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The Social and Interpersonal Dimensions of Measuring Loss of Autonomy:
Expectations among Family Caregivers and Home Care Social Workers in Québec

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Cette thèse intitulée:
The Social and Interpersonal Dimensions of
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RÉSUMÉ

Problématique: Le nombre croissant de personnes âgées, confrontées à des changements de santé physiques et cognitifs entraînant une perte d'autonomie, nécessite de la part des professionnels de la santé, un processus d'évaluation inclusif et efficace afin de s'assurer que ces personnes en perte d’autonomie reçoivent un soutien et des services appropriés. Pendant l’évaluation, la présence du proche aidant est un élément important qui pourrait influencer ses résultats. On sait peu de choses sur la manière dont les attentes, dans les services de santé publics du Québec, peuvent influencer le processus d'évaluation et les résultats. L'objectif de cette étude est donc d'explorer le concept des attentes tant du point des proches aidants, des travailleurs sociaux à domicile que de l’établissement de santé. Sous ce triple perspectif et dans le contexte de l’évaluation de la perte d’autonomie, l’exploration des attentes de chacun des acteurs est réalisée par l’entremise de services de soins à domicile (OEMC) du Québec.

Méthodologie: Afin d’étudier et d’explorer le phénomène de la perte d’autonomie des personnes âgées dans une perspective à la fois micro et macro, une méthodologie ethnographique ciblée a été utilisée afin de collecter les données. Ensuite, la notion d’autonomie a fait l’objet d’une analyse approfondie en vue d’une compréhension interdisciplinaire affinée. Pour ce faire, des entretiens individuels ont été menés avec des travailleurs sociaux d’un CIUSSS de Montréal, des aidants familiaux ainsi qu'un collectif de discussion composé de plusieurs soignants. En dernier lieu, afin de refléter les attentes des différents acteurs en présence, dans le contexte du système de santé actuel, articles et publications sur les réorganisations systémiques (selon les protocoles New Public Management et LEAN) ainsi que sur l’impact de l’environnement de travail des travailleurs sociaux professionnels, ont été consultés.

Résultats: Les résultats ont montré que les attentes des aidants familiaux, en matière de services et de soutien pour les bénéficiaires de soins, sont influencées par le processus d'évaluation proprement dit. De même, les résultats montrent qu'il existe des frontières floues entre leurs attentes concernant le service et les besoins des membres âgés de leur famille. En outre, les travailleurs sociaux se trouvent parfois piégés entre les pressions et les attentes qu'exigent le rendement et la productivité de l'organisation tout autant que leurs propres attentes à l'égard des membres aidants de la famille, qui deviendront eux-mêmes de futurs clients.

Conclusion: Les résultats de cette étude démontrent que l'interaction des différentes attentes, mises en évidence à travers les perspectives susmentionnées, crée un environnement de frustration et d'espérances déçues de la part des travailleurs sociaux et des aidants familiaux. Le climat de travail actuel dans le système de soins de santé public du Québec, qui se traduit par des contraintes budgétaires par un manque de cohérence dans la fourniture de services et de soutiens à la clientèle âgée, influence considérablement cette perception d'attentes non rencontrées. De ce fait, les impératifs administratifs influent de plus en plus sur la relation de service, contribuant à une certaine « clientélisation » des aidants familiaux.

Mots-clés: Soins de santé, travailleurs sociaux, personnes âgées, vieillissement, autonomie, perte d'autonomie, aidants naturels, instruments d'évaluation, attentes, nouveau gestion public, austérité

ABSTRACT

Problematic: The ever-increasing numbers of older people experiencing physical and cognitive health changes leading to loss of autonomy requires an inclusive and efficient assessment process from healthcare professionals to ensure they are receiving proper support and services. The presence of the family caregiver during the assessment is an important element that could influence its results. In public healthcare services, little is known about how expectations can influence the assessment process and outcome. The objective of this study is to explore the concept of expectations in the context of loss of autonomy assessment (OEMC) through Québec homecare services from the triadic perspective of the family caregivers, homecare social workers and the institution.

Methodology: To study this phenomenon, a variety of data-gathering techniques were employed using a reflexive, focused ethnographic methodology that explored this notion from a macro and a micro perspective. An extensive literature review examined the notion of autonomy to gain an in-depth understanding of its interdisciplinary meaning, individual interviews were conducted with social workers working at a Montreal CIUSSS and family caregivers as well as a discussion group with a group of caregivers. Also, to provide the context of the current healthcare system, articles and publications on the systemic reorganizations according to New Public Management and LEAN protocols and the corresponding effect on the working environment of professional social workers are included as the third part of the triad of expectations.

Results: The results demonstrated that family caregiver's expectations for services and support for their care recipients are influenced by the assessment process itself and there are blurred boundaries between their expectations for service and the needs of their elderly family members. As well, social workers sometimes find themselves caught between the pressures and expectations of performance and productivity of the organization and their own expectations of family members to provide care, until, the caregivers themselves become clients in their own right.

Conclusion: The results of this study demonstrates that the interaction of expectations from the three above-mentioned perspectives creates an environment of frustration and unmet expectations on the part of social workers and family caregivers. This is also influenced by the current working environment in the public health care system that is reflected in budget constraints and the inconsistency in the provision of services and supports to consumers. This phenomenon can contribute to the ‘clientization’ of family caregivers wherein administrative imperatives increasingly influence the service relationship.

Key words: Healthcare, social workers, elderly, aging, autonomy, loss of autonomy, caregivers, evaluation instruments, expectations, New Public Management, austerity

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List of abbreviations

AGGIR	Autonomie, gérontologie, groupes Iso-ressources
CESS	Centre expertise en santé Sherbrooke
CG	Caregiver
CIUSSS	Centre intégré universitaire de la santé et des services sociaux
CREGES	Centre de recherche et expertise en gérontologie sociale
FIM	Functional independence measure
Inter-RAI	International resident assessment instrument
ISQ	Institut de la statistique du Québec
MDS-RAI	Minimum data set - Resident assessment instrument
MSSS	Ministère de la santé et des services sociaux
OCCI	Outil de cheminement clinique informatisé
OEMC	Outil d'évaluation multi clientèle
OTSTCFQ	Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec
PRISMA	Programme de recherche sur l'intégration des services pour le maintien de l'autonomie
SAPA	Soutien aux personnes en perte d'autonomie
SW	Social worker

CONCEPTUAL DEFINITIONS

Caregiver: A family member, often a spouse or a son or daughter who provides care and support to an elderly family member.

Expectation: An expectation is “a strong belief that something will happen or be the case.” (Oxford dictionary) The term ‘expectancy’ in social psychology, is defined as: “the state of hoping or thinking that something, especially something good will happen.”

Health Care System: The organizational body, in Québec known as the health and social services ministry, which regulates care and services for all the population.

Homecare: Support and services to the elderly offered by local CLSC’s to help maintain their autonomy in their homes.

Loss of autonomy: Defined for the purpose of this thesis as the state of being of someone who has been referred to home care services for an evaluation of their need for care and support services. Most often considered as loss of functional autonomy, however, the evaluation process also takes into account psychosocial autonomy.

New Public Management: New Public Management is a set of assumptions and value statements about how public sector organizations should be designed, organized and managed and how in a quasi-business manner, they should function.

OEMC: The validated 27 page questionnaire created by the health and social services ministry that is used to assess clients in home care services. It includes a section on functional autonomy from which the data is entered into a computer which subsequently produces and *Iso-SMAF* score between 1 and 14 that indicates the degree of functional autonomy loss in the person. It also includes a psychosocial section that is completed by the social worker but the results are not integrated into the score.

Social Worker: A person who has a university degree in social work and who is a member of the professional order of social workers.

IN GRATITUDE

Getting older, of course, is the only game in town. It is really a very interesting process.
My friend [Irving] Layton called it 'the inescapable lousiness of growing old,' but I don't know
if I subscribe to this. I think it takes about 65 years to find your way around the block.
Leonard Cohen, 1934-2016

I am extremely grateful and thankful for all of the people who encouraged and supported me throughout this extremely fulfilling and satisfying process. My husband, family and friends were wonderful in their positive words and in convincing me that I wasn't crazy for pursuing this long-held dream. The wonderful team at CREGES: the director Patrik Marier; the coordinators, Julie Beauchamp, Maya Cerdes, Gabrielle Legendre; the administrative assistants, Virginie Tuboeuf and Stephane Pavrette, a team of research assistants as well as the librarian, Muriel Gueriton, offered a great deal of technical support and research advice that helped me through the process. Also, I am very appreciative of the SAPA team at the CIUSSS West-Central Montreal who were very enthusiastic and supportive of my endeavour.

Last, but certainly not least, I must express my lasting appreciation and admiration for my research director Annette Leibing. She was the person who started me on this journey just by simply asking me "Why not do it?" Annette has vast knowledge of the field of gerontology and research but she still had outstanding patience with my fumbling efforts at constructing a viable research project and was always ready with encouragement and support. She has continuously offered extremely helpful advice and endless editing and corrections to my text. I will be forever grateful to her for opening the door and giving me the opportunity to embark on this journey.

PREFACE

I can honestly state that I never imagined embarking on the journey of writing a doctoral thesis, especially at a time when I'm closer to the end of my working career than the beginning. However, one of my guiding principles has always been to keep an open spirit and seize opportunities when they are offered, particularly when they coincide with my core values of learning, engagement and benevolence. So, when events aligned that would allow me to pursue a doctorate and that also intersected with my working projects, I found the temptation impossible to resist. Thus, this doctoral thesis grew organically from my tasks as a researcher/practitioner in the *Centre for research and expertise in social gerontology (CREGES)* and, as well, has its origins in practice, intervention and homecare services to the elderly in the *Soutien à l'autonomie des personnes agées* (*(Support to Older People in Loss of Autonomy)* (SAPA) program of the CIUSSS west-central Montreal.

The second area of my professional responsibility that inspired this thesis was related to family caregivers. Over a period of ten years ending in 2015, I ran weekly and bi-weekly psychosocial support groups for family caregivers, as well as a monthly group for couples who are dealing with Parkinson disease. My role with the groups was to provide direct psychosocial intervention and information to caregivers and throughout the years I learned a great deal about their challenges and how they manage them. One frequently recurring topic of discussion for the group members was related to their unmet expectations about what they thought they should receive from home care in contrast to what was actually provided. It appeared to me that they had a lot of misinformation and misunderstanding about how the system works which was causing them a great deal of stress. Conversations with homecare colleagues supported my impression and it became even more complex when I realized that my colleagues and the healthcare system also had expectations of the family caregivers in providing care to their relatives. An exploration of the literature revealed some journal articles on the topic of what is expected of caregivers but practically none on what caregivers expectations are for support and services. Also, how expectations are formed and how they may intersect with health professionals expectations and perhaps influence homecare intervention and assessment was mostly absent from the literature.

I realized then that this area of intervention and homecare services to the elderly was largely unexplored and that developing knowledge in this area had the potential of having an influence on practice and intervention with elderly clients and their families during assessment. Although initially I wanted to include the elderly person as well in the interviews about expectations, I learned very quickly that these types of questions can provoke distress in those with cognitive impairment, so the idea was put aside for the moment. Instead, I made a decision to include a macro perspective that would include systemic healthcare reorganizations and how that has created another layer of expectations. That is, managerial and procedural expectations on social workers. Further study could add the important dimension of elderly clients expectations to the data provided here. It was in this way that my thesis, which appeared to be relevant and rooted in practice and intervention with the elderly experiencing loss of autonomy, became viable.

1. INTRODUCTION

By 2031, it is predicted that the number of people over sixty-five years of age in Québec will represent 25.2 percent of the total population and 28.5 percent by 2061 (*Ministère de la famille*, 2018). Since those who are over sixty-five are the heaviest consumers of health and social services and Québec is considered one of the fastest aging places in Canada (Institut de la statistique du Québec (ISQ) 2018), it is expected that the need for health and social services will also continue to grow as the population ages (Canadian Medical Association, 2013). Alarmist predictions describing the phenomenon as an "aging tsunami" that will produce an "economic and social burden" often reinforce a negative perception of the elderly and their role in society (Charpentier, Guberman, Billette, Lavoie, Grenier, A., & Olazabal, 2010). Much of the aging discourse centres on the topic of loss of autonomy in the elderly as regards to mental and physical health-related deterioration and its relationship to health service provision. Caregiving literature also highlights how their increasing dependence will impact family members who provide care. For instance, in Québec, over 80% of the care to the aging population is provided by the elders' families, who are themselves members of the baby boom generation (Van Pevenage, Freitas, Marier, Orzeck, 2018). In fact, the reality of population aging forecasts that the required needs for health and support services to maintain autonomy will also continue to greatly increase (Conseil du statut de la femme, 2018).

This thesis is about loss of autonomy assessment among older people in the public healthcare system in Québec. It is the result of a growing concern related to my own work as a psychosocial practitioner who worked for 19 years in an Integrated University Centre for Health and Social Services (CIUSSS) in Montreal. In the course of my work, the centrality of the question of loss of autonomy of older people, its assessment and the provision of care in the public system raised a number of doubts over the years – doubts I wanted to study and better understand in the milieu of public homecare practices with the elderly population and family caregivers (commonly called SAPA or *soutien à l'autonomie des personnes âgées;* in English: support for the autonomy of older persons). My initial doubts were linked to several contradictions I found in the use of the OÉMC (*outil d'évaluation multiclientèle; in English: Multi-clientele Assessment Tool, MCAT*),[1] the central assessment tool in Québec[2] that while I myself did not apply, I had to consult on a regular basis in order to understand the situation of the caregivers of older people I was working with. Often, information was missing or only partly provided, and especially contextual, psycho-social data on the caregiver's situation was omitted. The completion of the psychosocial section was often inconsistent and incomplete, for instance, some sections had no answers at all or were indicated NA (not applicable), and were unreliable sources of information about the client. These problems could lead to unanticipated effects on the rationality and equity of service allocation, particularly when being transferred from one professional to another. Also, detailed information about the caregiver was rarely included, and this although caregivers play an important role in the maintenance of older people in the community (Hollander, Liu and Chappell, 2009). Since the central notion on which such an evaluation is based is autonomy, the absence of the caregiver is even more astonishing: something like autonomy could only be maintained by relying on (mostly unpaid and mostly female) caregivers' work without which, as Hollander et al. argue, current

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[1] Although there is an English translation for the OÉMC (Multi-clientele Assessment Tool, MCAT), in actual practice in Quebec the instrument is referred to by the acronym OÉMC, even by English speaking practitioners as well. So, in the interest of congruity, this acronym 'OÉMC' will be used throughout this document to refer to the assessment tool.

[2] The OÉMC will be described in more detail in the section on assessment tools and a copy (in French) is included in Annex 11.

health care systems would implode. The research project that led eventually to my doctoral studies began first as an exploratory pilot study.

1.1 THE PILOT STUDY

In 2013, as a way to better understand my initial feelings of incoherence regarding the OÉMC and the assessment of autonomy, I initiated a pilot project under the supervision of Annette Leibing that was financed by three small pilot project grants.[3] From the primary analysis of 32 OÉMC questionnaires, we determined that health professionals using this evaluation instrument frequently emphasize the importance of physical functionality over social criteria, and further, demonstrate a certain ambiguity towards complex social issues. For instance, verification with some health professionals revealed that certain questions are not even asked. This illustrates both the time constraints associated with conducting a relatively long questionnaire, but also, the preferences and priorities – perhaps even unconscious prejudices – of health care professionals (e.g., questions regarding sexuality are usually omitted).

This exploratory research was helpful because it confirmed some lack of consistency and even coherence in the completion of the OÉMC. When I spoke to colleagues about my concerns I heard a number of critical remarks, although the utility of a central assessment tool was also acknowledged. Many complained about the length of the evaluation process, the insufficiency of care and services that could be offered, even if the result of the evaluation indicated the need of more care, and the difficulty of capturing individual needs through the final scores (or "profiles")

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[3] The pilot project was subsidized through (1) 2013/2014 – CREGES (Centre de recherche et d'expertise en gérontologie sociale), Practice development grant (3 234$). Title: Measuring loss of autonomy in homecare practice. (2) 2014/2015 - A pilot grant by the IRSPUM (Institute de recherche en santé publique) (15 580$), Title: Measuring Loss of Autonomy – Ageing, Functionality, and the Politics of Care. (3) 2015-2016 - Comité VIES scientifique – fonds de démarrage (4 500$). Title: Measuring Loss of Autonomy: Ageing, Functionality and the Policies of Homecare Interventions in Québec.

of the OÉMC. However, probably the most important critique reflected a general feeling that the almost exclusive reliance on a standardized assessment tool had significantly changed social work as a profession. In fact, although I initially spoke to colleagues from different professions, I ultimately decided to focus in this study on social workers, since they complete most of the OÉMCs and had articulated the greatest amount of dissatisfaction regarding the tool. Social workers spoke a lot about the general working climate, particularly regarding the increased bureaucracy they encountered due to managerial and public policy protocols that they felt were valuing quantity over quality. Verification of this stance through a quick document review revealed that what is known as New Public Management (NPM) strategies and LEAN[4] protocols that had been successively implemented across the public health system over the previous decades had greatly impacted frontline workers (e.g. Harlow et al, 2013; Grenier, J., Bourque, M., Boucher, 2018; Grenier, J. & Bourque, M. 2016; Bourque, D. 2009; Fournier & Jobin, 2018; Parazelli & Rueland, 2017).

When it was decided that more research was needed in order to understand the assessment of loss of autonomy, we identified three major points that needed to be clarified to reach that goal: 1. What had happened in the Québec health and social care system in the last years; 2. The role assessment tools like the OÉMC play in this kind of system; and 3. The importance of autonomy, the central issue being evaluated. A fourth point was added after the analysis of first interviews and observations: the notion of expectations. In fact, social workers talked a lot about what was expected from them (by their supervisors and the "State"), but also what they expected from

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[4] Between 2012 and 2016 the MSSS introduced the LEAN approach, based on an industrial model, to all health and social services establishments. One analysis of the process stated the following: "*En raison de ses origines dans le monde industriel, l'approche LEAN peut facilement susciter de la méfiance, voire de l'hostilité, tant chez le personnel que les représentants syndicaux"* (Berthilette et al, 2017).

caregivers in terms of care work; further, caregivers I interviewed expressed their expectations regarding the care they wished their older family members (and sometimes themselves) should receive. This complex assemblage of expectations eventually became the central issue of this thesis. The pilot study and its results are described in more detail in Chapter 7.

1.2 OBJECTIVES OF THIS STUDY AND RESEARCH QUESTIONS

The general objective of this study is to understand what is at stake concerning the assessment of loss of autonomy of older people in Quebec. More specifically, I would like to understand the centrality of an assessment tool like the OÉMC in current landscapes of care, the importance of autonomy within the health care system and, especially for evaluating needs of older people, and, finally, understand the different expectations involved in the process of evaluation.

1.2.1 Research Objectives

1. To better understand the assessment process of loss of autonomy in elderly homecare clients, its origins and how it is understood and defined through the perspective of the social worker, family caregivers and the public health system.

2. To explore the expectations of different social actors involved in the evaluation process by juxtaposing the following perspectives and to determine how these sometimes conflicting positions can influence the negotiation for care of the elderly client and their potential impact on service delivery:

   a) Social workers perspectives and expectation of the caregiver's role in caring for an elderly relative;

   b) The expectations of support and services harboured by family caregivers of the elderly.

c) The performance norms and expectations imposed on social workers.

Although the perspective of the evaluated older people themselves would have provided another important data set, I had to abandon this initially planned part of the research project because the majority of these persons were too fragile for interviews and time and granting resources were too limited for longer, observational studies.

1.2.2 Research questions

How does the conjunction of these three diverse expectations, 1) family caregiver's for services and support , 2) social workers of caregivers, and, 3) professional performance expectations of social workers as dictated by the healthcare system, influence the standardized assessment of loss of autonomy of elderly home care clients and how does the assessment influence expectations?

- Which role does autonomy play in the process of evaluating older people's loss of autonomy?
- Which role do assessment tools such as the OÉMC play in current landscapes of care?

In the following section, I will explain the theoretical stance taken in this thesis. This theoretical framework is tightly linked to the literature review that will deepen the four points mentioned above. This part will be followed by the description of the methodological approach helping me to understand the assessment of loss of autonomy in Québec. The presentation of the results from the empirical part of my study will be completed by a final discussion of my findings.

1.3. CONCEPTUAL FRAMEWORK AND THE POSITIONING OF THE RESEARCHER

The following discussion of the four ultimately interrelated points established above result in my conceptual framework that could be described as a problematization of assessing loss of autonomy.

However, I do not provide a classical Foucauldian study or problematization of my topic. Although I rely on some principles of this kind of approach – such as a partial de-familiarization of common knowledge – my objective is ultimately to understand the studied phenomenon on the interpersonal level that is more in line with my professional interests in more applied casework. This thesis then provides a hybrid gaze on the problem being studied that stems predominantly from social psychology, although my intention is to equally provide a first critical reflection on the topic. For instance, in the following problem-oriented literature review, the discussion on autonomy is more in line with a critical analysis of a central concept. The discussion of expectations, on the other hand, provides a gaze on this concept that is founded on insights stemming from social psychology.

It would not be possible to elaborate on the concepts described and the complexity of the topics in this thesis by relying solely on literary sources and research within one discipline, an interdisciplinary perspective is required. Loss of autonomy in the elderly, assessment utilizing a standardized instrument, social worker distress and dissatisfaction, the responsibilization of family caregivers by the State, and the interaction of expectations, are diverse topics that represent the key issues contained in this thesis. Therefore, I rely on literature from several disciplines, such as social work, anthropology, sociology, psychology, bioethics and (critical) gerontology.

The adoption of the OÉMC occurred at a critical moment and within the specific kind of governance without which the impact of the assessment tool could be only understood. As well, much social work literature of recent years paints a bleak picture of the impact on social workers of the introduction of New Public Management and neo-liberal policies that promote LEAN management protocols (Grenier, J. et al, 2016; Bourque, D., 2009; Harlow, 2013; Dustin, 2007).These authors state recent health policies have severely and negatively affected social workers ability to perform their interventions in the humanistic tradition of their professions, of which now almost 68 percent is related to client assessment and other administrative tasks (Delli-Colli et al, 2013). As regards to family care and support of the elderly, much literature in Social Gerontology on ‘caregiver issues’ highlights how the transfer of responsibility from the state to the private for care of the elderly has placed undue burden on families and individuals (Lavoie et al, 2013; Guberman & Lavoie, 2010; Beaulieu & Caron, 2000). By comparing and contrasting these perspectives from an interdisciplinary stance, it became possible to elaborate on the complexity and the multi-dimensionality of loss of autonomy as approached through a common standardized assessment tool.

The following four chapters present the results of the literature and document review. Chapter two presents the strategy for data collection followed by an overview of the concept of autonomy from an historical and interdisciplinary perspective. Chapter three presents the history and development of the OÉMC as well as other, similar tools used in other parts of the world. Chapter four traces the history of the Quebec healthcare system, focusing on how the years of reorganization have effected social services and the expectations placed on social workers in particular. Then, the literature review is finalized in the fifth chapter which offers an overview of expectations theories followed by a discussion on the notion of expectations and how it comes into play regarding caregiver’s expectations of social workers and the healthcare system, social workers expectations of family caregivers, and finally, stakeholder expectations regarding social workers as implanted into the current health and social system in Quebec.

2. PROBLEM-ORIENTED LITERATURE REVIEW: AN EXPLORATION OF THE NOTION OF 'AUTONOMY'

The literature review provided in this chapter and the following three was conducted in three stages: First – during the pilot project – a traditional literature review was conducted by searching common research motors (see below). Articles and other publications were first identified around five themes: assessment, autonomy, caregiving, social workers, and expectations. The results differed according to the discipline, but all had in common the overarching theme of aging and loss of autonomy. A large volume of articles was reviewed via their titles and abstracts and the first elimination of unrelated articles was followed by the imposition of further limitations or key word combinations to narrow down the amplitude of the results. Documents were eliminated for various reasons, such as, the study was not about the elderly or other aspects that were not relevant for the study. For example, in the case of the autonomy search, documents were eliminated if the study focused more on the geo-political aspects of autonomy and less on the health care system.

There is a vast field of research regarding caregiving and its related issues and the literature review produced an abundant number of articles. So, to narrow the field, articles that did not discuss caregiving to the elderly in the context of assessment and/or expectations were eliminated. In order to present a more macro perspective, since the themes reflected issues that are present in a global context as well, further literature research followed that broadened the horizons of the study to include publications by researchers in other areas of the world. Articles – in English or French - were selected according to relevance to the topic. The identifiers for the search focused on words appearing in the title and subject. A first read-through of the abstracts allowed for a more discerning assessment of relevance and a closer reading was done of the texts identified as most pertinent for the study. The principal key words that were combined in the literature search were autonomy, elderly, autonomy (loss of), assessment process (& tools or instruments), home care services (history, social work(ers), caregivers, expectations.

The search was conducted through the data banks accessible at the Université de Montréal through Maestro: for example, Ebscothost, OVID, Eric, and Medline. Google Scholar as well proved to be a very fruitful data source. Some exploration was done within selected Social Work, Health Care and Gerontological scientific journals, especially those deemed particularly relevant such as the Journals of Gerontology A & B, The Gerontologist, Age & Ageing, as well as the Canadian Social Work Review, The British Journal of Social Work, The Journal of Gerontological Social Work and the Journal of the Québec Order of Social Workers called Intervention.

Inclusion criteria: articles published between the years 2000 – 2018, with a few exceptions. For example, the development of assessment tools included articles published in 1980 and on since that was the time they were first investigated. The territory covered was Québec, Canada, USA, and Western Europe. If the article was frequently cited and the author was considered an authority on the subject it was also taken into consideration. The goal of the literature review was to determine the reason why loss of autonomy and in particular, functional autonomy, has become a keystone in assessment of the aging population. The review began with an initial scoping review of the literature using the above-mentioned search terms which led to the identification of some challenges. First, the notion of autonomy, especially when combined with other identifiers such as 'loss of,' & 'assessment' & 'elderly' as well as all of the appropriate synonyms for these words, showed that they can be conceptualized across many different disciplines.

The documents for the first review were chosen with the aim of presenting an interdisciplinary overview of the concept of autonomy, thus, preference was given to articles that discussed autonomy from several perspectives, in particular if they discussed the aging population.

An effort was also made to identify articles written within the last 10 years in order to reflect the reality of the aging population of today. However, tracing the evolution of the concept of autonomy made it necessary to go further back in dates regarding its origins. Also, some less recent documents were selected for the reason that they are frequently cited or the author is considered an authority on the subject (eg. Agich, Beauchamp, Dworkin, Ennuyer, Kant, Morin, E.). Figure 1 below offers a summary of the first literature review, the selection process and its justification:

Disciplines	**Justification**
Philosophy: 57 publications retained Authors e.g.: Barilan &Weintraub, Devisch, E. Morin, Ehrenberg, Sneddon.	Philosophy offers an overview of the concept of autonomy from its origins and how it has become such so important in western culture. Exploring the concept within this discipline also permits the laying of a foundation for this ubiquitous concept in order to trace its influence in other disciplines.
Bio-ethics: 19 publications retained Authors e.g.: Agich, Berke, Cole, Cowger, Dagneaux, Dworkin, Grenier. A.	Bio-ethics brings forward the important concept of informed consent and how it can be preserved and respected in older people when they are being assessed for loss of autonomy. Exploration within this discipline also allowed for the inclusion of the relationship of informed consent and dementia.
Social (and critical) Gerontology: 16 publications retained Authors e.g.: Ford, Rowe & Kahn, Biggs, Katz, Baltes & Baltes	Social gerontology research focuses on the social aspects of aging. Many publications have explored the idea of successful aging and its alternate definitions.
Public Policy: 32 publications retained Authors e.g.: Grenier, J., Bourque, D., Harlow E., Parazelli, M., Bellot, C.	Public policy instituted changes to how the healthcare system was organized following a marketplace model, New Public Management. This changed the way healthcare workers duties were organized and changed accountability.

Figure 1 Literature review process I

In the second stage of the literature review that was initiated after the pilot project and after the first interviews, we conducted a problem-oriented literature review, based on some principles stemming from an argumentative review (Markham 2014). Different from the first more common literature review, the objective here is to understand a more general problem, by deepening, in a more selective and focused way, previously established key notions (here, the four central concepts: autonomy, recent changes in the health care system, assessment tools and expectations) in line with the problem under study. In this sense, the literature review that follows merges with the conceptual framework – a separation that, as some scholars argue, is often based on an artificial separation in knowledge creation (Deane and Song 2015).

For the literature review that focused on the development of assessment tools 42 documents were selected for in-depth review. The final documents were either written by recognized experts in the area such as the Sherbrooke, Québec research team describing their process of OÉMC development, or were government documents, and/or opinion pieces. Through a continual process of snowballing (i.e. references of references) other documents were located that allowed for a broadening of the perspective to other countries and other disciplines that looked at assessment tools in a more critical, less applied way, such as sociology and education.

As well, in order to contextualize the study within the parameters of social worker's homecare assessment with the elderly that included the involvement of family caregivers, the literature review also explored documents that described the process, social worker/caregiver interaction and the current health and social services organizational climate in Québec and elsewhere. And finally, theories of expectations or expectancies and how they apply to healthcare services to the aging population was researched. Figure 2 below offers a brief overview of the main themes that were identified:

Primary search theme:	**Emerging themes:**
History and development of assessment tools: 42 documents retained Authors e.g.: Hébert (et al), Roy, Taylor, Seemator-Bagnoud, Ennuyer, Carrier	Population aging Deinstitutionalization Aging-in-place Functional autonomy Problematizing autonomy Loss of autonomy
Family caregivers: 16 documents retained Authors e.g.: Lavoie, Guberman, Wiles, Beaulieu, Canuel	'Partners' in care Untrained compensator role Merged-identities Burnout
Social work practice: 29 documents retained Authors e.g.: Bourque, D., Grenier, J., Harlow, Lavalette, Pelletier & Beaulieu	New public management Appreciation for the instrument Austerity Conflictual demands (organizational vs professional order)
Expectations (theory): 22 documents retained Authors e.g.: Bowman, Bowling, Janzen, Correll & Ridgeway, Sarkisian	Unrealistic expectations Communication Unmet expectations Adaptation

Figure 2 Literature review process II

The third stage of the process and after the analysis of the empirical part of this study – interviews and observations – the literature review was further refined, in order to add emerging points that before were not part of the initial literature review. The objective of this kind of literature review is primarily the contextualization and critical discussion of the four points that emerged from our first phase of thinking about the topic, including the pilot project. The search parameters included a range of publications within a variety of disciplines such as, public policy, healthcare, social services, social sciences and science and technology studies. The risk of becoming overwhelmed by the abundance of publications and the amplitude of information meant that key decisions had to continuously be made in order to keep this under control. For instance, when it was decided that it was important to elaborate in detail on the impact of healthcare reorganizations on social services and social work through the lens of 'expectations,' a decision was made keep the focus largely Québec-centric. However inevitably, documents were uncovered that detailed similar instances in other provinces and countries and some were retained because they provided an additional commentary or angle that enhanced the discussion.

Figure 3 below provides a summary of the articles that were ultimately retained. Please note that some articles appear in more than one category.

Title	Abstract	Abstract	Abstract
Theme (total articles retained)	+ key word	+ key word	+ key word
Expectations (44)	*+ Health(care) (16)*	*+ Social work(ers)(21)*	
Expectation theory (17)	*Expectation (STS)(7)*	*Expectation (Social science) (10)*	
Healthcare reform (25)	*+ New Public Management, LEAN, Austerity (39)*	*+ Social services (12)*	*+ Social Work (17)*

Figure 3 Literature review summary

2.1 AUTONOMY IN THE CONTEXT OF CARE

As a championed bioethical principle, a central tenet of Western healthcare models and an engrained ideal in many societies, the concept of autonomy has been influential in discourse throughout the biomedical, social and health sciences. Carrying the connotations of independence, self-determination and rational thought, the normative conception of autonomy is deeply rooted in a Western philosophical ethos of individualism. The historical pervasiveness of this concept throughout Western socio-political thought has rendered it a near taken for granted goal for many cultural institutions, including that of healthcare. In bioethical rights discourse, patient autonomy has become a dominant principle in guiding the doctor-patient relationship, and in the context of long term care and aging, respect for autonomy is considered paramount for maintaining dignity and demonstrating ‘success’ throughout the aging process. This is not to imply, however, that the concept of autonomy, and its contemporary applications in healthcare have been free of critique.

Indeed, much of the discourse surrounding autonomy has been subject to extensive debate from scholars spanning across the social and biomedical sciences. As an ethical concept and a cultural expression of independence, autonomy is one of the most ubiquitous and defended ideals in contemporary healthcare. Yet, in order to fully appreciate the status granted to the autonomy model in health sciences, and in turn, the critical discourse that now surrounds the autonomy paradigm, it bears first acknowledging the Western philosophical and historical foundations of this concept.

2.2 WESTERN PHILOSOPHICAL PERSPECTIVES ON AUTONOMY

According to Dryden (n.d.,'Autonomy'), early articulations of autonomy can be traced back to ancient Greek philosophers Plato and Aristotle, and their conceptions of rational souls and the ideals of human self-sufficiency (*autarkeia*). Rendtorff (2008) adds that for Aristotle, autonomy was intricately connected to an individual's ability to exercise unobstructed voluntary action, a definition that still is applicable today. While contemporary philosophical discourse may have dissenting opinions regarding the pre-Enlightenment origins of autonomy, the invention of 'the moral autonomy' in philosophical thought – and by extension, its subsequent adoption as a central tenet of twentieth century biomedical morality – is generally credited to the writings of Immanuel Kant (Schneewind 1998; Code 2000). Kant's (1724-1804) Enlightenment conceptions of autonomy was intricately connected to rationality and morality, and thus is often referred to as "moral autonomy".[5]

Importantly, as Tauber (2001: 304) reminds us, the Kantian articulation of autonomy was developed within the context of severe socio-political upheaval of Enlightenment Europe: this shifting political landscape included the erosion of the monarchical powers, the weakening of

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[5] For primary text refer to Kant et al. (2007).

religious authority, and the expansion of egalitarian ideals. According to Sneddon (2013) Kant proposed that people are free as long as they are rational – to have moral worth we must act out of respect for moral laws that stem from rational human nature. In the context of contemporary healthcare, Takala (2001: 74) asserts that a Kantian interpretation of autonomy would allow for the patient to make autonomous decisions regarding care but only to the extent that they are rational choices; failing to make a rational decision means, in effect, that the agent is no longer acting autonomously. The obvious conflict being, as Takala (2001: 74) points out, who is to decide what constitutes a rational health care decision?

As a subject of continual philosophical debate, any singular definition of the concept of autonomy is far from finding unanimous approval in contemporary discourse. Indeed, as articulated by Beauchamp and Childress (1994), autonomy has "acquired meanings as diverse as self-governance, liberty rights, privacy, individual choice, freedom of the will, causing one's behaviour, and being one's own person" (120). Given the range of conceptual interpretations, it is perhaps unsurprising that, as will be discussed in section III, autonomy continues to be subject to a variety of interdisciplinary critiques.

2.2.1 Historical perspectives: the emergence of autonomy in healthcare

While the patient autonomy model is arguably one of the most cherished (and debated) tenets of healthcare theory and practice, autonomy has not always been considered a taken-for-granted concept in the health sciences. Respect for autonomy emerged as a principle of bioethics in the twentieth century as a means to challenge the medical paradigms that had dominated since the Hippocratic tradition (Will 2011a; Beauchamp and Childress 1994): medical paternalism and the beneficence model.[6] In this section, I will provide a short cohesive historical foundation through which to examine how contemporary care models have adopted the concept of autonomy, as well as evaluating the *critical* voices of the autonomy concept, as addressed in the following sections.

2.2.2 Articulations of autonomy: the bioethics movement in context

The contemporary medical ethics movement was born in the socio-political context of the 1960s. In the intersection of rapid scientific and technological developments, and the growing pressure for social change from the counterculture movement, the authoritative role of the doctor began to be intensely challenged in the mid twentieth century (Beauchamp & Childress, 1994). In tracing the development of the autonomy doctrine in healthcare, many authors point to the slew of experimental atrocities exposed in the post-war era (WWII) as catalysts for igniting public discourse on *consent* in the context of health (Hoeyer and Hogle 2014; Will 2011b; Tauber 2001; Muller 1994). Commonly cited cases include: the publication of the Nuremberg code (1947);[7] Beecher's 1966 expose on unethical research occurring in postwar USA;[8] the Tuskagee Syphilis Study which took place in the United States during the 1940's in which almost four hundred African-American men were subjects of a Public Health Service study of the effects of syphilis over a period of forty years, but who had been denied treatment, including penicillin, which had become available midway through the study (Hunter, 2010). Autonomy, in the context of medical

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[6] Agich (2003:48) distinguishes between *beneficence*: "acting to benefit the other or pursue the other's well-being", and *paternalism*: "the imposition of a view of what constitutes the good for another against that other's own wishes".

[7] The first of the 10 ethical principles of the Nuremberg Code begins with the statement "The voluntary consent of the human subject is absolutely essential". (For complete Nuremberg Code, see: http://www.cirp.org/library/ethics/nuremberg/ references).

[8] Beecher's article, published in *The New England Journal of Medicine*, outlined 22 cases of research performed in the USA that occurred without patient consent. See Beecher (1966).

ethics, is primarily conceived of in terms of *informed consent*[9] and Agich (2003: 78) explains that informed consent "operationalizes the principle of autonomy in the medical care model" (78). To understand why choice and informed consent are conceptually coupled with autonomy in the Western medical paradigm, as well as to understand the implications of this association for contemporary care models, it is important to first examine the emergence of the principlist theoretical framework within medical ethics.

2.2.3 Principlism, autonomy and the informed consent doctrine

Principlism, or the ethical principles approach, is the conceptual framework most influential for shaping the development of contemporary medical ethics, as well as institutionalizing a normative measure of autonomy in healthcare (capacity for consent). One of the earliest examples of principlism is found in the drafting of the 1979 *Belmont Report* – a publication that would later serve as the legal foundation for government regulation of research involving human participants in the US (Wills 2011b: 1495). Authored by an interdisciplinary committee including lawyers and academics, as well as medical professionals, the Belmont Report explicitly measures autonomy through the practice of informed consent. The Belmont Report determines three basic ethical principles required for any research involving humans: [1] Respect for persons; [2] Beneficence; and [3] Justice (United States 1979).

In this context, autonomy is expressly conceived of in the liberal tradition of self-determination. The mechanism the Belmont Report concludes can best protect the principle of respect for persons (and thus, autonomy) is informed consent (US 1979: 10) – a measure now

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[9] Although the overwhelming majority of bioethical discourse maintains that the principle of autonomy forms the philosophical foundation of the informed consent doctrine, it should be noted that, in contrast to this conventional view, Taylor (2004) has argued that the ethical basis is not patient autonomy, but rather patient well-being.

considered the basis of the autonomy paradigm in healthcare (Beauchamp & Childress 1994: 128). As will be discussed in section III, the dominance of the principlist framework in contemporary health care models, and its individualistic conception of autonomy has received much critique from a range of disciplinary scholars. In her examination of anthropological contributions to the study of bioethics, Muller (1994) asserts that commitment to this interpretation of autonomy in healthcare has resulted in an altered conception of what constitutes the Western physician's moral responsibility: beneficence has been transformed into patient rights. However, as Sorell (2011) mentions when discussing principlism and telecare in the use of technology to monitor the elderly so they can live outside a care facility, autonomy and competence can only be *assumed* (orig. emphasis) to be in a cognitively normal range. Unger (2011) emphasizes that this tradition of principlism, particularly as articulated by Beauchamp and Childress, has had significant impact on the bioethical and medical climate of Canada. Indeed, Unger (2011) argues that as respect for autonomy is considered a "principle of primacy" to the Canadian public, and as our national narrative is premised on notions of inclusive pluralism and multiculturalism, a moral value that champions the free exercise of individual will is highly compatible with the Canadian ethos. Thus, Unger (2011) explains, Beauchamp and Childress' principle of autonomy – particularly as it relates to individual decision-making – has been highly influential in twentieth century Canadian legal, ethical and medical spheres.[10]

The intent of the following section is to outline the different ways the conventional conception of autonomy has been problematized both from scholars within the bioethical and

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[10] Unger (2011) explains that, in Canadian legal terms, "competence" is formally understood to be a legal *threshold* at which individuals are able to exercise autonomy over matters like health care decisions. This is contrasted with "capacity", which is a medical term that recognizes a degree of fluidity in an individual's ability to make autonomous decisions about their healthcare: capacity can change depending on circumstance, age, consciousness, etc. The assessment of one's capacity to give informed consent is largely left to the domain of the medical profession. Unger (2011emphasizes that "the view of the courts is that competence and capacity are assumed to be present and […] the burden is in proving they are not present, not in proving they are" ('Capacity to decide').

medical disciplines, as well as varied perspectives throughout the social sciences. This will form the basis for discussion in section IV, which looks specifically at how these critiques are applied in the context of aging and long-term care.

2.3 CRITIQUING AUTONOMY: DEBATES FROM THE BIOETHICS AND HEALTH SCIENCES LITERATURE

In their cutting critique of principlism, Clouser and Gert (1990) proclaim (while discussing the limitations of beneficence as a moral theory in medicine): "Autonomy would be an even better example, but its problems are so extensive as to deserve a separate article" (228). Clouser and Gert are certainly not alone in their dissatisfaction, and indeed, many authors have taken up their suggestion to expressly problematize the application of the autonomy concept within the health sciences.

2.3.1 Limitations of autonomy in practice

Some commentators do not reject the principlist moral framework in its entirety and instead offer modifications to the treatment of autonomy while still accepting the broader theoretical paradigm. Gordon (2011), for example, explores the limitations of the autonomy principle in the context of its presumed universality. Much critique, Gordon (2011) explains, has been directed towards Beauchamp and Childress' ethical model – particularly their conceptualization of autonomy and informed consent – because they premise their ideas on a theory of common, or universal morality.[11] In many non-Western contexts, however, autonomy is not conceived of in Western

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[11] As defined by Beauchamp and Childress (1994), the *common morality*: "comprises socially approved norms of human conduct. For example, it recognizes many legitimate and illegitimate forms of conduct that we capture by using the language of 'human rights'. The common morality is a social institution with a code of learnable norms.

terms of capacity for individual decision making and informed consent. Indeed, as Gordon (2011) explains, in some countries – he gives the example of China, Japan, and many African countries – family- or community- informed consent is valued above individualism. Gordon (2011) questions, therefore, whether cultural relativism functionally destabilizes the normative concept of 'autonomy' as individual informed consent. Rather than rejecting the four-principle approach,[12] however, Gordon (2011) contends that unlike Kantian ethics and Mill's utilitarianism, a revised *principlist* framework can in fact accommodate a theory of autonomy that allows for different specifications of the concept according to different cultural contexts. He concludes, therefore, that Beauchamp and Childress' framework can be used, with some modifications, "to bridge the gap between universalism and relativism" (Gordon 2011: 253).

