80]

4.5 - The role of professionals

Lastly, **professionals and practitioners** in the health & social services and community sectors can influence the sense of obligation.[31] For instance, they **may exert pressure on family members to provide support to the service user, without first validating their consent**. Such pressure often stems from organizational factors. When professionals are unable to meet the full range of care needs within reasonable timeframes — housing being one example — they have no choice but to delegate those responsibilities to the user's family.[31] One account from a caregiver illustrates this pressure:

> I loved my interactions with some social workers, but with others, I hated it. Why? Because I felt judged and oppressed. I wasn't getting any services; and so at one point, my brother said to my father's case worker, "Listen, are you waiting for my sister and mother to end up in the hospital before you do something?" . . . It was because she thought we weren't doing enough, that my mother wasn't doing enough. Excuse me, but my mother is 80 years old. . . . She has health problems, but it was still supposed to be her who took care of everything.
> (Diane)

Another account shows how professionals can contribute to the guilt caregivers might feel when trying to set certain boundaries:

> The [CLSC] social worker would tell me, "Lucie, if he [the care recipient with the neurocognitive disorder] wanders off and gets lost, you'll be responsible." Then she wanted me to put locks on the doors from the inside, but I wasn't comfortable with that. I mean, if there's a fire . . . I didn't feel good about that. Then she told me, "If something happens, you could be held criminally responsible." So you always get shouldered with this burden over decisions that aren't so easy to make.
> (Lucie)

Guidelines for professionals

Contrary to popular belief, **it is possible to adjust one's role as a caregiver even in the presence of an emotional bond and/or a sense of duty or reciprocity**. Professionals can assist in this process by encouraging caregivers to set boundaries.[31]

Indeed, professionals can **support caregivers in redefining their roles** by presenting the available options and addressing negative emotions such as guilt and feelings of betrayal.[80] One caregiver commented on the help she received from her psychologist in asserting her boundaries:

> I had to pressure the social worker, and honestly, it was my psychologist who finally said, "Okay, we're going to develop your acting skills," because when I speak, apparently I look composed and in control — I seem fine! She said, "You're distressed and you're not showing it, so I'm going to teach you how to show your distress so that the social worker understands where you're really at." So she coached me so that the social worker could really get the situation.
> (Lucie)

The sense of obligation: a confluence of multiple factors

In reality, the many elements described above are interconnected, making it **impossible to attribute the sense of obligation to any single factor. The obligation felt by caregivers** is **influenced as much by cultural norms** (familism, the sense of duty, reciprocity, emotional bonds, etc.) as it is **by societal norms** (gender norms, organizational factors, etc.).[19] We must also consider the influence of structural factors on individual factors. According to del-Pino-Casado and al. (2018), the obligation to care for a loved one has two dimensions: an **external obligation** related to social pressure, and an **internal obligation** related to personal beliefs about duty. Indeed, the multidimensional nature of the concept of obligation should be taken into account in research on caregiving obligation.[79]

Toward an improved distribution of caregiving responsibilities

Caregiving will always exist. However, the freedom of caregivers lies in **the ability to make choices within the caregiving context**.[25,36] In this regard, measures can be implemented to mitigate the negative effects of caregiving to the greatest extent possible:[25]

- **A better sharing of information about the role of caregivers**[36,57,63] (the extent of their involvement, consequences, alternatives and available resources).
- **Access to care and services** that meet the needs of caregivers and those they care for.[36]
- Professional help for caregivers in terms of **renegotiating and redefining their role**.[80]
- **Better social and governmental allocation of care-related responsibilities**, moving toward a more supportive and solidarity-based environment.[25,26,36,62,64,67,71,81,82]

By reinforcing the social perception that caregiving is solely an individual responsibility (based on a sense of duty) falling within the private sphere, **caregivers become vulnerable to invisibilization and instrumentalization**.[29,65] The ideological construct of individual responsibility **serves to mask the essential, unpaid and unrecognized nature of the work that is entrusted to caregivers**. Moreover, failing to consider caregiving as a public health issue can undermine caregivers' ability to recognize their rights.[25]

However, caregiving is not simply a private relationship between someone who provides care to someone who needs it: above all, it is a relationship between caregivers, care recipients and society as a whole.[26,81] Several authors argue that a **cultural shift** regarding paid and unpaid work is needed in order **to move caregiving out of the private sphere** and **recognize that unpaid work** (such as caregiving) **benefits not only the care recipient, but also society at large**.[26,25,28,80] This shift must certainly be reflected in the social and political organization of care and services. But it must also resonate in society overall through a **broadened participation in the support for individuals with disabilities** — for example, the involvement of extended family, neighbours, the community, non-governmental organizations, non-caregivers, employers, and government bodies at every level.[64,67,82] A better distribution of caregiving responsibilities would reduce pressure on caregivers, lower the risk of their being used or exploited, and ease their sense of obligation.