Sneddon (2013) refers to autonomy as a 'threshold phenomenon': "*We go from having it to not having it on the basis of development (or loss) of certain capacities*." Dementia would be an example for the loss of such a capacity. Cloos (2017) has questioned how we define the limits of normal and pathological aging which transforms the cognitively impaired elderly into 'the other' through an 'Alzheimerization' process, a disease which he states is "*embedded in uncertainty*" and suffers from "*a paucity of social interventions and resources*." Dworkin wrote about the limits of personal autonomy and dignity in his text "*Autonomy and the Demented Self*" [13] (1986) where he asks the questions: "*Do the demented have a right to autonomy and dignity? How far do they have*

Like language and political constitutions, the common morality exists before we are instructed in its relevant rules and regulations." (6) Beauchamp and Childress use the common morality approach as a "starting point for ethical theory" (6).

[12] The four-principle approach (Beauchamp & Childress, 1994) to biomedical ethics points to respect for autonomy, beneficence, non-maleficence and justice as the norms that should guide moral agents working in the biosciences, and particularly in health care.

[13] The word "demented" has been reproduced in this text to respect the author's original wording. However, it should be noted that the word itself has gone out of favour in current usage because of the implied risk of defining the person as the 'negative-other,' reinforcing the divide between the "demented them' and the "healthy others." As Sabat et el, (2011) and Cloos, (2017) suggest, more current usage includes the reframing of the term to include the recognition of the diagnosed person's agency in the conduct of their day-to-day lives.

a right to make decisions for themselves that others feel are not in their best interests?" He raises the point that if a person, while still competent, declares in their legal documents that no life-prolonging treatment be provided, yet, if at some point they develop dementia and beg for this treatment, should it be provided? As he points out, others have argued that personal identity requires psychological continuity, so when a person becomes seriously demented and loses their connections of memory and personality, they cease to exist. Neither Cloos nor Dworkin agree with this position. Dworkin states that "*the competent and demented*[14] *stages of life are stages in a* *single* (original emphasis) *life*," and that personal identity survives dementia and their rights should be maintained. Cloos (2017) iterates that dementia should not be reduced to a biomedical phenomenon, but rather to "*recognize the person in their specificity and unity*." In this narrative, dementia sufferers are relegated to a distant fourth age that Biggs (2018) refers to as 'negative othering.' Or, as evidence of even more distance in discourse and thought from aging successfully with disability, Kontos (2003) and Kitwood (1997) allocate the blame for the powerful and subversive negative image of the person with dementia to the biomedical and reductionist understanding of the disease, in which the individual with dementia is perceived as less than human.

2.3.2 What about paternalism?

As has been demonstrated in the previous text, respect for patient autonomy is an important achievement in healthcare, but it too is not without its criticisms, although, its limitations have been less articulated. Among the numerous critiques of the autonomy paradigm in healthcare, some authors express concern that normative conceptions of autonomy are lacking certain

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[14] A more appropriate phrasing today would be "stages of life, both competent and with dementia."

favourable elements present in alternative care models. One area that has garnered much debate in this regard is the extent to which there exists a place for paternalism in contemporary healthcare. Some authors – like Caplan (2014) and McCullough (2010) – categorically claim there is. For Caplan (2014), autonomy is, in practice, a fragile concept that is easily undermined by illness. In the context of healthcare, where an extreme asymmetry in medical expertise exists between the doctor and patient, Caplan (2014) believes there is a pressing need to return to "experience-based paternalism". Rather than perceiving the contemporary emphasis on autonomy as a form of patient liberation, Caplan (2014) views the trend as medicine eschewing professional responsibility: "*Whatever bioethics has sold as respect for autonomy is leaving too many competent and able patients and their surrogates unsure, guilty, bereft, floundering or angry*." (302) For McCullough (2010), the disciplinary shift from paternalism to the autonomy model renders what he calls the "de-professionalization" of medical ethics. Since the 1960's this paternalistic approach to patient care has been increasingly criticized and some have advised that a healthy approach to coping with illness should include the distribution of the means and responsibility amongst the total population (Illich, 2003/1974). Paternalism is seen in bioethics as an approach that favours the doctor's opinion and the notion that certain health decisions are best left in the hands of the health professionals. Considered a '*Doctor knows best'* doctrine it has been prevalent in health care for a great deal of time. In fact, paternalism in bioethics is considered in contrast to autonomy (Sjostrand, 2013). In the Hippocratic tradition it is believed that only the physicians have the skill and knowledge to know what would benefit their patients. Paternalism reflects courses of action that are assumed to be in the best interest of the person but can occur without or against that person's informed consent. However, in reality patients are not always as preoccupied with having a say in their treatment as with getting the best care. As Tauber (2001) states:

> *Patients, like individuals in other social roles allow themselves to fit into a structure in which they trust that their basic rights will be protected. By and large, they are far less concerned with their political or legal autonomy than with getting better*. (314)

Other authors grappling with the function of medical paternalism in healthcare are less emphatically decisive in their assertions. Sjostrand et al. (2013), for example, consider how certain normative interpretations of autonomy may in fact justify “paternalism in the name of autonomy”. The authors argue that despite usually being placed in contraposition to one another, autonomy and paternalism may not be antithetical concepts. To expand, Sjostrand et al. (2013) differentiate between two conceptualizations of autonomy: autonomy as a *value* versus autonomy as a *right*. If autonomy is to be conceived of in terms of rights language, respect for this right must be upheld regardless of time or context. However, if autonomy is understood to be a value, then the authors argue “it may be justifiable not to respect a person’s autonomous choice or action at one point if it leads to greater autonomy for that person overall” (Sjostrand et al. 2013: 713). The authors thus conclude that in some contexts, *weak paternalism* – paternalism directed towards patients deemed ‘less than autonomous’ – may be acceptable if it renders greater long-term promotion of autonomy. Of course, this interpretation of acceptable paternalism also carries with it the assumption that individuals have the ability to *return* to the normative ideals of autonomy, which in many scenarios – like aging, for example – is not a reality. Interestingly, not all scholars deem paternalism worthy of extensive debate within autonomy-centred discourse. From the perspective of Agich (2003), who examines autonomy in the context of old age and long-term care, paternalism is far less prevalent in practice than is ineffective communication.

2.4 PROBLEMATIZING THE AUTONOMY PARADIGM: CONTRIBUTIONS FROM THE SOCIAL SCIENCES

It should be evident from the previous discussion that despite the dogmatic influence of the autonomy principle in twentieth and twenty-first century healthcare paradigms, very little consensus has been reached regarding the application, interpretation and indeed relative value of the autonomy concept – even from scholars operating within the medical and bioethical communities. This is not to imply that autonomy has been immune to critique from scholars operating outside of these disciplines; and indeed, the concept has been subject to much debate within the social science literature – particularly that of anthropology and feminist studies. This section seeks to elucidate some of those critical perspectives.

2.4.1 Critiques from anthropology

The frailty and dependency of an aging population experiencing loss of autonomy and their place and continued role in western society has not been overlooked in the field of anthropology. Anthropologists began to study aging in the 1960s and 1970s, in part to disprove the reigning psychological and sociological theories of activity, disengagement and to combat myths and stereotypes of aging (Shield & Aronson, 2003; 28). The cross-cultural focus of anthropological inquiry also offers the contextual perspective by recognizing that decisions about care and illness are not made in isolation but are made in the context of everyday activities and social relationships (Muller, 1994). Anthropological research in aging has cast light on the aging process as a studied phenomenon and as an iterative socially-embedded process that requires adaptation to specific socio-cultural contexts (Perkinson & Solimeo, 2014). The contribution of anthropology to aging and autonomy discourse goes beyond theory-laden research; it allows elderly people to speak for themselves, it hears their "voice" (Shield & Aronson, 2003).

In the 1990's, with the move towards deinstitutionalization of the elderly and persons with disabilities, we find a corresponding increase in studies of aging-in-place[15] (Wiles et al, 2012; Leibing et al, 2016) or, supported independence (Hale et al, 2010). The notion of supporting autonomy in regards to care in the home from a relational perspective is described by Pols et al (2017). These authors, while discussing the limits of autonomy in regards to professional caregivers ideal of this concept, point out that while the notion of autonomy focuses attention on the rights of the individual to make autonomous choices, the individual himself or herself may not be good decision makers, thus, putting them at greater risk. The important notion of autonomy and risk-taking by the elderly is further discussed in a later section of this thesis.

Intersections between anthropology and normative conceptions of autonomy often fall within broader critiques of the Western bioethical field. Drawing on the methodological tools of fieldwork and ethnography, anthropologists (and sociologists) often emphasize a need for analyses of autonomy to be conducted with attention to reflexivity and cross-cultural analysis. Both Marshall (1992) and Muller (1994) have suggested that anthropological disciplinary strengths – including understanding the sociocultural determinants of morality, the multicultural character of bioethical dilemmas, and cultural pluralism – are especially critical to deepen understandings of biomedical theory and moral-political thought.

In the context of informed consent, Hoeyer and Hogle (2014) find – through a comprehensive review of the literature – that anthropological critique has been particularly helpful

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[15] Aging in place is a term used to describe a person living in the residence of their choice, for as long as they are able, as they age. This includes being able to have any services (or other support) they might need over time as their needs change. https://ageinplace.com/aging-in-place-basics/what-is-aging-in-place/

illuminating a paradox in what they call the "politics of intent": "*Taken as a whole, anthropological studies of informed consent illustrate an intriguing phenomenon: the consistent failure of informed consent to deliver on its promises does not seem to affect its appeal or political force*." (355) Hoeyer and Hogle (2014: 356) suggest that the resilience of the "politics of intent", or the informed consent doctrine, can be explained through its alignment with Western philosophical and political thought – particularly, as they explain, because the principle of autonomy is conceived in this context as "the very source of dignity and personhood" (356). Despite a long history of anthropologists critiquing notions of "*de-socialized human agency*" (Hoeyer & Hogle 2014: 354), the authors maintain that this entrenched conceptualization of personhood fuels ideological support for individualistic decision-making and consent models in healthcare, despite documented limitations.

Some scholars express resentment towards social science critiques – particularly anthropological – that characterize Western medical ethics as reductionist or ethnocentric. Turner (2008: 86), for example, challenges generalized notions that bioethical views on autonomy are necessarily universalist, and that "*bioethics is reducible to an ethos of 'individualism' or 'autonomy' concerned only with the patient-physician relationship and the promotion of respect for individual choice*". While of course generalizations of any discipline (bioethics included) rarely render meaningful insight or productive critique, social science analysis has irrefutably added nuance to the discourse concerning normative conceptualizations of autonomy. A particularly good example can found in Traphagan's (2013) ethnography *Rethinking Autonomy* where, through in-depth exploration into Japanese conceptions of socially embedded autonomy. Traphagan (2013) problematizes the deeply Western relationship between conceptions of autonomy and the self.

2.4.2 Critiques from feminist theory

In their collection of essays exploring feminist perspective on autonomy, Mackenzie and Stoljar (2000: 5-12) identify five major areas where feminist theorists have critiqued the autonomy concept: [1] *symbolic critiques* – the idea that the character ideal of the autonomous *man* informs mainstream moral theory; [2] *metaphysic critiques* – the claim that autonomy necessarily presupposes that agents are radically individualistic; [3] *care critiques* – the perspective that traditional conceptions of autonomy do not value historically female experiences as nurturers and caregivers; [4] *postmodern critiques* – the notion that autonomy is an "illusion of the Enlightenment conception of the subject" (11); and [5] *diversity critiques* – the perspective that individuals can be part of multiple groups that define autonomy in different ways, and thus have multiple, intersecting identities. While Mackenzie and Stoljar (2000) are adamant that feminist critiques have "*identified serious theoretical and political problems with some historical and contemporary conceptions of autonomy*" (3), they do believe feminism should not categorically reject the concept of individual autonomy. Indeed, Mackenzie and Stoljar (2000) maintain, "*the notion of autonomy is vital to feminist attempts to understand oppression, subjection, and agency*" (3). The authors therefore suggest, rather than abandoning the concept of individual autonomy, the task is to reconfigure the concept from a feminist perspective. The umbrella term given to feminist approaches to the autonomy concept is: *relational autonomy*.

There is no unified definition of relational autonomy in feminist discourse, and indeed the range of perspectives reflects the theoretical depth of the concept. What the varied interpretations of relational autonomy have in common, however, according to Mackenzie and Stoljar (2000), is the shared: "*conviction that persons are socially embedded and that agents' identities are formed* *within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity*." (4)

Central to the theory of relational autonomy is the acknowledgement that individuals are inextricably connected to other humans, socio-political institutions, socio-historical contexts, and all these factors have an impact on how decisions are made. As Sherwin (2008) articulates:

> *Feminists who have pursued the concept of relational autonomy provide an account whereby we can appreciate that autonomy is not achieved simply by choosing from among an array of options before us. It requires us to examine the types of options on offer and ask questions about how these have arisen and also about options that are not available or accessible.* (12)

Importantly, relational autonomy expands beyond the mere recognition of the individual situated in social context. Intrinsic to feminist relational autonomy is the explicit recognition – and rejection – of the structures of oppression that inform who can be identified as autonomous. As Mcleod and Sherwin (2000) explain, "*relational autonomy asks us to take into account the impact of social and political structures, <u>especially sexism and other forms of oppression</u>, on the lives and opportunities of individuals*" (260, emphasis added). Indeed, it is this that distinguishes relational autonomy from other theories like communitarianism, where the social self is also recognized.[16] As Barclay (2000: 67) asserts, because social relations are considered intrinsic to identity in communitarianism, there is also the tendency to view these identities and roles as immutable. For feminist relational theory, however, recognition of socially situated selves allows the opportunity to challenge these structures and identities. As expressed by Barclay (2000):

> *If women have lacked the skills and capacities, as well as the opportunity, to do certain things, such as exercise autonomy, this is not a natural fact about women but a consequence of social determination. The truth selves are socially determined carries with it a certain liberating potential. (67)*

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[16] For more on *communitarianism*, see Gauthier (2000).

As well as contributing to theoretical discourse, feminist relational autonomy is increasingly being recognized for its application in the healthcare context. Dodds (2000), for example, calls for the development of a 'feminist bioethics' that can contribute to an "*alternative conception of autonomy that more accurately reflects embodied existence and the "social context of health-care decision-making*" (218). Joseph, Tham and Letendre (2014) similarly assert the shift "from individual autonomy to relational autonomy in medical decision making invites new reflections on respecting personal dignity and autonomy" (182). For Wardrope (2015), a relational understanding of autonomy is critical in that it acknowledges how respect for autonomy extends beyond only the singular patient in a clinical encounter. Perhaps most significant for practitioners, is Cole et al.'s (2014) perspective that relational autonomy is especially important for challenging conventional notions of advocacy and autonomy in the context of nursing. Rather than simply assuming the role of patient advocate, Cole et al. (2014) argues, a relational autonomy approach would encourage care givers to acknowledge the patient's relational world: "*Within healthcare settings, the focus shifts from simply assessing whether patients have compromised autonomy and then taking on an advocacy role, to involving people who form part of the social context of patients in the decision-making processes*" (580). It is evident, therefore, that while normative conceptions of autonomy are being intensely challenged across multiple disciplines, many scholars do assert that modified interpretations of the concept remain to have value within the context of healthcare. In the following section, I will seek to ground some of the complexities of the autonomy debate by examining autonomy discourse in the specific context of aging.

2.5 AUTONOMY AND AGING: MAJOR THEMES AND CONVENTIONAL PERSPECTIVES

Given the high value of autonomy – often perceived as individualism, self-governance and capacity for rational decision making – within the socio-political, biomedical and ethical context of the West, it is not surprising that maintaining autonomy has also been invoked as a primary goal for the aging process (Becker 1994). Indeed much of the literature in gerontology, nursing and aging studies, among others has been devoted to finding mechanisms to institutionalize respect for autonomy in the context of aging and long-term care. Autonomy as independence is often considered intrinsic to *successful aging* (Ford et al. 2000; Rowe & Kahn 1997) – a now ubiquitous (albeit critiqued) concept in gerontology that, as Dillaway and Barnes (2009) explain, promotes measures of 'successful' aging in terms of productivity, independent activities of daily living (IADL), high cognitive and physical functioning, and social activity, among others. This expansive and influential articulation of autonomy for older people, has functionally rendered the maintenance of autonomy an unquestioned goal in normative conceptions of aging.

Modern conceptualizations and theories of successful aging have been predominant in social gerontology since it was first articulated by Rowe and Kahn (1997). Rowe and Khan's model, although it has been critiqued as a normative model that dictates the 'formula' to age well and diminishes a certain freedom in the elderly to take risks when they become incapacitated nevertheless, changed the way in which the aging process was viewed (Calasanti, 2016; Katz, 2015; Phelan et al, 2004; Stowe & Cooney, 2015). However, Stowe and Cooney (2015) criticize this model's sole focus on late adulthood as a point to make an assessment of an individual's "*successful aging*" while neglecting developmental processes and trajectories that could be found in a life course perspective, recommending instead taking a "*long view of aging*." Kahn (2002; 726) was not unaware of some of the shortcomings in his model, as he states:

> *The term successful aging may itself have the unintended effect of defining the majority of the elderly population as unsuccessful and therefore as failing. I believe that this problem, to the extent that it exists, reflects a characteristic of contemporary American culture rather than something intrinsic to the concept.*

Attempting to reconcile the notion of successful aging with those who develop dementia, other authors (Kitwood, 1997; Leibing, 2006, 2017; Lamb, 2014, 2017), write about 'personhood' as the presence of the person-within the person, whom we would be able to understand if we only learned to listen and read their signs. Lamb (2014) states that aging theories such as Baltes & Baltes SOC (selection, optimization & compensation) and Rowe & Kahn's successful aging, pay insufficient attention to, and acceptance of, the human realities of mortality and decline, and Katz (2015) highlights how in these theories the lifestyle choices of those living with disabilities are neglected. In fact, these theories have been castigated by critical gerontologists for several reasons, mostly related to the lack of recognition of the heterogeneity and diversity of the individual aging experience within these aging models. Kahn (2002; 726) however, stated that he feels these two models are complementary, rather than in contradictory because:

> *The Baltes and Baltes model emphasizes accepting age-determined decrements and doing the best you can with what you have.... . And the Rowe and Kahn model emphasizes what the individual can do to use, maintain and even improve what they have.*

Critical gerontologist Simon Biggs (2018) postulates that both narratives (successful and unsuccessful aging) can be connected to a form of aspirational reality, one positive and the other negative, linked through the hope generated by developments in bioscience., Lamb (2017), postulates that the prevailing successful aging models are in some ways counterproductive and lack acceptance of the human realities of mortality and decline. As she states "*According to the popular cultural narrative prevailing in North America, we each have the potential, and indeed, the moral and political obligation to make our own aging "successful…"*

Many studies have been conducted across the applied health sciences to examine how *greater* autonomy can factor into the aging process. For many authors, autonomy is considered to be requisite for care models promoting *dignity*: Black and Dobbs (2014), for example, found in their study on community-dwelling seniors' perceptions of dignity that "autonomy was the most prevalent theme that captured the meaning of dignity" (1301) in daily life. In this study, the authors determined that seniors themselves conceive of autonomy primarily in terms of "self-direction/self-choice" and "self-reliance/self-sufficiency" (Black & Dobbs 2014: 1301). Janlov et al. (2005) similarly found that for older people on the brink of requiring public help, the anticipated loss of autonomy – conceived of primarily as the inability to maintain daily tasks – was intricately bound to negative feelings of self-worth. The authors conclude, therefore, that health care professionals need a more holistic procedure for assessing needs that recognizes the psychological impact of the transitional phase, and caregivers should strive to empower seniors in to "make choices and strengthen their sense of autonomy" (335). In a similar vein, Johnson and Bibbo (2014) found that for older people transitioning into nursing homes in Midwestern USA, sense of autonomy, rather than physical space, informed the meaning of home, and "personal adjustment [to the nursing homes] seemed to be connected with finding a degree of autonomy" (62).

Discussions concerning autonomy throughout applied aging literature have also focused on: the importance of senior participation in decision-making (Lyttle and Ryan 2010), combatting health care provider paternalism (Tuckett 2006), the complexity of navigating autonomy in the caregiving relationship (Breitholtz et al. 2011), and how autonomy is linked to risk-taking in aging (MacLeod & Stadnyk 2015). This latter point, regarding autonomy and risk, highlights some hypocrisy inherent in the notion of respect for the elders' autonomy and how different perspectives of the definition of risk can influence how it is enacted. In fact, risk can be defined in different ways depending on the perspective of the person perceiving the risk. For instance, while the elderly person tends to relate to the biological dimension of risk as loss of identity, family caregivers tend to focus instead on the interpersonal impact of their elderly relative's risk-taking. In contrast, professional healthcare workers tend to emphasize the physical dimensions of risk and its negative consequences on the future of elderly person (Macleod & Stadnyk, 2015). This suggests the need for a reconceptualization of the notion of autonomy and risk regarding the elderly and 'successful aging' which will be further discussed in the following section.

While few would deny that maintaining autonomy, in some capacity, is deeply valued by many aging people, critics have problematized the tendency for narrow, normative interpretations of autonomy to be the primary indicators of 'success' in aging discourse. Indeed, in their review of recent literature concerning autonomy and residential care, Welford et al. (2010) determined that while there was seemingly no unified definition of autonomy in the literature, the term was consistently related to concepts of "freedom, independence, self-government and self-determination" (67) – characterizations that are very much a product of the Western liberal and bioethical traditions. As previous sections have illustrated, however, autonomy is a highly fluid and contextual concept that in practice, extends beyond the limited narrative of individualism. The following section will thus explore how conventional conceptions of autonomy have been challenged and reconceptualised in the context of aging and long-term care.

2.5.1 Re-conceptualising the concept of autonomy in aging discourse

The term 'loss of autonomy' when applied to the elderly can be misleading. It implies that the person has arrived at a certain decrepit and finite condition. Loss of autonomy in fact, is usually a gradual process that takes place over many years and it is very heterogeneous. It varies from person to person and the degree of deterioration is also experienced in different ways by each individual. Elderly people develop coping and adaptive strategies that should also be taken into account when conceptualizing the notions of autonomy and loss of autonomy. In fact, when they are asked about how well they are managing, many older people prefer to focus on their capacities, recognizing that although they may do things as quickly or efficiently as they did in the past, they are still getting along. Reconceptualising the concept of autonomy in aging discourse should include the older person's perspective, at any stage they are at. As the following text will reveal, even when a person has reached the stage where they need to enter an institution, some level of autonomy is still possible.

"Autonomy and long-term care are a remarkably paradoxical conjunction" (Agich 2003: 1) – these provocative opening words to Agich's (2003) extensive exploration into the ethics of autonomy in old age, illuminate the complexity intrinsic to any invocation of autonomy as a primary goal of aging.[17] While it may seem from this quotation, that Agich (2003) perceives autonomy to be conceptually incompatible within the context of older peoples care, the perspective he develops throughout his book is, in fact, quite the opposite. For Agich (2003), the paradox rests in the *liberal* conception of autonomy – which, as discussed, privileges ideals of robust independence – versus the realities of long term, which involve "individuals who need support and companionship, needs that seem inimical to this [autonomy] ideal" (1). Within this liberal medical paradigm, Agich (2003: 42) explains, those who are able-bodied, rational, and thus autonomous, are granted the right to make healthcare decisions; those who lack these traits of autonomy are subject to healthcare decisions made on their behalf – surrogate decision-making, or paternalism.

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[17] Agich (2003: 77) broadly defines *long term care* as "a diffuse set of phenomena ranging from various formal and informal in-home help services, professional home nursing care to institutional skilled nursing and medical care. Long term care is an extended family of practices rather than a single practice."

Rather than acknowledging the range of autonomous expression for older people, this model marks a clear delineation between those who are deemed to have autonomy, and those who have lost their autonomy.

Some questions have been raised as to whether autonomous elders even have the right to take risks or to make poor decisions regarding their health and related lifestyle behaviours. The healthy aging movement as exemplified in the World Health Organisation's Active Aging policy framework (WHO, 2002) has been influential in shaping a shift to 'active', 'healthy' or 'positive' aging strategies. Amyot (2012), also examined how aging can be regulated through social control, well-aging directives and risk reduction through the '*dictate of well-aging'* that tells people how to live in conformity with their age, placing the responsibility for their aging, health and well-being directly on their shoulders. Crawford (1980) had earlier referred to this as '*healthism*' which encourages people to take responsibility for their health and this approach has been implicated in the creation of health promotion messages that are abundant in today's media. More recently, this paternalistic approach was labeled by Simon Biggs (2018) as the '*process of age-imperialism'* a sort of age discrimination wherein the life priorities of other, more dominant age groups, or from extrinsic social and economic forces, are colonized to the aging population. This could be seen as one of the unfortunate side effects of the Rowe and Kahn successful aging paradigm; the unconscious creation of a class of people who age unsuccessfully, inherently suggesting that those who age in this way are at fault (Rubenstein & Medeiros, 2015, Kahn, 2002). Nevertheless, the promotion of physical health is a significant part of aging successfully and also supports the ideology of 'healthism.'

At first glance, healthism would appear to be a positive movement when one considers it as an approach that supports personal autonomy in health choices and behaviours, particularly for the elderly. However, critics (Stephens, 2016; Clarke & Bennett, 2012) point out that this creates a moral imperative that differentiates those who diligently follow the health dictates and are seen to be living virtuously from those who are unhealthy or indifferent to the prescription and are irresponsible or even to blame for their own illness. The focus of successful aging discourse is on the maintenance of health and avoidance of decline which fails to take into account normal health-related changes and losses that accompany the aging process (Stephens, 2016). Amyot (2012; 4) states that the "*the right to choose and the right to take risks is denied to the elderly, particularly if they have deficiencies and incapacities*." (my translation) In other words, an elderly person's individual autonomy comes into question.

Much of the problem with a bio-ethically-informed conception of autonomy, Agich (2003) argues, is that it is based on a medical model of acute, short-term care fundamentally at odds with long-term care and the associated realities of aging. Whereas the medical model of autonomy is primarily oriented towards situations of temporary crisis, in which medical beneficence is more often accepted because it is understood to be temporary – elders requiring long-term care are not living with curable conditions, and thus cannot return to 'normal' functioning (Agich 2003: 72). In the acute care model, the primary mechanism used to support patient autonomy, informed consent, functionally "involves presenting patients with an array of options that are discrete and readily understandable" (Agich 2003: 72). In contrast, as Agich (2003) explains, elder care often involves uncertainty, increased ambiguity over risks and benefits, and perhaps most significantly, may "involve multiple, overlapping physical, psychological, and social dimensions that cannot be readily conceptualized, much less managed, in strict medical terms" (72). Autonomy in the context of aging therefore involves a nuanced negotiation with a multiplicity of factors comprising the daily reality of an elder person – far beyond the realm of mere choice and consent. Indeed, as

Butterworth (2005) explains, consent in the context of long term care does not represent a singular event, but rather a "continuum of involvement". Agich (2003: 117) adds, that even if more choices are presented to an older person in attempt to respect their autonomy, autonomy is not necessarily enhanced if the choices are lacking in meaning for the older person. Therefore, as Agich (2003) espouses:

> *Respecting autonomy of persons in long term care entails a commitment to identifying and establishing the concrete conditions that encourage individuals to face adversity and threats to self that are the inevitable result of the chronic illnesses and functional deteriorations that bring elders to long term care in the first place. Respecting autonomy requires attending to those things that are truly and significantly meaningful and important for elders. (*123)

Another critique voiced by Agich (2003), and indeed echoed by scholars elsewhere (Dillaway and Byrnes 2009; Naue 2008), concerns the impact conventional narratives of autonomy have on framing dependence as a moral deficit. As Agich (2003) explains,

> *Because we culturally prize independence, it is natural to view dependence of any sort as a defect. This cultural attitude distorts our understanding of human development and our interdependent existence*. (103)

In the context of 'self-care', Naue (2008) finds the perquisite of 'independence' similarly problematic. She argues that although the self-care concept may appear empowering – as it encourages independent decision-making and personal health management – for those who do not fit this characterization of autonomy, it "*becomes an excluding practice*" (Naue 2008: 318). Through her article, Naue (2008) examines the complex impact these unattainable standards of independence can have on conceptions of personhood for older people with dementia. For Becker (1994), who used narrative interviews to explore how older people conceptualize their own autonomy, the ideals of autonomy espoused by gerontology do not reflect the spectrum of meanings attached to the concept by older people. Indeed, even in situations of increased impairment, Becker (1994) found that informants continued to adapt and alter their definition of autonomy, and thus continued to perceive themselves as autonomous despite falling outside the normative notions of autonomy. In their critique of normative conceptualizations and measurements of wellbeing in old age, Barnes et al. (2013) found, through interviews with older people, that many continue to “resist help because they have learned it is bad to be dependent” (489). This tendency is reflective of the previously mentioned ‘successful aging’ paradigm which, as Dillaway and Byrnes (2009) explain, was initiated to combat pejorative notions of aging, but has since contributed to a societal image where “older adults must remain active and fully productive members of society” (716).

Much of the critical discourse surrounding conventional interpretations of autonomy in aging seeks to illustrate how the human experience is inextricably linked to relationships, and thus autonomy must also be ‘relationally contextualized’. In fact, in their study of caring relationships and nursing home residents, Custers et al. (2012) found that out of relatedness, autonomy and competence, residents considered *relatedness* to be the most important need in care. In Hwang et al.’s (2006) study of senior’s perception of autonomy in a Taiwanese senior’s home, the authors found that access to social support was the major predictor of perceived autonomy. Relational approaches to autonomy are thus unsurprisingly becoming increasingly more prominent in discourse and advocacy literature concerning aging and long term care.

A final note before concluding is simply the reiteration that conceptions of autonomy in aging are infinitely diverse, and for some, exercising autonomy may not factor as a priority in the aging process. Citing O’Neil, Custer’s et al. (2012) reminds us that for some recipients of long term care “deciding for themselves [may be] a source of frustration and anxiety rather than a source of satisfaction and that many residents [in fact] want relief from the burden of autonomy” (324).

For others – in line with one of the critiques explored in the previous section – autonomy may be an important value, but not the *most* important value for aging. As an example, Chan and Pang (2007) found that for elders receiving long-term care in Hong Kong, although autonomy was considered important, the continued care of their family was much more central to conceptions of dignity in the aging process. Thus, it is clear from this critical examination of autonomy in context, that purely narrow definitions of individualist autonomy – born from the Western bioethical, liberal tradition – have little to offer in the complex landscape that is an aging person's lived reality. At the same time, it should be recognized that the extent to which the debate surrounding the concept continues to persist in aging discourse, indicates that autonomy is still a highly valued (albeit disputed) concept, and more inclusive conceptualizations of autonomy may very well render more ethical and holistic care for seniors.

Critics of the conventional autonomy paradigm have challenged, among other aspects, its perceived universality and embedded ethnocentrism, the lack of attention paid to the plurality of interpretations and expressions of autonomy, and an absence of sufficient theoretical acknowledgement of the social and relational contexts that inform how an individual's autonomy may be expressed. In the context of aging, the use of autonomy as a primary indicator of 'successful' aging has been widely critiqued for promoting ideals that do not accurately reflect, and in fact exclude, the lived reality of many people in the aging process. Furthermore, scholars have pointed to a dissonance that exists between the conventional biomedical understanding (and measurements) of autonomy, and the diverse ways in which older people perceive and conceptualize their own autonomous experience.

Despite growing critique towards the normative interpretations and applications of autonomy in health care generally, and more specifically in the context of aging, scholars do recognize that respect for autonomy is a deeply valued social concept that may be best modified rather than discarded. Critical scholars of autonomy, particularly in the context of aging discourse, have therefore called for a broad re-conceptualization of autonomy as it relates to caregiving and care receiving. In doing so, a view of autonomy may be developed that does not place dependency in antithesis to autonomy, that acknowledges the social context in which an individual is embedded, and that allows for meaningful recognition of the diversity of autonomous expression that exists in the context of everyday lives.

3. THEMATIC LITERATURE REVIEW I: ASSESSMENT TOOLS IN HEALTH CARE – THE SPECIFIC CASE OF THE OÉMC

The goal of this section is to respond to the general objective of this thesis, as stated in the introduction: “to understand what is at stake concerning the assessment of loss autonomy of older people in Quebec.” More specifically, I would like to understand the centrality of an assessment tool like the OÉMC in the current landscapes of care …” To achieve this objective a literature search was performed that traces the history of the instrument in Québec. A detailed description of the OÉMC itself is included as well as a critical analysis of assessments tools in general.

3.1 THE DATAFICATION OF HEALTH

If we follow Foucault’s observations regarding bio-politics (Foucault 1980), before the 18th century, the individual’s body and the life of the population were matters of indifference to authorities. Afterwards, and as Ewald (1990) argued in this regard, the interest of the individual body to authorities became increasingly linked to statistically normal behaviors – so that assessment scales also became important for health management. Assessment tools such as the OÉMC are part of a wider phenomenon that Ruckenstein and Schüll (2017) call “the datafication of health.” With this the authors describe the increasing accumulation of health-related data by governments, insurance companies and other interested institutions, including self-tracking devices of citizens considered responsible and health-conscious. This phenomenon has been described predominantly in richer societies that, although different regarding local health policies and welfare system, are confronted with an aging population, rising rates of chronic disease, unsustainable health care costs, and the retreat of social welfare. As Lock (1993: 371, quoted in Ruckenstein and Schüll 2017: 263) observes, this results in objectified bodies that get “*abstracted* *from real time, actual location, and social space*" – explaining, at least partly the repeated observation by social workers that the OÉMC often does not capture individual needs of older people they work with (see also Timmermann 2014).

Some scholars argue that Foucault's concept of surveillance does not capture the trend of datafication – they suggest rather that it should be called "dataveillance" (e.g., Van Dijck 2014). Rather than originating from a singular source positioned "above," dataveillance is distributed across multiple interested parties—in the case of health, including caregivers, insurance payers, pharmacies, data aggregator and analytics companies, and individuals who provide information (either wittingly or unwittingly). Another feature that distinguishes dataveillance from surveillance is its predictive purpose; its aim is not to "see" a specific behavior so much as to continuously track for emergent patterns (Ruckenstein and Schüll 2017: 265). However, Ruckenstein and Schüll also caution that looking at the datafication of health only as an oppressive instrument, will exclude aspects of agency and creative forms of including health data into people's lives (see also Leibing forthcoming), and that detailed, ethnographic studies would consider more nuanced accounts of leading with health data: Whereas a bio-medicalization framework tends to place a negative emphasis on the reductive, fragmenting, decontextualizing effects of quantification on selves, ethnographic studies show that self-quantification raises "*the expectation that citizens take play a more active role in caring for themselves […] replacing the notion that the state should care for the health of its citizens…*" "(Sharon 2017:101), instead, it involves a "situated objectivity" (Pantzar & Ruckenstein 2017) in which certain prior experiences, understandings, and shared expectations come to matter (Ruckenstein and Schüll 2017: 263).

The focus of the previous section on the datafication of health in which the person turns the medical gaze to themselves to digitally track progress towards their health goals is the ultimate ‘healthism’ perspective, even seen by some as promoting an ‘*extreme form of healthism and individualization*” (Sharon, 2017: 101). Self-tracking devices such as the Fitbit and the numerous smartphone and tablet Apps that monitor and track health conditions such as obesity and diabetes boast that they will “*transform the passive patient into the engaged consumer who takes ownership of his or her own health*” (Sharon, 2017, 97). However, as we will see in the following section, datafication of health based on algorithms in the context of elder’ assessment has been in place for some time. The electronic version of the OÉMC produces not only an Iso-SMAF score that determines eligibility for care and services, it is a powerful databank that enables researchers to conduct evidence-based research and managers to track health trends and develop innovative programming.

3.2 THE HISTORY OF THE OÉMC

> *Standardized assessments are systematic protocols used to gather information using well-defined standard elements and procedures, often yielding information about multiple domains of functioning and well-being. Standardized measures go a step beyond assessment to yield scores to describe various attributes of older people and their worlds*.
>
> (The Oxford Handbook of Social Work in Health and Aging, 2nd ed., 2016).

The OÉMC was developed in a climate of economic crisis and a ‘future vision’ that had begun to emerge in terms of aging. This was highlighted in the inverted ‘aging pyramid,’ that forecasted an increase in the number of elderly in the coming decades who would need healthcare services and who would “*need to be managed carefully and appropriately*” (Légaré, 2009). This is illustrated in the alarmist predictions that began as long ago as the 1960’s (Katz, 1992; Charpentier et al, 2010; Carrier & Légaré, 1993; Rosenberg, 2000) of the so-called "tsunami of old people" expected to overburden the health care system and younger generation as a reason for tightening of resources and is in fact, one rationale behind many of the subsequent healthcare reorganizations.

In the early nineteen-eighties, Dr. Réjean Hébert, at that time in Lévis, Québec and who would in 2004 become the Director of the Sherbrooke Research Centre on Aging, and then in 2012 the Québec Provincial Health Minister, was one of the early identifiers of the need to have an assessment instrument that could assess elders' loss of autonomy in a metronomic, quantifiable manner and from a global perspective. Hébert, although focusing primarily on loss of functional autonomy, stated in his early writings that the system already in existence placed too much emphasis on the geriatric or medical situation of the patient without taking into account the influence of other factors such as their social environment and available support (Hébert, Carrier, Bilodeau, 1984). Before the decision would be made to fully integrate any specific instrument and in order to determine if there was a real need for an integrated needs assessment instrument unique to Québec for people in loss of autonomy, a government advisory committee was created to closely analyze the situation (MSSS, 2000). Ultimately, after examining the already existing instruments and others in development elsewhere, the committee's recommendation was to proceed with province-wide implementation of the OÉMC for the following reasons:

> 1) A preliminary paper version created by the Hebert-led Sherbrooke research team[18] which could be computerized was already in use across Québec, and, according to this report there already had been a high degree of satisfaction with it;
>
> 2) Some other existing instruments, although considered excellent for determining the intensity of required services, were ultimately not selected because they did not take into

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[18] ©RSSS Montréal-Centre (Multiclientèle), 1994, revised in 2002. © Hébert, Carrier, Bilodeau, 1983 (SMAF) revised in 2002.

account how changes in a person can be connected to environmental factors or their social network (MSSS, 2002).

3) Other tools such as OACIS and the Canadian Inter-RAI were at that time newly developed and had not been tested in home care; and,

4) Ultimately, the question of copyright came into play and the committee decided there was a need to have a tool for which they would have control and the flexibility to make future adaptations or modifications as needed.

Hébert and the team he created at the Sherbrooke research centre thus became the developers of the revised and computerized *Outil d'évaluation multiclientèle* (OÉMC) now in implementation across the province of Québec.

Québec was not alone, during the 1980's other countries around the world were also creating the tools they needed to assess an aging population. For example, the Minimum Data Set - Resident Assessment Instrument (MDS-RAI) is used in the rest of Canada; the Functional Independence Measure (FIM) is used in the USA, UK, Sweden, & Japan; and the *Autonomie, Gérontologie, Groupe Iso-Ressources* (AGGIR) is commonly used in France. The commonality of all these instruments lies in the fact that they focus on measuring an older person's functional autonomy as it related to the activities of daily living (ADL's) and instrumental activities of daily living (IADL's) The one that is in use internationally by more than 30 countries is known as the Inter-RAI, which has many sub instruments that identify other aspects of loss of autonomy such as need for placements, etc. and that can be used in different situations such as in institutions, home care and communities. While the OÉMC is considered a global instrument used by all healthcare professionals that assesses both functional autonomy and the person's psychosocial situation, the inter-RAI is composed of separate questionnaires that can be administered by different healthcare professionals across different settings[19].

From 1983, the *système de mésure de l'autonomie fonctionnelle* (SMAF) was developed as part of the OÉMC in an '*effort to synthesize existing scales*' and the first published description of the instrument appeared in 1988. It also defines level of autonomy relative to access to three types of resources: individual (own capacities), social (status and network) and material (including environment and transportation). Other instruments have also been added: for instance, The PRISMA is a short 7 item questionnaire to help health care practitioners quickly identify need. In Québec, the SMAF has been integrated into *Outil d'évaluation multi-clientele* (OÉMC) since its adoption in 2002 by the Ministry of Health and Social Services. The OÉMC is used in all types of living environment for the evaluation of adults with temporary or permanent loss of autonomy, including the disabled. The SMAF tool has some modest success internationally and is now used in France, Switzerland, Belgium and Brazil. Critics of the SMAF mention that the classification of SMAF profiles do not correspond to individual characteristics but rather the most frequent characteristics of individuals in each group, meaning that the result does not necessarily reflect the individual but rather the group profile and the information within the algorithms are difficult to access (Seematter-Bagnoud, et al., 2012). To get a more precise picture of the individual, social workers and other health professionals must refer to the *Euclidian distance*[20] between the norms of standards and the results of their client. Other critiques mention that the tool itself is not well

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[19] A criticism that I have heard about this approach is from older people themselves who complain about a constant stream of different people coming to them with different questions, which they find confusing and disturbing.

[20] The Euclidean distance is a measure that indicates the similarity between two profiles and helps to verify that the person is in the correct profile (of 14). It is useful for verifying to what measure the characteristics of one individual is closer to or farther from others, on average, within the same profile. If the distance is greater than 5 it is recommended to go back to the assessment and look at other factors that may have influenced the result. *(Source: OÉMC training session documents, November 2015)*

adapted for use in institutions nor for those with handicaps (Rapport ORS Aquitaine, 2010). See Figure 4 below for a detailed description of the Iso-SMAF profiles.

THE 14 ISO-SMAF PROFILES ARE GROUPED INTO FOUR CATEGORIES:

Category 1 (Iso-SMAF profiles 1, 2 and 3): Predominant loss in instrumental activities of daily living (IADL).
Category 2 (Iso-SMAF profiles 4, 6 and 9): Predominant loss in mobility functions
Category 3 (Iso-SMAF profiles 5, 7, 8 and 10): Predominant loss in cognitive functions
Category 4 (Iso-SMAF Profiles 11, 12, 13 and 14): Serious mixed alterations

Iso-SMAF profiles are used to establish the profile of clients residing in establishments where residents have been assessed with the SMAF evaluation grid. They offer a way to estimate the required time of intervention on a collective level and to calculate an "index of burdensomeness of the clientele" which allows for comparing different environments (residential settings) or units of analysis.
Source: http://www.demarchesmaf.com/en/tools/iso_smaf_profiles/

Figure 4 The Iso-SMAF profiles

Three concepts, impairment, disability and handicap, first articulated by the World Health Organization as part of a three-level model of the individual and social effects of disease and trauma (1980), also comprise the basis of the SMAF. Impairment and disability are functional limitations that can lead to a person's restriction or lack of ability to perform and activity that can lead to a handicap if the disability is not compensated. In the assessment process, a handicap can be compensated by the person themselves, a family member, or resources that are supplied to them. Thus, the OÉMC in application, promotes a comprehensive approach to client assessment and is meant to assist and support practitioners and/or the multidisciplinary teams in translating requests into needs, matching needs with services and allocating available resources based on clientele requirements. The clinical advantages of this assessment tool includes the possibility of collecting the essential biopsychosocial data required to assess each case to determine the uncompensated needs of the client, as well as information on the expectations of the users and their families. There are also some organizational benefits such as the standardization of communication through the use of a common terminology and the avoidance of the multiplication of assessments using different tools. As well, the use of this computerized instrument allows for the creation of databanks that assist manager's decisions in allocation of human, material and financial resources.

The OÉMC[21] that has been in use in Québec until very recently,[22] is 20 pages long and is divided into 3 sections containing 11 themes covering 58 areas related to autonomy assessment. The first section focuses on data gathering and includes questions about the clients' personal and family health history, physical and psychological health, current medications and any specific care or health services they may be receiving. It also covers questions about their lifestyle habits in relation to nutrition, economic conditions, sleep, smoking, drug and alcohol use, and leisure activities.

The second section is called the SMAF (*système de mésure de l'autonomie fonctionelle*) and the results of this part produces the 'score' on which the client's needs are identified and appropriate resources are allocated. This section allows the evaluator to measure the client's autonomy in reaction to the concepts of impairment, disability and handicap by assessing the their activities of daily living (ADL's), mobility, communication, mental functions and instrumental activities of daily living (IADL's). According to the training manual for the assessment tool,

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[21] A copy of the complete OÉMC is included in the Annex section of this document.

[22] A new assessment instrument, called the *Outil de cheminement clinique informatisé* (OCCI) or the Computerized-Integrated-Care-Pathway system (Dubuc et al, 2016), has been developed and is currently being disseminated throughout the province, with training sessions to be offered at all the health care centres during the Spring and Fall of 2018 and full provincial implementation is expected by 2019. This instrument has all the elements of the OÉMC but this electronic version is intended to be more user-friendly for the practitioners. A telephone conversation (March 27, 2018) with a health care manager who is familiar with the new version and who is organizing the training produced the following comment: "The OCCI is the new enhanced version of OÉMC that incorporates other, already existing tools such as PRISMA and the Social SMAF and the PSI. The new version is meant to be completed with the client being actively involved in the process and drop-down menus will propose additional questions to the health professional depending on the answers they get from the client and the caregiver. However, although the social-SMAF is included in the questions it does not modify the functional autonomy score and Social Workers will still be required to complete the additional Psychosocial Assessment as ordained by their professional Order." It should be noted that because the development and implementation is so recent this thesis will not explore the results of this new modification.

functional autonomy is briefly defined as "*A person's ability to independently go about their daily affairs*." It is considered that there is loss of functional autonomy whenever a person with physical or mental disabilities cannot overcome or compensate for those disabilities with the material and social resources at their disposal. People are evaluated on a scale of 0 to minus 2 with a score of 0 meaning they are fairly autonomous and minus 2 not autonomous at all.

The third section of the form completes the portrait of the clients living situation and overview of their life by evaluating their psychosocial situation. It covers the person's social history, family situation, social network and community resources that may be at their disposition as well as person's affective state, economic conditions and how they perceive their situation. Their physical environment is also assessed for cleanliness, safety, accessibility and proximity of services. Answers provided in this section are noted by the assessor but they are not taken into account in the Iso-SMAF score. The resulting client profiles are intended to support the decision-making process on an individual level but are not meant to replace the social workers clinical judgement. The profiles make the global needs of the client easier to recognize in order to put services in place. On a larger perspective, the profiles can also serve as analytical indicators for decision-makers to identify gaps in services in different regions of Québec and any needs for adjustments in budgetary allocations of resources. The Iso-SMAF profiles can also track the any changes in the client's needs and functional autonomy at subsequent re-evaluations.

3.3 A CRITICAL ANALYSIS OF STANDARDIZED ASSESSMENT INSTRUMENTS

The importance and need for assessment tools is without question, but some authors (e.g.,Lydahl, 2019; Marmol, 2016; Carrier et al, 2015; Dagneaux, 2007; Olaison & Cedersund, 2006) suggest it does not capture the multi-layered and complex reality of the evaluated individuals, while other critics suggest that the social aspect of the person being assessed and their families is neglected (Beaulieu & Caron, 2000). Harlow (2003: 35) further states that standardized assessment instruments impoverish a more complex evaluation: "*for social workers to undertake a questionnaire approach undermines their professional judgement and objectifies the person who is being assessed.*" However, this simplification is further aggravated by the fact that the OÉMC is a tool used by workers from several health profession disciplines, thus requiring a one size fits all generic assessment instrument, intended to be implemented by a variety of professionals in a multitude of contexts (Levasseur, Carrier, & Turcotte, 2016). The OÉMC, like any standardized instrument, becomes part of the client's permanent file and how it is completed in terms of accuracy, complexity and professional insight can guide further interventions. However, at times practitioners fail to complete sections of the form which is referred to as 'strategic information sharing' shaped by the demands of limited resources and high demands on services (White, Hall & Peckover, 2009). Interdisciplinary form completion can lead to incomplete assessments and become challenging for other members of the team in their interventions with elderly clients and can have a clear negative influence on outcome generation (Vanneste et al, 2015).

Gubrium (1989), a sociologist, in his writing highlights the disparity between the use of forms and questionnaires as a way of assessing patient needs and the potential barrier it creates for those in the helping professions such as social work to create a therapeutic relationship with their clients. As well, according to White, Hall & Peckover (2009), there is an organizational assumption made about forms; they are meant to standardize professional activity and ensure that everyone does everything in the same way and in the same amount of time, under the same set of circumstances. Gubrium (1989) questioned the use of standardized paperwork that he labeled '*people forms,'* the completion of which he referred to as '*bureaucratic tyranny*.' He felt that they "*become* *documented descriptions of clients 'in need*' and stated that they limit the description of the situation to what they are requested to document rather than what they know about the client. "*A form does not, in its own right, produce client needs, but at best, objectively conveys needs …*"

Gubrium (1989) proposes that standardized assessment questionnaires dictate "*unidimensional timing,"* which he describes as the need to complete forms (check boxes, progress notes or case notes) in the order and chronological manner of the form to reflect an issue or how an event happened. He comments that form completers must be creative in meeting chronological, stylistic and interpretive demands. As an example, during the pilot study for this research the creativity of some social workers was discovered when they described how in the electronic version of the OÉMC they could not advance in the questionnaire until something, even a symbol (*) was entered in the space. Thus, for Gubrium, successful form completion means social workers must be aware of and respect two things: 1) What sorts of descriptions the forms require that reflect the "*reportorial expectations assumed to underlie acceptable organization description*" (P, 197), and, 2) The creative, artful, rational and moral capacities required of form-completers using everyday moral judgement in an organizational context.

In Gubrium's more recent writing (2014, 2016), he discusses the increasing influence of administrative imperatives (2016; 5) on human service relationships and links assessment to the current bureaucratic environment that has developed with the "*rise of the welfare state and the rapid proliferation of human service professionals*" (2014; 5) comparing it to the "McDonaldization" of society (see, Ritzer 1993) and the abundance of regulatory processes. Other authors have also highlighted specific challenges of form completion in light of the current health care systems' frequent reorganization and restructuration and some controversy in the utilization of instruments, particularly for social workers. The use of standardized assessment grids to determine access to services is even viewed by some social workers as a renunciation of professional judgement which has the effect of forcing practitioners to become service *organizers* instead of service *providers* (Bourque, D., 2009; Carrier, Morin, P. & Garon, 2012). As a result, managerial and administrative expectations on social workers has created a working climate with a high employee turnover and increased absenteeism that has become difficult to manage (Grenier, J., Bourque, M., St-Amour, 2016; Bourque, D., 2009). Productivity is now measured by sophisticated information systems and professional acts are distributed and rationalized according to best practice and data gathering (Bourque, D., 2017). Carrying heavy caseloads, social workers, who act as case managers to their home care clients, now coordinate services to the elderly in what Carrier (2012) refers to as '*standby mode'*. That is, a safety net coordination system that although designed to compensate for deficiencies in service integration in home care risk management, nevertheless waits for the situation to deteriorate until the client requires more direct and instant intervention. One example is the case of family caregivers who are involved in the care of their elderly relative; they must wait for the caregiver to burnout before they can provide more support. Standardized assessment instruments such as the multi-clientele assessment instruments also support the standby mode which leads to the sharable electronic client chart (Carrier, 2012).

The usage of standardized tools has now become an integral part of healthcare services and they are always being adjusted and adapted to changing circumstances. In the last decade, because the OÉMC allows for the precise measurement of a person's functional autonomy, the results (ie. The quantitative Iso-SMAF scores) serve as the basis for following the natural evolution of their autonomy loss (Hébert, Raîche, Dubois, Gueye, Tousignant, 2012), but there is also a risk of reducing the person to a set of numbers that disregards their humanity. Dagneaux (2007) also acknowledges the usefulness of assessment instruments for estimating the workload and care resources for an elderly clientele, but she cautions that although concepts of autonomy, capacity, dependence and vulnerability are used in many situations, they are not always clearly defined. As Gubrium (1989; 213) states "*physically, forms are mere pieces of paper. Ostensibly, they ask fairly simple and straightforward questions of those completing them. But their simplicity belies demands on the experience and knowledge of those who complete them.*"

3.3.1 Clinical judgement versus a standardized instrument?

As was mentioned previously, the OCCI (*outil de cheminement clinique informatisé*), a revised version of the OÉMC assessment instrument, has been introduced in Québec in the past year, with full province-wide implementation to take place by the end of 2019. Its implementation as a replacement for the OÉMC has met with the protest that this instrument is placing professional clinical judgement as secondary to the results of a standardized instrument. Very recent publications in the media have shown that its reception amongst healthcare staff has not been enthusiastic. Although this thesis does not include the OCCI or a detailed analysis of both its and the OÉMC's content problems, some of the recent complaints bear noting since it does reflect similar comments that were made about the OÉMC. For instance, a report published online by Radio-Canada on November 5th 2018[23] on the implementation of the OCCI software mentions the excessive length of this questionnaire (described as 50 pages) and that it takes between two to six hours to complete. As well, it is only available electronically, so healthcare workers must bring the portable computer with them on home visits.[24] This report, which describes interviews with social workers mentions the rigidity of the instrument that forces the assessor to follow its order

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[23] "*Les algorithmes provoquent un malaise dans les services sociaux*" A. Touchette. https://ici.radio-canada.ca/nouvelle/1134036/soins-domicile-algorithmes-questionnaire-malaises-services-sociaux

[24] The topic of computers and health professional's use of them during home visits is discussed in more detail in a later section of this thesis.

and not the natural order of the interview they are having with the person being assessed. Others mentioned that they felt the instrument was compromising their clinical judgement. A survey administered by the APTS (*Alliance du personnel professional et technique de la santé et des services sociaux)* union which represents professional healthcare workers revealed that half of those who responded felt that the synthesis produced by this software program does not adequately reflect the needs of the clients being assessed and that it often made errors that contradicted their clinical judgement. For instance, as described in the afore-mentioned article, the algorithm results may indicate suicidal ideation or nutrition problems regarding the client, even when according to their clinical judgement, this was not the case. As a result, they would then be required to pass even more time on these cases to explain why they are disagreement with the algorithm in order to obtain the necessary services for the elderly person. Those interviewed complained that what they were able to achieve in the past during one home visit now required two or three. According to the APTS survey, 58% of the respondents needed two to four hours to complete the OCCI in the home and 7% needed another two to three hours to finish it at the office. On August 3rd, 2019 another article on the usage of the OCCI this time by nurses appeared in La Presse[25]. This article reports similar sentiments to the one previously discussed and also mentions nurses speaking of the absurdity of how the form dictates the questions to be asked that are not always relevant to the situation, but that they must take the time to ask them because of the way the questionnaire is organized. The author laments that the massive wave of nurses quitting homecare services are doing so because of the excessive bureaucracy of the OCCI, which she feels should be abolished in favour of health professional's clinical judgement, which she states is "*a thousand times more valuable.*"

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[25] *« OCCI », ce sigle toxique qui met en péril les soins à domicile »* E. Gaillardetz.

The next chapter continues the literature review by tracing the history of the Québec healthcare system with a focus on specific projects and commissions that have influenced the way it functions today. Although, the main objective of this thesis is not to do an in-depth analysis and critique of government policies per se, I feel it is important to present a summary overview of a system that has been in continuous reorganization for decades, placing it in the context of how these changes have affected the homecare practice of frontline social workers. Turgeon, Jacob & Denis (2011) who wrote about government reforms in the Québec healthcare system that have occurred over a fifty year time period, explain this process as follows: "*To understand a reform project we need to first know where it is coming from, in what context it is situated (political, economic, social and cultural) and how in its new context if it is closer to or further from those which preceded.*" (My translation)[26]

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[26] Original text: « Il faut examiner d'où on vient et dans quels contextes (politique, économique, social et culturel) se situe un projet de réforme pour le comprendre, saisir comment, dans un nouveau contexte, il se rapproche ou au contraire s'éloigne des réformes qui l'ont précédé. »

4. HISTORICAL REVIEW OF THE QUEBEC HEALTHCARE SYSTEM

4.1 INTRODUCTION

This chapter presents the results of a literature review that was undertaken with the goal of responding to the general research objective: *"... to understand the centrality of an assessment tool like the OÉMC in current landscapes of care, the importance of autonomy within the health care system and, especially for evaluating needs of older people…*" To meet to this objective and to develop a solid theoretical foundation for the subsequent study, we recognized that an exploration of how the healthcare system evolved into its current state and how expectations played a role was required. Two underlying issues that were identified during the pilot phase of this project guided the process: (1) that the notion of organizational 'expectations' resulting from decades of healthcare reorganization, has influenced Québec social services and social workers on a macro (systemic) level. And, (2) that expectations, on a micro (interactive) level, in OÉMC assessment of the elderly experiencing loss of autonomy may influence the interaction of the social workers and the family caregivers, and potentially, the assessment itself. Thus, the analysis is divided in two parts. The first assumption, presented in this chapter, explores the healthcare system in Quebec, focusing in particular on the impact of specific reforms and the related underlying expectations placed on the social services system and on social workers. The second assumption, which explores the interaction of expectations during assessment will be presented in the next chapter and then will be further elaborated during the presentation of the analysis of the interviews.

4.1.1 Decades of commissions, reforms and reorganization

In Quebec, like in other parts of the world, healthcare can be viewed as an ever-changing, delicate balance between public expectations, medical knowledge, technological change, economic and human resources and political will. What makes the healthcare system in Quebec unique compared to other Canadian provinces and most European countries is the fact that social services have always been integrated in the delivery of health services (Grenier, J. & Bourque, M., 2014). Although, usually medical services are prioritized, and as a result social services often must take a backseat (Renaud, M. 1977; Roy, 1994, Bourque, D. 2009). The number of reforms over the last fifty years in Quebec that introduced an administrative system based on what is commonly called "New Public Management" and that has successively reduced public services, has also had a great impact on how social services are organized and distributed (see: Grenier, J. & Bourque M. 2014; Turgeon, Jacob & Denis (2011); Bourque D. 2009; and Parizelli & Ruelland, (2017) for a detailed analysis of this phenomenon). According to the Dictionary of Public Administration[27], "New Public Management" is a "model of public administration originally proposed by Christopher Hood in a 1991 article. It serves as an umbrella term that bridge American and British approaches." According to Gruening (2001) NPM stems from public choice theory and managerialism as a response to economic recession and tax revolts. In Quebec, it was introduced about twenty years ago (Larivière, 2005; 1), as response to a *"classic administration style considered too hierarchical and subject to heavy processes*" (Grenier & Bourque, 2016; 10). NPM is driven by what is referred to as the 3D economic principles: *downsizing, devolution and defunding*, the basic principles of which can be summarized in the following five ways: (text summarized and translated from Grenier & Bourque, 2014; P. 11-12)

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[27] http://www.dictionnaire.enap.ca/dictionnaire/docs/definitions/definitions_anglais/new_management.pdf

1. Decentralization and fragmentation of decision-making: dedicated budgets are allocated to individual health and social services agencies (ASSS) who must, in turn, create public\private partnerships.

2. Horizontal coordination: highly controlled management of public "actors" who are considered "champions."

3. Competitive bidding: bidding wars for public funding encouraged between public organizations and community service organizations in a quasi-marketplace style.

4. Client-centered approach and quality control: service delivery is based on client satisfaction and managers become 'public agents" subject to performance measures. Clients are now "users"

5. Ensuring efficiency through performance measurement and results-based management: allows public administration to select objectives, measure performance and ensure efficiency in order to control costs through strict accountability.

In spite of decades of reform and reorganization, the healthcare system in present-day Québec is described by some as 'broken' and articles and reports in the media easily confirm this perception.[28] Recognizing that the education, experience and expertise required to do an in-depth analysis of public healthcare policy exceeds what is required for this particular thesis, I have elected to place a greater focus on several key documents that together, span over forty years of discussion and provided a comprehensive analysis of the reorganizations of the Quebec healthcare system from an historical, economic and social services perspective. As we shall see, criticisms of healthcare reforms are not a recent phenomenon.

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[28] An Internet search of "Système de santé Québec" produced these headlines over the last year from well-known Québecois news sources :
L'Actualité le juin 2019; "Dossier – 7 idées pour améliorer le système de santé du Québec. »
Le Devoir l1 avril 2019; « Un système de santé qui rend malade ses soignants. »
Montreal Gazette, October 2, 2018; "Québec election: Fixing a broken health-care system, a tough task."
Huffpost 17 mars 2018; « Le système de santé: pourquoi ça ne marche pas? »
These examples are selected randomly from many others. Overall, their verdict for possible causes point to: economics, over-bureaucratization, staff shortages, privatization, constant systemic reorganization, centralization (and decentralization), etc. The abundance of explanations serves as an illustration of the problem; a broken system that nevertheless, still keeps on 'working.'

4.2 THE EARLY YEARS - 1960'S & 1970'S

The post-war era in Québec saw the beginnings of the movement towards separation of church and state, the increase in population due to the baby-boom generation, the questioning of traditional values and economic and social upsets. Over forty years ago, Marc Renaud (1977), a health sociologist, expressed strong criticism of the manner in which Quebec had implemented early healthcare reforms by questioning whether it was really a reform or just an illusion of one, stating: *"The appearance of change is the best disguise for the perpetuation of the status quo*" (my translation) [29](128). Renaud provides an overview of the historical origins of the reorganizations and discusses the need for them, also comparing them to the rest of Canada. In 1965, with the announcement of health insurance programs by the Federal government, Quebec began, with the appointment of the Castonguay-Nepveu Commission (1966-1972) to examine the implementation of healthcare changes in Quebec and the transfer of care responsibility from the religious community to the welfare-state. The recommendations of this commission ultimately altered Québec's healthcare system by proposing universal healthcare and decentralisation of the healthcare system through the regionalization of services (Renaud, 1977). The three-tiered system proposed in this report included recommendations for the development of Regional health offices, local health centres and community health centres which were eventually put into place around 1971. According to Renaud, the "*hopes and expectations*" engendered by this report promised to democratize the health care sector and "*improve the health of the population*." (128)

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[29] Original text: "*Les apparences du changement constituent le meilleur masque pour la perpétuation du statu quo"* (128)

4.2.1 Social work practice

Meanwhile, in parallel to healthcare reorganization, during this time social work practice also became nationalized and social services became centred on the offer of services through the newly created local health centres (CLS) and community health centres (CSS) which later became known as CLSC's (Grenier, J. & Bourque M. 2014). As well, the practice of professional social worker became officially recognized with the creation of their professional order in 1974. Social workers however, also discovered that their expectations of professional autonomy to advance their casework practice in a traditional manner as they'd had in the CSS's had changed because questions were raised about the lack of oversight and supervision of this staff (Grenier, J. & Bourque, M., 2014). As we will see, further reorganizations and government policies that were integrated in later years sought to address this problem.

4.2.2 Introduction of the OÉMC

In terms of the OÉMC, around this time period as well, the first edition of the *outil d'évaluation multiclientèle* (OÉMC) which had a primary focus on functional autonomy of the elderly was created for use in healthcare services to assess, amongst others, the elderly clientele in homecare services. Hébert (1982), at this time recognizing the need for a multifunctional global assessment instrument, and in light of the projected increase in numbers of the aging population, described the four objectives of the first articulations of the OÉMC as follows: 1) Planning – the instrument would help managers and politicians understand population needs and gaps in services in order to create new programs and resources; 2) Placement – measuring autonomy could serve as a guide for effective and beneficial interventions and identify risk factors and incapacities; 3) Care – regular evaluation of the persons activities of daily living allows practitioners to oversee the clients capacities and avoid crisis; 4) Research – use of the instrument, Hébert felt, would allow for epidemiological studies and the testing of various hypothesis. In addition to acknowledging that an assessment instrument like the OÉMC evaluates the situation of the elderly patient, Hébert (1982) also mentions that appropriate care and assessment requires maintaining an equitable balance between an individual's resources and exterior resources. Which, from the perspective of today's healthcare system and how it functions, could certainly be seen as a precursor to the prudent healthcare management philosophy of public governance (NPM) that came later. As we shall see in the next section, with the integration of New Public Management strategies, whose objectives also focus on efficiency and cost-effectiveness, (Diefenbach, 2009) an instrument like the data-based OÉMC, became very useful for managers and decision-makers.

4.3 THE MIDDLE YEARS - 1980'S & 1990'S

Nineteen eighty-five saw the end of the reign of the Parti Québecois government which had been in power since 1976 and the arrival of a Liberal government and the creation of another health commission soon after. The Rochon commission (1988), driven by a vision of the future needs of an ever-increasing aging population that will place greater demands on the healthcare system, recommended a person-centered approach as opposed to an illness-centred one (Turgeon, Jacob, & Denis, 2011). This was a period of fiscal restraint and the search for the most efficient and cost-effective way to organize healthcare services continued, and with the increased inclusion of the community on health institution's boards of directors we see beginnings of the move of transfer of responsibility for care from the state to the community (Grenier, J. & Bourque M. (2014). Ultimately, a population approach to healthcare services based on the determinants of health and oriented around the needs of patients was also ultimately proposed by the Rochon commission

(Contandriopolous & Brousselle, 2010; 147). Although confronted with severe financial restraints, the succeeding government attempted to put these recommendations in place, helped by Jean Rochon himself, who by then had been named Health and Social Services Minister in 1995 (Turgeon et al, 2011). According to Grenier, J. & Bourque M. (2014), the Rochon commission report helps us understand the dichotomy of values in healthcare services reform since on the one hand it defends an accessible public system and on the other it proposes management strategies of accountability borrowed from the private sector: New Public Management (NPM). Bourque, D. (2009) states in his report that the subsequent influence of New Public Management brought notions of decentralization, accountability and responsibilization to the forefront, blending public and private sectors of healthcare.

This era, which was also driven by the afore-mentioned economic crisis had the effect of creating a parallel crisis within the welfare state (Turgeon et al, 2011). During this time, the prospect of accelerated aging and the burden it would place on services led to the shift of patients from institutional care to homecare (Roy, 1994). Called the outpatient shift (*virage ambulatoire*) this period also saw the closing of long-term care and hospital beds (1995) with the follow up care of this population now under the responsibility of homecare and community services.

The notion of supporting people in their homes was promoted as maintenance (*maintien à domicile)* which corresponded to ideas of individual autonomy and the distribution of care as a 'shared community responsibility' (Firbank, 2011). Firbank also mentions that when the outpatient shift from long term care to homecare services first began, the expectation was that this clientele would be relatively autonomous, because heavier cases would have already been hospitalized or institutionalized. However, as Contandriopolous & Brouselle,(2010) mention, it was soon discovered that the transfer of the responsibility for care from institutions to homecare had provoked a change in the ‘weight’ of the cases that frontline social workers were required to service. As well, deinstitutionalization and the transfer of responsibility to the community and the family for support and care had an enormous impact on the older population who, although preferring to remain in their homes as long as possible, never really fully received the services that would make this successful because the corresponding budgets that would allow this and the increase in support personnel never materialized (Contandriopoulos & Brousselle, 2010; Lavoie & Guberman, 1997).

4.3.1 Social work practice

During this period, because of the aforementioned transfer of the weight of cases from the institution to homecare, social workers were obliged to take on cases that would require more of their already thinly spread time. In an effort to counteract this phenomenon, employers began to narrow social workers’ mandates where they would retain the heavier cases and lighter ones would be transferred to allied fields or social assistance technicians (*Techniciennes en travail sociaux, TTS*) (Trocmé, 2016). In 1997, explained as an economic measure, the Québec government under Premier Lucien Bouchard of the Parti Québecois offered voluntary early retirement packages to healthcare workers and about 18 000 employees accepted the offer, twice as many as expected. This move ultimately backfired because the government then had to turn to private agencies for healthcare workers, at a much higher cost to replace them (Vaillancourt, 1991; in, Grenier J. & Bourque M., 2014). The ultimate impact on social workers, as mentioned by some authors (Bourque, D., 2009; Grenier J. & Bourque M., 2016; Grenier A. & Wong, 2010; Contandriopolous & Brousselle, 2010), was ultimately, a reduction in their own expectations of professional autonomy because of increased caseloads and heightened managerial expectations. For example, Grenier & Bourque (2014) in discussing working conditions in healthcare, mention social worker's concerns for rationalization of services and that the withdrawal from the social dimensions of care would result in an increase in the bio-medical aspects where social practitioners would be forced to become simply 'care-organizers' in this administrative, bureaucratic model (p. 85).

4.3.2 Computerization of the OÉMC/SMAF

During this era, the paper version of the OÉMC developed by Hébert et al. (1983), and which was already being used in homecare services in Québec, was also being converted to a computer-based program which would ultimately be implemented as the SMAF in 2002. The SMAF, as mentioned previously, is the part of the larger OÉMC that is codified, the results of which constitute the client's Iso-SMAF score. The introduction of a digitized version of the assessment was in line with the recommendations of the Rochon commission of "*applying the most recent innovations in computer networks to health information systems […] and the computerization of clinical data…*" (Contradriopolos & Brousselle, (2010). As well, it responded to one of the fundamental objectives of the NPM philosophy of '*increased efficiency, cost-effectiveness and productivity as defined and measured in functional and technological terms'* (Diefenbach, 2009). Because, not only does computerized form completion, and its results, indicate the health status of the elderly person, it can also frame the manner in which the form is completed, guide the assessment and track how much time the health professional takes to do it (see previous discussion re: Gubrium and 'people forms'). And, as discussed previously, would eventually lead to the standardization and datafication of health in elderly assessment (Ruckenstein & Schüll, 2017).

The technological challenges of data entry were met with some resistance from many health professionals, including social workers who had received their education during a time when computers were not so ubiquitous; they were uncomfortable with technology and thus were required to take additional, basic computer training. In addition, the move towards technology was considered by social service workers as a move away from the fundamental, humanistic interventions of their profession (Grenier & Bourque, 2016; Harlow, 2013; Parazelli & Ruelland, 2017). Social services departments in homecare in Quebec were thus being brought into the wave of NPM reforms that would signal for some the bureaucratization of social work practice, which Timmermans and Almeling (2009) have referred to as a weakness in the healthcare system because it depersonalizes care and replaces it with bureaucratic control.

4.4 THE LATER YEARS – 2000 TO TODAY

The early 2000's brought about a third wave of reforms that introduced a management philosophy based on private sector practices, performance indicators and including the public and private sector in the search for solutions (Turgeon, Jacob & Denis, 2011). During the early twenty-first century we began to hear more about the economic burden on homecare services the aging population will eventually place. The concepts of interdisciplinarity and partnership (with the community) began to be promoted.[30] Another commission, called the Clair Commission (2000) was created with a mandate to look at the economic situation in healthcare and access to services. Echoing the recommendations of previous commissions, this one proposed that the organization of primary care should be decentralized with a focus on population health and the creation family medicine groups (*groupes de medicine familiale, GMF*).

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[30] It was during this time that I began to work at the CLSC as a Community Organizer and I remember that one of my performance objectives related to the number of official "ententes" that I could create with community organizations. An entente, officially signed by the organization's Director and the CLSC Director, meant reaching an agreement with an organization that clearly outlined shared responsibilities, goals and evaluation strategies.

In 2003, the homecare policy of *'Chez soi, le premier choix'* (, in English: *Homecare is the First Choice)* was published, and was later criticised by the Quebec public curator because of disparities between territories in the offering of services to the population as well as lacking the necessary budget transfers from hospitals to the community that would have supported this move. Social workers and other health professionals began to be trained on LEAN management strategies that reflected the Clair commission's recommendations of the need for performance indicators such as quality, efficiency and accountability. LEAN is a set of operating philosophies and methods intended for public health organizations and that claims to create maximum value for patients by reducing waste and wait times.[31] First developed in 1988 by MIT's John Krafcik, the term refers to a combination of principles, tools and techniques that includes committed management and respect for people (Fournier & Jobin, 2017). LEAN was formally implemented in Québec in 2011 (Fournier & Jobin, 2017) to three healthcare organizations, followed by a second phase in 2014 in sixteen others which together, implicated more than thirty-five percent of the workers in the public healthcare system (Berthillette et al, 2017). However, the relationship between its implementation and improved performance has been much disputed (Fournier & Jobin, 2017). For instance, Joosten et al (2009), mention that business approaches like LEAN thinking, with their emphasis on standardization, neglect the sociotechnical aspects unique to healthcare, which risks interference with "*the delicate therapeutic process and potential increased work stress and burnout for professionals*" (p. 341). Fournier & Jobin (2017) studied the context of LEAN and its process in Quebec over a three year period and concluded that LEAN had encountered several problems in taking hold in the institutions and that managers and practitioners had experienced great difficulty in adapting it to their context. They suggest a better understanding of public

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[31] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4171573/

healthcare organizations could lead to more successful implementation. However, Berthillette et al (2017), in their analysis of its implementation in the nineteen establishments, take a more positive position by highlighting its significant contribution to improved access to services for the population and optimal utilization of resources. Although, they do acknowledge that the process did provoke a great deal of mistrust and hostility amongst the personnel and union representatives.

In 2007, with the election of a liberal minority government, it is finally acknowledged that despite all of the major reforms of the healthcare system and the massive injection of money since the beginning of the century, there were still a lot of problems, such as a health system still too centralized, trapped by micromanagement and still too oriented towards planning and performance indicators (Turgeon, Jacob & Denis, 2011; P. 78). Economic concerns still prevailed as well during this time and so the government once again appointed Claude Castonguay, the same person who put into place the major reforms of the 1960's, to examine the stubborn problems of the healthcare system that had still not been resolved, such as finances, access to care and governance of the system (Turgeon, Jacob & Denis, 2011). Castonguay's new report, released in 2008, recommended a 'new social contract' that included, again, decentralization of services and adjustment to New Public Management values. The number of private clinics during this period increased as well, privatization was introduced and another fusion of establishments was suggested. Further reduction of beds in CHSLDs took place, thus creating long waiting lists for those who required long term care. As another way of reducing costs, the number of hours of homecare services per day was lowered to three hours from the seven that had been offered previously (Bureau de protecteur de citoyen, 2012).

In 2012, the office of the *Bureau de protecteur de citoyen* published a report that outlined some of the inequities in homecare services that included criticisms of the disparities between regions on needs assessment. Particularly, the ceilings that were being placed on the number of hours of homecare to which people are entitled, as well as how the way services were being offered that did not really respond to homecare clients changing or increasing needs.

In 2014, the Liberal government of Premier Phillippe Couillard with Gaetan Barrette as health minister launched another reorganization. This time, what was referred to as a 'mega-fusion' of all healthcare organizations was created, merging all health institutions into the version to be called the CISSS or CIUSSS (*Centre intégre [universitaire*] *de santé et des services sociaux*) which grouped together CLSC's, CSSS's, hospitals, CHSLD's, rehabilitation centres and youth centres. One of the objectives announced of this massive reorganization of the health and social services was "*to facilitate access to services by removing inter-agency and cross-professional barriers to collaboration*" (Trocmé, 2016). However, from first-hand knowledge, I can say that the creation of these large centres and the decentralization of care, became challenging for staff who now found they had to use valuable time travelling between institutions on a daily basis.

4.4.1 Social work practice

The implementation of LEAN practices effected social work practice in a profound way (Grenier & Bourque, 2016). Performance indicators that were implemented during this time included a quota system on the number of homecare visits to clients per day, time limitations on completing assessments and the constant tracking of time spent on form completion and even telephone conversations with clients and their family members. During this time, the CLSC's were merged with other establishments in their territories in 2004 and became known as CSSS *(Centre de santé et des services sociaux)* and they were charged with creating a clinical and organization project, in partnership with the community. Reorganisation also occurred at the managerial level, creating a top-heavy system where healthcare workers went from having one supervisor to several.

Social workers also discovered that they had to manage increased time constraints that were initiated with introduction of LEAN policies, which meant more time spent on paperwork and less time spent with clients (Bourque, D. 2009; Grenier, J. & Bourque, M. 2014). In 2009, Law no. 21 -, which modifies professional codes in Quebec, was also passed by the government that included norms for social workers that now would require them to complete, in addition to the OÉMC, a psychosocial evaluation of all of their clients. This, in fact, became a point of contention for social workers who were already protesting the lack of time to complete their current assessments. This important point will be further elaborated in a later chapter that presents the results of the interviews with social workers.

In 2012, the professional order of social workers and family therapists in Québec (OTSTCFQ) created a committee, giving it the mandate to better understand the impact of all the changes and reorganizations of the healthcare system on the professional practice of social workers. This committee launched a survey amongst its members whose results exposed some of the stressors and discontent felt by these workers. In the first survey 61% of the respondents indicated that the last reform, the Couillard/Barrette one, had an enormous negative impact on their on their stress. A year later, in a follow-up survey, this number had risen to 74% (as reported in Grenier J. & Bourque, M. 2014) and a third survey a year later had a similar result. Some of the things frequently mentioned as contributing to this were, lack of employment stability, lack of clinical supervisory support, difficult work relations, lack of knowledge regarding internal changes such as frequently changing managers, time constraints, heavy caseloads and excess bureaucracy. The workers who responded to the surveys indicated that because of the reorganizations they often felt ill prepared and lacked the training to completely integrate the changes. Overall, the results indicated that the many changes that were executed over the years had resulted in poorly prepared managers who were unable to assume the leadership required to mobilize the personal in an ever growing climate of uncertainty (for a full report of these surveys see, Lariviere, 2010).

These issues were not only identified by the social services staff. In fact, in 2018 the *Fédération de la santé et des services sociaux* (FSSS-CSN), the union of the para-technical and administrative staff, published the results of a similar survey[32] sent to their members. The over 12 000 people who responded produced similar answers to the social services survey. They indicated their problems as overwork (80%), staff shortages (72%), lack of recognition (57%), and management issues (52%), amongst others. Almost seventy percent of those who answered the survey indicated that the workload was affecting the quality of the services, their personal relationships with their family members, delays in services to the population and a negative effects on their own health.

4.4.2 The OÉMC - OCCI

During the 2000's the OÉMC has continued to be tested and validated with the goal of continuous improvement. The SMAF technology was officially integrated in the programming in 2002 and training was offered to all healthcare workers (Tousignant et al, 2003). Other, questionnaires were developed and integrated: A shorter version for short term use (e.g. *Évaluation de l'autonomie clientele de soins courte terme, 2002*) which includes a condensed SMAF, and a paper PI (*Plan d'intervention et d'allocation des services, 2002*). Development of a social subscale of the SMAF

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[32] https://www.fsss.qc.ca/download/vpp/rsultats_sondage_surcharge_vf.pdf (25 p.) Downloaded June 6, 2019.

(Pinsonnault, 2003) was being explored as a response to criticisms that the social situation of the person being assessed was neglected. The six-item social-SMAF was ultimately developed and officially integrated in the assessment process however much later, in 2016. But it should be noted that the results of the social-SMAF are not integrated into the Iso-SMAF score. In 2009, the Québec government passed Law 21 in the National Assembly which modified the professional code of social workers. One important change was that the professional order (OTSCFQ) decreed that all social workers must also complete a psychosocial assessment of each of their clients in addition to the OÉMC. The problems and issues this raised for social workers in regards to their already time-constrained tasks will be discussed in more detail in a later section of this thesis. In 2018, the introduction of the previously mentioned OCCI began, first it was pilot tested in three different health regions of Québec and now it is being fully implemented across the province.

4.5 CONCLUSION

The previous section outlined a history of decades of reorganization and change in the healthcare system in Quebec. It would be logical to presume that each study, commission and subsequent reform implemented over the last decades were undertaken with the goal of improvement in how health services are offered to the population in the most efficient and cost-effective way. But, it appears the years of change and expectations placed on the professionals working in the system have created a climate of insecurity and employee dissatisfaction as I have documented. The following section will explore the concept of expectations, first by identifying how it is defined from several theoretical positions and disciplines and then from an interactive perspective: that of family caregivers of the healthcare system and social workers in particular and social workers of family caregivers.

5. THEMATIC LITERATURE REVIEW II: MULTIPLE EXPECTATIONS AND EXPECTATION THEORIES

5.1 DEFINING EXPECTATIONS

This section describes the theoretical underpinnings of several kinds of expectations that, as explained in the introduction to this thesis, emerged as a central issue early in the research process and especially during the interviews. Relying on what could be called 'expectation theories' will provide a framework that will enable me to respond to research objective (2) "*To explore the expectations of different social actors involved in the evaluation process by juxtaposing the following perspectives and to determine how these sometimes conflicting positions can influence the negotiation for care of the elderly client and their potential impact on service delivery*." Thus, the following section presents a basic understanding of the term 'expectations,' as well as an overview of how it is integrated within the specific scientific disciplines of social psychology and health psychology and how it can shape interpersonal exchanges.

The Mirriam-Webster dictionary defines 'expectations' as the act of expecting – anticipation, while the Cambridge dictionary places a positive slant on the word, "the feeling that good things are going to happen in the future." The Handbook of Social Psychology (1996) informs us that expectations are personal beliefs about the future that develop from a combination of a person's personal beliefs and knowledge. In social psychology, the term 'expectancy' is also used, stating; "*Every deliberate action we take rests on assumptions (expectancies) about how the world will operate/react in response to our action*." (Olsen et al, 1996; 211). Ozegovic et al (2012), writing about health expectations, states that to really understand health problems we must move beyond a simple biological approach towards a biopsychosocial one that also acknowledges how environmental, societal and interpersonal factors can be influenced by expectations and vice versa.

Defining expectations from a theoretical point of view and how they have been influential in developing theories is of course important. However, I consider it equally important to also define expectations from a person's point of view that is, in the case of this study, caregivers and social workers. During the preliminary phase of this study, while questioning both family caregivers and social workers on their opinion of the assessment process, the sentiments they expressed appeared to often reflect surprise that things had gone better (or worse) than they expected (in the case of caregivers). Or, when speaking to social workers we heard statements from them of frustration because the 'system' was expecting too much from them as well as expressions of disappointment in the family caregivers for not living up to their expectations. Because, taken-for-granted values and expectations have the potential of leading to 'fallacies of care' (Leibing, 2019). Fallacies, or mistaken ideas, while appearing to be based on logical commonly-held knowledge, expectations and beliefs, for example, "caregivers are willing and able to care for their aging relative" and "social workers can solve my problems" also "the healthcare system will provide the care I need" and finally, "the OÉMC will provide an accurate assessment of this person," can be fragile when put to the test of real-life situations. Linking the concept of expectations – in all of its potential permutations – mistaken, unrealistic, hopeful, manipulative, and so on – to the several theories – in order to understand the process of expectation development in a specific context – will allow us to isolate the processes which can lead to them and how they may play a potential role in the assessment process.

5.1.1 Expectation theories in the social and health sciences

The following section discusses how expectations are articulated in the wider fields of social psychology and health sciences which have been selected as relevant to this exploration. Social psychology, a field that Allport (1985: 5) defines as "*the scientific study of how people's thoughts, feelings and behaviors are influenced by the actual, imagined or implied presence of others*." I will focus on these fields, because my central aim is to explore the interaction among different social actors involved in the evaluation process. And in fact, Albert Bandura (1994), a respected scholar and social psychologist specialized in expectation studies, defines expectations as a "*motivational process influenced by one's beliefs in their self-efficacy*." (p. 4) He argues in what he terms "Expectancy-value theory" that, "*Motivation is regulated by the expectation that a given course of behavior will produce certain outcomes and the value of those outcomes*."[33] Thus, people act on their beliefs about what they can do, as well as on their beliefs about the likely outcomes of performance. However, human motivation scholars Ryan & Deci (2006: 1570), while agreeing with Bandura's view that self-efficacy is a necessary condition for understanding expectations as a motivation for action, disagree on the result it may produce: "*Yet the belief that one can successfully perform an action or control an outcome does not address why one acts*." For this reason, they state, Bandura's self-efficacy theory cannot differentiate alienated from autonomous actions or predict the consequences that follow from this action.

The concept of expectations has also been employed in other areas, such as in health research to understand the outcome of placebo effects (Olsen, Roese & Zanna, 1996), and in social psychology cognition studies as an element (expectancy) that can influence interaction (Holmes, 2002). The term 'expectation' is often mixed with other, related terms such as beliefs, hopes, prediction, and even attitudes. However, Ozegovic, Carroll & Holm (2012) speculate that the lack of definition and understanding of expectations may be due to its lack of a theoretical framework. The nature of expectations, as regards to human behaviours, are intrinsically oriented towards the

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[33] Source: http://www.des.emory.edu/mfp/BanEncy.html

future and can be linked to motivation theory and rewards (Baumann & Bonner, 2017; Bowling, 2013; Correll & Ridgeway, 2006; Lente, 2012, Ozegovic et al, 2012; Berger, Conner & Fisek, 1974). From social psychology (e.g., Ridgeway 1998, Wentzel et al. 2016, Berger et al. 2018) we learn that expectations can shape behaviors, practices, and outcomes. Referring back to classical sociologists like Weber, Mead and Schultz, all three stressed that future orientation is in fact an inherent characteristic of human behaviour, since decisions and activities are framed by intentions and ideas about a future situation (In, Lente, 2012). The level of expectations may range from encompassing, abstract sketches of the future (macro) to detailed elements (micro).