5

HOW DO ETHICAL ISSUES MANIFEST AMONG DIFFERENT CAREGIVER GROUPS?

Since recognition and self-recognition manifest differently among certain caregiver groups, this section addresses the ethical issues specific to young caregivers, 2SLGBTQIA+ communities, and ethnocultural or immigrant communities.

HOW DO ETHICAL ISSUES MANIFEST AMONG DIFFERENT CAREGIVER GROUPS?

5.1 - Young caregivers

For a young person, being recognized as a caregiver can result in social stigma. In fact, many young people who provide physical or emotional support to a parent will seek to downplay their caregiving responsibilities to avoid judgment.[22,44] Some will even go as far as to try and conceal their caregiving role from friends, hesitating to invite them over, which can lead to social withdrawal and isolation.[44]

Stigma can also arise through association. Young caregivers of individuals with disabilities, especially those caring for a parent with a more stigmatized condition like a mental health issue, can face social disapproval and negative reactions simply by virtue of their proximity.[39] Parents who experience stigma themselves may also hesitate to discuss their condition or seek support, fearing that their children will be stigmatized by association.[17,40] When a care recipient (parent) wants their young carer to conceal their role, it can create tension within the caregiving dyad, since the young person's needs are left unacknowledged.[17]

Young caregivers are therefore less likely to self-identify as such due to fear: of stigma, of discrimination, and/or of intervention from child protection services.[39] In the latter case, they may fear being removed from the family home if their caregiving role is discovered.[83] Still, depending on their age, caregiving is often all that the young person has known. Within the family structure, it is seen as a normal and expected part of life, rather than a specific role with defined responsibilities. In such circumstances, self-recognition is rare, if not impossible.[45] A further reason young caregivers can go unrecognized by professionals relates to the relative lack of knowledge about this particular group of carers.[21] As a result, they remain invisible, which negatively impacts their access to support services.[22,39,42,44]

When it comes to the sense of obligation, young caregivers often don't have the luxury of choosing whether or not to care for a family member. Indeed, it can be a matter of survival — for instance, when the care recipient is a parent. As a result, most young caregivers take on the role out of a sense of family duty and/or reciprocity.[17]

5.2 - Caregiving in 2SLGBTQIA+ communities

As mentioned previously, family plays a significant role in shaping the sense of obligation. Individuals who identify as 2SLGBTQIA+ are often designated as caregivers by their family, typically because they are unmarried or childless, and particularly when they have not come out to their family of origin.[6] A caregiver supporting someone from the 2SLGBTQIA+ community may also feel pressured into the role, knowing that the care recipient is isolated and no longer in touch with their own family.[84]

2SLGBTQIA+ caregivers frequently go unrecognized, including by:

- Professionals, since the caregiving relationships in these cases may extend beyond the biological family (friends, ex-partners, etc.), which can lead to their role being overlooked and their exclusion from decision-making.[46,85]
- Their biological family, who may not acknowledge the carer's relationship with the care recipient or to whom they have not come out.[46]

2SLGBTQIA+ caregivers are also less likely to identify as such due to the prevalent societal view that caregiving is only tied to biological connections.[6] An online survey conducted with adults across Quebec revealed that 39% of the general population believed that someone supporting a friend could not be considered a caregiver.[86]

This lack of recognition and the challenges of self-identifying as a caregiver contribute to the isolation and increased burden for caregivers from 2SLGBTQIA+ communities, who may also be reluctant to access caregiver support services for fear of judgment or discrimination.[46]

5.3 - Caregiving in cultural and immigrant communities

Caregivers from ethnocultural communities form an extremely diverse group made up of various sub-groups that differ significantly in their characteristics and traditions. Nonetheless, certain trends have been observed in the literature.

One such trend is the prominence of familism, a cultural value that is particularly strong in many ethnocultural groups, as well as in First Nations and Inuit communities and certain immigrant families.[29,73,87] Familism emphasizes the importance of family over individual interests, with a strong focus on dedication, reciprocity, intergenerational solidarity, and attachment to both immediate and extended family members.[79] These cultural norms shape caregiving decisions and motives by reinforcing the sense of duty.[88]