Although some researchers have examined the notion of expectations as regards to health, (see, Janzen et al., 2006), the concept of expectations has not been explored in relation to loss of autonomy assessment of the elderly. Particularly, the aspect of the role of expectations is missing in the literature when different social actors involved in the process harbour differing expectations of each other and in which one party has a distinct power advantage as the assessor or, as an employer. For instance, based on what I was able to observe in the field, during the OÉMC assessment process, the family caregiver in some cases would perceive the social worker, as the one who controls the dispensing of services since they are acting as the representative of the government. If that is the case, then, it raises the question of how this may influence their expectations and how care is negotiated under these circumstances.

The following section will now discuss how the concept of expectations has been theorized by several authors, examining this concept from different angles as it applies within the following theoretical approaches and disciplines: Expectation States Theory looks at group interaction to understand how it affect expectations; Expectancy Theory, which studies how people are motivated by their expectations to choose certain behaviours; and Health Expectations Theory, which explores how people's expectations related to health interventions may influence its outcome. Each of these discussions help to cover parts of the phenomenon under study, while joining the different perspectives helped me to conceptualize and become aware of the complexity of expectations in the OÉMC evaluation process.

5.2 EXPECTATION STATES THEORY

From social psychology stems a theory that is relevant for the discussion on assessment tools in that it can be applied to the process by which the participants in the assessment, both the assessor and those participating in the assessment develop their expectations and how they are articulated. 'Expectation States Theory' is concerned with the interaction processes by which social actors draw information from their social or cultural environment and then organize that information into states of expectation that determine their interaction with others (Berger & Wagner, 2016). This theory originated in previous studies that examined interpersonal behaviour in small groups and was also influenced by the status hierarchies of social power structures (Correll & Ridgeway, 2006).

According to Correll & Ridgeway (2006), in application, Expectations States Theory supports the collective orientation in groups[34] under three conditions: (1) A common orientation toward a collective goal or task; (2) Motivation toward solving a problem or answering a question; and, (3) The group considers it important to take into account each other's perception. The shared focus of the group and their mutual collaboration generates a pressure to anticipate the relative

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[34] Groups are defined by these authors as two or more people.

quality of each member's contribution to completing the task. In terms of the OÉMC assessment process, while Expectations States Theory could be useful as a guideline for analyzing the process when, as was mentioned previously, all the actors understand it and are in agreement of their roles (see common orientation, above), it falls short when the assessment outcome itself fails to meet the caregivers expectation and is contested by them. Or, conversely, when the social worker finds the assessment outcome is not what she expected. In the case of the OÉMC assessment, for instance, while the common goal is determining the elderly person's needs there is an inherent power hierarchy in which the person doing the assessment holds the higher position as the determiner and dispenser of services. Performance expectation-states can thus shape behaviour in a self-fulfilling manner since when they anticipate that one person will make more valuable contributions, the other members of the group are more likely to defer to them.

In their early work, Berger, Conner & Fisek (1974) attempted to use this concept as a theoretical basis for a research program that aimed to quantify expectations as predictors of outcome. For example, it was used in research into the influence of teachers on raising their student's expectations of their performance in the classroom. This study drew somewhat positive results, however, as some pointed out, the results could be considered inconclusive because of too many difficult to control variables which confounded the results (Webster & Entwhistle, 1974; in, Berger, Conner & Fisek, 1974). Although some criticisms (see Knotterus, 1988) suggest Expectation States Theory is merely a rehash of interactionist theories, nevertheless, it continues today as a theoretical regrouping of numerous other expectation theories[35] that serve as a basis for

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[35] Berger & Wagner (2016) list a total of nineteen different expectation theories (4) to illustrate the cumulative growth of the program.

a cumulative research program that has extended beyond the United States (Berger & Wagner, 2016).

5.3 EXPECTANCY THEORY

Although the term ‘expectations’ and ‘expectancies’ are sometimes used interchangeably in social psychology, Expectancy Theory differs from the afore-mentioned Expectations States Theory because it goes beyond the interaction of the different parties by also including motivation – that is, how expectations are developed. The development of expectancy theory is largely credited to V.H. Vroom (1964), which he created in the study of work motivation and organizational behaviour and has been the subject of numerous empirical studies (Van Eerde & Thierry, 1996). This theory is considered by Vroom (2005) as interactionist and motivational, which provides a powerful heuristic for predicting human behaviour. Expectancy theory focuses on motivation for human behaviour by asserting that at any given time a person has a set of potential behaviours he or she could attempt. The chooser evaluates each of these behaviours based on three characteristics: the desirability of outcome, the impact of each behaviour on these outcomes and the expectation that attempting the behaviour will result in success (Baumann & Bonner, 2016).

Expectancy theory is not limited to organizational behaviour and motivation. Like the previously mentioned Expectation States Theory, it has also been extended to other situations such as the interactions in collaborative group behaviour and coordination (Baumann & Bonner, 2016). Examining behavioural choice rather than motivation, these results were consistent with previous research in that expectations and perceptions of expertise play an important role in group behaviour and creating boundary conditions. And finally, to terminate the discussion on expectancy theory, Olson, Roese and Zanna, (1996) developed an expectancy process model with the aim of summarizing the major elements of the relation between expectancies and behaviour.

Starting with a detailed clarification of the definition of the concept of ‘expectancy’ – which is explained by these authors as the basis for virtually all behaviour, Olsen et al. state that *“Expectancies can be defined as beliefs about a future state of affairs,”* linking the future with an outcome at some level of probability ranging from merely possible to virtually certain. Similar to previously mentioned authors, they explore the properties of expectancies and the origins of beliefs and their consequences. Where these authors differ is that Olsen et al. link expectancies and their expectancy process model with the concepts of *self-fulfilling prophecies* and *placebo effects.* In a self-fulfilling prophecy, a perceiver’s expectancy elicits behaviour from the target that confirms the expectation that might not have occurred otherwise. Thus, the individual discerns others’ behaviour or an event in a way that is consistent with their expectation.

As regards placebo effects; a placebo is a substance or procedure that is administered with suggestions that it will modify a symptom or sensation, but which, unknown to its recipient, has no specific pharmacological impact on the reaction in question (Olsen et al, 1996). To present their expectancy process model, they propose that the importance of expectancies is in the facilitation of the encoding and interpretation of information and fulfilling important function for the individual. They offer the model as a framework summarizing the major elements involved in the relation between expectancies and behaviour. A replication of their model is offered in Figure 5 below. According to this model, expectancies come from three main sources: direct experience, other people and beliefs, which themselves are interrelated. Once formed, expectancies vary along four dimensions, certainty, accessibility, explicitness and importance. The remainder of the model outlines the cognitive, affective, and behavioural consequences of expectancies, producing behaviour consistent with the content of the expectancies. In this way, the authors assert, expectancies can affect behaviour.

An adapted version of this model has been used as a theoretical frame work for the articulation of the two process models that have been created for this thesis; the Adaptation Process regarding Caregivers Expectations as well as the Adaptation Process regarding Social Workers Expectations that will be described in more detail in a later chapter which presents the results of this research.

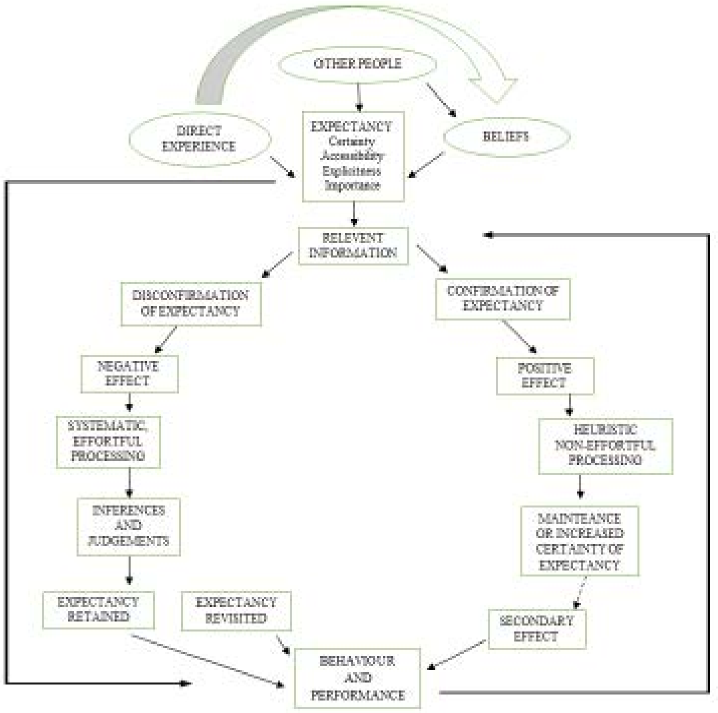

Figure 5 A model of expectancy processes Source: Olson, Roese & Zanna, (1995)

5.4 HEALTH EXPECTATIONS THEORY – HEALTH SCIENCES MODEL

Publications in the health sciences field regarding expectations differ from social psychology theories that present expectations as a source of motivation for behaviour, particularly in human interaction. Instead, often relying on biopsychosocial models, in the health sciences conceptual models and questionnaires have been created to determine patient’s beliefs and expectations of a treatment or intervention. Health expectations can be considered as especially relevant for this thesis because it relates directly back to the expectations caregivers have for care and services for their elderly relative and even for themselves.

A health expectation can be considered as a prediction about the consequences of certain health-related phenomenon (behaviours and conditions, both internal and external), on the body and may be focused on interventions and treatments (Janzen et al, 2006). Attempting to measure expectations as regards to patient satisfaction or dissatisfaction of services, psychometric testing was developed by a team of researchers in the United Kingdom (Bowling et al, 2012; Bowling & Rowe, 2014). With the aim of quality assurance, it seeks to understand how patient's expectations are influenced and how pre-visit expectations may differ from post-visit. Unsurprisingly, we can draw a link in this research to the marketing principles of the neoliberal-inspired managerial values within New Public Management.

In an attempt to fill what they describe as a lack of conceptual agreement and consistency in understanding expectations, Thompson & Sunal (1995) developed a conceptual model to illustrate the relationship between expectations, hopes and patient satisfaction. By problematizing the concept of expectations, they examined research on placebo effect, patient satisfaction and the interaction of pre-formed expectations in what they refer to as a disconfirmation paradigm. The disconfirmation paradigm is based on a cognitive process and the assumption that people who enter into an exchange bring with them pre-formed expectations that can lead to satisfaction or dissatisfaction. The greater distance between prior expectations and perceptions of the services confirms or disconfirms the expectation. These authors raise the point that in order to fully understand the influence of expectations they need to be understood from their personal frameworks that include the emotional (hope), social and service contexts.

Janzen et al, (2006) also propose a conceptual model for expectation development that envisages the development of a health expectation as incorporating several longitudinal phases precipitating phenomenon, prior understanding, cognitive processing, expectation formulation, outcome, and post-outcome cognitive processing, see Figure 6 below (Janzen et al, 2006, 40). They suggest that their model differs from Thompson & Sunal's because they remove the notion of 'hope' which is more emotion-based, from its configuration. The model they describe uses a social-cognitive approach that highlights the process of expectation formation and how it relates to prior behaviours and attitudes, and to subsequent ones.

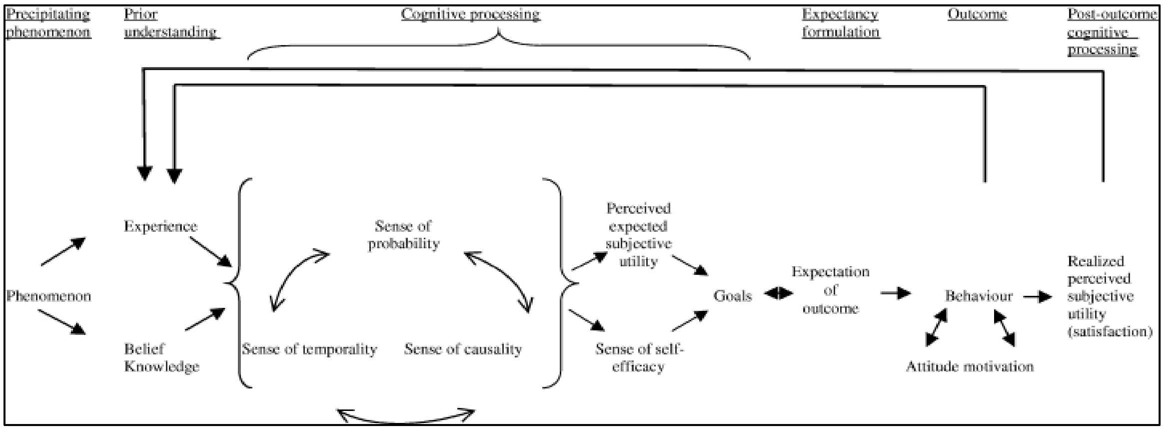

Figure 6 Conceptual model for the process of expectation development

Janzen et al. propose that this model has some bearing on the situation of family caregivers in regards to their ideal expectations which if not satisfied, they suggest could lead to increased caregiver stress. They state that the expectation of the level of care that caregivers themselves must provide is another determinant of caregiver burden (45). These authors acknowledge that although their model is not yet supported by empirical evidence, they believe that it does have hypothetical validity based on the illustrative material they presented. Other criticisms of both Thompson &

Sunal's and Janzen's health expectation models also include the lack inclusion of the changeability of patient's expectations which take time to develop and may improve over time (Ozegovic et al, 2012).

The following sections will now make a more direct link between the notion of expectations and the research topic; it will offer the results of an exploration of the literature and further the concept of expectations in regards to (1) Caregiver's expectations for care and services, (2) Social worker's expectations of caregivers, and, (3) Bureaucratic expectations of social workers. This has been done to fulfill research objective (2), parts a, b and c. The results of this review also served as grounding for the questions posed during the interviews with social workers and caregivers, the results of which will be presented in the next chapters.

5.5 CAREGIVERS AND THEIR EXPECTATIONS

Family caregivers have expectations for the healthcare services and support that they and their family members should or will receive in the future. This is highlighted in the 2015, Ipsos Reid report of the results of a cross-Canada survey (n = 1230) in which they questioned Canadians about their expectations of the health care system. Their findings also highlight some of their fears and concerns: 81% of older Canadians (45+) are concerned with the quality of care they expect to receive in the future, 78% are concerned about having access to high quality home and long-term care in their retirement years, and 61% of the respondents lack confidence that hospitals and long-term care facilities can handle the needs of Canada's elderly population. Other research on aging baby boomers also demonstrated that older adults and their family members have high expectations for support and care from the health and social service system (Guberman, Lavoie, Blein, and

Olazabal, 2012). According to this research, the elderly and their families believe that when they begin to experience aging-related health issues that threatens to compromise their autonomy, it will be possible to maintain a satisfying level of independence provided they receive help from the government homecare and social services.

However, some misgivings still exist; in the above-mentioned Ipsos Reid report (2015) only 48% of respondents believed that there is enough health care support for seniors in their area to live at home as long as they are able to do so. This worry was also reflected in a 2016 report from the *Commissaire de la santé et au bien-être* (Québec), that revealed that many people believe that the health and social services offered to older adults have not been adequately adapted to contemporary health and social needs. This report further highlights that navigating the health and social services system to obtain assistance can be difficult and confusing, especially for older adults at a time when they need it the most. Surprisingly, although the notion of elderly assessment is so prevelent and much has been written about the development of assessment instruments, very little has been written about caregiver's expectations regarding this process itself.

A literature review combining the key words 'caregivers' and 'expectations' and 'healthcare' demonstrated that caregivers harbour a range of expectations of the health and social services system and of what they feel they are entitled to in regards to services and support for the care of their aging relative (Coyne, 2013; Sims-Gould & Martin-Mathews, 2010; Neufeld & Harrison, 2003). In one study in Quebec (Guberman & Lavoie, 2010) found that caregivers expect to have their own skills respected, to receive adequate support, and to be recognized as partners by the healthcare professionals with whom they interact, since they perceive their caregiving role as a collaboration between themselves and the state. For some caregivers, expectations regarding their interactions with social workers were more personal: the primacy of the relationship they develop with their social worker was important and even described as a *friendship* (emphasis added) which they valued (Beresford, Croft & Adshead, 2008). In other instances of caregiver/healthcare worker interactions, caregivers discovered that their expectations of support from the healthcare worker for their elderly relative was not entirely the choice of the worker but was restricted by the bureaucratic limits placed on them (Sims-Gould & Martin-Matthews, 2010), since the workers could only do what was included in the Care Plan or as dictated by budgetary constraints. Thus, family caregivers experience support as a 'constantly negotiated process' (Wiles 2003, 205) between themselves and the care workers.

Caregiver's identity in relation to how they perceive their role appears to influence their expectations for care and support services, for their care receiver and also for themselves. The literature, as outlined in the afore-mentioned Health Expectations Theory, indicates that what people anticipate or expect to receive from their health care, compared with their perceptions of what they receive in practice, are potentially important in predicting patient satisfaction and dissatisfaction with the care, treatment and health outcomes (Bowling, 2014). But, there is a lack of rigorous conceptualization and measurement in the literature on this topic which reflects the multidimensionality and complexity of the concept of expectations (Bowling, 2014). However, family caregivers also report that the amount of work they are expected to do sometimes causes them physical and emotional exhaustion, social isolation and strained family relationships (Ward-Griffin & McKeever, 2000). Studies also revealed that the relationship between the caregiver and care receiver can be complex, especially between elderly spouses in which one assumes care of the other, often provoking a fundamental alteration in their marital roles on the pathway to their caregiver 'us' identity (Montgomery & Kosloski, 2013; Davies, 2011).

5.6 SOCIAL WORKERS AND WHAT THEY EXPECT OF CAREGIVERS

In the context of homecare services and care of the elderly, social workers and other healthcare professionals often find they are in a position where they must enforce the guidelines and expectations of the healthcare services system on family caregivers, while also being guided by their personal values and beliefs which may run counter to those of their employer. As the discussion below will demonstrate, this creates a paradoxical situation for social workers in which, while they recognize that the demands and expectations for care being placed on caregivers is causing them distress, contradicting the humanistic values of their profession, they must also remain within the dictates and protocols of the bureaucratic and economic constraints of their organization. This issue was in fact highlighted in the previous section which described the changing norms and protocols of the healthcare system in terms of working climate and staff attrition.

In the context of loss of autonomy assessment and the social worker, elderly person, caregiver interaction, family caregivers are not alone in having expectations of the outcome. Some studies have demonstrated that social worker's expectations of the role of family caregivers can also influence their interaction and, ultimately, the intervention plan (IP) that is developed for the elderly client (Guberman, Lavoie, Pépin, Lauzon, 2008; Lavoie, & Guberman, 2009). Caregivers occupy a somewhat ambiguous status in homecare policies and services, despite their significant role in providing care, their outcomes are only considered the 'by-product' of the care system (Twigg, 1989). The primary intervention model with caregivers is based on the overall expectation that they are resources to be mobilized to assume more and better care and complete tasks as a subordinate and defined in terms of their own professional mandate (Guberman et al, 2006). For instance: "*When asked to describe caregiving work, practitioners not only list the tasks* *accomplished by the caregivers, they also describe the work that they feel caregivers should be doing, thus expressing their expectations of caregivers*" (Guberman et al, 2006, 47).

Healthcare professional's conceptions of family caregivers and their role have come under scrutiny by researchers for quite some time. One argument is that the way practitioners understand the caregivers' role can influence their expectations. For instance, Twigg (1989) condenses the caregivers' role into three categories: caregivers as resources, caregivers as co-workers and caregivers as co-clients. She also acknowledges that these frames of reference are common to the culture of social services and senior managers are more likely to be more concerned with the caregivers as resources aspect and front-line practitioners with the caregiver's well-being. Ward-Griffin and Mckeever (2000) examined the relationships between nurses and caregivers and produced a similar typology: nurse-helper, worker-worker, manager-worker and nurse-patient. Guberman and Maheu (2002) agree with Twigg's categorization of caregivers as a resource and caregivers as a co-client but instead of qualifying caregivers as co-worker, substitute the term that is more frequently used in Québec healthcare today, caregiver as partner[36]. A "partner" is obviously a problematic term, as well, parting from an ideal of equality that is rarely found in most health care systems and that might even become a fallacy of care when structural and power relations are not taken into account (see Leibing 2019).

Different expectations are attached to each caregiver conceptualization (Guberman & Maheu, 2002). For instance, when caregivers are expected to be a resource, public services play a secondary role; the responsibility for caregiving is placed mainly on the caregiver and intervention is mainly aimed at empowering them to care for their dependent relative and encourage their autonomy. In this sense, empowerment and autonomy become contested concepts, since in the

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[36] See : Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux. MSSS, 2018. http://publications.msss.gouv.qc.ca/msss/fichiers/2018/18-727-01W.pdf

name of empowerment a lack of services can be made invisible (see e.g., Calvès, 2009). The caregiver as co-client approach focuses on the problems of both the caregivers and the care recipients. Interventions are aimed at providing them support and to alleviate their stress. However, when one considers the socio-political context in which the State expects families to take responsibility for caring for dependent adults, this puts caregivers in the ambiguous position of being both the problem and the solution (Guberman & Maheu, 2002). The caregiver as co-worker or partner approach views the caregiver as key partners where their expertise and knowledge are recognized. In theory, this viewpoint encourages a move away from the traditional hierarchical relationship between professionals and family caregivers and recognizes the caregiver's lay-expertise (Guberman & Maheu, 2002. However, as Twigg (1989) mentions, the two systems do not mesh easily since care work in the formal sector is guided by a formal knowledge base governed by rational-legal authority and rules of accountability and procedure, while caregiving in the informal sector is guided by affective values, relationships and reciprocity. An age-factor can also play a role in terms of social worker's expectations of caregivers and could even influence the care plan. Twigg, (1989) reports that elderly spouse caregivers, because of their age and possible disability, are more likely to be defined as a 'co-client,' while younger spouses or adult children caregivers are more apt to be perceived as a resource or co-worker.

Contradictory expectations and discrepancies in values and norms between the healthcare practitioner and the caregiver also can be a source of tension (Ward-Griffin & McKeever, 2000). For instance, the high expectations placed on caregivers can be viewed as contradictory when one considers that healthcare workers acknowledge that caregivers are overburdened (Guberman, 2009; Ward-Griffin & McKeever, 2000). Lavoie & Guberman, (2009) identified diverging expectations regarding the definition of 'partnership' between caregivers and practitioners as the cause of difficult relationships between these two parties. For instance, these authors describe that 'partnership' according to caregivers includes wanting to be consulted regarding decisions that affect their loved ones care and to be treated with empathy and respect by the practitioners. For practitioners, however, partnership is more closely defined by how well the caregiver fills the role of resource person, co-worker and collaborator. Despite the unequal expectations regarding partnership and paradoxical values, practitioners do not want the caregiver to burn out. As the previous authors highlighted in a quote from a practitioner referring to caregivers: *"My expectation is that they will tell me what they can or can't do, at least minimally, that's what I try to learn, my greatest expectation…"*[37] (141) (my translation)

Formal care to the elderly provided by the healthcare system and informal care provided by family caregivers can have different normative-value bases. (Twigg, 1989, 59). Guberman et al, (2009), report that in their study which examined the values and beliefs of practitioners regarding the provision of care, the majority felt that the primary responsibility for care rests with the family and thus, leads to high expectations of caregiver participation, while public services should be considered a back-up. However, in a different cultural context, such as when practitioners perform assessments with people whose origins are from other countries, the expectations can be somewhat different. Ducharme et al, (2007) report that practitioners interacting with family caregivers whose values and beliefs are not guided by 'normative' Canadian values, and who consider their caregiving status as a natural role, focus their expectations of them more directly on guiding them through the healthcare system and encouraging them to seek help.

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[37] Original text: "*Mon attente c'est qu'ils viennent nous dire si ils sont prêts minimalement ou non à faire quelques chose, c'est ça que j'essaie de savoir, c'est ma plus grand attente…*" (141)

5.7 BUREAUCRATIC EXPECTATIONS OF SOCIAL WORKERS

Social workers in the healthcare system are often caught in the middle of multiple expectations. On one hand, as health professionals they are expected to perform their duties according to the norms and protocols of their profession as well as organization for which they are working. In this context social workers are also expected to respect any budget limitations regarding service delivery and any criteria regarding client assessment. On the other hand they, as the result of a process that inter-mingles their beliefs and values and the expectations of the State, as exemplified in the previously described transfer of responsibility to the family, social workers are put in the position of prioritizing the position of the State's expectations of family caregivers over their own humanistic interventions. .

If the social worker believes that the expectations of performance from the organization on them are unrealistic or even unfair, how does this impact their ability to perform their duties? Over the last decade in Quebec, a series of reforms in the health care system that introduced a neoliberal management model (Bourque, D., 2009) through the previously mentioned LEAN system, have led some researchers to examine the impact of this new public management system on social workers and their interventions (Grenier, J., Bourque, M., & St-Amour, 2016). Social workers who work in home care services for the elderly have revealed the stress and anxiety they experience related to completing their professional duties in light of recurring budget freezes, reorganization and management changes that have taken place in the last decade (Bourque, D., 2009; Rossiter, 2011; McDonald & Nixon, 2016) and certain regulations and requirements of their professional order (OTSTCFQ). Referred to by some authors as the "*injection of economic reality into social spheres and practice*" that have transformed social services and healthcare systems in the (Western) world through managerial technologies "*embodied in neoliberalism*" (Foth, Lange &

Kim, 2018). Marketization principles such as time management, productivity and client satisfaction, are now in the forefront, placing additional pressures on all home care workers to meet quantifiable objectives (Grenier, J., Bourque, M., St-Amour, 2016). By their estimation, almost three quarters of their time is spent on tasks related to completing elderly client assessments employing the OÉMC and other paperwork (Bourque, D., 2009). The technical expertise required to complete the assessments, although meant to aid decision making, has led some researchers to state that it can override the lived experience of the clinical encounter (Freshwater & Cahill, 2017; 133) and "*professional identities are worked in the gap between the increasing neoliberal pressures for accountability and audit, or 'economies of performance', and individual and collective 'ecologies of practice', contending that the professional is framed as an implementer of policy*" (Gannon, 2012: P. 868).

The use of standardized assessment grids to determine access to services is viewed by some as a renunciation of professional judgement which has the effect of forcing practitioners to become service organizers instead of service providers[38] (Bourque, D., 2009; Carrier, Morin, P. & Garon, 2012). Managerial and administrative expectations on social workers has created a working climate with a high employee turnover and increased absenteeism that has become difficult to manage (Grenier, J., Bourque, M., St-Amour, 2016; Bourque, D., 2009). Social workers are also members of a multidisciplinary team that utilizes the OÉMC to assess all clientele which includes the evaluation of the client's social functioning, in order to determine a plan of intervention and ensure its implementation, as well as support and restore the social functioning and optimal development of the person in concordance with his or her environment (extract from law 21,

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[38] This is one of the core issues that are described not only by social workers but also nurses and other healthcare professionals. Some feel that the abundance of paper and form-filling is compromising professional judgement. The argument is still very current. See the previous discussion on criticisms of assessment instruments that is in the media. (section 3.3.1, this document)

Québec National Assembly, 2009, my *translation*). As well, like other professionals who work in homecare, social workers are required to complete an additional psychosocial evaluation as an obligation of their professional order (TCFQ) and *Law21*[39]. The contextual analysis of the immediate social environment and circumstances of the client is what distinguishes social work practice from other professions (OTSTCFQ, 2011). This evaluation is considered complementary to that of the OÉMC because it brings in an understanding of the person in a global way by identifying any social issues they are facing while still respecting individual rights, autonomy and self-determination.

Thus, expectations that come into play during the interaction of healthcare professional with elderly clients and family caregiver, can potentially have an impact on the results of the assessment. What will also be presented in a later chapter is an additional angle of examining expectations that have not been mentioned in the afore-mentioned theories and that is the notion of adaptation. Because, expectations development, confirmation or disconfirmation is a process which will be described in the caregiver and social worker adaptation models in an upcoming chapter. By focusing on expectations, we gain insights into what *should or could be*, and what *is not*. This gap between expectations and what is – and the shaping of expectations regarding older people's autonomy (through ideologies in the wider sense) – is the main insight of this thesis.

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[39] *Loi 21 – Loi modifient le Code des professions et d'autres dispositions législatives dans le domaine de la santé mentale et des relations humaines. Adoptée le 18 juin 2009.*

6. METHODOLOGICAL SECTION

6.1 INTRODUCTION

In 2013, as a way to understand autonomy and answer questions that had arisen in a concrete context from professional practice in homecare services with caregivers, a two-phase pilot study was launched, in which during phase one we analyzed 32 completed OÉMC questionnaires[40] looking specifically at the psychosocial section for inconsistencies. In phase two of the pilot study we broadened the scope of the exploration to further our knowledge on the notion of 'autonomy' and its role in assessment of the elderly and to contextualize it within the biomedical, social and health sciences. The first goal was to better understand the importance of the concept of autonomy within elder care and related practices in Québec. The second goal was to explore the application of the OÉMC with healthcare practitioners through informal interviews to understand some of the inconsistencies that were revealed in phase one of the pilot study. It was also during this phase that N. Gilbert and A. Leibing took part in the ten hour training sessions that professionals receive on the OÉMC and its application that was given by professional trainers from the CIUSSS of West-central Montreal with the objective of gathering greater insight on its application.

The exploration was then continued with the addition of two other research questions: (1) Do assessed patients and assessing health professionals differ in their understanding of the various dimensions of the OÉMC? And, (2) What are the expectations of assessed elderly and health care professionals regarding optimal interventions within a given health care system? This phase also launched my doctoral research study that began in September, 2015. The research questions were

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[40] The data from the pilot study will be presented in more detail in the results chapter of this thesis.

altered eventually to include family caregivers instead of the assessed elderly patients for reasons of their incapacity. This decision is explained in more detail below. The notion of expectations which was revealed in the informal interviews and through the professional experience of N. Gilbert also was selected during this time as the foundation for the theoretical framework.

6.2 METHODOLOGY

This chapter presents the methodology selected to attain the targeted objectives of capturing the expectations of different social actors regarding the assessment of autonomy among older people and a wider analysis of autonomy as a central issue in care practices. It includes the research process, including the type of study, the choice of the interviewees, the selection criteria, ethical considerations, participant recruitment, the data gathering and strategies of analysis. As stated above, the study described in this thesis is qualitative and exploratory in nature. Qualitative research is *"an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem"* (Cresswell, 1998, p.15). According to Stebbins, (2011) social science exploration is a broad-ranging, purposive, and systematic. It is often a prearranged undertaking designed to maximize the discovery of generalizations leading to the description and understanding of an area of social or psychological life. Exploratory research, frequently used to formulate core questions in an understudied area, is inductive and open, allowing the researcher to capture "what is at stake" and often lead to subsequent studies that then will deepen topics that had emerged during the first phase. As mentioned before, this study relies on sources from different disciplines. In order to capture methodologically the multiple perspectives – perspectives that, as I argued, will help me to problematize, at least partly, the taken for granted – needs to develop a reflexive methodology. According to Denzin & Lincoln (2008), in interdisciplinary qualitative research that examines a particular social problem, the researcher must be able to 'interweave' ('bricoler') a variety of elements that, in a coherent way, allow for in-depth exploration and interpretation of the data that, ideally will lead to the development of new knowledge. Cresswell (1998), holding to the bricolage metaphor, also describes qualitative research as an "*intricate fabric composed of minute threads, many colors, different textures and various blends of material*" held together by general frameworks.

6.3 FOCUSED ETHNOGRAPHY

Focused ethnography was selected as a pertinent methodology for this study for the following reasons: it is intended to be done in a timely manner, it reflects the reality of healthcare settings, the results are meant to be communicated back to community or healthcare practice and it incorporates reflexivity and has the potential to improve care and care services in health care (Higginbottom, 2013; Morse, 2007). Further, it incorporates varying levels of in-depth analysis, which could be described as an iterative, cyclic and self-reflective process; ideal since the doctoral candidate is a practitioner-researcher with a wealth of first-hand practice-based knowledge to contribute to the reflection. As an insider, this allows for privileged access and in-depth knowledge but, as several authors argue, carries the danger of overlooking taken for granted, often everyday practices and value systems can be an ontological challenge (see Dwyer & Buckle 2009, Asselin, 2003). The methodology of this approach allows for predetermined and emerging, generally semi-structured, interview questions that can provide 'deeper' data when compared to conventional interviews, especially of everyday practices (Knoblauch, 2005). However, it also requires further preparations and precautions such as constant self-observation and the explicit declaration of previous knowledge and expectations on the part of the researcher (Kuhn, 2013).

Focused ethnography differs from traditional ethnography not only because of its shorter period of fieldwork, in that the researcher conducts the research with an identified concept and familiarity with the culture and the environment and focuses on their shared behaviours and experiences. However, although the researcher may know the studied environment well, he or she needs to be open to emerging topics and problems. According to Wolf (2012), focused ethnography is the "*study of small elements of one society, group or culture: focus on distinct problem within a specific context among a small group of people*." Wall, (2015) stated that "*focused ethnography preserves the essential nature of ethnography and allows researchers to explore cultural contexts that cannot be studied using conventional ethnographic methods.*"

In the case of this study, conventional ethnographic methods in which the researcher immerses herself in the environment of the healthcare workers was not possible due to low availability of the workers and their time constraints.[41] Although the methodology for traditional ethnography usually involves the researcher observing the participants in their environment over a longer period of time, some researchers using a focused ethnography approach have dropped the participant observation component of ethnography and rely solely on interviews with the subjects as well as intensive data collection and analysis (Morse 2007). What makes focussed ethnography nevertheless an ethnography is that it preserves the element of studying a culture, in the case of this study, the culture of assessment of the elderly by social workers in interaction with family caregivers, but accepts that the traditional neutrality of the researcher is not present because of insider knowledge and experience.

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[41] It was communicated to me by a supervisor that some workers were concerned that having a researcher present at their homecare assessment would take up some of their time with the client. (NG)

6.4 INSIDER KNOWLEDGE AND REFLEXIVITY

According to Denzin & Lincoln (1998) reflexivity refers to a process by which 'researchers are obliged to delineate clearly the interactions that have occurred among themselves, their methodologies and the settings and actors studied.' It is focused on making explicit and transparent the effect of the researcher, methodology and tools of data collection on the process of the research and the research findings (Higginbotton, 2013) and is considered one of the major criteria for assessing quality in qualitative research (Mays & Pope, 2000). Reflexivity reminds the researcher to be attentive and conscious of the political, cultural, social, linguistic and ideological origins of one's own perspective and voice as well as the perspective and voice of those interviewed (Patton, 2001). While ethnographers are usually regarded as objective observers, this study required that I have both insider and background knowledge as well as previous experience of my field of study. "*In carrying out qualitative research, it is impossible to remain 'outside' our subject matter; Our presence, in whatever form, will have some kind of effect. Reflexive research takes account of this researcher involvement".*[42]

Many years of working in the health care field as a practitioner with family caregivers inspired the interest in this project so the need for reflexivity grew evident very early on in this process.[43] Reflexivity entails the researcher being aware of his effect on the process and outcomes

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[42] The Sage dictionary of Qualitative Management Research (2008).

[43] Because of my longstanding work within the environment I am studying, and the impossibility of bracketing completely my own lived experience of care work, a short reflection of reflexivity is needed. Reflexivity, although often difficult to apply to research, is considered one measure to deal with 'insiderness,' it guides both the process of data collection and analysis. I am fortunate to have had years of experience in psychosocial intervention which requires a professional demeanor that includes constant awareness of one's role and potential effect on the therapeutic process. Training in this field includes heightened vigilance, reflexivity and extensive note-taking as fundamental skills which I discovered to be similar to those that are required of a researcher.

of research based on the premise that "*knowledge cannot be separated from the knower*"[44] Steedman (1991). When the researcher is also a practitioner, this could be a major advantage or a shortcoming in research in healthcare. The advantage being, as was already mentioned, easier access to resources and having knowledge from an insider perspective. The disadvantage is inherent in the risk of becoming too personally embedded in the process, thus increasing the chance of personal bias in interpreting the results. Pires (1997), illustrates the challenge for the researcher/practitioner/doctoral student in his proposition for a methodological model in social sciences. He recommends a process of object construction as a fluid *come-and-go* strategy from the internal and external point of view of the researcher. Many authors, for instance Alvesson & Skoldberg (2009); Higginbottom (2013) and Poupart (2009), have proposed that reflexivity is an important element in qualitative research.

As a result, a reflexive approach was consciously integrated in this thesis in order to add coherence and to guide the development of the interview questions, the data collection and interpretation as well as the data analysis of this thesis. When interviewing the social workers I was aware that they shared information with me that they may not have with someone who was unfamiliar to them. As such, during the data analysis I took special care to be aware of this by discussing this with my thesis supervisor so as to not allow it to influence my conclusions, however, as previously mentioned, I realized the advantage for me was that years of training and experience as a psychosocial practitioner has also provided the ability to distance myself from the process and to maintain a more neutral stance throughout. This became especially evident when

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[44] In, Sage Dictionary of Qualitative Management Research, Introduction, p. 2. http://methods.sagepub.com/base/download/ReferenceEntry/the-sage-dictionary-of-qualitative-management-research/n86.xml

reading and rereading the interviews; by doing this it was easier to achieve a more etic point of view (see Roulston, 2010).

6.5 SAMPLING STRATEGY

The recruitment strategy of the social workers and caregivers for this study was both purposeful and opportunistic. "*Purposeful sampling is widely used in qualitative research for the identification of information-rich cases related to the phenomenon of interest*" (Duan et al, 2013), and aids in elaborating on the research question (Emmel, 2013). Although, Pires (1997) advises that the recruitment strategy must be flexible, since it may need to be adapted as the research progresses and to be open to new opportunities (Miles & Huberman, 1994). Creswell (1998) recommends that the selection of participants must be done with clear criteria and decision-making rational in mind. Opportunistic, or emergent sampling aims to take advantage of circumstances events and opportunities for additional data collection as they arise (Duan et al, 2013).

6.6 SOCIAL WORKERS: RECRUITMENT

The study was undertaken internally, within one CIUSSS (*Centre intégré universitaire de santé et des services sociaux)* in Montreal - a regrouping of CLSC's, hospitals, long-term care establishments, and rehabilitation centres. The possibility of recruiting social workers from other healthcare institutions was not an option since the ethics approval from that specific research centre required that the study remain within this organization. Presentations that described the project were made to homecare managers as well as during two SAPA (*soutien à l'autonomie des personnes âgées*) staff meetings, one at CLSC (*Centre local de service communautaire)* and another CLSC where social workers were asked to volunteer to be part of the research. The selection of this location for the research was purposeful and deliberate, based on the previous knowledge that these organizations respond to the needs of a high number of elderly people and s that social workers from this agency were well-versed in caregiving issues and related challenges because of the many years research that was done in this centre on caregiving issues. For instance, the first CLSC has a reputation for developing expertise and innovative practices in the domain of caregiver support. In the late 1990's a Caregiver Support Centre was created that had the mandate of offering services to caregivers, in fact, above and beyond those which are normally considered part of the *offre de service'* of other healthcare centres. For over 23 years a caregiver drop-in centre was available in which caregivers could bring their care recipients for the afternoon, social workers in the program offered short-term counseling and a variety of support groups were available to caregivers. In addition, they developed The C.A.R.E Tool (Fancey et al, 2008), an instrument that assesses caregivers health and well-being and along with the CREGES social gerontology research centre, conducted research on issues related to caregiving. As well, social workers and other practitioners with this agency are well-versed in issues related to the caregiver experience and in the support and services they may require[45].

6.6.1 Inclusion/exclusion criteria: Social Workers

As was previously mentioned, all homecare professionals, are trained and qualified to do OÉMC assessments. However, social workers and social work technicians were selected because, they perform the majority of the assessments and, as well, clients who may have multi-problematic

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[45] I can personally attest to this, having worked there for almost twenty years, during at least ten of which I was the psychosocial practitioner responsible for the caregiver support groups. As part of a team working in the Caregiver Support Centre, we made regular presentations to other practitioners on caregiving challenges and we offered them the opportunity to consult on any difficult situations they may encounter related to caregiving interventions.

situations comprising multiple psychosocial problems, as well as some functional autonomy challenges, are referred to social workers. Therefore, it was expected that interviews with professional and technical social workers who perform OÉMC assessments would be more likely to reveal more complex issues related to loss of autonomy and the challenges of developing negotiated care plans with the elderly person and their families. Social workers or social work technicians recruited for the study had to be working in the SAPA (homecare) program of the chosen CIUSSS and be performing OÉMC assessments, first time and follow up, on a regular basis. They must be willing to participate in a one to two hour interview and be available to answer follow up questions, if needed. Although all social workers are qualified to perform complex assessments of homecare clients, in some cases the social worker was uniquely doing assessments for institutional placement or worked solely in palliative care. These workers were eliminated. Thus, the practitioners targeted were professional social workers or social work technicians who regularly perform first-time OÉMC assessments of the elderly. The reason I focussed on first time assessment was that at this occasion the complexity of the "case" is being evaluated and more time is being allocated for this, while follow-up assessments often are done in a much shorter time and if there has been no change in the clients situation the assessment is not completely redone, just revised. All the social workers interviewed did so on a volunteer basis. In order to ensure that the workers did not feel obliged or coerced to participate, they were recruited through the SAPA home care programme of the CIUSSS (through the program managers who were asked to provide a list of potential health care workers who could be contacted by the researcher. Contacted by the researcher, the interviewees were not pressured to participate ad could withdraw at any time.

6.6.2 Profile of the social workers

Figure 7 below presents a profile of the social workers. We do not provide more data such as education or age in order to preserve the anonymity of the respondents. For the same reason, years of experience are also simplified: initial means 1-5 years; middle 5-10 years, a lot over 10 years.

	SW 1	SW 2	SW 3	SW 4	SW 5	SW 6
Gender	F	F	M	F	M	F
Years of experience (SAPA)	middle	initial	a lot	a lot	middle	middle
Duration of interview(s)	(1) 1.5 hr (2) 30 min. telephone	1:40 min.	1:55 min.	1:54 min.	1:40 min.	1:56 min.

Figure 7 Social worker's profiles

6.6.3 Recruitment challenges

There were some challenges encountered in the recruitment of social workers, primarily due to their work-related time constraints and caseload. The organization advised that because of their close affiliation to a research centre, the requests for staff liberation for research participation was abundant, so, managerial permission was required for the liberation of staff to participate in this research. A letter was requested and received from the assistant director of the SAPA programme in the CIUSSS. (A copy of this letter is included in the Annexes). The CREGES research centre has formulated a unique entente with the organization for the liberation of staff for research purposes in which the research centre reimburses the homecare program for practitioners time spent to participate in various studies. Nevertheless, even with the letter and entente, recruitment of social workers remained challenging. The question of saturation did not come into play per se, rather, when after six months passed and no new social workers volunteered to take part in the study, despite repeated telephone calls to managers and polite reminders, it was decided to remain with the six interviews in-depth interviews that had been done.

6.7 CAREGIVERS: RECRUITMENT

Individual interviews (n=6) and a focused discussion group (n=12) were conducted with a total of eighteen caregivers. The choice of the focus group of caregivers who were already familiar with each other was made because it was felt that their prior years of discussion with each other and with a professional social worker would provide a deeper degree of insight into caregiving issues. The strategy to recruit the caregivers was devised so as to not place any additional time constraints or workload on the healthcare professionals. Social workers or social work technicians were asked to identify caregivers and gain their verbal permission to be contacted by the researcher to explain the study and obtain their agreement to be interviewed. The social workers who referred caregivers were not required to be a part of the study themselves. The caregivers were then contacted by telephone, at which time the study was explained in detail. In addition, written consent for the audio recording of the observation and the interviews was obtained at the first contact. Having explained the study and procedure to the participants in advance, on arrival the written information was presented and the consent forms were signed by the subjects.

The focus/discussion group participants came from an already constituted body that met weekly with a social worker in the form of a support group. The social worker who led the group in question discussed this option with them in a prior session and explained the study to them in order to gain their permission. All of the group members agreed and at the start of the group interview consent forms were presented for their signatures. The opportunity to meet with this group was considered very fortunate because it was felt that caregivers having prior knowledge of one other and of some of the issues of caregiving in general, would potentially provide a deeper level of insight as well as an already established comfort with expressing themselves in front of each other. This in fact turned out to be the case.

6.7.1 Inclusion/exclusion criteria: Caregivers

Caregivers were defined as a family member such as a spouse, or an adult child, or a close friend or person who provides support and care to an elderly person on a regular basis and who self-defines as a caregiver. The caregiver was expected to have some awareness and knowledge of the assessment process and have taken an active role during it. They must be willing to participate in a one to two hour interview and be available to answer follow-up questions, if needed.

6.7.2 Profile of the caregivers

The caregivers were a diverse group of people representing a wide range of experience in a variety of caregiving situations. In the discussion group, there were eight women and four men ranging in age from sixty-four to eighty-three all of whom were caring for their spouse over a period of one year to more than ten years. At the time of interview, one spouse was deceased, six spouses had already been admitted to a long term care facility and the remainder were still living in their homes. The diversity of this group in terms of numbers of years of care and the situation of the care recipient provided the opportunity for a rich discussion and cross-situational comparison. In terms of the six caregivers who were interviewed individually, there was some variation in the care situation. There were four woman and two men with an age range of sixty-five to eighty-eight years, whose caregiving experience covered one and a half years to over twenty years. All were caring for their spouse with the exception of the one adult son caregiver, one mother caregiver to her daughter and one woman who played a double role of spouse caregiver as well as caregiver to her intellectually disabled adult step-daughter.

The nature of the relationship between the caregiver and the care receiver can play a significant role in determining expectations. In Table 5 below, this value is interpretive and is based on my judgement - reflection and analysis of how the caregiver spoke during the interviews about the person for whom they were providing care. In this table, the column on the far right describes this and is based on analysis of how the caregiver spoke during the interviews about the person for whom they were providing care. Six caregivers who used expressions such as '*he/she just sits and stares'* (CG10) or '*he/she is there but not there*' (CG7) and *'he/she doesn't know who I am'* (CG5) were given the classification of 'absent,' although this is not meant to imply that their relationship is not a good one. It means rather a *psychological absence* because they frequently mentioned the lack of interaction with their care recipient and as a result, their caregiving duties may be more intense. Five caregivers who described their care receiver as recalcitrant, '*this time I hope he lets the social worker come in'* (CG16) and resisting of help, '*Everything has to be planned, and double planned and triple planned and quadruple planned then he changes his mind*' (CG11), have the designation of conflictual because they spoke about how it affects their caregiving tasks. Other caregivers, who spoke of their relationship primarily as caring were assigned the designation 'good,' indicating, more or less, lack of conflict and that they still were able to interact with their care recipient. Figure 8 that summarizes the caregiver profiles is presented below:

CAREGIVERS						
	Age	Gender	Identity	Years caring	Status of Care Receiver	Nature of relationship
CG1	79	Female	Spouse	5 yrs.	LTC	Absent
CG2	75	Female	Spouse	2 yrs.	LTC	Conflictual
CG3	73	Female	Spouse	10 yrs.	At home	Good
CG4	67	Female	Spouse	3 yrs.	At home	Good
CG5	77	Male	Spouse	1 yr.	LTC	Good
CG6	80	Male	Spouse	3 yrs.	LTC	Absent
CG7	82	Female	Spouse	4 yrs.	LTC	Absent
CG 8	83	Male	Spouse	3 yrs.	Deceased	Absent
CG9	70	Female	Spouse	10 yrs.	LTC	Absent
CG10	74	Female	Spouse	4 yrs.	At home	Absent
CG11	64	Female	Spouse	10 yrs.	At home	Conflictual
CG12	74	Male	Spouse	2 yrs.	At home	Good
INDIVIDUAL INTERVIEWS						
CG13	88	Male	Spouse	2 yrs.	At home	Good
CG14	76	Female	Spouse & step-mother	6 yrs.	Spouse & daughter at home	Conflictual
CG15	78	Female	Spouse	20 yrs.	Deceased	Conflictual
CG16	72	Female	Spouse	1.5 yrs.	At home	Conflictual
CG17	68	Female	Mother	10 yrs.	At home	Good
CG18	65	Male	Son	2 yrs.	At home	Good

Figure 8 Caregiver profiles

6.8 ETHICAL CONSIDERATIONS

This research was approved by the ethics committee of the (CODIM-FLP-16-222) as well as the ethics committee of the Université de Montréal (16-147-CERES-D). As well, it received approval from the Feasibility Committee of the. Feasibility approval is required for research in healthcare settings to ensure that there is no undue burden placed on professionals by research activities. All participants were required to sign a consent form to indicate they understood the nature of the research and that they agreed to the interview being recorded. They were advised that they could withdraw at any time with no penalty or adverse consequences. However, research in a healthcare setting that potentially involves vulnerable adults must be flexible and at one point an adjustment was required to the protocol.

6.8.1 Research adjustment

As was mentioned in the introduction, an adjustment was required to the research protocol. The older person, who is the social worker's client, of course occupies the central role in the assessment since they are the person being evaluated. Initially, during the development phase of the thesis, the elderly clients were included as key players and expected to be able to articulate their needs and expectations for themselves. However, during the pilot phase, conversations with some older people, family caregivers and social workers revealed this was not always the case and some elders seemed to find that expressing their opinion was very challenging.

Unfortunately, when an elderly person reaches the stage at which they require homecare assessment, their cognitive functions and abilities are often already compromised to the point that they allow their family members to do most of the talking for them. This phenomenon is particularly true in the case of the clients of social workers since they may have been referred for assessment due to psychosocial issues, which often includes cognitive deficits, sometimes not yet diagnosed. A few conversations with some older people in the initial stages of this research revealed that when they were encouraged to express their thoughts and opinions it seemed to cause them some distress and confusion and they deferred answering to their family members. When this happened it was concerning and in fact ran counter to the ethical considerations as outlined in the protocol for this project: Communication with a person who has cognitive losses can be challenging, often relying on non-verbal signs and highly time-consuming interactions, so unfortunately it was impossible to include this population within a realistic timeframe for a PhD thesis. According to the text of the ethics approval:

> "*In the case where it becomes apparent after the interview has started that the elderly person is not capable of responding in a cognitively apt manner, the researcher will remain until such time as she can withdraw without making the elderly person feel uncomfortable and any audio or written data already gathered will be immediately destroyed.*" (Research protocol CODIM-FLP-16-222, p. 11)

Thus, the part of the protocol that planned for assessment observations was abandoned and a decision was made to conduct further interviews only with family caregivers and social workers. Also, during the interviews with the social workers it became apparent that their working environment and managerial protocols were placing a great deal of performance expectations on them. Thus, another decision was made to add the perspective and expectations of the health and social service administration which could be gathered from the already-planned interviews with the social workers and published documents. After verification, since another stakeholder was not being added, it was decided that a formal alteration in the research protocol was not required.

However, it must be noted that the role and involvement of the elderly person in their own assessment cannot be discounted and should be explored in greater depth with further research. An interesting angle of approach to this has already been identified through some studies that discuss the ‘personhood’ of the elderly person and how that is impacted by their aging-related loss of autonomy and cognitive deficits (Leibing et al., 2016; Lamb, 2014; Sabat, 2003; Kitwood, 1997; Dewing, 2008). The *“personhood-in-Alzheimer’s movement”* (Leibing, 2017, p. 214), although showing intriguing promise as an avenue for exploration in aging and homecare assessments, unfortunately surpasses the scope of this thesis, but definitely merits further study.

6.9 DATA COLLECTION AND ANALYSIS

Five strategies of data collection were adopted for this study: 1) Analysis of 32 OÉMC questionnaires completed by Social Workers was conducted during the pilot phase of the project. 2) The researcher and the research director for this study both attended one and a half days of training on the usage and interpretation of the OÉMC offered by the CIUSSS. This was done in order to be able to make informed interpretations of the questionnaires and to learn first-hand how social workers are trained in its usage. 3) A focus group with 12 spousal family caregivers was conducted, and 4) Separate semi-structured interviews with 6 family caregivers and 6 professional Social Workers were done; 5) a literature review that also included documents that informed the context in which assessment practices were undertaken: guidelines , health policies, etc.

Additionally, one observation of an in-home assessment by a social worker with a family caregiver was done in order to gain familiarity with the application of the tool in context. In addition to the aforementioned data collection methods, Semi-structured interviews were selected as the method because it allows the researcher to gather the participant’s point of view and opinions of the subject in a free and in-depth manner. Semi-structured interviews also allow the researcher to predetermine some of the themes to be explored which could ultimately assist in the data analysis (Miles, Huberman & Saldana, 2014), but maintain open to emerging questions.

Prior knowledge of the healthcare system, professional experience with family caregivers, as well as preliminary investigation that was done during the pilot phase of this project allowed for the identification of initial interview themes. These themes were further elaborated during the interviews themselves. Two interview guides were created, the first, used for the interviews with social workers was composed of three themes and constructed in the following way: (copies of the interview grids for social workers and caregivers are included in the Annexes)

1. The first theme explored their opinions of the OÉMC and was divided into three sections:
    a. General information
        i. Length of time to complete
        ii. Scoring anomalies
        iii. Recommendation for changes
    b. OÉMC process
        i. Description of process to client and caregiver
        ii. Participation of family in the assessment
        iii. Caregiver impact on the assessment
    c. OÉMC results
        i. Disparity between score and client situation
        ii. Explanation of results to client and family
        iii. Reaction of client and family to assessment
2. The second theme focused on their expectations of family caregivers and was divided in two themes:
    a. General expectations
        i. Of caregiver
        ii. How they are communicated
        iii. Detection of caregiver expectations
    b. Communication of expectations
        i. Caregiver competency
        ii. Inclusion of caregiver
3. The third theme explored organizational expectations of social workers and was also composed of two sections:
    a. General expectations
        i. Perception of managerial expectations

        - ii. Perception of support from organization
    - b. Workload expectations
        - i. Realistic expectations
        - ii. Discussion with colleagues
        - iii. Caseload/Numbers of clients
        - iv. Additional assessments

The second guide was for the caregiver's interviews and followed the same pattern as the social workers interviews; it was divided into four themes:

1. The first theme explored their caregiving experience and was divided into two sections:
    - a. Care recipient status
        - i. Duration of illness and caregiving
        - ii. Caregiver self-identification
    - b. Present situation
        - i. CLSC services
2. The second theme focused on the loss of autonomy assessment process of their elderly relative:
    - a. Their understanding of the process
        - i. How it was explained
        - ii. Their participation
    - b. The results
        - i. Expected or not
        - ii. What services were offered
3. The third theme examined their expectations for care
    - a. Description of expectations
        - i. Inclusion of caregiver
        - ii. Communication of expectations to social worker
        - iii. Satisfaction of expectations
4. The fourth theme explored the meaning of loss of autonomy
    - a. Loss of autonomy meaning
        - i. Effect on their life
        - ii. Agreement of definition between caregiver and care receiver

In the case of both interview guides, each theme was followed by a series of sub questions that could be used as follow-up, if necessary.

For the caregiver's discussion group interviews, a shortened version of the interview grid was used and the questions were posed using plural pronouns to reflect the composition of the group. During the process and as the data were gathered and analyzed, the questions were modified as necessary. Copies of the complete interview guides can be found in Annexes 9 & 10 located at the end of this thesis. The interviews were recorded and once all of the recordings had been transcribed, a deductive coding process allowed for detailed analysis.

Data analysis – Miles, Huberman & Saldana (2014) recommend *anticipatory data condensation* (p. 18) - a process in which the researcher prepares a list of preliminary codes based on the research design, knowledge previously gathered (example: from the literature review) and the targeted areas of research. These early codes can help guide the interview grids and early analysis; they will be augmented throughout the process of interviewing, memoing and note taking, and analysis. This process was also possible because of the researcher's familiarity with the domain of study and the previous pilot study that had taken place. Below is an example of how the preliminary codes related to autonomy were formulated for caregiver's expectations.

Figure 9: Illustration of a start list of codes for Expectations (Caregivers)

(Source: Miles M.B., Huberman A.M., Saldana J. (2014). *Qualitative Data Analysis: A Methods Sourcebook*, Thousand Oaks, Sage Publications)

CATEGORY: Services	ABBREVIATION: SER
SER – no expectations	SER-NE
SER - support	SER-SUP
SER - information	SER-INF
SER - placement	SER-PLA
CATEGORY: Autonomy	ABBREVIATION: AUT
AUT – decisions	AUT-DEC
AUT – loneliness	AUT-LON
AUT - socialization	AUT-SOC
CATEGORY: Assessment	ABBREVIATION: ASS
ASS – no expectations	ASS-NE
ASS - disappointment	ASS-DIS

ASS - Placement	ASS-PLA
CATEGORY: Social worker (Expectations of)	ABBREVIATION: SW
SW - Positive SW - Negative SW – Don’t know	SW-POS SW-NEG SW-DK

Figure 9 Initial coding of expectations

The researcher kept a personal journal throughout the process which, in fact, proved to be invaluable in helping to maintain a reflexive position in analyzing the data. Analysis of the field notes and the transcribed data were initially done with the computer program QDA Miner but that proved to be more complicated than needed. The data was then transposed to a WORD document that ultimately proved to be more useful because it provided more control over the data and eliminated superfluous categories. Tables were created in the WORD document and each question and sentence was treated as an individual, numbered statement. Two adjacent columns allowed for the identification of themes and codes which were highlighted in different colours. On the basis of the transcription of the interview recording a first content analysis was performed to verify the preliminary codes and in order to construct themes and sub themes. The themes were regrouped into categories to arrive at a second level of analysis. Subsequently, the codes were reorganized and regrouped in another table under appropriate themes. In this way, the interviews provided comparative data on practices, interpretations and expectations of evaluation. Storylines were ultimately labelled and inserted in another table. See Figure 10 below as an example.

Themes: A = Blurring/Merging of identities, (placement) B = care receiver agrees, C = care receiver is a non-participant in decision, D = decision is mutual, E = decision is taken out of cg hands
F = SW was helpful and supportive (X1) or unhelpful (X2), G = surprised at quality of services
H = you’re stuck, I = loneliness, J = living widow, K = still organizing life around their needs
CG = Caregiver, ltc = spouse in long term care, ho = spouse living at home, de = spouse deceased. SW = social worker

STORYLINES

Character	Assessment/relationship w/CR					Expectations		Loss of autonomy			
Type	A	B	C	D	E	F	G	H	I	J	K
CG 1-ltc	X	X			X	X2			X	X	X
CG 2-ltc	X		X		X	X2			X		X
CG 3-ltc	X		X		X	X1	X			X	
CG 4-ltc		X			X	X1					
CG 5-ltc	X	X			X	X1	X	X	X		X
CG 6-ltc	X	X			X	X1		X	X		X
CG 7-ho	X	X				X1		X			X
CG 8-ho	X			X		X1					X
CG 9-ho	X			X		X1	X	X			X
CG12- de	X		X		X	X1		X	X		

Figure 10 Caregiver storylines

Miles, Huberman & Saldana (2014) suggest that in an inductive approach to data analysis, recurring themes and phenomenon in the data leads to the discovery of links and relations between them. A double codification strategy was used to this. Excerpts of the transcribed interviews were assigned to the various pre-determined themes. Then, a more inductive procedure was used to identify further categories and themes. First, verbatim excerpts were assigned to descriptive categories and were then merged to produce more conceptually dense categories. As the analysis advanced, categories were confirmed or modified as the analysis of other interviews were added.

The next chapters will present the results of the pilot study of the OÉMC questionnaires, the interviews with family caregivers and the interviews with social workers.

7. RESULTS

7.1 INTRODUCTION

The context of this study and the problematic it addresses were outlined in the previous chapters, now, the research results will be presented in the following way. The first part of this chapter offers the results of the two stages of the pilot study and how it served as a springboard for the larger study and ultimately, this doctoral research. The results of the interviews with social workers have been separated into in two stages. The first offers the analysis of their interviews as regards to their opinion and usage of the OÉMC (Objective 1). The second stage describes the interview results in relation to their expectations of caregivers (Objective 2a). In the third section, continuing with the social workers interviews, the focus shifts from their own expectations to the macro perspective of the previously mentioned healthcare reorganizations and neo-liberal policies that have influenced the expectations placed on them by their managers and bureaucratic organizational policies (Objective 2c) and how that has impacted their own professional practice. This section also offers a discussion on the changing face of social work. This section terminates with the presentation of the Social Worker Expectations Adaptation Process.

During the interviews with family caregivers they were first asked what their expectations were for services and support (Objective 2b), then they were asked about the meaning of autonomy and loss of autonomy (Objective 1). Then caregiver's responses to the question posed to them on the meaning of autonomy. This is followed by some additional findings from the caregiver interviews that deepen our understanding of the notion of expectations and also presents the Caregiver Expectations Adaptation Process that was conceptualized from these results that, although not directly connected to the research objectives, nevertheless, they have some relevance in regards to the overall theme of the research.

First, a reminder of the research questions and the objectives of the research:

The general objective of this study is to understand what is at stake concerning the assessment of loss autonomy of older people in Quebec. More specifically, I would like to understand the centrality of an assessment tool like the OÉMC in current landscapes of care, the importance of autonomy within the health care system and, especially for evaluating needs of older people, and, finally, understand the different expectations involved in the process of evaluation.

Research objectives:

1. To better understand the assessment process of loss of autonomy in elderly homecare clients, its origins and how it is understood and defined through the perspective of the social worker, family caregivers and the public health system.

2. To explore the expectations of different social actors involved in the evaluation process by juxtaposing the following perspectives and to determine how these sometimes conflicting positions can influence the negotiation for care of the elderly client and their potential impact on service delivery:

    a) Social workers perspectives and expectation of the caregiver's role in caring for an elderly relative;
    b) The expectations of support and services harboured by family caregivers of the elderly.
    c) The performance norms and expectations imposed on social workers.

Research questions:

How do family caregiver's, social worker's and the health care system's expectations influence the standardized assessment of loss of autonomy of elderly home care clients and how does the assessment process itself influence expectations?

- Which role does autonomy play in the process of evaluating older people's loss of autonomy?
- Which role do assessment tools such as the OÉMC play in current landscapes of care?

7.2 THE PILOT STUDY

The pilot phase of this project took place over a period of three years and was developed in two stages.

7.2.1 Phase one of the pilot project

The first phase of the pilot project was launched as a result of an application for funds that had been made available to practitioners working in the CREGES research centre who wished to further explore a question related to their practice. In this case, it occurred as the result of questions I raised about the assessment instrument (OÉMC) in regards to how loss of autonomy is measured and how caregivers were included in the evaluations. During this phase, the psychosocial sections of 32 randomly chosen, completed questionnaires were examined in detail. The decision to focus our attention on the psychosocial part of the questionnaire for our study was made because we felt the questions in this section are most susceptible to the subjective interpretation by the assessor by offering more leeway to record their written impressions of the user. For instance, the questions themselves are all accompanied by several blank lines in which they are expected to write a few sentences in response. The SMAF section, in contrast, is largely completed by checking boxes.

The questionnaires to be studied were chosen by the CIUSSS Archivist who was provided the following parameters: it must be a first time OÉMC assessment done within the 12 previous months, conducted by any SAPA professional. No guidelines or restrictions were provided as to age since SAPA clients are all over sixty-five, or gender, or the personal situation such as living environment, of the assessed person. The archivist then supplied a list of 32 client dossier numbers that met these criteria, as well as a personalized password so they could be accessed on the computer through the OACIS system[46]. The profile of the persons being assessed in these questionnaires included 24 females and eight males ranging in age from 71 to 100; the mean age was 87. Twenty-three lived alone, six were married and lived with their spouse and five lived with their children or other relatives. Among the twenty-three who lived alone, three were in residences for semi-autonomous seniors and one was in temporary placement for medical issues. They were experiencing a variety of physical and mental health challenges and various degrees of autonomy.

The aim of this pilot study was to get an overall picture of how the psychosocial part of the questionnaire was completed, looking for potential inconsistencies, anomalies, or patterns. In our examination we also included the last page of the questionnaire, which is meant to summarize the situation of the user and that showed how evaluators sometimes highlighted and privileged certain issues found in the OÉMC questionnaires.

In summary, the objective of our study was focused on *how* the psychosocial section was completed within the 32 questionnaires; not so much on *what* was said but rather, whether *anything* and *how much* was indicated by the assessor regarding these nine categories. Each of the nine categories of the psychosocial section of the OÉMC is accompanied by several explicatory words to assist the assessor in completing the form. The text of this section of the OÉMC has been reproduced verbatim below (Figure 11).

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[46] OACIS (Telus) is a clinical information system implemented in Québec healthcare that consolidates patient data into one central repository. It centralizes patient information to provide a complete summary for health professionals of the patient's health condition, status, treatment plan and test results. Source: https://www.telus.com/en/health/organizations/health-authorities-and-hospitals/clinical-solutions/oacis

1. *Social history*: Occupation, married, divorced, mourning, education level, immigration, moves, other major events, etc.
2. *Family situation*: Family makeup (age, sex, place of residence or genogram); Family dynamics (interaction of user with family and family members with each other, user's satisfaction with family situation, how the family reacts or is affected by the user's situation, signs of abuse, violence or negligence, etc.
3. *Main caregivers*: Involvement, level of fatigue, impressions of their situation, expectations, desire to get involved, etc.
4. *Social network*: Including school and work environment; Significant persons (friends, neighbours, colleagues, teachers, etc.); Relationship dynamics (interaction of user with members of his/her social network, satisfaction of user with regard to his/her relations with them, how they react to or are affected by the user's situation, signs of abuse, violence or negligence, etc.)
5. *Community, public and private resources*: Volunteers, associations, day centers, paratransit, services included in lease, etc. Specify the type of services, their frequency, and the user's interaction with them.
6. *Affective state*: Mood, self-esteem, feelings of usefulness or isolation, anxiety, etc.
7. *User's impressions*: how user perceives his/her situation, reacts or adapts to it, motivation, solutions envisioned, etc.
8. *Sexuality*: satisfaction of user, preoccupation, socially unacceptable behaviors, etc.
9. *Personal, cultural and spiritual beliefs and values*: (e.g. impression) Difficulties experienced or specific observations, no/yes, specify.

Summary (p. 20): Context of assessment, urgent problem's identified, users expectations, risk factors, suggested orientations.

Figure 11 Psychological section of the OÉMC (p. 17-20)

The most frequent types of responses identified were: 1. Not answered (section blank), or, no particularities, 2. Not (or none) applicable, or, 3. A brief statement. Each of the nine questions of the psychosocial section also has a place to answer 'yes or no' where the assessor can indicate whether or not a problem has been identified, the column on the far right displays the frequency of the 'yes' answer. Figure 12 below provides a tabulation of the answers.

	Not answered or no particularities /32	Not (or none) applicable /32	Brief statement /32	Problem identified
1. Social history			32	x 2
2. Family situation			32	x 5
3. Main caregiver			32	x 6
4. Social network	1	1	30	x 4
5. Community, public and private resources	5		27	x 3
6. Affective state			32	x 5
7. Sexuality	19	11	2	x 0
8. Personal, cultural and spiritual beliefs and values	9	4	19	x 0
9. Personal and environmental safety	8	7	17	x 6
Summary			32	

Figure 12 OÉMC responses (psychosocial)

The length of the written responses (brief statement) ranged from as short as one word (e.g. on three occasions the word 'self' was indicated in response to question 3 regarding the caregiver), to several sentences, with question 10, the 'summary' section generally providing the most details about the person being assessed. For the first three categories: social situation, family history and main caregivers, a brief statement was provided in all cases. Most of the questions were answered with a statement of some degree or another, with a few exceptions. For instance, the question on sexuality was indicated as 'no problem' or left blank the most often.

In many instances, the amount of detail provided in the information was inconsistent both *within* and *between* the assessment instruments. As an example, a closer inspection of question 3, which investigates the caregiver's situation, revealed the following: of the 32 questionnaires, 9 of the answers indicated that there was no caregiver in the picture. As mentioned above, in the three cases where the respondent answered ‘self’ they were indicating that they felt they were independent and took care of themselves, or, felt they needed no help. Among the remaining 23, some answers to question 3 were very short, as in; “*her son*” and “*positive relationship*,” others were more informative about the caregiver’s situation: for example: “*Dtr is main caregiver, has a lot on her plate, very resourceful and open to help client and spouse.* Comments*: A lot of responsibilities, but managing so far. Would appreciate some help with things*.” (OÉMC23) Overall, of the 32 responses to question number 3, thirteen provided some (minimal) information about the caregiver’s status and of those thirteen, six were signaled as a problem situation.

Although question 3 is intended to identify caregiver needs or problems, there seems to be some overlap in these answers with those of question 2 ‘family situation.’ In five of the six cases where a problem was indicated for question 2, a problem was also indicated for question 3. Perhaps indicating problematic overall family dynamics, but nevertheless, a potential rich source for information about the caregiver as well. Where there would seem to be some area for potential problems would seem to be related to the questions not answered at all or with such brief answers they provide little information. Since the client dossiers are accessible to all health professionals involved in each case, it could cause some confusion for others doing follow-up on the same client.

Conclusion phase one: From a first analysis of the 32 questionnaires we found that the way this evaluation instrument is being used by health professionals often shows the importance of physical functionality over social criteria, as well as a certain ambiguity towards complex social issues. Some questionnaires provided a lot of detail about the person being assessed, their family and their caregivers and others were very sparse. The lack of consistency between and within questionnaires is an area that would need to be clarified with healthcare workers because there could be potential repercussions on the clients and caregivers in terms of support and services.

The first phase of the pilot study helped to answer some of our questions about the application of the OÉMC, but it also confirmed that further exploration was required if we were to truly understand all of the dynamics associated with measuring loss of autonomy in the elderly. Although this small sample of questionnaires cannot be considered representative, it did however provide some guidelines for the areas to explore in the subsequent interviews with health professionals.

7.2.2 Phase two of the pilot project

The objective of the first part of phase two of the pilot study which began in 2014, was to continue the exploration that began in phase one in order to study the questions in more depth. Three initial questions guided the research:

(1) Why is autonomy such an important value in many western societies and, more specifically, in elder care?
(2) How is the development of the OÉMC discussed in literature in relation to the health and social service system?
(3) How exactly do practitioners apply the OÉMC, and what does this reveal about the central dimensions measured by this screening instrument in terms of: time management, health professional's value system and related interventions and services offered to the older person?

Question one was investigated through an extensive interdisciplinary literature review that traced the theoretical development, and multidisciplinary critiques of the conventional conceptualization of autonomy as it relates to health care generally, and more specifically, for aging populations. The literature review was guided by questions that led to an examination of the genesis of the autonomy concept in Western philosophical and liberal thought. Critical perspectives from both the bioethical and medical literature as well as the social sciences – particularly of anthropology and feminist theory were investigated. The broader theoretical exploration was grounded in an examination of autonomy in the specific context of aging and long-term care challenging normative conceptualizations of autonomy in the aging process. An abridged version of the final forty-seven page document, which highlights the main points it contains relevant to the doctoral thesis, with the addition of other pertinent references, was included in chapter three.

The second question, which was in regards to the OÉMC itself, was addressed through another literature review that explored the development of the OÉMC, assessment tools and their general application to an aging population. A deliberate focus was put on the history of the instrument in Québec but comparisons are made to other tools employed elsewhere in Canada and other countries. Particular interest was paid to critiques of assessment instruments in healthcare and their impact on the intervention process and dispensing of services. The result of this literature search was also presented in chapter three of this document.

We elected to seek answers to the third question through informal exploratory interviews with healthcare professionals, managers and researchers. The overall objective of these interviews was to gather general impressions about the OÉMC and the assessment process from a variety of homecare professionals. The duration of the interviews ranged from thirty minutes to 1 hour. Recruitment was done on an ad hoc basis through word of mouth and personal contacts. (ie. at meetings or through informal encounters where people were asked if they would agree to a short interview. Interviews were done with: 3 Social Workers, 1 Nurse, 1 Physical therapist, 1 Occupational therapist, 1 SAC (*soutien aux activités cliniques*) supervisor in a long-term care institution, 1 CAP (*chef aux programmes*) SAPA, 1 researcher in aging issues at UQAM, and 1 researcher and her assistant in a long term care institution. As well, email communication with Nicole Dubuc, one of the developers of the OÉMC to clarify some points regarding the algorithms of the questionnaire too place. The informal discussions were not recorded but notes were taken. The questions posed to the health professionals and researchers, which were based on the results of phase one, centered on the application and utility of the OÉMC and we also interrogated them about the reason for completing or not completing certain parts of the questionnaire.

All of the people questioned expressed positive comments about the instrument overall, recognizing it as an obligatory and necessary part of the job. When asked to elaborate on any issues or challenges they encounter or have heard of in administering the tool their responses highlighted the exceptions to the 'norm.' That is to say, when the questionnaire is utilized in standard circumstances, such as the person's home, to an individual who fits the normal and expected loss of autonomy profile, then the instrument is effective. Examples of exceptions to the norm were provided by a social worker who stated that when other social issues like mental health problems or social isolation are part of the user's profile, then the results become less reliable since these issues are not always identified on the first visit, nor are they included in the person's Iso-SMAF score. Another mentioned what she believes is a gender bias in the questions; she felt they are more slanted towards a woman's situation and they had to invent their own examples for their male clients.

When we questioned why some questions were not completed or not asked, we were told that if they felt it was not pertinent to the situation of the client, they didn't ask it. One person told us that there is some leeway in how the questions are asked since, "*The worker has an instinct that comes with experience about which questions to ask – or not bother to ask.*" (Clinical supervisor) Another social worker told us that the question about sexuality is often not raised with the person being assessed because it makes many workers as well as the older person uncomfortable. She cited as a typical example the discomfort of a twenty year old female social worker asking an elderly man about a question about his sexuality. Another person whom we met with who is doing research on the topic of aging and sexuality informed us that this is not uncommon. As the researcher told us, the question is included in the form because it should not be a taboo subject, but nevertheless, old attitudes and prejudices harboured by many people still make it an uncomfortable topic for discussion.

Two of the people we questioned during our exploration mentioned some of the challenges related to the application of the OÉMC when it is administered in a long term care setting. According to government regulations, the OÉMC must be redone every year regardless of whether the person is still living in the community or in an institution. These two respondents speculated that administering something so complex and time consuming as the OÉMC to institutionalized patients may be unnecessary when the person is already in long term care. She felt the amount of time spent on it was a waste of resources and often put a great deal of stress on the already overburdened staff, suggesting instead that a simpler version would be more appropriate in an institutional setting. When we questioned why it was done this way we were told that the assessment result, even in institutions, is linked to the patient's Iso-SMAF score and subsequent budget allocations. We also learned from them that the Iso-SMAF score of 10 or above as a criterion for placement was not always respected and that about thirty percent of the patients in their facilities had a score lower than 10. They were in the institution for reasons other than their score, such as isolation and having no resources. This demonstrates that, especially in a placement scenario, other factors that have no impact on the Iso-SMAF score such as lack of support or social network, must also be taken into consideration. The results of these discussions helped to conceptualize the theoretical framework for the eventual, larger research project.

As mentioned before, to further our knowledge and gather more insight into the application of the instrument N. Gilbert and A. Leibing participated in the ten hour training sessions for professionals on the OÉMC. As well, it came to our attention that another research team at CREGES headed by Patrik Marier, the research director, was also investigating the concept of autonomy on an international scale. We were invited to participate in some meetings with this team to explore areas of common interest and collaboration. This eventually led to another application for funds for a larger project from the Canadian Institutes of Health Research (CIHR) in 2015 which was unsuccessful.

In 2015, having completed the first part of phase two, we began to explore what further steps we could take to continue this project. After examining the data sets that had already been gathered we were able to make some preliminary observations. First, we realized that the notion of autonomy is complex and that when employing the rather narrow definition of 'loss of functional autonomy' as the criteria for determining care, support and services for the elderly, it falls short. This point was raised in the previous section on the discussion on relational autonomy and how employing this concept in assessment would provide a more global portrait of the person being assessed as well as in the section on criticisms of assessment instrument. As a running theme, it is also included in a later part of this thesis; the discussion and conclusion. Second, measurement instruments such as the OÉMC, while efficient at supplying biometric data on the person related to their functional autonomy, produces ambiguous, and obviously subjective results regarding the older persons' psychosocial situation – an assessment that additionally can be influenced by the assessors' time constraints, personal values, experience and caseload. Third, our conversations with healthcare professionals, researchers and managers gave us the impression that some of the distress they were observing and vocalizing was due to the disappointment and disillusion they felt, which by our observation, appeared to be based on expectations of a rewarding job in an efficient healthcare system. In this manner, the topic of 'State' expectations and their influence became an issue that we felt required further exploration.

Thus, the project was continued with the addition of two other research questions. (1) How do assessed patients and assessing health professionals differ in their understanding of the various dimensions of the OÉMC? And, (2) What are the expectations of assessed elderly and health care professionals regarding optimal interventions within a given health care system? This phase also launched the doctoral research study of N. Gilbert that began in September, 2015. The research question were altered eventually to include family caregivers instead of the assessed elderly patients for reasons of their incapacity. This decision is explained in more detail in the thesis. These questions were eventually adapted to become the research questions and objectives of the doctoral thesis.

7.3 INTERVIEWS WITH THE SOCIAL WORKERS

This section presents the results of the interviews with social workers that examined how their expectations were influenced from two different, but not opposing, perspectives. The first is their perception of the OÉMC and their expectations of it as a tool to assist them in their work. This point of view was selected because the OÉMC assessment often represents one of the first points of contact between social workers, elderly clients and family caregivers. The second perspective is their expectations of family caregivers who are providing care to their elderly clients. This angle was chosen because the inclusion of the family into care emerged in the pilot project, but is also a critical point in the literature (e.g., Wolff et al. 2016). Thus, the results of the interviews are divided in two parts. Part one begins with an analysis of the interviews with social workers regarding their perceptions and expectations of the OÉMC as an instrument that helps or hinders their assessment tasks. Part two then presents the analysis of the interviews from the perspective of their expectations of the family caregivers.

7.3.1 The assessment instrument (OÉMC)

“The OÉMC is not really a dynamic portrait of the person’s autonomy; it’s how they are at their worst.” (SW6)

In the previous chapter, the dynamics of loss of autonomy assessment of the elderly was presented with a focus on how the process has become one of datafication and categorization. This process is efficient for budget and resource allocation because it provides concrete evidence of the person’s needs. So, the OÉMC instrument itself quantifies the functional autonomy level of the aging person, while seeming to pay less attention to the person’s psychosocial situation which reflects their quality of life and the humanistic values of the social workers intervention. This raises the question then, of how social workers reconcile their expectations of being able to provide support and services to their clients with their expectations of the OÉMC itself. Is it then a help or a hindrance for them?

The interviews revealed that social workers encounter two specific challenges related to the task of loss of autonomy assessment of their elderly clients. The first challenge is related to their perception of the instrument itself, and their expectations of its efficacy or hindrance in their role as evaluator of the elderly client’s loss of autonomy. The second challenge is regarding organizational changes that have occurred over the last years in relation to administrative tasks and the working climate that have made some of their responsibilities more challenging. According to the respondents, the changes that have been initiated and the expectations for performance and productivity that have been placed on them, has transformed their traditional, humanistic role to one more closely related to marketization principles. Organizational challenges and expectations of social workers will be discussed in more detail in a later part of this chapter. Eight themes were identified in their answers which reflected their concerns regarding how the assessment is completed by their co-workers, the way it is formatted, its pertinence for creating a full portrait of the elderly person's needs, its length, and its content. A copy of the interview is included in the Annexes. Figure 13 below presents a summary of the main themes identified.

1. A guarded positive opinion of the OÉMC
2. Inconsistent utilization by others
3. The manner in which the OÉMC is formatted
4. The types of questions being asked.
5. The time required to complete the questionnaire
6. The exclusion of family caregivers needs in the assessment
7.The efficacy of the Iso-SMAF score for reflecting client's reality
8. Recommendations for improvement of the OÉMC

Figure 13 Themes regarding the OÉMC

1. A guarded positive opinion of the OÉMC

During the interviews with the social workers, when asked about the OÉMC it was striking that in general, their first response was positive but with qualifiers. In fact, no one with whom we spoke gave it a whole-hearted endorsement. What actually became apparent during analysis of the question on the OÉMC was that most felt that some sort of assessment instrument is important but that the one they were using could be improved.

2. Inconsistent utilization by others

In their answers to questions on their opinion of the OÉMC, many social workers made comments on how it is completed by others. Comments included statements like: "*if used properly*," seeming to imply that it is not always correctly completed by their colleagues. Follow up questions for clarification revealed that many had the opinion that on occasion, other workers sometimes took shortcuts by not always filling in all the required information, making it more difficult for other members of the multidisciplinary team to follow-up. When data is not entered correctly by one worker and other workers later review the file, if they don't know what was meant by an answer they have to spend valuable time tracking down previous case managers to verify the information. One social worker, who described feelings of frustration when reviewing an incomplete client file that had been transferred from another worker, made the following comment, "*So I suspect that a lot of our updates, a lot of the times that we do them they are not done as thoroughly as would be professionally ideal. So it's a bit fast, we're always under the gun*" (SW5).

3. The manner in which the OÉMC is formatted

One of the peculiarities of the OÉMC electronic version is that it is formatted in such a way that each question must be answered before the person entering the data can move on to the next one. During the training sessions in which we participated we learned that to get around questions that they feel are irrelevant or they don't want to ask, they sometimes fill it out with 'NA' (not applicable) or even a symbol '*' that would allow them to move on. The example most frequently given for this behaviour was the question in the OÉMC form on 'sexuality' (Psychosocial section, no 8), which some felt made the clients feel uncomfortable. This comment is also confirmed in our analysis of the 32 OÉMC questionnaires that was done during the pilot phase of this study. The question on sexuality was in fact the one most frequently not answered. As will also be discussed in a later section, the awkward programming of the form itself on computer dictates the order in which the questions must be asked, which they felt compromised their more informal way performing the assessment to gain the trust and confidence of the of the person being assessed and their family members who are present. This was also one of the reasons provided for not bringing the computer with them to complete in the home.

4. The types of questions being asked

As several social workers admitted, they were also occasionally uneasy in asking questions about sexuality to the elderly client. The content of the questionnaire was thus brought into question. Questions they consider irrelevant to the person's situation are not asked as is reflected in the following comment; "*…if I already know the answer I don't ask the question or I fill it in as 'non-applicable*" (SW4). .

5. The time required to complete the questionnaire

Time, or lack of time to do everything the OÉMC requires was mentioned frequently by the social workers. The questionnaire is long, the time allotted to do it is insufficient and sometimes, for the social worker, creating a trusting relationship with the client is a higher priority. As one said; "*It takes about an hour and a half to do the first assessment but it takes several visits until we can really get to know them*." (SW6). There is a lot of pressure on social workers to create the most accurate picture possible of their client's situation in a very short timeframe, but many expressed during the interviews that to create a true portrait takes time which they don't feel they have. The expression '*it's a snapshot'* was repeated several times by many of the social workers interviewed. The snapshot reference is related to the perception that when they do an assessment, they are only seeing the reality of the person on that given day and that time, since on another day and another time the client can present a totally different picture. Some respondents expressed frustration with this since, in the traditional social worker role, relationship building is very important, but because of the way things had been organized, there was no time for that anymore. Many felt the length of the questionnaire was a deterrent to creating a therapeutic relationship with the older person.

Also referring to the time it takes to do assessments one social worker said: "*…it's a good 70% of our work…*" (SW4) Assessment for placement of an elderly client in an institution is even more complicated, "*To do placement applications we used to have 10 days. Ten business days to complete all the paperwork. It was brought down to 5 last year and then 2 months ago it was brought to 4*" (SW5).