Robust networks of mutual obligation within the family can enhance the caregiver's psychological well-being and promote relational harmony.[89,90] Adhering to traditional values often provides individuals with clear expectations and a sense of acceptance regarding their caregiving responsibilities.[90] Family solidarity may also facilitate a more equitable distribution of caregiving tasks among family members.[90] Finally, caregiving, especially for elderly relatives, is often viewed as a sign of respect and a privilege, making it a source of pride within many ethnocultural and Indigenous communities.[29] Similarly, in some cultural contexts, strong religious and spiritual beliefs can help caregivers view their responsibilities more positively, promoting acceptance of the role and offering support in decision-making.[58,91]

However, traditional norms of family solidarity can be gradually eroded through the process of acculturation.[75] Immigrant caregivers who are more acculturated (e.g., second or third generation) are less likely to adhere to these cultural norms, which can result in a greater caregiving burden and heightened emotional distress.[75,90] Tensions may also arise with older family members if younger caregivers fail to meet traditional expectations.[90]

It is common for professionals to assume that caregivers and care recipients from an immigrant background will have strong family support, given the emphasis on family solidarity in certain ethnocultural groups. In reality, these caregivers are often isolated or struggling with financial insecurity.[92,93] Two aspects commonly associated with the migrant experience — namely, the fragmentation of family or social networks due to migration, and socio-economic instability — significantly increase the vulnerability of caregivers from immigrant communities.[14,29,75,92,93] As a result, the decision to take on the caregiving role is often influenced by limited social networks, compounded by a lack of affordable alternative services.[58]

That said, caregivers from ethnocultural and immigrant communities can have significant support needs.[14,58,75,89] Furthermore, it is not uncommon for immigrants to expect access to services for themselves or their care recipients when choosing Canada as their country of settlement.[73] Some individuals who are already established in Canada may even bring their care recipients over from their country of origin as part of a family reunification process in order to provide care for them.[58]

Despite this, caregivers from these communities have been observed to underuse the available services, for reasons that include the following:

- The desire to address problems privately, coupled with the shame associated with certain physical or mental disabilities.[75] Some conditions (e.g., mental health issues, ASD, dementia) are particularly prone to stigma within certain ethnocultural groups.[58]
- A lower likelihood of self-recognizing as caregivers. Research has shown that individuals from ethnocultural communities in Quebec are generally less likely to identify with this role.[58]
- The fear of exposing themselves to racism or discrimination.[75]
- Language and cultural barriers, lack of information on how to navigate services.[58,73,75,94]
- Reluctance to seek support if their immigration status is precarious or illegal.[75]
- Lack of flexibility in the services.[73]
- Lack of understanding or openness from professionals, practitioners and other workers.[58,94,95]

All of this calls for the health and social services system to enhance the availability and flexibility of primary care and social services, especially home services,[58] while ensuring a culturally appropriate and safe environment.[14,58,85,90] Such measures would help promote the well-being of caregivers from ethnocultural communities and/or immigrant backgrounds.

Caregivers in Indigenous communities

The sense of obligation experienced by Inuit and First Nations caregivers often arises from the lack of services in their communities. Consequently, they find themselves compensating for the gap, often at the expense of their own mental and physical health.[96] Indeed, with housing resources in Indigenous communities already limited, long-term care facilities are virtually nonexistent. Caregivers are therefore faced with the difficult choice of relocating their loved one to an outside community, often an unfamiliar and potentially culturally unsafe environment, or else intensifying their own burden as a family caregiver.[96]

6

CONCLUSION

CONCLUSION

This report on the state of knowledge aims to highlight the ethical implications surrounding the recognition and self-recognition of family and informal caregivers. Through a review of both grey and scientific literature and the insights provided by caregivers, it becomes evident that these concepts — while essential for supporting and valuing caregivers — can also generate unexpected consequences and raise ethical dilemmas. Specifically, reasons why some individuals may not self identify as caregivers were identified. In this context, it remains preferable not to pressure these individuals into identifying as such. The discussion also addressed issues arising from recognition and non-recognition, including invisibilization, stigmatization, formalization and professionalization.

Caregiving is largely considered a choice in our society. Therefore, it is essential to recognize the factors that hinder the expression of this choice in order to more effectively address the diverse needs of caregivers while respecting their autonomy.[26] Equally crucial is exploring how both structural factors (e.g., instrumentalization and partnership) and individual factors (e.g., the roles played by family, professionals, and the caregivers themselves) contribute to the sense of obligation felt by caregivers.

Lastly, the specific challenges faced by youth, 2SLGBTQIA+ communities and ethnocultural communities were examined. These groups encounter unique challenges related to recognition and self-recognition. Addressing them separately is one way to begin addressing the diversity of their experiences and needs.

Throughout the text, guidelines for professionals have been provided to help update current practices related to recognition and self-recognition, with the ultimate aim of better supporting caregivers in their role.

7

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info@observatoireprocheaidance.ca

observatoireprocheaidance.ca

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