6. The exclusion of family caregivers' needs in the assessment

The OÉMC assessment is of the elderly person who is the primary client, but many times there is a family caregiver present who plays a key support role. Social workers are very aware that caregivers often need support themselves, however, time spent with them cannot be counted or 'statted' as they face organizational pressure for time management. Every intervention has a code which is entered into the computer and these statistics used to they account for time spent with clients. As one social workers said; "*Our services are not geared to caregivers; they're geared to the client*" (SW4). Several respondents mentioned that although the family caregiver's compensatory role is acknowledged in the assessment, there is no formal means included in the instrument to evaluate if they are performing their tasks adequately or willingly, or even if they are at risk for burnout. As one social worker stated; "*There's nowhere to say it on the form that the person who's compensating is actually having trouble or is overwhelmed…*" (SW3) They must stay alert for caregiver burnout; "*The caregiver may say its fine, I'm compensating. But in your follow-up you see that the caregiver can't, it's too much for them*" (SW1). And, as another stated; "*So it's very objective, it's not ... there no nuances in the scoring whereas there are a lot of nuances within the psychosocial clientele*" (SW6). For example, there is a small section of the OÉMC that covers the capacity of the caregiver but, as one worker put it, "*…this is the part we gloss over a lot of the time*" (SW5). Because, as another pointed out, "*we know that it will not change the score* *and completing it takes more time*" (SW3). Several mentioned that they liked it when a family caregiver was involved and present during the assessment, even though it sometimes made their job more difficult if the family member interjects and answers for their client, or calls them on the telephone a lot, or insists on things that they are unable to provide. In reality, the fact that there is a caregiver in the picture can actually influence the resulting OÉMC score because they are considered a compensating factor and as such, their contribution could change the handicap score. The social workers interviewed were very aware that supporting the caregiver was also important. As one respondent said:

> *Because it's a negotiation to get the client to accept some help and the caregiver to let go of some of the tasks and allow some other people to step in. In fact, the caregiver is the resource. ...they should be, because they're the one compensating. Part of your assessment is to see that the caregiver is comfortable to do the tasks (SW6).*

Caregivers are not considered clients and as previously mentioned, they are not included in the statistics that are gathered for the client, therefore in that sense they don't count. However, sometimes there are multiple family members caring for one individual, who are at odds with one another about the best way to care for their elderly relative. The presence of several caregivers can be helpful but, on occasion, can also complicate things. As one social worker remarked: "…*we're assessing a situation and there's a caregiver usually present but there are many caregivers we don't assess*" (SW4). And, "*We assess the caregivers who's present. But how many caregivers are out there that we don't assess*? […] *We are assessing one part of a very small reality*" (SW5). Also, as was pointed out if the caregiver is compensating for the elderly person's loss of autonomy, but not being evaluated, it is never sure how long they would be able to do the job.

7. The efficacy of the Iso-SMAF score for reflecting client's reality

For the client being evaluated a great deal rides on this one assessment since services are allotted according to the score. Inconsistency of a score that doesn't match the expectation of the social worker is an illustration of how the OÉMC is not always efficient in measuring changes in the psychosocial situation and in social autonomy. As one said, *"The score is important, too important maybe. So you really want it to be reflective of the client's reality because it influences your ability to get services and it influences your ability to get into residential care. So there's a lot riding on that number"* (SW3). Many respondents also mentioned that the score does not always reflect the impact that cognitive deficits can have on reality of the client nor their lifestyle. "*The 1 or the 2 that these people get sometimes makes it sound like they're doing really better than they are when really they're very, very vulnerable*" (SW5). For them, it's not just that the client is not able to do something related to functional autonomy, but also it's the impact on their life and social autonomy this deficit has. For example, a person may have mobility issues but may not also be cognitively impaired. "*So there's not just physical loss of autonomy but there's still things to process, like change of lifestyle and that's not reflected anywhere except in your psychosocial evaluation"* (SW6).

Some also expressed the opinion that the tool does not adequately reflect the social challenges of the client, since the score is the determinant for services and when the score is lower than expected it makes it harder to get services for them: "*The clients are very isolated and the social score doesn't reflect in the OÉMC*" (SW1). And the voice of the client and caregiver is unheard. "*There's not always a lot of room for the client or the elderly person to say this is where I need help…" and functional autonomy is prioritized over psychosocial "…it's not in the mandate of the OÉMC to talk about their feelings or impressions*" (SW3). When the score does not reflect the true status of the client who needs support for their social needs even if they are relatively functional, social workers must expend valuable time to advocating for the client, sometimes unsuccessfully, with their supervisors in order to convince them that services should be offered.

As mentioned above, advocating for a client whose score does not reflect the reality of their situation is not always successful. As one respondent said: "*The Iso-SMAF score does not reflect the psycho-social situation of the client at all. It might say that there are memory problems but it doesn't say how they are dealing with it, how the family is coping, what kind of information they have on it*" (SW5). One worker explained how when she was unable to get the needed services for a client just being released from the hospital, it was embarrassing, because she had already told the client what she would get, "*I got back and it was refused, it was waitlisted! I had to go back to her and eat humble pie. Because I thought I had done a good… I'm really evaluating the details*" (SW5).

8. Recommendations for improvement of the assessment

Another challenge the social workers frequently mentioned was related to the current organizational climate and the introduction of performance indicators and supervision related to what is discussed in research as the New Public Management policies (NPM) which have been introduced in the last decades. Overall, as previously stated, social workers who participated in this research stated that they appreciate the assessment tool; however, some indicated that they have encountered some specific challenges in its application. That is, clients of social workers often present with psychosocial issues which are not taken into account in the Iso-SMAF score, requiring them to expend valuable time advocating for their clients whose 'score' does not match their reality.

In this light, a few suggestions were made for improving the OÉMC and its process. Some suggested that when an elderly person is assessed there should also be an evaluation of the caregiver's skills and even their willingness to be a caregiver; in fact actually having another tool at their disposition. Although, one has to question whether that would just end up being another form to complete that gets left by the wayside. One social worker was adamant; "*I would make it systematic that you would do an evaluation with the client and then you would also have time to do an evaluation with the caregiver*" (SW6). Another suggested that having a more complete history of the client's past and how they were before would help them tailor the care plan better to meet their needs. Several social workers wished the implementation of the form was more efficient as well as less cumbersome, "…. *do we really want to spend this much, 30 to 40 dollars an hour for people doing paperwork*?" (SW5) In this instance, the respondent was referring to the hours of follow-up, clerical-type duties and telephone calls that are required post-assessment. It was also suggested that some of the tools for caregivers that already exist are not being used to their best capacity. "*We don't use the tools that we should with some of the caregivers, written information, short videos. Things like that; that are available…*" (SW6)

7.3.2 Social workers expectations of caregivers

As was discussed in the previous chapter, over the last decades the State has transferred a major part of the responsibility for care of the elderly to the family and the community and the toll this has taken on family caregivers is well documented. While the community may have been marginally consulted in this decision process and some assistance provided to them to develop community resources, aging spouses and adult children who were expected to assume this care had little say in the matter. As such, it was apparently assumed that they would step in, so that now, according to the Health Council of Canada (2012) seventy to eighty percent of care to the aging population is provided by informal caregivers. As representatives of the public health system, social workers, like all health professionals must respect the guidelines that follows the government's expectations that the family will assume the care of their aging relative. In our interviews we asked social workers about how ‘the system’ dictates the expectations of caregivers and if this creates any conflict with their own personal or professional values.

Overall, the interviews revealed that social workers have a great deal of appreciation and respect for the important role caregiver’s play in the support and care for their family members. However, many acknowledged that maintaining the delicate balance in their relationship with family caregivers can be challenging. Reflecting on the ambivalence of this relationships, some social workers suggested that they do not want to empower the caregivers in their interventions so much that they become too demanding. This sense of maintaining balance and keeping the relationship somewhat ambiguous is not an apparent willful act on the social worker’s part in order to take advantage of, or to confuse the caregiver. It is rather, an acknowledgement of the complexity and evolutionary nature of the caregiver’s role that sees them move between reporter and advocate for their family member to unofficial client in need of support services of their own. Interestingly, the data analysis of the interviews with social workers also reflected similar results describing the roles of caregivers already discussed in the previous chapter on expectations of caregiver (See, Guberman & Maheu, 2000; and Twigg, 1989). Analysis of the interviews with social workers revealed three main themes related to social workers expectations of caregivers (Figure 14):

1. Caregivers are expected to be **reporters** and **information givers**. This category sees the caregiver as a collaborator and partner in the care of the elderly family member;
2. Caregivers are expected to act as the **resource** and **compensator**. In this theme, the caregivers assume many of the instrumental tasks of caring for the client;
3. Caregivers are expected to be **help seekers**. The help they seek is usually for the client but sometimes also for themselves.

Figure 14 Social workers expectations of caregivers

1. Caregivers as reporters and information givers

The expectation that family caregivers play the role of reporter and informant regarding the status of their care recipient is grounded in the reality of loss of autonomy assessment. As mentioned previously, the assessment creates a snapshot of the persons situation at a given point in time, and any alterations in the situation where the person being assessed worsens or deteriorates, must be communicated to their case manager either by the person themselves or a concerned family member. The caregiver plays a key role in making sure this is done. Experienced social workers make great efforts to promote collaboration and partnership with the caregiver that would allow them to benefit from their proximity to the situation. Also, caregivers, when present during the assessment, play a key role in helping the social worker determine the needs of the elderly client. During the assessment and even after, social workers expect that family caregivers will be their "*eyes and ears on the ground*" (SW4) because the "…*family has much more of a view of the situation than I do*" (SW2) and to "… *keep me in the loop of any changes*." (SW5) Other interviewees shared the same opinion, although some felt the caregivers have "… *a tendency of speaking for but … they are also a wealth of information*." (SW2)

To create the trusting relationship with the family caregivers that will lead to open communication and information exchange, social workers sometimes must first clarify why they are there. For other professions the reason for doing the assessment is usually clear, the function of the nurse or the physiotherapist or occupational therapist or even the home care aid who assists in bathing and dressing is obvious to most. However, social workers have discovered that their role is sometimes less understood by clients and their families. Unrealistic expectations can be fostered when the client and family caregivers are unclear about the reason for the visit. For instance, at the first contact, the client and caregivers are told that a social worker will be coming to the house to do an assessment with the goal of identifying needs for support and services. It would be logical to assume that this would cause the family to have some expectations that some services and support would be offered as a result. But, the family may not be aware that the offer of services is determined by level of need and on available resources. Thus, one of the first tasks of the social worker may be to clarify their role, because "*A lot of the time it's unclear, they don't even know why I'm there. They don't know why I'm filling out this form again.*" (SW4) As one social worker explained "*It's probably because of how we are viewed by the general public ... they think we just place seniors or children in foster homes, so some clients may have that representation.*" (SW4)

Creating a climate of trust and communication with the client and partnership with the caregiver can also be challenging on other levels. Several people interviewed mentioned that a disparity between information provided to clients by other institutions about available services and what is actually available in reality may cause the caregiver to have unrealistic expectations. For instance, when someone is released from hospital and referred to the SAPA program of the CLSC they are usually informed by a hospital healthcare worker regarding the process and what services they can expect to receive. One interviewee explained the situation as follows:

> *Very often the hospital will say, we'll send a referral, someone will call you for front line services. So they may explain very casually what we offer so the client right from the get go will think we'll help them with this and that. When we do arrive and do an evaluation, and then with our limited funds clients are put on the waitlist for a single bath a week.* (SW5)

Situations in which the elderly client and family caregivers have expectations that are impossible to meet need to be discussed openly, otherwise, the caregiver's role as reporter and information provider is never well-defined. Social workers have developed some strategies to counteract misinformation and unrealistic expectations. As one said: "*We have to do some psycho-education. Because I think that narrow definition of what a service is, is part of the problem with their* *expectations ... so the lowering of their expectations is an important part of the intervention*." (SW3)

As was said previously, a lot of responsibility for care of elderly family members and information giving has been transferred to family members in the last decades. As one social worker said, "…a*nd you have to re-discuss expectations in the context of austerity and budget cuts and all these things. And so basically from the get-go this has to be a discussion if you're going to avoid problems in the long-term.*" (SW5) Nevertheless, even misinformed, demanding caregivers are preferable to none at all, as another stated: "*I prefer negotiating with 10 family members for one patient than to have nobody involved because it limits the choices. There's nothing much out there. Even though it's more headaches managing a big group*." (SW4)

Interview analysis revealed that there was another, underlying paradox in creating a successful relationship with the family caregivers. When successful, the caregiver may start to feel like an equal partner in the decision making, falsely believing that some decision making can be done by them. For instance, as one social worker said;

> *…like we try to work with them as partners, but they're actually more of a resource, and then when they express that they can no longer do what it is that they're doing then they ask us to move them [care receiver] to the next level of care and then we kind of block them and in that sense we say, we understand that this is your need but then we have to ask the clients permission to do that.* (SW4)

Another stated, "*It's think it's systemic – keeping the caregiver's role ambiguous you can say – we really want to acknowledge what you are doing so we are going to give you a compassionate care benefit*."[47] (SW6) Whether the caregiver is the spouse or an adult child, social

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[47] Compassionate Care Benefits are Employment Insurance (EI) benefits paid to people for a maximum of 6 weeks who have to be away from work temporarily to provide care and support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (6 months).
Service Canada (2012). http://www.chpca.net/media/7577/compassionate.pdf

workers are trained to treat the caregiver as a partner-collaborator in the process, as part of the decision making team. Except, as one stated, "*When it comes time for them to ask for more services or placement for their care receiver.*" (SW5) Then, the social worker must insist that they cannot do that without the consent of the client if they are still cognitively apt. This creates some confusion for the caregiver who may have been led to believe that as reporters they have some say in the way services can be offered or organized. "*…it's all part of the caregivers responsibility … that's often not discussed in our conversation because we're so client-focused that we forget all the extra care that's around it.*" (SW1)

2. Caregivers as the resource and compensator

In addition to expecting caregivers to be accurate reporters of what is going on with the elderly client, social workers also expect them to be one of the resources and compensators for the elderly client. In the context of eldercare, a 'compensator' is a person or a service that helps the elderly client maintain their autonomy by taking over tasks or by providing other compensatory assistance. For example, bathing, medication supervision, toileting, are considered compensations for activities of daily living (ADL's). As a resource, caregivers are expected to help with the instrumental activities of daily living (IADL's) such as shopping, cooking or cleaning. As one supervisor stated; "*I think right now when the worker goes to do an evaluation I think they look at the caregiver as a resource.*" (SW6) When an elderly person is assessed, it is for their ability to perform certain tasks usually related to functional autonomy such as bathing themselves, feeding themselves, cooking, cleaning, etc. The score they receive can be altered by the presence of a caregiver. That is to say, according to the assessment, the first level of compensation is always the person themselves according to how well they are able to compensate for their difficulty. The second level of compensation is considered the caregiver who is expected to provide the needed assistance, and the third level comes from the services that are sent to the home or that are purchased from an agency. While the caregiver is not considered a client in her own right, her needs must still be taken into account so she doesn't burn out or give up.

Family caregivers provide assistance to their ailing relatives for many reasons such as love, duty, responsibility or even desperation, sometimes before they even self-identify as 'caregivers.' Professional experience with caregivers and the interviews for this study revealed that they sometimes enter into the role without any real sense of what they should be doing, have little or no training in the tasks and completely unaware that what will be required of them will inevitably escalate over the years. Illustrating her awareness of the difference between institutional values and the professional values of social workers, one social worker stated: "*They're coerced into doing that stuff. And at the cost of their own health, at the cost of their financial well-being and their personal development*." (SW3) Although the caregiver is not the official client, the social worker still has to be alert to their well-being because often they are not the best judge of their own capacity. For instance, as one social worker said: "*The caregiver may say it's fine, I'm compensating. But in your follow-up you see that the caregiver can't, it's too much for them*." (SW4) Then the social worker must try to intervene. The question then becomes, since the caregiver is not officially considered a client, what action can the social worker take when they sense they are at risk for burnout and, as a result, the elderly client may be lacking the support they need? As one mentioned "…*there's all kinds of lacking in areas where the caregiver is supposed to be compensating but it's not really that great actually*." (SW5)

Using caregivers in this way is not a perfect solution and social workers are well aware of this, but this is how the system has been designed. Maintaining the precarious balance between encouraging the caregivers to be reporters and supporters of their family member and to ensure that they do not burn themselves out in the process is challenging. As one respondent stated: "*Things don't look that good. I think we rely a lot on our caregivers, we have very high expectations about what they should be doing and what they can be doing. Some of that might be value-laden, some of it is because we use them as a resource*." (SW3)

It is not really surprising that some caregivers burn out; the tasks that they are expected to do can be overwhelming. When their care recipient can no longer take care of their own hygiene the caregiver is called upon to bathe and dress them and change incontinence diapers. Nursing tasks can include: medication management, giving injections and changing dressings. One social worker recalled how a caregiver, who had been trained by a nurse to manage her husband's pain medication, was so petrified of giving him too much, she was consistently under-dosing him. Medication management can be complicated, but the nurse in question was frustrated that the man was suffering. However, further questions revealed that the caregiver had not really understood the instructions but was too embarrassed to admit it. Another small training session corrected the problem. As she said: "*We train them to do things but we really don't know how well they understood. The caregiver presence is a modifying influence on the score but we don't know whether the caregiver is skilled or even wants to do it, or even willing*." (SW5)

3. Caregivers as help seekers

On occasion, the role of the caregiver transitions from being the caregiver and reporter to becoming someone more insistent; a help seeker for their relative but also, they want help for themselves. As one worker stated "*The caregivers ....sometimes have higher demands than the client because they're the one compensating. They need to understand they are not our first priority. They ask a lot but they don't know what they want*." (SW3) Except, as one worker stated "*They want us there* *all the time*." (SW4) To the point where social workers sometimes "*Feel bullied by the families*." (SW6) One supervisor of the social workers spoke of how they deal with that:

> *…they feel threatened by the families, the families are not appreciating what they're trying to do and they are not able to respond to that kind of request without involving the client. ["Place my mom, I'll sign the request, but don't tell her"] The families will call and say: ["... place my mother now!"]* (SW6)

The partnership that had been built up where the caregiver was the resource collaborator and reporter becomes more tenuous during this time. Caregivers may come to believe they have more decision making power than they thought. They say to the social worker, perhaps misunderstanding their role: "*Why? I have a mandate, I have power of attorney; I have this and that." And we're like, ["yeah, but your Mom is still the person that's the client."]*" (SW5)

The social worker's role is to mediate the balance between providing the services that the elderly person needs and helping them and their family understand that the services are limited and the budgets are tight. For example, as one stated, "*I think getting them to see just how much is done for them behind the scenes is important. They need to know that there's all of this going on for them. That we had a group meeting to discuss what is best for you*." (SW3) The notion that caregivers do not always understand what is being done for them 'behind the scenes' could lead to the misconception that they are not getting enough services, and which sometimes makes social workers feel undervalued and underappreciated, was a theme running through many of the interviews.

Some social workers felt the demands were coming from the caregiver's misplaced sense of entitlement. That is, they feel that paying taxes means they should get the services they feel are needed on demand. As one stated, "*The caregiver says, ['I pay my taxes and I deserve this for free'] And I say ['you're getting a lot of things that you're not paying for'*]" (SW3) Another reflected the same thought; "*So with that said, it's important to highlight what they are getting for* *free*." (SW5) Or, as one pointed out, there are: "*The ones that feel they aren't getting enough so they exaggerate the issues." which means – "if the caregiver is glazing over the reality it does make it harder. It is a barrier to getting the right portrait for the person*." (SW1)

Most of the social workers interviewed seemed to understand where the family was coming from, for instance, as one said, "*I think they want the best for their families and I think that's right. They want what's best and they feel if they don't push they're not going to get. Which is valid, completely valid .... As you get more experienced you kind of believe everything and nothing at the same time."* (SW5)

7.4 EXPECTATIONS PLACED ON SOCIAL WORKERS BY THE HEALTHCARE SYSTEM

As was mentioned previously, the spontaneous comments social workers made in the interviews also revealed some of the challenges they face regarding their working conditions and how the expectations placed on them by their organization have affected them. The social worker's comments were spontaneous and were evoked by the questions on expectations regarding assessment and caregivers that were put to them during the interviews. As was discussed in the previous chapter, decades of reorganization and changes in the healthcare system in Québec has had a great impact on homecare services. However, the voice of the workers directly affected by this is rarely heard, especially in the context of loss of autonomy assessment. The frequency and emotion with which they spoke on this subject brought it to the forefront in this study in an unexpected way that made us realize that further exploration was required. Several themes, which will be addressed individually, emerged: 1) budget constraints and time management, 2) acts of resistance or survival strategies, and, 3) the changing face of social work. The following text presents a summary of the social workers remarks.

7.4.1 Budget constraints and time management

In the milieu of public homecare services and assessments offered by professionals to the elderly, budget constraints are on one side of the coin that represents challenges they must face. The other side, also linked to budgets, is related to time constraints or limitations and heavy caseloads. Analysis of the interviews with social workers was particularly revealing when examining their responses to questions about managerial expectations regarding their tasks and workload. Their answers reflected their challenges in balancing what they are expected to do with their professional values and training. Ultimately, the interviews also revealed that for some respondents, issues related to budgetary and time constraints have led to feelings of disempowerment.

Respecting budgetary constraints and time limits are another key component of NPM strategy. In fact, several interviewees pointed out the importance of the expectations around managerial budget limitations and pressures attached to the OÉMC, for example; "*If we're not able to meet our targets that means there will be reduction in our budget so they'll have to cut positions*." (SW4) For social workers, budgets cuts are related to decreases in the services they can offer and subsequent waiting lists for services. For instance, the first interview for this study took place in January 2017 and at that time the organization was still offering up to six respite hours per week to caregivers. By the last interview in December there were no more respite hours being offered at all, a significant reduction in the space of 10 months.

One of the challenges that social workers encounter each time they administer the OÉMC is to match the assessed need of the client to the available resource. Unfortunately, this has become more difficult because of budgetary constraints. As one worker stated, "*When we do arrive and do an evaluation and with our limited funds clients are put on the waitlist for a single bath a week*" (SW3) because for them, "… *in SAPA that's how you quantify or monetize the work. That's the big problem*." Many expressed the belief that budget considerations were related to the objectives placed on them for performance and productivity "… *the systems asking and our manager wants us to do more OÉMC because that creates stats and budget for them*." (SW4) putting their employment in jeopardy because, "*If we're not able to meet our targets that means there will be reduction in our budget so they'll have to cut positions*" (SW5) and she added, "*We're now in another freeze about services, we're over budget, so now they're watching over every penny that goes out*" (SW5). Where this places additional stress on the frontline staff is in, as representatives of the government, they must be continually justifying cuts in services to the elderly, which many felt places them in an uncomfortable position where "*You have to re-discuss expectations in the context of austerity and budget cuts and all these things*." (SW6).

Managerial pressure on the workers sets limits on time for the visits and the number of clients to see in one day. As one newly employed social worker put it: "*We have to do a minimum of two home visits a day plus all the paperwork and follow-up phone calls. I haven't been able to reach that target yet*." (SW1) When administering the OÉMC, social workers, like all healthcare professionals, are obliged to follow specific guidelines related to the time it takes to complete and the number of clients they must see every day. During the interviews, many revealed that they sometimes find it difficult to meet these norms. When asked how long it takes to complete, one replied "*I would say an hour, an hour and a bit it's not really easy to do in one sitting because it's a long form*." (SW4) and another highlighted the dilemma of being caught between time constraints and waitlists, "*You're there to assess the needs and sometimes the clients are not ready* *to get services but in the back of your mind you know there's a waitlist. So you can't make the referral. So that other disciplines or services…and… the problem is the time factor - all the work behind the scenes takes time."* (SW3) As case managers a lot of pressure is placed on them to stay on top of things, but as one stated, "*It takes time. For us, as the social worker case manager it's a good 70% of our work… the case management part takes up a lot of our time* (SW4). The guidelines and norms for the time required to do certain things keeps changing, even getting shorter according to some. For instance, to do a first assessment the average time is about two hours and a follow-up assessment usually takes less. However, placement assessments take longer. As one social worker stated, "*To do placement applications we used to have 10 days. Ten business days to complete all the paperwork. It was brought down to 5 last year and then 2 months ago it was brought to 4.*"

A study by Delli-Colli et al. (2013), on the usage of time of social workers with older people, found that it was generally divided into four categories: direct activities, indirect activities, non-clinical activities and personal activities, with the majority of time (68%) being spent on direct and indirect activities related to their clients including administrative tasks. Direct activities are considered those that involve direct contact with an older person or their family caregivers, such as psychosocial assessment at their home or a telephone follow-up with the caregiver(s). Indirect activities include discussions with other team members and verifying eligibility for services and case documentation. Non-clinical activities are defined as administrative tasks and professional development. Personal time includes lunch and other breaks during the day. Some feel disempowered and not respected because even though a great deal of their work is related to assessment, decisions that directly affect their day to day work are being made without consulting them or considering what impact it would have on them. As one worker stated: "*I think it's all* *about the numbers. Sometimes I wish that I had been around the table when they kind of decide on say, more visits.*" (SW5)

7.4.2 Acts of resistance, or survival strategies?

In May 2017, a CREGES conference in Montreal (*The Impact of Austerity on the Living Conditions and the Health of Older Adults*), offered a global, multidisciplinary view of how government austerity policies have had a wide-spreading effect on health and social services, the manner in which care is provided by health care professionals, and its ultimate impact on older people and on institutions. Some presenters at this conference (St-Amour, Bourque, M., & Grenier, J., 2018) mentioned that the optimization and austerity measures that have been promoted by the Québec government have forced healthcare workers into 'acts of resistance' or a 'survival mode' of operating, (see also Benoit & Perron, 2018, Thomas & Davies, 2005). During the interviews with the social workers, two of what could be considered 'acts of resistance' or 'survival strategies' were identified: not using the portable computer during home visits, and, not completing the psychosocial functioning assessment as dictated by their professional order. Interestingly and paradoxically, it could be speculated that neither of these behaviours could be considered in their own best interest.

Not using the portable computer during home visits: One of the key strategies outlined in NPM policies is to encourage use of technology to increase efficiency and accountability (Berthilette, 2017; Grosjean & Bonneville, 2016; Carrier et al, 2012). In the early 2000s, the OÉMC and related programs were transformed to software that could be used on laptop computers, with the expectation that they would be brought on home visits by healthcare workers. However, not all of the social workers were comfortable to bring the laptop with them for a number of reasons. In fact, none of the social workers interviewed for this study brought the laptop with them regularly on home visits. Some felt it was a barrier to connecting with the client, for example: "*It's impersonal to be sitting in front of a computer. A lot of the questions are personal and intimate and I think it creates a boundary between you and your client*." (SW2) Others mentioned that issues with technology in the home was problematic: "*I bring the paper version. The computer I didn't find it was nice to have during my visit. I found it inconvenient to have the computer on my lap and there's connectivity issues, there's the whole idea of navigating and clicking, clicking. I found it far more efficient to have my paper guide.*" (SW1) Several social workers interviewed mentioned the condition of the home as another factor that influenced their choice of not bringing the computer with them, for instance: "*I don't like doing it by the computer. Sometimes the house is dirty; I don't like to bring it.*[48] Also, *"It's too impersonal and I don't like to go question by question. I find it better to do it more informally and then enter the answers back at the office. But it's always strategic to have the questions with you*." (SW3) Another issue that they must deal with is also related to sanitation; homecare workers try to keep their personal belongings to a minimum because of the risk of contamination by bedbugs or cockroaches, which is an ever-present reality for many of them. As one social worker expressed it:

> *I didn't find the computer enhanced the interview in any way. I found it heavy lugging it around and there's so much clicking. I found also that some of the homes we go into for various reasons you kind of want to keep your things together. I mean we talk about infestations, bedbugs, cockroaches. I try to kind of keep my things really tight and together. Sometimes I even have my things in bags. I mean depending on the site I'm going to. I've often kept my things on I don't want to be more spread out. I'm really trying to be very guarded about these things.* (SW5)

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[48] The problem that healthcare workers have with insalubrious homes is often related to infestations such as bedbugs or unhygienic conditions. When they know in advance that a home has them they try to keep the amount of materials they bring with them to a minimum and use special bags to hold their personal belongings such as shoes and purses. The more items they bring with them increases the chance they will bring the insects home with them. Showers have now been installed in the CLSC's so the homecare workers can clean off after a visit to an infested or unclean home.

Many workers interviewed felt that their memory was sufficiently good for remembering the answers. For instance: "*I had to do the evaluation from memory. I can pretty much do it from memory ... a lot of it is copy-paste… I go by instinct.*" (SW2) There seemed to be little consistency in how the form is completed. Some did not complete it at the first visit, preferring to use the first visit as an ice breaker and a way to start to get to know the client before arriving with the long form. Experience does not seem to be a factor in their decision to not complete the assessment form right away, since both experienced and less experienced social workers who were interviewed stated they just took notes and relied on their memory to complete the form later at the office. Shortcomings in the actual computer software was also mentioned. For instance, in follow-up interviews, one social worker (SW5) described how when entering the answers on the computer a drop-down list appears, depending on the data entered. For example, if someone, is incontinent but does not use any incontinence briefs or pads, he must still enter that they do and later write a longer note that he wrote that just so he could move to the next question. The option of 'no compensations' is just not on the list.

An interesting point that emerged from the interviews is that several social workers mentioned that they suspected some tampering had been done with the formula or algorithm that evaluates the data and produces the score for the client. "*…what we find I mean is that when we're doing the evals we're finding the score is often really low and not reflecting the vulnerability of the person.*" (SW5) As one worker stated, "*As those scores are becoming more and more important, something has shifted. It's a lay person's observation though, it's not based on research but we all have this feeling that there's something going on with that score*." (SW6) Scores that are lower than the worker expects and that do not represent the needs of the client can be problematic, as one added: "*Advocating for services for a client who's between a 1 and a 3 takes valuable time*." (SW4)

An attempt to confirm this speculation with a person involved in the instruments' origins and algorithms, produced the comment that these rumours were unfounded and any inconsistencies in the scoring were more likely due to a mismanaged system. (Nicole Dubuc, personal communication, 2017). As well, an attempt to verify this with a home care services manager brought forth the observation that the workers must have made errors or the result was miscalculated. Regardless of whether the workers or the managers are correct in their perception, the fact that several social workers interviewed mentioned this seems to reflect a general climate of suspicion, mistrust or even paranoia in the workplace.

Not completing the psychosocial evaluation (OTSTSFQ): In addition to completing the OÉMC assessment of clients and all of the other relevant assessments, social workers are also expected to complete an assessment of the client's social functioning, mandated by the law through their professional order (OTSTSFQ). The social workers interviewed are aware of this, as one stated: "*Only recently that the Order said that the OÉMC is not sufficient as a tool for assessing the social functions.*" (SW5) In their winter (2016, no. 128) bulletin, the difference between the OÉMC assessment and the social functioning assessment is outlined:

> *The assessment of social functioning is at the heart of the social work profession. The perspective of social functioning is what distinguishes social workers from other professionals when they take a look at some situations and speak out about them. In short, although it is part of it, social functioning goes well beyond the concept of autonomy.* (Translation)

The interviews with social workers revealed that the expectation to complete the social functioning assessment is causing conflict for them. In fact, it seems that it is just not being done by some of them for reasons they state are mostly for 'lack of time.' The fact that many are not doing this and they don't feel supported by their managers has lately become a matter of discussion in team meetings, for instance: "*The psychosocial evaluation, they* [referring to the managers] *couldn't care less about it. ... our Order is asking us to do it but our managers are not allocating the time for us to do it*" (SW4). Social workers may be actually risking their professional license to practice by not completing this form and the situation is causing a great deal of stress. One interviewee described that when she realized that she was going to be undergoing a standard audit by her order she had to go back into the files and complete these forms in retrospect.

> *My psychosocial evaluation should be valued as much as the OÉMC but it's not right now ... But if I get inspected by the order if I don't do my psychosocial I can get suspended*." She adds, "*It's not so much it's been mandated by the Order, but it's actually mandated by the law. And it's kind of fallen to the wayside because the OÉMC has taken over and because people say 'I'm not doing two evaluations'* (SW5)

One supervisor, when questioned about this stated: "*I think they get the value of it. I just think they feel they don't have the time to do yet another assessment, another evaluation.*" (SW6) One worker reported that at a staff meeting, the subject of these uncompleted evaluations came up and when the workers stated they had no time do them they were told by a manager that if they took the time to do them, then there would be staff reductions.

As we saw in the beginning of this chapter, during the pilot study in which we examined several OÉMC's, there was some inconsistency in the amount of information provided about the clients in some questionnaires. During the interviews the social workers were asked about this. Some were aware that this could be a problem since the client's files are available to all disciplines, for instance, "*If my covering worker will be able to follow up to know exactly what I mean it has to be clear. It has to be clear in terms of ... the problem is the time factor*." (SW3)

7.4.3 The changing face of social work

Social Work is a respected helping profession that is recognized world-wide as an essential ingredient for organizing and offering services to a vulnerable population. Social Workers play an essential role in home care programs to assess, support and obtain services for the frail elderly who are in loss of autonomy as well as to support their families. Yet, many social workers feel stressed and undervalued in their duties. According to some authors, the choice of social work as a profession is often influenced by idealistic values such as altruism, the desire to help others and to enhance their professional skills and opportunities (Stevens et al, 2010; Csikai & Rozensky, 1997). Yet, today with increased emphasis on productivity and budgets that rely on results and targets, as mentioned by some during the interviews, social workers can find themselves spending "over 70% of their time" on administrative paperwork. As one social worker said during the interviews in response to questions about working conditions; "*I didn't sign up for this*!" (SW3)

The frustration that social workers are experiencing in light of management decisions and the transformation of their profession from one of humanistic, empathic values to one where the 3Ps – productivity, professionalism and performance guide their interventions, was apparent in the interviews. NPM, with its emphasis on austerity is a lofty and widespread initiative that has been implemented in many developed counties (Bellot, Brisson, Jetté, 2013). But, how has that and its effects trickled down to the commonplace reality of social workers and their clients? The interviews revealed that the social workers role has gradually transformed from one based on humanistic and caring interventions based on getting too know the person and their needs and forming a trusting relationship to one based on bureaucratic protocols and administrative tasks. The changed role of the social worker from relationship-based to the assessment of need and the coordination of services delivered by others, has been called the '*management-technicist'* perspective (Harlow, 2003:34). More recent studies have also highlighted the move away from standardized assessments and objectivity in testing towards a "*social turn*" to understand assessment as a social practice as well (Kearney, et al, 2018). Shay (2008) explains the social turn in assessment as providing a deeper understanding of the internalized judgement-making processes of the assessor which may be unconscious. The processes, she states, are often the result of familiarity with the field of knowledge and reflexivity on the part of the assessor can help avoid bias. A parallel can be made with the profession of social work in the following statement by Foth et al. (2018) writing about the impact of neoliberalism on the nursing profession. They stated that: "*In a neoliberal techno-rational paradigm, it is often the case that nursing practice is considered ahistorical, that there is little questioning of the assumption that underpin contemporary practice, no critique of the policies and philosophies which have shaped, and continue to shape how nursing practice has evolved*."

One of the fundamental characteristics in NPM strategy is the increased use of information technology (Gruening, 2009) which has placed another expectation of social workers and, as evidenced in some of the comments outlined in the previous section, some see it as even a burden. For over 20 years information and computer technologies have played a central role in healthcare organizations in Québec when they were introduced as a way to improve outcomes, manage information and increase profitability (Bonneville & Jauréguiberry, 2007; Grosjean & Bonneville, 2016). Some researchers have examined health professionals' reluctance to use technology such as portable computers in home care visits, referring to it as 'resistance to change' that represents an attempt by the workers to regain power in a bureaucratic system that disempowers workers (Bonneville & Sicotte, 2008; Grosjean & Bonneville, 2016).

While some managers prefer to lay the blame for the lack of use of computers on the workers, referring to it as 'digital insecurity,' workers themselves state that their reluctance to use it has nothing to do with lack of skills, but rather that they see the computer as a barrier to building a trusting relationship with their clients (Bonneville & Grosjean, 2016). In fact, social workers in these studies stated that they felt the computer could be an obstacle to human interaction with their clients. As Grosjean and Bonneville (2016) state: *"It is therefore not possible for health care professionals, in ambulatory care, to subsume systematically a technical device (laptop computer) into the frame of interaction which could cloud in many ways the bond of trust upon which this interaction is founded."*

Thus, we can see the irony of an initiative, namely, 'using portable computers for assessment' that was intended to improve time efficiency and data management related to client support and intervention, that is not wholly adopted by the professionals for whom it was meant to benefit.

7.6 THE ADAPTATION PROCESS OF SOCIAL WORKERS REGARDING EXPECTATIONS

Adapting to ever-changing expectations that have been placed on social workers because of differing budget priorities and time constraints is now a hallmark of professional social work practice. As mentioned in the previous chapter, we can also include heavier caseloads and staff turnover that means social workers are obliged to cover for missing colleagues. The interviews demonstrated that social worker's expectations are influenced by three things, their personal beliefs and values, their professional experience, and their training. As well, the organizational climate and bureaucratic imperatives have played a significant role in how their expectations are enacted during their interventions with their clients.

Figure 15 below, presents the schema I developed to illustrate social workers expectation adaptation process. This diagram illustrates the professional and managerial imperatives placed on social workers that also impact their own expectations and ultimately, may also have an influence on the assessment outcome. As was previously mentioned, the profession of social work as it is practiced today in the healthcare system has evolved to be less humanistic and more bureaucratic. This was revealed in the pilot study for this thesis and subsequently confirmed through a publications search. The expectations and professional imperatives that have been placed on social workers is well-documented. However, the specific impact of these expectations on their social work practice as regards to assessment of their clients, has not. Also indicated in the diagram is an additional level of expectations that social workers must acknowledge; the expectations of family caregivers and their clients and how they are communicated to them. The diagram also reveals that social workers occupy a place in the centre of the expectations as they negotiate the difficult position of respecting the norms of their organization, even in times of austerity and the demands of the caregivers who act as representatives of their clients.

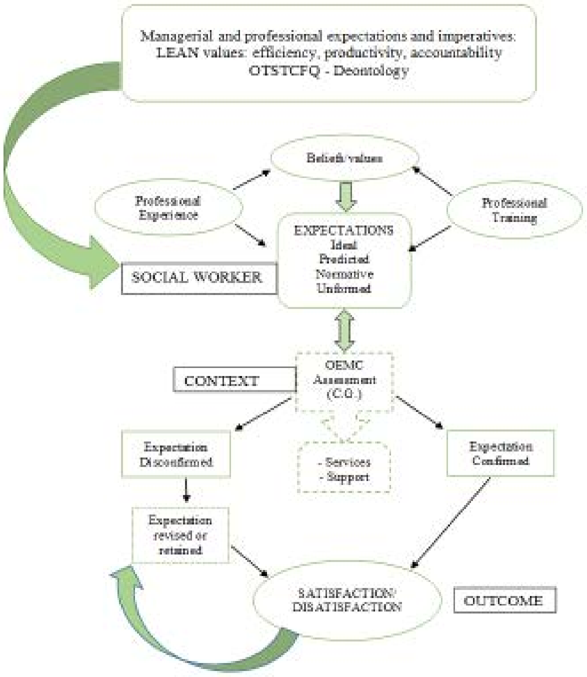

Figure 15 The adaptation process of social workers regarding expectations. N. Gilbert, 2019

7.7 INTERVIEWS WITH THE FAMILY CAREGIVERS

We questioned caregivers about their expectations for support and services both for themselves and for their care recipient during the interviews. This was done with the objective of gaining an understanding of their expectations and to identify any points of convergence and divergence between their expectations and those of social workers. The interview questions with caregivers focused primarily on two themes. The first aimed at determining their expectations regarding homecare services and support in the context of their interactions with the social worker and how it influenced their degree of satisfaction with the services offered. The second theme explored with them the notion of loss of autonomy and its effect on their expectations and the relationship with their care recipient. Interviews guides can be found in the annexes at the end of this document.

7.7.1 Caregiver's expectations

The role caregivers play in the care and support of their elderly family member can be complex and fraught with many unknowns and unexpected challenges. It has become a contemporary phenomenon that for caregivers, the future can be highly uncertain and unpredictable because of several factors such as the precarious health status of their elderly relative and the undependability of health care services. Despite this unpredictability, there remains a profound need for caregivers to be proactive in regards to the present and future needs of their elderly family member in order to anticipate and prevent potential risk. This implies that through a greater understanding of the influence of expectations an uncertain future can be made controlled so the caregiver and to be able to make certain arrangements and interventions in the name of what is yet to come (Alvial-Palavicino, 2015). Caregivers, with the best of intentions and while wanting to ensure that their family member receives the best care and services possible, are not always aware that their degree of participation in their relative's care, their expectations and how they interact with health care professionals could also influence the assessment and intervention plan.

Several factors can play a role in defining caregiver's expectations and satisfaction with services, for example: the nature of their relationship with their care recipient, their levels of perceived stress and burden, and number of years spent caregiving. Thus, gaining an understanding of how their expectations can contribute to their satisfaction with the services offered can help illuminate the sometimes complicated relationship they have with health professionals. Table 1 below summarizes the five predominant themes related to caregiver expectations for care and services from the social workers that were identified through the interview analysis and which will be discussed in more detail in the following section. As well, two sub-themes that emerged in the analysis will be presented: 1) the origins of their expectations and, 2) how caregivers communicated their expectations to the social workers. This chapter will then terminate with a discussion of the juxtaposition of the key concepts of this thesis, loss of autonomy, aging and assessment and expectations (4.6.4).

CG# and years of caregiving	**To be treated as 'expert'**	**Information**	**Care at home (services)**	**Support for themselves**	**Placement for relative**
CG1 (5)				✘	✘
CG2 (2)				✘	✘
CG3 (10)	✘		✘	✘	
CG4 (3)			✘	✘	
CG5 (1)			✘		✘
CG6 (3)	✘	✘			✘
CG7 (4)			✘	✘	
CG8 (3)			✘	✘	
CG9 (10)	✘	✘	✘	✘	
CG10 (4)	✘		✘	✘	✘

CG11 (10)			✘	✘	
CG12 (2)					✘
CG13 (2)			✘	✘	
CG14 (6)	✘	✘	✘	✘	
CG15 (20)		✘	✘	✘	
CG16 (1.5)	✘	✘	✘	✘	
CG17 (10)			✘	✘	
CG18 (2)		✘	✘		

Figure 16 Caregiver expectations themes

1. To be treated as an expert

The word ‘*expert*’ is in italics because it is not the word that the caregivers themselves used to describe their expectations for how they wished to be treated. The ‘expert’ in this instance can be defined as someone who has knowledge and insight about what is going on with their elderly relative and who feels that this information can be helpful to the social worker. Some caregivers stated that they were surprised or they appreciated when the social worker “listened” to them and asked their opinion. But, the overriding sentiment seemed to be disappointment that their opinion was not solicited and when they did express one, they felt their voices were unheard. Some spoke of social workers who didn’t return their phone calls or who they felt were not sufficiently available to them. One caregiver recounted how she felt so desperate she contacted the head manager of the homecare department. In her words:

> *I came to the CLSC with my husband about 3 or 4 years ago. She interviewed my husband and she took my name. And she said she would be in touch with me and she never was. So finally about 6 or 7 months later I called and they said, ‘oh we closed his file because you don’t need any services.’ At that time my husband was deteriorating, slowly, and that’s when, I forget her name, the lady who’s in charge* [text excluded for anonymity]. *She had a letter sent around to people saying that there’s going to be a whole revision of services and so on. Anyway, I called her and I told her what happened. She got me into this* [caregiver] *group right away and she had a social worker assigned to me right away. But that’s only because*

> *I have a big mouth and I'm not afraid to do things for myself and to get services if I need them. But I was very disappointed with the social worker that I had dealt with here. (CG7)*

In their responses, however, some pointed out that their feelings of not being heard were not limited to social workers, for them other healthcare professionals didn't listen either. For example, when asked about her expectations regarding assessment, one caregiver instead spoke of her difficulty in having her opinion acknowledged by the doctor when she felt her husband needed to be referred for an assessment, even though he had recently become lost when walking by himself through the park on the way to the grocery store:

> *He had a physical, an annual physical at his doctors. He went to that the first time. When he was in the other room I tried to speak to the doctor about this incident. When he came back the doctor said your wife thinks you're losing it, what do you think about that? Like some kind of joke, you know. My husband doesn't like joking about anything of this nature first of all and he just blew up. You're talking to the doctor behind my back. He doesn't need to hear all this. You're not coming back with me ever again.* (CG16)

Her biggest struggle at that point was trying to get him to agree to let the social worker into the house, although she had already met with the social worker herself, privately.

2. Information about resources

Several caregivers replied that they expected to receive information from the social worker, usually in two areas: 1) information about the illness of their care recipient, or, 2) information about resources such as day centres or recreational centres. Some mentioned that lack of knowledge about the system and what is available was sometimes a hindrance to getting what they needed. For instance one caregiver expressed her disappointment and that if she had known:

> *I would have asked for some kind of group support. I would have asked for some kind of activities for my husband. I would have asked for… I well expected that the memory clinic would have some kind of program. Treatment or therapy. They have nothing. They do a very, very slipshod, um, I hate to say it but that's the way it is. But I really had no idea how much care he needed. That's the thing*. (CG7)

3. Homecare services

The types of homecare services for their care recipient that caregivers most often mentioned were related to instrumental tasks such as bathing, dressing, shopping and housekeeping. For instance, as one satisfied caregiver said: "*The CLSC was wonderful. They came every few days and dressed his wound. We had a social worker who helped and an OT who made sure we had a raised toilet seat. So very, very good, wonderful care from the CLSC.*"(CG15) Help with meal preparation and medication management was also often mentioned. Many also stated that they would have liked to have someone come in and "babysit" so they would be able to have a break or to go out and take care of their personal needs. As one caregiver said: "*I asked for someone to come and take my husband for a walk but they said they don't do that… I need relief.*"(CG16) Usually social workers provide caregivers with names of community resources who supply services for a small fee but some caregivers expressed disappointment that they would have to pay out of their own pocket.

4. Care and support for themselves

Those who specifically mentioned additional support for themselves were usually referring to services such as a support group or individual counseling. Several caregivers seemed to be seeking validation from the social worker that they were doing the right thing, especially in their decisions regarding keeping their care recipient at home with them or, as the case may be, regarding placement. As mentioned previously, those who had a perception that the social worker's visit was for both of them were surprised to learn that they were not included in the service plan that was subsequently drawn up for the client. They were told that if they had specific needs, a file would need to be opened in their name and another social worker assigned to them. However, getting help for themselves was not always easy. One caregiver interviewed found getting help for herself after the death of her mother was a frustrating and disappointing experience:

> *When I called it was about grief counselling it was a year. […] Six months after I called there someone called and said I was still on the list was I still interested. I said yeah, what would happen if I was really desperate and felt like committing suicide for example? It made me really angry the way they were, six months and nothing. So my expectation would be at least some feedback within a couple of months. Someone would call within a couple of months*. (CG16)

5. Relative to go into long term care

One third of the caregivers interviewed said that initially, their primary expectation for the assessment was placement of their relative in long term care. Several caregivers admitted that they were surprised to discover that the decision to put someone into a long-term care facility was not entirely up to them. They found that it was their choice only if they had the financial means to pay for a private facility, which, depending on the level of care required, can cost many thousands of dollars per month. To enter a public long term care facility the person must have a sufficiently high Iso-SMAF score that reflects their candidacy. However, unless they are in a crisis situation, most people even with a high score are put on a waiting list that could last up to a year or more.

So, although the caregiver may feel that their elderly relative is a candidate for institutionalization, the social worker's assessment may not agree. Lack of knowledge of the limits of their responsibility and where social services can step in was revealed as the greatest cause for confusion and consternation and in which the caregivers interviewed seemed to be the most misinformed. The level of lack of knowledge and surprise they expressed when they learned about waiting lists for placement and the homologation of protection mandates[49] was revealing. Their faith in their social worker to guide them in the process is revealed in the statement below:

> *I had a very good social worker. I looked after […] for the last 4 years 24/7 to the point where I was having major health problems myself. I had congestive heart failure. Even though I got a reprieve once in a while … I had her name* [his wife] *in* [LTC facility] *for quite some time. She* [social worker] *said […] 'the only way I'm going to get your wife out of your care and into*[LTC facility] *is for you the next time you go to the hospital is to refuse to bring her home. And that's pretty dramatic. She said, 'I'm telling you if you do that I can take over. If you go there and say 'I'm sorry I can't take my wife home anymore, I can't look after her. Then I have to get involved from the hospital standpoint. And that's what happened.* (CG6)

For some caregivers, even more startling was the fact that their care recipient had to provide permission for placement if they had not already been declared inapt, which reveals a significant gap between unmet expectations and satisfaction with services. Of the six caregivers who did indicate this as their main expectation, only two managed to place their spouse in an institution because they had agreed and signed permission.

7.7.2 Caregivers and loss of autonomy

Since loss of autonomy and aging is a core component of this thesis, during the second part of the interviews, caregivers were also asked some open-ended questions about what meaning the expression *loss of autonomy* has for them which allowed us to explore the concept of autonomy. These questions were followed with an unstructured but guided discussion about loss of autonomy and how it may have affected their expectations regarding care for their relative. The caregiver's

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[49] A protection mandate lets a person name one or more people to take care of them and manage their property while they are incapable and still alive. However, before being able to use the powers in a protection mandate, a mandatary must get a judgment from the court regarding the person's incapacity. The judgment makes the mandate official. This procedure is called homologation. https://www.educaloi.qc.ca/en/capsules/protection-mandates-naming-someone-act-you

responses revealed that, for them, loss of autonomy has become a central characteristic of their caregiving role with far-reaching effects, not just on the person who is experiencing it but as mentioned previously, there is also a corresponding ripple effect on themselves. Many of the responses revealed, for them, an overwhelming sense of loss and loneliness and even injustice that in many areas could be directly linked to their unfulfilled expectations of how they would live the final years of their lives.

Since most of the respondents were spouses, loss of a partner was a prevailing theme. As one caregiver said during the discussion group, "*Loss of autonomy means loneliness ok and making the decisions. Before you were making the decisions with your husband and now you have to make the decisions yourself.*" (CG1) Another caregiver stated referring to her spouse with an advanced dementia: "*It's like saying I'm a widow with a husband. Someone said that to me once and I can't get it out of my mind. What's worse? A widow without a husband or a widow with a husband? It's sad. It really is*." (CG2) The caregivers' answers also sometimes reflected the inner conflict they experience because of the years they have invested in caring for their husband, their identities merged, but not really: "*He seems happy, he's in his own little world. But when I go into the house he's not really there. There's no conversation because even if I try to talk to him he doesn't really understand what I'm trying to say to him.*"(CG10)

The sense of loss and even sacrifice is not entirely unique to spouses. The caregiver/mother interviewed experienced it in a somewhat different way, a loss of socialization, freedom and the expectation that her child would someday grow up and be independent:

> *Well I'm more of a loner than not. I don't mind being alone. I've been alone a lot of my life. I like to work, I like to read, and I've got a dog. But it gets too much even for me. It's not that I want to socialize so much in Montreal, I'm so busy. But I haven't travelled, I haven't been to Europe since 2005 because I can't afford the time*. (CG14)

And finally, during the interviews and discussions, some of the caregivers revealed that their expectations of support also included friends and family and they were surprised it was not always forthcoming. As one caregiver said:

> *My brother doesn't give a crap about anybody in the family which is going to continue. Unless he experiences a Saul to Paul conversion which I doubt. Really god would stick his foot out of heaven and kick him in the butt. I had a little bit of help from my sister in law because she's a very good soul but she was living with those people…* (CG17)

Sometimes the lack of support came from denial on the part of others about the seriousness of the illness: "*My mother just died and for years she didn't even believe my daughter was sick because she would see her in her good periods*." (CG17) And another caregiver decided that her only recourse was to take their lack of support as a rejection: "*She goes we have to always watch what we say with you because you get mad. No, I don't get mad I get offended. My sister thinks it's not normal, she thinks I'm acting like a little kid*."(CG14)

However, and perhaps unfortunately, the scope of this research was not intended to cover the topic of expectations of care and support on the part of caregivers to include others outside of the professional health care system. Since the responses of some of the caregivers spontaneously included those in their descriptions it gives rise to the speculation that expectations themselves are not experienced in a compartmental way. Once a caregiver begins to speak of expectations, they brought up other relationships, daughters, sons, and siblings that were important to them.

7.7.3 Communicating expectations to social workers

The caregivers interviewed were asked how they let the social workers know about their expectations for homecare services. Their answers seemed to reflect their pre-conceived notion of why they thought the social worker was performing the assessment of their care recipient. For instance, when asked what they had been expecting from the visit from the social worker. One caregiver, who happened to be a retired social worker herself, minimized the encounter and replied in a straight forward manner; “*The process was pretty simple, nothing to make us uptight or anything, she came by, we sat, we chatted, she asked questions.* (CG8) Others were more confrontational because they had past experience with homecare services. “*I knew what we needed, I had a cousin who told me how hard it is to get what you need, so I pushed. If you don’t ask you don’t get. I just kept calling.*” (CG1). It is interesting to note that this sentiment was also confirmed in the social workers interviews in which one stated “*If they don’t ask, we don’t offer*.” (SW4) Savvy caregivers are aware that the social worker will notice the condition of the environment and can use it in their favour. For instance, some admitted that before the social worker visited they made sure that the house was clean and tidy and that theirs and the care receiver’s appearance and grooming were impeccable. *As one said, “I wanted the social worker to see that we were managing okay. That I was handling things*.” (CG4) This effort seems contradictory since the social worker was coming to assess need. When asked why this was important it seems that, as caregiving spouses they had a fear of placement for their care receiver. During the discussion group, when this subject came up, one caregiver pointed out that appearing too capable could work against them because the social worker may think they were doing so well they didn’t need any support and services. Social workers also verified during interviews that the appearance of the home, the client and the family caregiver were all visible clues that confirmed for them that the client’s situation was being managed.

7.8 THE ADAPTATION PROCESS OF CAREGIVERS REGARDING EXPECTATIONS

In addition to determining the nature of caregiver's expectations, how expectations were developed and in what context, also were revealed during the interviews. They were described as potential sources of satisfaction or dissatisfaction with homecare services and their relation with their social worker. As the diagram below illustrates, the expectations are also value-laden, for instance: 1) Predictive: i.e., related to their satisfaction with any services they had received previously, and 2) Ideal: i.e., based on their degree of embeddedness in their role as caregivers, and, 3) Normative: i.e., influenced by how and from whom they heard about homecare services.

Inspired by the Expectancy Processes Model (Olson, Roese & Zanna, 1995) described in the previous chapter (P. 71), Figure 16 below presents the model I have created to illustrate the process of how family caregivers develop their expectations and adapt as their expectations are confirmed or disconfirmed. Similar to the previously described social workers adaptation process, the adaption process of caregiver's regarding expectations conceptualizes the above-mentioned three factors and values related to the caregiver expectancy process. The descriptive, 'Unformed' as a value is also included in this diagram due to the number of caregivers who responded initially to the questions on expectations that they didn't have any. Ultimately it seemed that they did have some but they were not aware, so they are called unformed. The text which follows will further explore these elements and the process, making links to the caregiver interviews. For caregivers, the reality of having expectations and what they are is not a permanent situation. They can be adapted according to changing circumstances which are often related to deterioration in their care recipient's situation or even in their own health status. The figure below illustrates the caregiver expectation adaptation process in the context of home care assessment of their elderly relative. As some authors have suggested, expectations are influenced by their personal experiences, values and beliefs, as well as by what other people may have told them about their experiences (Olson et al, 1996; Ozegovic et al, 2012). The double arrow between the OÉMC assessment and the expectations demonstrates how the assessment contributes to the expectations. This diagram also illustrates the fluid nature of expectations.

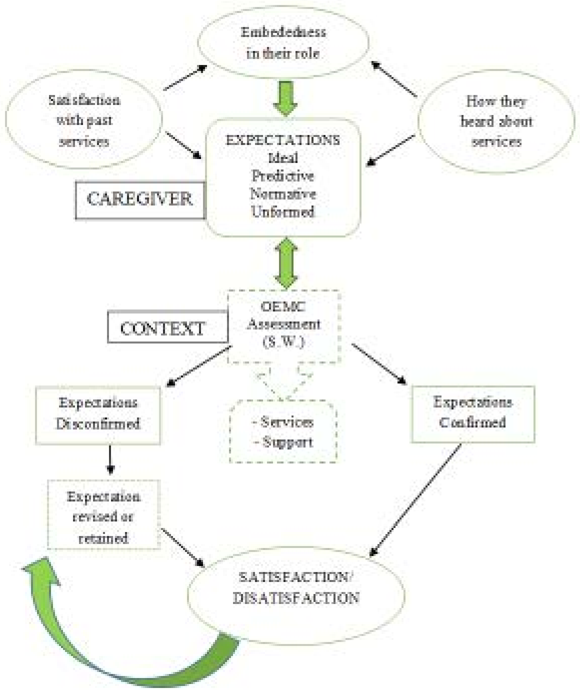

Figure 17 The adaptation process of caregivers regarding expectations. N. Gilbert, 2019

During the interviews, caregivers were asked how they heard about the services and if they had any past experiences with homecare and how satisfied they had been both with the services and their interactions with their social workers. As mentioned above, three factors were identified.

7.8.1 How and from whom they heard about homecare services (Normative)

Hearing from others about their experiences and services from the healthcare system sometimes gives other caregivers the expectation that the same services would be available to them. This was especially true in the group discussion interview where caregivers had the opportunity to exchange experiences with each other and compare what each was receiving from ‘the system.’ For instance, one caregiver who had been taking care of her husband for many years spoke about her ‘Cadillac level’ services they receive because they started when the system had certain services available in more abundance. Unfortunately, most caregivers are unaware that services are allocated according to many criteria, making every case unique and different. Several caregivers often conflated their answers to the question on how they heard about the services to include information they had received from their interactions with all health care professionals, including doctors and hospital staff. If, as sometimes happens, the other health service, clinic, or doctor, is not up to date on what the CLSC is able to offer, then there is a risk that inaccurate information may be given which can lead to false hopes or unrealistic expectations. As one caregiver stated, “*My doctor said I should get homecare in the form of bathing and dressing and the social worker says we can’t have it*.” (CG1) Actually, during the interviews with social workers this was also revealed as a source of frustration for them. For instance, when their client’s family has been misinformed by other health professionals, they have to start their intervention by clarifying what they can and cannot provide.

7.8.2 Satisfaction with past experiences (Predictive):

Some caregivers had previous personal experience with the health care system; usually because they had taken care of another family member in the past. As such, these past services become predictive for what they should also get in the future. As one said: *“I was telling my social worker when my father needed help four years ago we got wonderful services to help us. They were always there. You would just call them and they were always there. Now you call them and they are always down*.” (CG10) As this illustrates, a reason for misunderstanding and unrealistic expectations can simply be because the services they have previously received were based on a healthcare system of the past. That is, one that was more abundant and better financed. Another caregiver said; "*I didn't understand at first. When I cared for my mother we were offered so much. I thought we would get the same thing*."(CG9) A similar experience was had by those who had been told by other about their own experience caring for someone, no two cases are alike. Expectations, met or unmet, appear to play a significant role in whether caregivers feel satisfied or not with their social worker and with the support and services offered by the healthcare system. Actually, thirteen of the eighteen caregivers interviewed had positive things to say about their experience with the social worker and with the healthcare system. But, it should be noted, their satisfaction is largely based on whether they received the care, support, and services that they had already decided were required. In short, if their expectations were met. As one caregiver stated: "*We're not satisfied at all, not with the services or with the devices the CLSC has on offer*." (CG17) Those who expressed positive feelings highlighted the fact that they felt cared for, supported and that their voice was heard by the social worker. Some caregivers also judged the social workers competence by the number of services and support they were offered and the follow-up, as one said: "*As of right now, fortunately we do not need further services but she's been fantastic at following us up*." (CG12). Those caregivers who expressed a negative opinion often did so for two main reasons. 1) The social worker either did not agree with their opinion, particularly when it came to placing the care recipient in a long-term-care institution, or, 2) when the social worker 'drops the ball' and by that they meant that the social worker did not follow up to their satisfaction or return telephone calls in a timely manner. A link here could also be made to the expectation mentioned previously, that they want to be treated as 'experts.' One caregiver recounted how she had spontaneously brought her husband to the CLSC with the hope of getting some services and how disappointed she was when no follow-up was made and she was later informed that his file had been closed. In her words; "*But I was very disappointed with the social worker that I had dealt with there….. I got nothing. I expected to have something, some kind of services, and some kind of evaluation. But I got nothing*." (CG7) To be clear though, she admitted that what she had been attempting to do was to bypass the usual referral and waitlist process to get some much-needed services. She only finally received services when a technician in the blood test center flagged him during a visit and after that he was short-listed for assessment. Another caregiver was dissatisfied when the social worker did not agree with her that her husband should be placed. In fact, it was she herself who was not well and continuing to care for him would place her own health, which was also precarious, in jeopardy. Later, a social worker at the hospital when he was admitted for a health issue did agree with her and her husband agreed to go into care. In her words;

> *The social worker in the hospital told me [...] should be placed because they couldn't regulate his low blood pressure. I found our CLSC social worker was not very helpful. I felt the hospital social worker was working for me. Whereas she was saying why don't you take [...] home and we'll send some care to the house.* (CG9)

These two stories actually illustrate what is often experienced as a dilemma by healthcare professionals when their professional opinion differs from that of family members. The notion of placement of an older person who needs care can also go in the other direction. One caregiver wanted to keep his wife at home, even though she was a candidate for placement and he too had precarious health. Finally, his social worker advised him to refuse to bring his wife home the next time she would be hospitalized. In this way she would go to the front of the line for placement which is, in fact, what happened. Her initial placement was quite far from his home but within a short time she was transferred to a nearby facility.

7.8.3 Embeddedness in the caregiving role (Ideal)

As mentioned in the previous chapter, caregivers are not considered ‘clients’ to the social worker in their own right, even though, in an ideal world they should be. However, despite this, many caregivers caring for their relative think of themselves as a client, experiencing their own loss of autonomy as a result of the hours of care they invest. The interviews with spousal caregivers also revealed that some of them view the assessment as an inclusive operation in which they consider ‘they’ are being evaluated for care and support services. In addition, there seems to be what could be what I have termed a ‘loss of autonomy rebound effect’ in which the caregiver spouse of someone undergoing significant autonomy loss also experiences, sometimes self-imposed, a sort of ‘mirrored’ autonomy loss because of which they consider that their caregiver role has also cost them their own autonomy. During the interviews some caregivers also mentioned that they sometimes view and portray themselves as a sort of co-client of the social worker, especially in the case of spousal caregivers. This could be for multiple reasons: to obtain sympathy, to highlight their own needs, or to create an alliance with the social worker, with a view to perhaps obtaining more services.

The storylines that emerged were revealing, for instance: the usage of plural pronouns when talking about the assessment seemed to indicate a blurring or merging of their identity with the care receiver. Many viewed the assessment itself as a dual process; ‘they’ were being assessed, as if their needs were one and the same; caregiver and care receiver. When they were talking about the assessment, they frequently used the plural pronouns ‘we’ ‘our’ and ‘us’ to refer to it. The social worker was ‘their’ social worker. As one caregiver stated: “*She was responsible for my husband and she became a social worker even with me ... she was our social worker.*” (CG4) Some caregivers realized that their needs were often inextricably connected; “*Then a moment came* *when I thought, we need to be followed*." (CG4) And another caregiver considered it very normal and acknowledged that she was part of it, "*I think we first saw our social worker, I say 'our' because she takes the whole picture into account and I'm certainly part of the picture*."(CG4) Others expressed some surprise at being included: "*One thing I thought it would be more for my wife but they were also concerned about me…. I had a very good social worker.*" (CG6)

The use of the plural pronouns could be indicative of two things:

1) The *merging of identities* that the spousal caregivers who have been in the role for a long time experience, so that they perceive what is happening to their spouse is also happening to them. As in "*we had a doctor's appointment*." This phenomenon is well documented in research that has examined how embedded a caregiver becomes in their role, sometimes to the point where their own identity is sacrificed (Montgomery & Kosloski, 2013, Davies, 2011; Graham & Bassett, 2006; McGraw & Walker, 2004; Horowitz, Goodman, Reinhardt, 2004). In fact, it became common at the beginning of the interviews, which usually started with asking caregivers how they are doing that they often initially answered by telling the history of their care recipient and how, in fact, the other person was doing. As if the status of their care recipient was the barometer for their own state of being. Which in many cases it was.

2) The effort on the part of the social worker to make the spouse feel included in the process. As previously mentioned, the social worker wants to make the caregiver feel like part of the team. This is done so that they feel consulted and involved in the decision-making for their care recipient. Although the social workers are there primarily to evaluate the situation of the spouse, taking the well-being of the caregiver into account is part of the psychosocial assessment. As well, the caregiver, of necessity, sometimes assumes the position of communicator.

Caregivers with no expectations (unformed): During the interviews some caregivers revealed that, perhaps due to lack of any comparable experience or knowledge, they had no expectations at all in the beginning, but during the interaction with the health care system some expectations began to emerge. When asked the question about their expectations regarding the assessment and interaction with the social worker some of the caregivers indicated that they had started out with none. As one caregiver eloquently said:

> *Well I didn't know what I needed. Even though I'm a psychologist myself I had never dealt with this kind of situation and the emotional component. So I really needed to have somebody tell me look this is the best thing you can do right now. Maybe later on you could do something else. I had no idea. The only expectations I had was that somebody was going to help me find some kind of assistance.* (CG7)

Caregivers starting out with no expectations, at least stated ones, can be either surprised or dissatisfied with what they discover:

> *I didn't have any expectations because I didn't know what to expect. I knew the services were out there and now that I see that there is an established network I'm kind of impressed. Especially with the social workers. […] I didn't know that social workers can be so much better than those shrinks and psychologists.* (CG17)

Caregivers who stated they had no specific expectations for care and support also often mentioned that in retrospect, they wished they had known what to ask for at the beginning. For instance, lack of knowledge and understanding of what caregivers may be offered is well illustrated in the question of entitlement to respite. Respite is offered to caregivers either in the form of breaks of up to eight weeks a year that can be taken in smaller increments of a few hours or weeks at a time or for the full eight weeks. Sometimes respite is offered because the caregiver herself needs a medical intervention such as surgery, but it can also be for a much-needed break or a vacation. During this time, the care receiver is placed in a long term care facility such as a CHSLD for a very minimal charge. Many caregivers are unaware that this is available and so don't ask.

However, respite is also a service that is cancelled or put on hold when budget constraints come into play. Some long-time caregivers occasionally find they are receiving services that are no longer available to all, short-term respite of a few hours a day for example. One caregiver describes her situation as follows:

> *And basically I leave him at home and I go and I have respite once a week for 4 hours. And I have someone come in twice a day to bathe him and dress him. A shower twice a week if we wanted, morning and evenings. And because I didn't want evenings they gave me the grandfather clause. Which means that when the time comes* [when she needs more services] *I go to the head of the line. They don't have that anymore*. (CG11)

Although respite is not always available and it very much depends on the CLSC budget, it is usually greatly appreciated by the caregivers

8. DISCUSSION

As was stated in the beginning of this thesis, the general objective of this study was to understand what is at stake concerning the assessment of loss autonomy of older people in Quebec and to understand the centrality of an assessment tool like the OÉMC in the current landscapes of care. To achieve this objective, the concept of expectations was selected as a unifying element to see how they influence interaction between persons and as a bureaucratic imperative. We also studied the importance of the notion of autonomy within the health care system, especially for evaluating needs of older people. The text which follows summarizes the results and links them to the objectives.

8.1 UNDERSTANDING THE ASSESSMENT PROCESS

The first research objective was to gain an understanding of the assessment process through three perspectives: the social worker, family caregivers and the healthcare system. While acknowledging that some form of standardized assessment instrument is necessary for the reasons described in this study, (i.e. equitable distribution of scarce resources and quantification of budget needs), two potential shortcomings were also identified: 1) the assessment process itself may promote expectations and, 2) the inherent risk of 'clientizing' the caregiver (and care receiver).

As previously mentioned, as early as 1989 Gubrium wrote about what he named "*the descriptive tyranny of 'people forms'*" to illustrate how the bureaucratic process of form completion focuses so intensely on its rational production, that moral considerations become lost. This statement appears to highlight the core of the difference between the tasks of social workers pre-reorganization of the health and social services in Québec in which social workers considered they had more autonomy and say in their work and interventions with clients (Grenier, A., &

Wong, 2012; Bourque, M. 2016) and what it has become today. Some authors have mentioned that the move to standardize, quantify, equalize and organize homecare services to the elderly has to some degree devalued the practice of social work (Grenier, Bourque & St-Amour, 2016; Harlow et al, 2013; Rossiter & Heron, 2011; Wallace, 2011; Harlow, 2003). One goal of assessment is to offer services that would allow the person to safely stay in their homes for as long as possible. When Gubrium (1989) wrote about the use of standardized paperwork he labeled '*people forms'* and that "*become documented descriptions of clients 'in need*'" he felt that they limit the description of the situation to what they are requested to document rather than what they know about the client. As Gubrium (1989) states. "*A form does not, in its own right, produce client needs, but at best, objectively conveys needs* …" Standardized assessment questionnaires such as the multi-clientele assessment dictate "*unidimensional timing*" and form completers must be creative in meeting chronological, stylistic and interpretive demands (Gubrium, 1989).

8.1.1 Assessment can promote expectations

When the family is contacted by the social worker to begin the assessment of the older person they are told that they will be evaluating their needs for care and services. It would seem to be logical to assume that supportive services are available and could be offered if a healthcare professional contacts someone to say they will be making a home visit to evaluate someone's loss of autonomy and to determine their needs for care and services. In fact, it could give a false impression and create the expectation on the part of the elderly person and family caregiver that this is how the system works. But, social workers know that when they arrive at a client's residence to perform the assessment, one of their first tasks must to acknowledge and manage the expectations of both the elderly client and the family caregivers. Some social workers interviewed felt that by disillusioning them first, they can control and manage expectations. This highlights the more ambiguous and misunderstood role of the social worker in their assessment and how it is understood by homecare clients and their family caregivers, compared to other professions such as nurses, physiotherapists and occupational therapists.

In this way, the intersection, or one could even say, the collision of expectations comes into play right from the first home visit. The presence of a family caregiver during the assessment can promote the expectation to the social worker that they are ready, willing and able to provide the care and support their spouse or their aging parent requires. As was illustrated during the interviews, the assumption of caregiver's adequate skills and their constant presence is not formally evaluated nor is it an integral part of the OÉMC assessment. However, to be clear, the social workers who were interviewed indicated that they were very aware of the caregiver's important role and try to find ways to offer them support. Having a more formal caregiver assessment integrated into the OÉMC assessment was one of the recommendations offered by several social workers.

8.1.2 Questioning the role of family caregivers

The assessment process can potentially problematize the role of family caregivers. The apparent double-standard that illustrates the delicate balance social workers must maintain towards the role of family caregiver is evidenced in some of the comments of those who were interviewed. The balance in question is that of treating them as partner-collaborators, until they ask too much, and eventually treating them as service-seekers in their own right. Or, as Gubrium and Järvinen (2014) explain, until their 'troubles' become 'problems. When the social worker first meets the client and family caregiver their relationship is asymmetrical from the outset, "*the client of a social worker* *depends on the worker for needs assessment and service intervention, not the other way around*" (Gubrium and Järvininen, 2014). The caregiver is encouraged to be a collaborator and partner in the care of the older person but often does not get recognized until their own burden becomes too great. Social workers are aware and sensitive to the caregivers' role and contribution but they sometimes face a paradoxical situation where the caregiver, who may also be elderly, is in almost as much need for care and support as their primary client. As one stated, "*They are clients in their own right but not officially, until we burn them out*." (SW4) Or, until their 'troubles' have become 'problems.'

'Troubles' can be vague, they exist at the border of acceptable and unacceptable (Gubrium & Järvinen, 2014) and can be ignored and until they are "*constructed as problems for professionals to appropriately respond to them*." Some caregivers quickly learn that to get attention they must become a 'problem.' This is demonstrated in the comments from the social workers who mentioned repeated telephone calls and ever increasing demands for services. Over time, the caregivers become increasingly aware that their 'troubles' will not get the attention they feel they deserve until it becomes the social worker's 'problem.' Gubrium and Järvinen (2014) refer to this as the 'clientization' process. As they state: "*Human service provision starts from there*." It is questionable however, whether ever-increasing administrative imperatives for efficiency, budget control and time constraints, that lead to the point where the growing demands created when the caregiver transforms into someone requiring care and support for themselves, represents the epitome of inefficiency. Several social workers mentioned that if the caregiver doesn't ask, they don't offer, for the simple reason that budget uncertainties make services unstable and they don't want to talk about what may not be available if the need should arise. Some social workers feel that occasionally caregivers try to exaggerate the urgency of their situation hoping that will get better or quicker results. For, as one of the respondents said, referring to a caregiver;

> *But he knows I'm also very firm and like this (sound of fist punching hand). So he doesn't like calling me here because he knows I don't get kind of 'oh, that's terrible, let me do something about it' he knows I'm not going to do that. So he's also kind of stopped calling me that way too much. He knows I'll be there for him if he needs me. I'll absolutely be there but not for nonsense. You have to train them a little. You have to show them that you're there for the real deal.* (SW5)

Finally, what Gubrium (2016) terms the human services relationship is increasingly prevalent today, which, as he states "…*leads the way in turning troubles into problems*…' (p.4). Non-professional involvement in service provision and the recognition of experiential knowledge of the client and caregiver can alter the scope of control on the user side of the service relationship (Gubrium, 2016) and can impact the aforementioned asymmetrical relationship. The movement today in homecare services is toward greater client and family involvement in assessment and creating the care plan, to allowing them to have a greater say (Dubuc, 2014) since the new assessment instrument (OCCI) to be implemented by the end of 2019 is intended to be completed with the full participation of the user and family.

8.2 THE ROLE OF AUTONOMY

The first objective of this study was to undertake an exploration of the notion of autonomy from multiple perspectives and to understand it within the context of assessment of the elderly. As some researchers mention, (Dagneaux et al, 2009) loss of autonomy in one domain does not necessarily imply a similar loss in another, since a person experiencing loss of functional autonomy can still stay very autonomous in their choices and decision making. Dagneaux (2007) also questions whether the notion of "autonomy" alone is sufficient for really understanding what is at stake for the elderly at this stage of their life. She points out that for other, younger age groups, the term “handicap” is more often used, while terms like ‘dependence,’ ‘incapacity’ and ‘loss of autonomy’ are reserved for the elderly and old age. As she reports, the confusion of terms can lead to the exclusion of elderly people from systems of protection reserved for other age groups and focusing solely on notions of loss of autonomy and frailty runs the risk of excluding the voice of the elderly person’s evaluation of their own needs from the assessment.

Also, as was described in the discussion on autonomy there is some question regarding limiting the definition of autonomy in assessment to one domain; that of functional autonomy. When as feminist authors point out, a more relevant definition would also include the relational aspects of this notion.

8.3 AN EXPLORATION OF EXPECTATIONS AND THEIR INFLUENCE

The second objective of this study was to gain an understanding of the concept of expectations and their interaction in the following way: social worker’s expectations of caregivers, caregiver’s expectations for care and services, and finally bureaucratic expectations placed on social workers. The interviews revealed that expectations can play a role in how caregivers interact with the social worker and their satisfaction with the services. Some caregivers who stated they had no expectations at the outset were pleasantly surprised at the quality of care they received. Others were disappointed that they did not get what they felt they were entitled to. Although some researchers have claimed that the relationship with the care recipient and the number of hours and years spent caregiving could influence perception of satisfaction, no correlation such as that was found in this study. Although in such a small sample size, this is not unexpected.

The expectations that have been placed on healthcare professionals since the latest reforms in health care services in Québec is also reflected in other western world countries. In Québec and elsewhere, the role of social worker has become increasingly technical and managerial with practitioners assessing need and then coordinating the work of others, as opposed to engaging in direct work with service users, which has greatly affected their professional autonomy (Wallace & Pease, 2011; Harlow et al, 2013; Grenier, J., Bourque, M., St-Amour, 2016). According to Lavalette (2011, p. 8): "*In Canada, Australia, Britain and the United States, the neoliberal assault is fundamentally changing our economies, our welfare systems, our cities and the roles procedures and activities of social workers in the field."* Another by-product of the transformation of public services as stated by Dustin (2007, p. 26) is the "McDonaldization" of social work service delivery which involves "*the application of factory management techniques to the delivery of intangible services, characterized by efforts to increase efficiency, predictability, calculability and control*." She states that social workers as care managers could now be said to be working in a 'McDonaldized' context in that their work is increasingly directed by managers and they are expected to be more consumer oriented or needs-led and to assess needs and tailor packages of care to meet individual needs. As well, the term 'McDonaldized' could be seen as describing a way of working that is related to assembly line and mass production.

The policies which are widely associated with the private marketplace (Bellot, Bresson & Jetté, 2013) have been a key component of the restructuring of the health and social services in Québec and in many countries yet, an evaluation of the 'lived' experience of social workers who must adapt to these reforms has been largely neglected. Kirkpatrick et al. (2005: 898) state "*numerous studies reveal how social workers now devote an increasing proportion of their time to administrative tasks associated with completing forms and recording information and they* *criticize the growing burden of red tape*" (as reported in Diefenbach, 2009). As some authors have also mentioned, (St-Amour, Bourque, M., & Grenier, J., 2018; Diefenbach, 2009; Thomas & Davies, 2005); few studies have examined the impact of these changes on the people working in these organizations. According to one study; the organizational changes experienced at the ground level have had unforeseen consequences on front-line workers because of a lack of consultation and available support information. (Grenier, A. & Wong, 2010).

Approaches aimed at optimizing service delivery in healthcare such as the previously mentioned LEAN method which is based on the Toyota model of cost control and productivity, began to be integrated and subsequently criticized by workers' unions and pressure groups for favouring quantitative measures over the quality of the intervention (Grenier, J., & Bourque, M., 2016). As these authors state: "…*we highly doubt that certain practices that have been put in place in organizations which promote efficiency, cost control and productivity and that are measured by increased speed and the number of interventions, can have no impact on the quality of services*." (Grenier, J. & Bourque, M., 2016; 11), (my translation).

8.4 JUXTAPOSING LOSS OF AUTONOMY, AGING, ASSESSMENT AND EXPECTATIONS

When the overall results of this study are juxtaposed and compared through the lens of expectations, the realization that much of the interactions, macro and micro are based on the notion of commonly-held stereotypes becomes evident. Because, when people or organizations are expected to act or react in a certain way we are invoking our own self-fulfilling prophecy based on our own values and norms and stereotypes. As was mentioned in chapter 2, self-fulfilling prophecies have been linked to expectancies as well and the expectancy process model that tries to elicit behaviour that confirms their expectation. For instance, if the social worker has an expectation of the family caregiver that they have the skills and willingness to continue in their role, how do they communicate this and take this into account during the assessment? In reality, family caregivers are expected to play an important role in the care support of their elderly relative and social workers role is to mobilize them, to use them as a resource. But this expectation may contrast in fact with the caregiver's perception of themselves as a co-recipient of services. If the family caregiver has the expectation and belief that the assessment will result in increased support and services for their family member and themselves what means do they use to let the social worker know? This point was explored in depth during the participant interviews. Thus, the social worker often assumes that the caregiver is able to continue in their role and the health care system might take it for granted that the social worker employee can perform according to the norms and time constraints that are placed on them.

Leibing and Dekker (2019) write about 'fallacies of care' to mean that care, even with good intentions, can sometimes paradoxically result in harm. The multi-leveled, triadic relationship represented in family caregiver, social worker and healthcare system is based on expectations knowledge, and values that were once accurate, but are no longer. We now see the negative fallout from this in caregiver burnout, social worker dissatisfaction and a healthcare system in crisis.

So, the interaction between family caregivers and social workers in the context of loss of autonomy assessment that often takes place in an atmosphere of mutual expectations, preconceptions, stereotypes and traditional role occupation has been fundamentally altered. As a general rule, in literature, both research-based and popular, the glorified family caregiver is portrayed as one who is kind, giving and selfless; providing 24/7 care to their spouse or parent. In avocation and training, the humanistic social worker is also seen as kind, giving and selfless, but also holds the position of power in the relationship as the evaluator of the aging person's needs and the controller of goods and services. The contrast between the idealized version of caregiver and social worker and reality exposes the gap between how they see and portray themselves and how they are seen and interpreted by the other and even their expectations of how each other should behave. This affects their relationship and their interchange by perpetuating a false version of themselves that carries the risk of misunderstanding, and ultimately the danger of not providing the optimum care and services to the elderly person.

Added to the notion of false representations is the one of the all-powerful government-run health and social services organizations who will be providing the needed care and support to the aging population when it will be required. Frontline professionals such as social workers, discover that their daily tasks are more oriented towards administrative form completion and telephone calls; far from the humanistic, caring profession they had imagined during training. Family caregivers, in their turn, find that they are considered the purveyors of care, supplemented with scarce resources, only when they have reached their own psychological and financial limits.

By juxtaposing the comments made during the interviews with social workers and family caregivers, I have been able to isolate some of these false representations which are presented below as mistaken beliefs or 'fallacies,' which were described previously as mistaken ideas or beliefs.

8.4.1 The fallacy of the caregiver as partner

There is a notable paradox between what social workers expect from caregivers and what caregivers expect from the system, the perpetuation of which I have termed the 'caregiver as partner fallacy.' This paradox is illustrated on the one hand by social workers expectations that family caregivers will be sources of information and even partners in the care of the aging person.

On the other hand, we can juxtapose the caregiver's expectation that they are the manager-in-charge, or at least a major decision-maker in the care of their relative. As we saw in the interviews and in the literature review, there is an illusion created around the caregiving role that encourages them to take charge, while homecare services are supplied according to a very narrow definition according to a 'score' and the availability of resources. In reality, leaving family caregivers very little say in how care should be provided. As we saw, many caregivers stated in the interviews that far from being treated as a partner and source of information, rather, they felt their voices were unheard. Contradicting this sentiment, during the social worker interviews the impression they gave was that sometimes caregiver's voices are heard too much. Although the position of Quebec homecare policy is inclusion and to have the voices of caregivers included in care, as was mentioned previously, social workers felt that the line between treating caregivers as a partner in care could also open the door for them to voice their opinion too often and limits could only be respected by maintaining strict boundaries with caregivers.

Families find that the 'caregiver as partner' fallacy which is reinforced in their early interactions with social workers becomes shattered when the question of placement of the relative arises. This is the moment when they learn that the complex decision process of when and where it will be done is almost entirely controlled by the system in the form of the assessment and scarce availability of resources. While initially they were told the assessment is about determining needs and services, it now changes to criteria for placement and their initial expectations and fear that the assessment would lead to placement is confirmed and the decision sometimes even taken out of their hands. As some caregivers, whose objective was avoiding placement, stated in the interviews, when the decision is taken from them, it felt like a betrayal.

8.4.2 The fallacy of the caregiver as assistant

While it may seem like a contradiction to treating them as a partner, caregivers are also expected to be resources and compensators for their care recipient. In fact, as was mentioned in the previous chapter, sometimes the caregiver role is objectified to the point of removing sentiment and treating caregivers as assistants or lower-level co-workers (see, Twigg 1989), which is also reflected in the social workers comment that "*they are our partners until we burn them out*" (SW6). This diverges in fact from caregiver's desire and expectations to be treated as experts and partners in care, since they do not view themselves as lower-level assistants but rather, they feel they are in charge of the care for their relative. The ambiguous and even dichotomous 'us and them' position in which they have been placed, between how they see themselves and how they are seen, can be traced directly back to the afore-mentioned transfer of responsibility for care by the State to the family. As was illustrated in the interviews, in this rubric of responsibilization, not uncommon in neoliberal governance (see Pyysiäinen et al, 2017), of family caregivers are now trained to perform tasks they had never imagined doing such as giving injections and managing complex medication schedules. A position in which they have been put without their knowledge or permission, yet that which must be upheld by all healthcare practitioners.

8.4.3 The fallacy of the altruistic caregiver

According to the Merriam Webster dictionary altruism is defined as "an unselfish regard for or devotion for the welfare of others" or "a quality possessed by people whose focus is on something other than themselves." While not being entirely untrue as a description of some caregivers, it is very one dimensional when one takes into account the impact of their caregiving role on their own health and well-being. As we learned, the interviews with caregivers did reveal their expectations for care and services from the social worker and the healthcare system but as we will see in the next section in which they answered questions about what loss of autonomy means for them, they also have great expectations of themselves. For some, the caregiving role is not easily adopted. They may have started the role out of love and a sense of duty but over the years when faced with the ever-increasing dependence of their aging relative, it becomes more difficult. One social worker told us about how a caregiver just left her abusive, dependent husband, "*she just gave up*" we were told. But, when the social worker said this I felt that she was reflecting her own disappointment in the caregiver for not meeting the expectations that had been placed on her. Because, while perpetuating the myth of the all-giving, altruistic caregiver in their relationship, the social worker can avoid addressing their needs for care and support (especially since services for caregivers are very scarce, in fact, practically non-existent) until, as was stated before, they burn out which is also a critique made by some feminist authors regarding care work. (eg see: Aulenbacher at al, 2018).

8.4.4 The fallacy of the benevolent/powerful social worker

There are certain helping professions like nursing, religious workers, teachers, to which we often attach higher values, as if we assume that someone in those professions are more kind and giving, even more powerful. I believe social work is another one of those. Although some social workers seem to feel that people see them otherwise: "*they think we are there just to put them in an institution"* (SW2), overall though, most of the caregivers interviewed made positive comments about their social worker. However, social workers today, faced with ever-increasing bureaucratic imperatives, have little power over the distribution of resources. Although they still may be benevolent and caring, there is little they can do to get the resources for their clients short of advocating, which as was described previously is not always successful. Where the problem is starting to be acute is in the recruitment of new social workers to homecare services. One question that became evident during the analysis of the data gathered during the interviews with social workers was how new social workers just entering the system were managing the demands placed on them as newcomers. The question was inspired by the thought that if experienced workers were struggling to adapt, maybe it would be easier for those who didn't know how it was before. Some follow-up interviews were done with some of the social workers in this study who had been respondents revealed that little had changed. For instance:

> *I have been in social services for 20 years... I have been in many reforms and changes of structures. For the new staff, I don't think that the university can really prepare them to the work field. Hence, the importance of field placement to immerse them in the work and the context. The field placement gives them only a little flavor of the real work of case management, the paperwork, the social functional evaluation that we have to do, but the management doesn't support us in doing... It is all about the OÉMC tool and intervention.* (SW4)

One of the social workers mentioned that the paperwork can be an obstacle to recruiting newcomers to working with an older clientele since SAPA is not always their first choice of workplace. She said, "*I have heard students and new employees say that SAPA has the most paperwork, and that is becoming a deterrent to working in homecare, and nobody goes into the field to push paper.... some are frankly discouraged by it*" (SW6). A third social worker reflected on the present challenges as well as future ones: *"New arrival social workers seem to be overwhelmed by the complexity of the system. The grind is tough and it's hard to maintain. They go on the treadmill and it's hard to keep up with the demand. The new OCCI* [the successor instrument to the OÉMC] *is longer, it's going to involve more paperwork, more numbers and more stats*." (SW5) Another social worker in the follow up interview indicated that she has decided to run for public office because of working conditions in public healthcare. As she said, "*I guess I* *am so frustrated at the reality of my job that I felt compelled to accept the offer to run as a candidate to try and bring awareness to the fact that my profession is really threatened when government policies favour cutting services."* (SW3)

Interestingly, a group of undergraduate social workers at the University of Sherbrooke, in the context of a class on ethics, recently created a short video to illustrate what they see as the challenges of New Public Management[50] to the profession of social work. The video, entitled *New Public Management: the Execution of Social Work?* (my translation) is based on the results of a series of surveys (Lariviere, 2012) that were answered by social work professionals and their responses highlight many serious issues. For instance, their feelings that new public management strategies are at the heart of deteriorating working conditions, that their skills are underused and underappreciated, that the clients are really not at the heart of decision-making as they should be, and that they are not truly recognized for their work. The video ends with a message that social workers should fight back and resist. It was also posted on Facebook and of the 56 public comments that appeared on that day more than half indicated that the video was an accurate representation of the reality of social workers. The others, with the exception of one, were congratulatory and positive.

Some authors have questioned why the social work profession seems to be in a state of upheaval as a result of organizational changes and employee/manager conflict and, a reductionist vision of psychosocial issues. (Richard, 2018). The tendency towards the standardization, protocols and technology has, the order of social workers (OTSTCFQ, 2012:12) states made it more difficult to do their work in a manner they judge honorable, dignified and professional. The

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[50] La Nouvelle Gestion Publique : la mise à mort du travail social? Posted online by the Ordre de travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec (OTSTCFQ), March 18, 2018. https://www.youtube.com/watch?v=RDB-dBrbGIE

NPM effects are not, after all, limited to social workers, all professionals in the healthcare system are faced with the same challenges. In fact, social work and other professions such as nursing have all experienced a great impact on their workload after the legislation to modify the organization of the health and social services system was passed by the government (Grenier, J., Bourque, M., & Boucher, 2018, Parazelli & Ruelland, 2017).

8.4.5 The fallacy of the all-providing health and social system

Many Canadians who have lived for many years receiving services in a healthcare system that provides all services share a common belief that when the services will be needed they will be available. However, as was described in chapter three of this study, the healthcare system is struggling. The healthcare reorganization and services can influence the caregiver's transition from their role of care provider to clients in their own right (clientization). The results of the interviews demonstrated that caregivers often begin with little or no knowledge of the healthcare system but quickly learn that the experience is not necessarily what they expected. Not surprisingly, those who had lived in Canada for many years had some expectations that care and services would be available to them and their family once it was needed. Even the caregivers who were interviewed and who declared they began with no expectations admitted they thought the 'system' would tell them what they needed. The erosion of support and services could add to their own burden for care because what may have previously been available is no longer an option. Caregivers are thus obliged to compensate or find other resources at their own expense. How might that contribute to their chances of transitioning from their caregiver role to becoming clients in their own right? The burden of care placed on caregivers and its consequences is a much-researched topic of study. An Internet search reveals that caregiver burden and caregiver burnout literature is abundant. As early as 1980 Steven Zarit and his team published the 'Zarit Burden Interview' (ZBI) which is used primarily in dementia caregiving research. Since then, many adaptations to it have been made so that it could be used in different contexts as well. As mentioned above, there is some consensus among researchers that the caregiving role, particularly, but not exclusively, in the case of dementia caregiving, is stressful in of itself and can have detrimental effects of the family caregiver's health. A recent article (Cheng, 2017) confirms that the effects of caregiver burden and burnout is still an on-going issue and the search for effective interventions remains relevant (Beinart, Weinman & Brady, 2012).

One would not be surprised to learn that many people expect the government to provide adequate and appropriate home care services to older adults so that they can stay in their own homes. Since the early 2000s, this has been a well-defined and publicly stated objective of the Government of Quebec, particularly in two policy documents: *Chez soi, le premier choix* ["Home Support: Always the Option of Choice"] (2003) and *Vieillir et vivre ensemble. Chez soi, dans sa communauté, au Québec* ["Aging and living together—At home, in your community, in Quebec"] (2012). These policies are based on abundant scientific literature that advocates keeping older adults as long as possible in the environment in which they feel they have the most independence—in other words, in their own homes. However, there are a number of indications that inadequate spending in recent years has led to a decrease in the level and duration of services provided to support aging individuals at home. In the mid-1990s, people experiencing loss of autonomy received 20 hours a week of home care services[8] that included bathing, housekeeping, meal preparation and a few errands. Budget cuts and an attempt to harmonize services led to changes in how home care services are provided. These changes included, for example, a reduction in the hours allocated and the addition of ineligibility for services criteria. As noted in the Quebec

Ombudsman's 2012 and 2016 reports, recent reforms have had a significant impact on many older adults,[9] and the level of services provided is by no means uniform, but varies from district to district. In other words, if an older adult moves or is admitted to a care facility in a different location, the services they once received may no longer be available. Despite a recent budget increase approved by the Government of Quebec, the Health Ministry admitted that funding was still insufficient, in part because of the growing number of older adults requiring services. At the individual service level, therefore, budget increases are not necessarily reflected in a more ample provision of existing services.

Some of the negative effects of cutbacks in homecare funding and the corresponding decreases in services and supports to elderly clients and family caregivers were reflected in the interviews with the social workers and the caregivers and how they expressed their expectations. As indicated in the analysis of the interviews, some caregivers discovered that they had to seek other resources because what was offered was inadequate (CG17), or they had to find a nursing home on their own (CG2) or they had to overcome disappointment at not getting the help they needed (CG7, CG9). As one study concluded, referring to caregiver's delay in seeking help: "*[...] in a system premised on expectations for family caregiving and personal responsibility for self-care, and which then accordingly severely rations care and actively dissuades help-seeking behaviour, we wonder whether caregivers can be expected to respond otherwise.* (Lilly et al, 2012).

A system that fails to provide the needed support and services to the elderly and family caregivers could be seen as promoting the clientization process, thus accelerating the process of caregiver to future clients of the healthcare system. This results in what Gubrium (2016) and Järvininen (2014) have termed 'The Organized Service Relationship' where administrative imperatives increasingly influence the service relationship which then “turns troubles into problems” and “contributes to the clientization process” (Dustin, 2007; Grenier, J. & Bourque, M., 2016; Harlow, 2013). As Gubrium (2016) stated: “*In an era of hyper-individualism, it is easily forgotten that we experience life in relationships and by not noticing, or ignoring, or not acknowledging the ‘troubles’ they turn into problems.”*

9. CONCLUSION

9.1 OVERVIEW OF THE PROJECT

As stated in the introduction, the general objective of this study was to gain insight into the complexity and what is at stake regarding the assessment of loss autonomy of older people in Quebec. Several questions originating from practice with elderly homecare clientele and from psychosocial intervention with family caregivers contributed to the identification of the multifaceted problematic. Initially, it appeared that when the elder person enters the domain of homecare, the heterogeneity and complexity of the individual aging process, as well as the needs of family caregivers was not being adequately captured, or reflected in the formulaic assessment (OÉMC). The results of a preliminary pilot study to study this issue ultimately led to the decision to concentrate on loss of autonomy assessment of the elderly, specifically in the context of the interplay of expectations, from the micro perspective of the social worker/family caregivers' interaction and the macro perspective of social worker working within the bureaucratic process of the healthcare system. A focus was placed on the multiclientèle assessment tool used in this province since it had been implemented for many years and had been validated with each revision.

Early on, it was decided that an interdisciplinary, scoping review of the literature was required in order to understand the importance of autonomy within the health care system in the current landscapes of care and the centrality of an assessment tool like the OÉMC. The results of this literature review led to the realization that, while the notion of autonomy is ubiquitous in social science literature and is an applied doctrine in many disparate disciplines, it is critiqued and questioned by many researchers when it is employed strictly as a criteria for measuring the increasing functional dependence of the elderly. As well, the results of the subsequent literature review that explored the history of the healthcare system in Québec, revealed the fragility of the underfunded and continuously evolving homecare services system. In particular, the negative fallout from the transfer of responsibility for care of the elderly to the community and family members, and the dissatisfaction of many healthcare workers due to the introduction of NPM marketing principles to homecare services and the resulting difficult working climate.

The notion of expectations was first identified as relevant to this research during the afore-mentioned process of exploring the notion of autonomy and the Quebec healthcare system and it became concretized during the follow-up discussions we had of the pilot project interviews and discussions. It was selected because of the potential for its transversal application within all three identified scenarios (caregiver → social worker, social worker → caregiver, and, managers → social workers) and the possibility of locating relevant expectation theories in social science such as social psychology and health sciences that would assist in developing the theoretical underpinnings of the project.

Interviews were conducted with family caregivers to explore the notion of loss of autonomy and how it has effected them in relation to the care of their elderly relative in particular in regarding their expectations for care and support from the healthcare system. As well, other interviews were done with homecare social workers to ascertain their expectations of family caregivers to provide care. During the interviews, their expectations of the assessment instrument itself was also questioned in an effort to identify how it serves to hinder or improve the evaluation process. Ultimately, the results of the literature reviews and the interviews were coded and analyzed and summarized. The following section presents a summary of the findings.

9.2 SUMMARY OF FINDINGS

9.2.1 The limitations of standardized assessment tools

Assessment instruments play an important role in evaluating the health and dependence status of the person. By identifying a list of standards and guidelines they can serve as a checklist that allows the assessor to create a basic profile of their needs for care and support. As the social workers interviewed for this agreed, they serve a purpose and have their place in creating the client's profile. But, they have their limitations in capturing the complete situation of the person being assessed, particularly in regards to their psychosocial situation. Social workers also mentioned some of its shortcomings in the disparity of depth of analysis between-workers. While some provided many details of the situation, others provided very little. Leaving them to wonder if the lack of detail was because of lack of information, or, lack of time to provide it. In a healthcare system in which the social worker who performs the assessment also is the person who continues to follow the case this would not be an issue. However, systemic human resource shortages because of staff turnover, as was highlighted in this thesis in the section that discussed the state of the Québec healthcare system has exacerbated this situation because social workers covering for absent colleagues must constantly backtrack to obtain the information they need.

The other important limitation of the OÉMC is in regards to the somewhat narrow definition of autonomy it encompasses. There is no denying that functional autonomy as in indicator of a person's ability to take care of their physical and health needs provides important information. However, when the notion is broadened to include other definitions such as relational autonomy, another dimension, that includes their own perception of autonomy becomes available. As mentioned in the previous discussion on *relational autonomy*, this approach would allow for respect of the person and reflects their embodied existence and their personal dignity. As the OÉMC is formulated in its present version the psychosocial section, which has the most potential for assimilating a relational approach to autonomy does little more than provide another checklist of items that are completed in an inconsistent pattern, at the discretion of the form completer. The perspective of the person being assessed and the family caregiver is largely absent. As well, while it appears that the order of social workers recognizes this shortcoming and has created an additional form, it seems that the social workers themselves have objections to spending the additional time that would be needed to do so. Once again, this highlights the organizational directives that have dictated time and caseload limits and norms which has exacerbated the time related pressure they experience. And finally the OCCI, the more recent adaptation of the OÉMC and although not directly targeted by this study has come under fire for its increased length and what practitioners feel is the undermining of professional judgement in favour of a standardized instrument.

9.2.2 The role of expectations in assessment of the elderly

It would be safe to assume that the relationship between social workers and family caregivers is built on the common goal of achieving optimal care and support for the aging person experiencing loss of autonomy. As described in the section of this thesis that discusses the evolution of the healthcare system in Québec, the movement towards transfer of responsibility for care of the elderly to the family and community was entrenched early on in their policies and reforms. But, it appears to be predicated on several false premises or fallacies that were described in the discussion section. Regarding the expectations placed on caregivers, the traditional narrative of caregiving often focuses on the burden of providing care and less so on their willingness and ability to do so. However, despite the awareness of the stress associated with the caregiver role, it is still taken-for-granted that they have the willingness and skills required to do the tasks. Hence, the fallacy of the previously discussed altruistic, partner/assistant caregiver becomes perpetuated in the relationship and support services are not made available to them until they are mentally and physically diminished enough to be considered clients in their own right.

9.2.3 The influence of assessment on expectations

It is more challenging to discern how expectations are influenced by the assessment process, however, some conclusions could be drawn from the interviews with family caregivers. As was shown in the caregiver adaptation process illustration, expectations are influenced by several pre-assessment factors. As caregivers become familiar with the process and the purpose of the assessment their expectations are revised and rearticulated accordingly to match the evolving reality of the circumstances. For instance, the example of the caregiver situation that was described in the results section of this thesis in which the caregiver expressed her disappointment in the system that didn't offer the support and services she believed were needed, when ultimately she took action herself that she believed helped her get what she needed. Another caregiver spoke of her previous experience with the healthcare system while caring for her parents. This experience had led her to expect that care and services from homecare would be similar to what had been provided before. Amongst all of the caregivers interviewed, she had the most negative perception of her more recent experience and stated that she felt disappointed in how her husband's situation was handled.

9.2.4 Expectations placed on social workers

Like any profession, there are expectations related to job performance placed on social workers, usually tied in with their job description. However, as was described by them during the interviews and confirmed through the literature review, the norms and standards for social workers, as for all health professionals, are closely affiliated with other criteria such as budgets and scarce resources. This becomes the core of the expectation paradigm which is closely related to the transfer of responsibility for care and support from the State to the family of the aging person. This is exemplified in the gap between the public's perceptions – specifically in the case of this study the perception of family caregivers – social workers – and the policies of the State.

9.3 LIMITATIONS OF THE STUDY

While recognizing the exploratory nature of this study that attempted to gain insight into the complex negotiation of measuring an elderly persons state of being and functioning with an assessment instrument such as the OÉMC and while also taking into account the influence of expectations, three particular limitations can be acknowledged. The first is related to the size and scope of the research, the second refers to the exclusion of elderly people themselves from the study and the third is reflected in the evolutionary nature of the Québec healthcare system.

This study cannot be considered representative because of its limited size in terms of number of subjects interviewed and the geographical limits of the CIUSSS territory it covered. The CIUSSS was located in an urban setting in Montréal and was limited to the profession of social work. Also, when cultural differences are taken into account it is possible that another dimension of autonomy and expectations would be revealed. It could also be speculated that other settings and other healthcare workers from other professions could offer different insights. Although, it should be mentioned that homecare services in Québec have been designed to have uniformity in the way services are organized and offered between sites and within professions so it is possible that some comparisons could be made. Also, the OÉMC itself is a clinical instrument intended to be used in multiple contexts and settings and it is possible that in another setting such as long-term care different results would be obtained. Also, in regards to the assessment instrument, as was mentioned in this thesis, the introduction of the OCCI during the last year within healthcare organizations, which, although considered a continuation if not even more complex version of the original OÉMC, seems to have provoked another level and frustration and consternation amongst social workers. So, it could be questioned if the responses we received from social workers regarding the OÉMC could be extrapolated to include their opinion of the newer version OCCI. However, it is possible to speculate that the negative reports regarding the implementation of the OCCI would reflect a similar response from social workers to how they responded to questions on the OÉMC.

The second limitation of the study is in regards to the exclusion of the elderly person in the research. As was explained in the methods section, the decision to exclude them was made because of ethical considerations and to respect the research protocol. However, other research designed to include this population and their point of view has the potential expanding the results beyond its present limits since it cannot be taken for granted that family caregivers and their elderly share the same point of view and expectations.

Thirdly, the current landscapes of care in Québec have evolved over decades of reforms and reorganizations put in place according to the priorities identified by successive governments. The reforms have included the mergers of large institutions, it is assumed all with the goal of providing better, more efficient care to the population. Although the objective of this thesis did not include a detailed analysis or critique of the systemic changes which is beyond the skills and purview of this study, it did however offer an overview that at the very least was able to demonstrate that recurrent changes will likely continue. Both in its structure and in the instruments that are made available to healthcare professionals. This is evidenced in the latest instrument, the OCCI, as described above. Actually, taking into account the negative reception it has had and the circulating petition against it, it is entirely possible that another revision may be done in the future. Which presents the possibility that any research conducted on current assessment instruments may become obsolete or inapplicable.

9.4 PRACTICAL APPLICATIONS AND RECOMMENDATIONS

The practical applications of this research specifically target homecare interventions with the aging population. It provides practitioners with insight into the expectations that family caregivers may have towards support and services and highlights the inherent paradox of a situation in which caregivers are expected to compensate for the loss of autonomy of their family member without first verifying their own capabilities. It also sensitizes practitioners about the potential dichotomy of conflict of their humanistic, professional values versus the values of an economics-based healthcare system. Regarding the instrument itself, which in its most recent formulation (OCCI) seems to have already demonstrated some controversy, prior consultation with healthcare professionals may have offset some of this problem.

The interviews with family caregivers regarding their expectations revealed that they often do not have a great deal of knowledge about how care and services are organized in the Québec healthcare system. It appears that they only discover whether or not their expectations are realistic when they are need of services, both for their care receiver and for themselves. Taking into account the fact that the predicted number of people requiring care is expected to continue to rise in the coming years, it would be important to diffuse their concerns prior to their needing services by holding public information sessions and improving the quality of information available on government websites.

During the course of this study and the interviews several people made comments regarding how the reforms and reorganization in the healthcare system seemed to them to be done randomly with no prior consultation with the people most affected, frontline workers. Although the intent of this research was never to analyze reforms, it would appear that decision-makers and managers should take this into consideration when future changes are planned.

REFERENCES

Agich, G. (2003). *Dependence and Autonomy in Old Age: An Ethical Framework for Long-Term Care*. Cambridge University.

Agich, G. (2007). Reflections on the function of dignity in the context of caring for older people. *Journal of Medecine and Philosophy*, *52*, 483–494.

Alvesson, M., & Skoldberg, K. (2009). *Reflexive Methodology: New vistas for qualitative research*. Thousand Oaks, CA. Sage publications.

Alvial-Palavicino, C. (2015). The future as practice: A framework to understand anticipation in science and technology. *Tecnoscienza*, *6*(2), 135–172.

Amyot, J.-J. (2012). Vieillesse, contrôle social et idéologie sécuritaire: entre autonomie et indépendance. *Vie Sociale*, *1*(1), 125–143. https://doi.org/10.3917/vsoc.121.0125

Aulenbacher, B., Lutz, H., & Riegraf, B. (2018). Towards a global sociology of care and care work. *Current Sociology Monograph*, *66*(4), 495–502.

Baars, J., Dannefer, D., Phillipson, C., & Walker, A. (2006). *Aging, globalization and inequality: The new critical gerontology*. Amityville, N.Y.: Baywood.

Balard, F., Gely-Nargeot, M.-C., Corvol, A., Saint-Jean, O., & Somme, D. (2016). Case management of the elderly with complex needs: cross-linking the views of their role held by elderly people, their informal caregivers and case managers. *BMC Health Services Research*, *16*(16), 1–10.

Balard, F., Pin Le Corre, S., Trouvé, H., Saint-Jean, O., & Somme, D. (2013). Exploring representations and experiences of case-management users: towards difficulties and solutions to leading qualitative interviews with older people with complex living conditions. *Quality in Primary Care*, *21*, 229–235.

Ball, M.M., P., M. M., Whittington F.J., H. C., & King, S.V., C. B. L. (2004). Independence in assisted living. *Journal of Aging Studies*, *18*, 467–483.

Baltes, P. B. (1987). Theoretical propositions of life-span developmental psychology: On the dynamics between growth and decline. *Developmental Psychology*, *23*(5), 611–626.

Bandura, A. (1989). Human Agency in Social Cognitive Theory. *American Psychologist*, *44*(9), 1175–1184.

Baraldi, R. (2016). *Coup d'œil sur les soins et services à domicile par les aînés au Québec en 2013-2014* (No. 57; p. 8). Institut de la statistique du Québec.

Barclay, L. (2000). Autonomy and the social self. In *Relational autonomy: Feminist perspectives on autonomy, agency and the social self* (pp. 52–72). New York: Oxford University Press.

Barilan, Y. M., & Weintraub, M. (2001). Persuasion as respect for persons: an alternative view of autonomy and of the limits of discourse. *Journal of Medicine and Philosophy*, *26*(1), 13–33.

Barrett, P., Hale, B., & Gauld, R. (2012). Social inclusion through ageing-in-place with care? *Ageing & Society*, *32*, 361–378.

Baumann, M. R., & Bonner, B. L. (2016). An expectancy theory approach to group coordination: Expertise, task features and member behavior. *Journal of Behavioral Decision Making*, *30*, 407–419.

Beauchamp, T. L. (2011). Informed consent: Its history, meaning, and present challenges. *Cambridge Quarterly of Healthcare Ethics*, *20*, 515–523.

Beauchamp, T. L., & Childress, J. F. (1994). *Principles of biomedical ethics* (4th Ed.). New York: Oxford University Press.

Beaulieu, M., & Caron, F. (2000). La place de la personne aînée dans la définition de son autonomie. *Le Gérontophile*, *22*(3), 47–55.

Becker, G. (1994). The oldest old: Autonomy in the face of frailty. *Journal of Aging Studies*, *8*(1), 59–76.

Beinart, N., Weinman, J., Wade, D., & Bradt, R. (2012). Caregiver Burden and Psychoeducational Interventions in Alzheimer's disease: A Review. *Dementia and Geriatric Cognitive Disorders*, *2*, 638–648.

Bellot, C., Bresson, M., & Jetté, C. (2013). *Le travail social et la nouvelle gestion publique*. Québec: Presses de l'Université du Québec.

Bengston, V. L. (1997). Theory, explanation, and a third generation of theoretical development in social gerontology. *Journal of Gerontology: Social Sciences*, *52B*(2), S72–S88.

Benoit, M., & Perron, L. (2018). Aging "at home" in an era of austerity: home care services under pressure. *Pluralages*, *8*(1), 20–23.

Beresford, P., Croft, S., & Adshead, L. (2008). "We don't see her as a social worker": A service user case study of the importance of the social worker's relationship and humanity. *British Journal of Social Work*, *38*, 1388–1407.

Berger, J., Conner, T. L., & Fisek, M. H. (1974). *Expectations states theory: a theoretical research program*. Cambridge, MA. Winthrop.

Berger, J., & Wagner, D. G. (2016). Expectations states theory. In *The Blackwell Encyclopedia of Sociology* (pp. 1–5). John Wiley & Sons.

Berger, J., Webster, M., Ridgeway, C. L., & Rosenholtz, S. J. (1998). Status cues, expectations and behavior. In *Status, Power and Legitimacy: Strategies and Theories* (pp. 155–173). N.Y.: Routledge.

Berke, R. (2014). Older adults living at risk: ethical dilemmas, risk, assessment and interventions to facilitate autonomy and safety. *International Journal of Nursing Student Scholarship*, *1*, 1–14.

Bernd, R., Doyle, Y., Grundy, E., & McKee, M. (2009). *How can health systems respond to population aging?* (Policy Brief No. 10; p. 43). Denmark: World Health Organization.

Berthillette, D. (2017). *Leçons apprises d'un déploiement de l'approche lean dans des établissements de santé et de services sociaux au Québec*. Le Point en santé et services sociaux.

Biggs, S. (2005). Beyond appearances: Perspectives on identity in later life and some implications for method. *Journal of Gerontology: Social Sciences*, *60B*(3), S118–S128.

Biggs, S. (2018). *Negotiating Ageing: Cultural adaptation to the prospect of a long life*. New York: Routledge.

Billette, V., Marier, P., & Séguin, A.-M. (2018). *Les vieillissements sous la loupe: entre mythes et réalités*. Québec: Presses de l'Université Laval.

Boily, M., & Bourque, S. (2011). *Cadre de référence: L'évaluation du fonctionnement social*. Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec.

Bonneville, L., & Grosjean, S. (2009). L'ordinateur portable en soins à domicile: l'espace interactionnel soignant/soigné en mutation. *Questions de Communication*, *http://questionsdecommunication.revues.org/594*.

Bonneville, L., & Jaurequiberry, F. (2007). Health professionals who are disconnecting from ICT. *Journal of Telemedicine & Telecare*, *13*(5).

Bonneville, L., & Sicotte, C. (2008). Les défis posés à la relation soignant-soigné par l'usage de l'ordinateur portable en soins à domicile. *Communication*, *62*(2). http://journals.openedition.org/communication/839

Borup, M., Brown, N., Konrad, K., & Van Lente, H. (2006). The sociology of expectations in science and technology. *Technology Analysis & Strategic Management*, *18*(3/4), 285–298.

Boucher, Y., Grenier, J., & Bourque, M. (2017). Repositionnement des travailleuses sociales: un travail hors les murs à partir d'un modèle d'intervention concertée. *Intervention*, *146*, 7–23.

Bourgeois-Guérin, V., Guberman, N., Lavoie, J.-P., & Gagnon, E. (2008). Entre les familles et les services formels, le désir des aînés ayant besoin d'aide. *Canadian Journal on Aging*, *27*, 241–252.

Bourque, D. (2009a). La création des CSSS et certains de ses effets sur les pratiques des travailleuses sociales. *Intervention*, *131*, 161–171.

Bourque, D. (2009b, Cahier numéro 0907). *Transformation du réseau public de services sociaux et impacts sur les pratiques des intervenants sociaux au Québec*. Chaire de recherche du Canada en organisation communautaire.

Bourque, D. (2017). *Évolution et enjeux de la transformation du travail social au Québec, communication dans le cadre du Colloque international, « Les mutations du travail social : regards croisés sur l'état des lieux et perspectives internationales*. Retrieved from http://w4.uqo.ca/crcoc/Fichiers/cahiers/1705_enjeux_transfo_TS.pdf

Bowling, A, Rowe, G., Lambert, N., Kenton, C., Waddington, M., Mahtani, K. R., Francis, S. A. (2006). The measurement of patients' expectations for health care: A review and psychometric testing of a measure of patients expectations. *Health Technology Assessment*, *16*(30), 1–5.

Bowling, Ann, & Rowe, G. (2014). Psychometric properties of the new patients' expectations questionnaire. *Patient Experience Journal*, *1*(1), 111–129.

Bowling, Ann, Rowe, G., & McKee, M. (2013). Patient's experiences of their healthcare in relation to their expectations and satisfaction: a population survey. *Journal of the Royal Society of Medicine*, *106*, 143–149.

Braye, S., & Preston-Shoot, M. (2006). The role of law in welfare reform: critical perspectives on the relationship between law and social work practice. *International Journal of Social Welfare*, *15*(1), 19–26.

Breitholtz, A., Snellman, I., & Fagerberg, I. (2013). Older people's dependence on caregivers help in their own homes and their lived experiences of their opportunity to make dependent decisions. *International Journal of Older People Nursing*, *8*(2), 139–148.

Brown, N., & Michael, M. (2003). A sociology of expectations: retrospecting prospects and prospecting retrospects. *Technology Analysis & Strategic Management*, *15*(1), 2–18.

Bureau du protecteur du citoyen. (2012). *Chez soi: toujours le premier choix? L'accessibilité aux services de soutien à domicile pour les personnes présentant une incapacité significative et persistante.* (No. Rapport d'enquête du protecteur du citoyen). Québec.

Calasanti, T. (2016). Combating ageism: How successful is successful aging? *The Gerontologist*, *56*(6), 1093–1101.

Calvès, A.-E. (2009). Empowerment: The history of a key concept in contemporary development discourse. *Revue Tiers-Monde*, *4*(200), 735–749. https://doi.org/10.3917/rtm.200.0735

Canuel, C., Couturier, Y., & Beaulieu, M. (2010). Le rôle des proches dans le processus de détermination de l'inaptitude de la personne âgée en perte d'autonomie du point du vue des professionnels. *Enfances, Familles, Générations*, *13*, 97–115.

Caplan, A. L. (2014). Why autonomy needs help. *The Journal of the Institute of Medical Ethics*, *40*(5), 301–302.

Carrier, S. (2012). Service coordination for frail elderly individuals: an analysis of case management practices in Québec. *Journal of Gerontological Social Work*, *55*(5), 392–408.

Carrier, S., Lambert, A., Garon, S., Morin, P., Gagné, A.-A., & Bossé, P.-L. (2015). Évaluer les effets que produisent les services sociaux dans la vie des personnes usagères: proposition d'un cadre analyse. *Intervention*, *142*, 17–27.

Carrier, S., Morin, P., & Garon, S. (2012). L'approche centrée sur les résultats: l'exemple des réseaux de services intégrés pour les personnes âgées en perte d'autonomie. *Intervention*, *137*, 47–56.

Carrière, Y., & Légaré, J. (1993). Vieillissement démographique et institutionnalisation des personnes âgées: des projections nuancées pour le Canada. *Cahiers Québécois de Démographie*, *22*(1), 63–92. https://doi.org/10.7202/010135ar

Chan, H. M., & Pang, S. (2007). Long-term care: Dignity, autonomy, family integrity and social sustainability: The Hong Kong experience. *Journal of Medicine and Philosophy*, *32*(5), 401–424.

Charpentier, M., Guberman, N., Billette, V., Lavoie, J.-P., Grenier, A., & Olazabal, I. (2010). *Vieillir au pluriel: perspectives sociales*. Presses de l'Université du Québec.

Chénard, J., & Grenier, J. (2012). Concilier des logiques pour une pratique de sens: exigence de solidarité. *Intervention*, *136*, 18–29.

Cheng, S.-T. (2017). Dementia Caregiver Burden: a Research Update and critical Analysis. *Curr Psychiatry Rep*, *19*(64), 3–8.

Chodos, H., & Leduc, D. (2004). *The Aging Population and Canada's Health Care System* (p. 4). Ottawa: Library of Parliament.

Church, J., Gerlock, A., & Smith, D. L. (2018). Neoliberalism and accountability failure in the delivery of services affecting the health of the public. *International Journal of Health Services*, *48*(4), 641–662.

Clarke, L., & Bennett, E. V. (2012). Constructing the moral body: self-care among older adults with multiple chronic conditions. *Health*, *17*(3), 211–228.

Clouser, K. D., & Gert, B. (1990). A critique of principlism. *The Journal of Medicine and Philosophy*, *15*(2), 219–236.

Cole, C., Wellard, S., & Mummery, J. (2014). Problematising autonomy and advocacy in nursing. *Nursing Ethics*, *21*(5), 576–582.

Commissaire à la santé et au bien-être. (2017). *Perceptions et expériences des personnes de 65 ans et plus : le Québec comparé*. Gouvernement du Québec.

Contandriopoulos, D., & Brousselle, A. (2010). Reliable in their failure: an analysis of healthcare reform policies in public systems. *Health Policy*, *95*, 144–152.

Corrazzini-Gomez, K. (2002). The relative effects of home care client characteristics on the resource allocation process: do personality and demeanor matter? *The Gerontologist*, *42*(6), 740–750.

Correll, S. J., & Ridgeway, C. L. (2006). Expectation states theory. In *Handbook of Social Psychology*. N.Y.: Springer.

Couturier, Y., Gagnon, D., & Belzile, L. (2013). La gestion de cas comme analyseur des paradoxes de la nouvelle gestion publique. In *Le travail social et la nouvelle gestion publique* (pp. 105–120). Québec: Presses de l'université du Québec.

Couturier, Y., Gagnon, D., Belzile, L., & Salles, M. (2013). *La coordination en gérontologie*. Montréal: Presses de l'Université de Montréal.

Cowger, C. D. (1994). Assessing client strengths: Clinical assessment for client empowerment. *Social Work*, *39*(3), 262–268.

Coyne, I. (2013). Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health Expectations*, *18*, 796–808.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.

Cruz, E. V., & Higginbottom, G. (2013). The use of focused ethnography in nursing research. *Nurse Researcher*, *20*(4), 36–43.

Csikai, E. L., & Rozensky, C. (1997). "Social work Idealism" and students perceived reasons for entering social work. *Journal of Social Work Education*, *33*(3), 529–538.

Culo, S. (2011). Risk assessment and intervention for vulnerable older adults. *BC Medical Journal*, *83*(8), 421–425.

Curie, R. (2010). *Le travail social à l'épreuve du néo-libéralisme: Entre résignation et résistance*. Paris: L'Harmattan.

Custers, A. F. J., Westerhof, G. J., Kuin, Y., Gerritsen, D. L., & Riksen-Walraven, J. (2012). Relatedness, autonomy and competence in the caring relationship: The perspective of nursing home residents. *Journal of Aging Studies*, *26*(3), 319–326.

Dagneaux, I. (2007). Usefulness and limitations of evaluation scales in the care of elderly people. *Ethical Perspectives:Journal of the European Network*, *14*(2), 175–191.

Dagneaux, Isabelle. (2009). Autonomie, dépendance, déficience,...plus que des mots! In *Des échelles pour prendre soin: Cailloux pour santé fragile* (pp. 94–106). Louvain-la-Neuve: Presses universitaires de Louvain.

Dannefer, D., & Settersten, Jr., R. A. (2010). The study of the life course: implications for social gerontology. In *The Sage Handbook of Social Gerontology* (pp. 3–19). Thousand Oak, CA. Sage publications.

Davies, J. C. (2011). Preserving the "us identity" through marriage commitment while living with early-stage dementia. *Dementia*, *10*(2), 217–234.

Deane, P., & Song, Y. (2015). *The key practice, discuss and debate ideas: conceptual framework, literature review, and provisional learning progressions for argumentation* (Research No. ETS RR-15-33; p. 21). ETS.

Deci, E. L., & Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior.* New York: Plenum.

Delli-Colli, N., Dubuc, N., Hébert, R., Lestage, C., & Dubois, F. (2013). Identifying psychosocial variables for home care services and how to measure them. *Home Health Care Services Quarterly*, *32*(4), 197–217.

Delli-Colli, Nathalie, Dubois, M.-F., Dubuc, N., Hébert, R., & Trottier, L. (2013). Caractéristiques des personnes âgées et des travailleurs sociaux associées au temps fourni au soutien à domicile. *Intervention*, *1*(138), 33–44.

Delli-Colli, Nathalie, Dubuc, N., Hébert, R., & Dubois, M.-F. (2013). Measuring social-work activities with older people. *Practice*, *25*(5), 281–296.

Demers, L. (2005, Juin). *Le rôle des acteurs locaux, régionaux et ministériels dans l'intégration des services aux aînés en perte d'autonomie*. École National d'administration publique.

Devisch, I. (2010). Oughtonomy in healthcare. A deconstructive reading of Kantian autonomy. *Med Health Care and Philos*, *13*, 303–312.

Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, *3*, 3–13.

Diefenbach, T. (2009). New public management in public sector organizations: the dark sides of managerialistic “enlightenment.” *Public Administration*, *87*(4), 892–909. https://doi.org/10.1111/j.1467-9299.2009.01766x

Dillaway, H., & Byrnes, M. (2009). Reconsidering successful aging: a call for renewed and expanded academic critiques and conceptualization. *Journal of Applied Gerontology*, *28*(6), 702–722.

Dodds, S., Mackenzie, C. (Ed), & Stoljar, N. (Ed). (2009). Choice and control in feminist bioethics. In *Relational autonomy: Feminist perspectives in autonomy, aging and the social self*. New York: Oxford University Press.

Donelan, K., Hill, C. A., Hoffman, C., Scoles, K., Feldman, P., Levine, C., & Gould, D. (2002). Challenged to Care: Informal Caregivers in a Changing Health System. *Health Tracking*, *21*(4), 222–231.

Dove, E. S., Kelly, S. E., Lucivero, F., Machirori, M., Dheensa, S., & Prainsack, B. (2017). Beyond individualism: Is there a place for relational autonomy in clinical practice and research? *Clinical Ethics*, (0), 1–16.

Dryden, J. (ND). *Autonomy*. Retrieved from http://www.iep.utm.edu/autonomy/#H1

Duan, N., Bhaumik, D. K., Palinkas, L. A., & Hoagwood, K. A. (2014). Optimal design and purposeful sampling: Complementary design for implementation research. *Https://Www.Researchgate.Net/Journal/0894-587X_Administration and Policy in Mental Health and Mental Health Services*, *42*(5), 1–10.

Dubuc, N. et al. (2013). Development of integrated care pathways: toward a care management system to meet the needs of frail and disabled community-dwelling older people. *International Journal of Integrated Care*, *13*, 1–13.

Dubuc, N. (2014). *Les outils de cheminement cliniques informatisés (OCCI) et l’intégration de meilleures pratiques cliniques pour le maintien de l’autonomie*.

Ducharme, F., Paquet, M., Vissandjee, B., Carpentier, N., & Trudeau, D. (2007). *Attentes et solutions des aidants familiaux et des intervenants: pour une offre de services culturellement cohérents* (p. 84). Montréal: Conseil de recherche en sciences humaines du Canada (CRSH).

Dustin, D. (2007). *The McDonaldization of Social Work*. Burlington, VT: Ashgate.

Dworkin, R. (1986). Autonomy and the demented self. *The Milbank Quarterly*, *64*, *supplement 2*, 4–16.

Ehrenberg, A. (2009). L’autonomie n’est pas un problème d’environnement, ou pourquoi il ne faut pas confondre interlocution et institution. *Comment penser l’autonomie? Marlene Jouan et Al*, 219–235.

Emmel, N. (2013). *Sampling and choosing cases in qualitative research: A realist approach*. Thousand Oaks, CA: Sage publications.

Ennuyer, B. (2001). Les outils d’évaluation de la dépendance dans le champ de l’aide à domicile. Ou comment le pouvoir des experts contribue à déposséder de leur vie les gens qui vieillissent mal! *Gérontologie et Société*, (99), 219–232.

Ennuyer, B. (2002). *Les malentendus de la dépendance : de l’incapacité au lien social*. Paris: Dunod.

Escandell-Vidal, V. (2017). Expectations in Interaction. In *Pragmemes and Theories of Language Use, Perspectives in Pragmatics, Philosophy and Psychology*. Switzerland: Springer.

Farrell, C. M., & Morris, J. (2010). Markets, Bureaucracy and Public Management: Professional perceptions of bureaucratic change in the public sector: GPs, Head teachers and Social Workers. *Public Money and Management*, *19*(4), 31–36.

Firbank, O. E. (2011). Framing home-care policy: a case study of reforms in a Canadian jurisdiction. *Journal of Aging Studies*, *25*, 34–44.

Ford, A. (2000). Sustained personal autonomy: a measure of successful aging. *Journal of Aging and Health*, *12*(4), 470–489.

Fournier, P.-L., & Jobin, M.-H. (2017). *Understanding the context for LEAN implementation in public healthcare organizations*. HEC Montréal Pôlesanté.

Fournier, P.-L., & Jobin, M.-H. (2018). Understanding before implementing: the context of Lean in public healthcare organizations. *Public Money & Management*, *38*(1), 37–44.

Freshwater, D., & Cahill, J. (2017). Professional responsibility and technologically informed decision making: The rise and demise of the compassionate algorithm. *Critical Approaches in Nursing Theory and Nursing Research*, 133–149.

Gagnon, E., & Saillant, F. (2003). Des contraints à l'autonomie: regard des aidés. In *De la dépendance et de l'accompagnement* (pp. 133–139). Québec: Les presses de l'université de Laval.

Gannon, S. (2012). Globalizing education, educating the local: how method made us mad. *Journal of Education Policy*, *27*(6), 867–869. https://doi.org/10.1080/02680939.2012.666054

Gardner, J., Samuel, G., & Williams, C. (2015). Sociology of low expectations: recalibration as innovation work in biomedicine. *Science, Technology and Human Values*, *40*(6), 998–1021.

Gergen, K. J., & Gergen, M. M. (2000). The new aging: self-construction and social values. *Social Structures and Aging*.

Gignac, M. A. M., Cott, C., & Badley, E. M. (2000). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journal of Gerontology*, *55b*(6), 362–372.

Gilbert, N., Leibing, A., & Marier, P. (2018). Multiples autonomies: naviguer l'univers du soutien à domicile. In *Les vieillissements sous la loupe: entre mythes et réalités* (pp. 249–256). Québec: Presses de l'Université Laval.

Gordon, J. (2011). Global ethics and principlism. *Kennedy Institute of Ethics Journal*, *21*(3), 251–276.

Graham, J. E., & Bassett, R. (2006). Reciprocal relations: The recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies*, *20*, 335–349.

Graham, J. R., & Shier, M. L. (2014). Profession and workplace expectations of social workers: Implications for social worker subjective well-being. *Journal of Social Work Practice*, *28*(1), 95–110.

Gregory, A., Mackintosh, S., Kumar, S., & Grech, C. (2016). Experiences of health care for older people who need support to live at home: A systematic review of the qualitative literature. *Geriatric Nursing*, *xx*, 1–10.

Grenier, A. (2008). Recognizing and responding to loss and "rupture" in older women's accounts. *Journal of Social Work Practice*, *22*(2), 195–209.

Grenier, A., & Wong, T. (2010). The process of health and social service reform in Quebec as experienced on the front line. *Canadian Social Work Review*, *27*(1), 41–61.

Grenier, J. (2011). *Regards d'aînés: justice, autonomie et responsabilité partagée*. Doctoral Thesis.

Grenier, J., & Bourque, M. (2014). *L'évolution des services sociaux du réseau de la santé et des services sociaux du Québec: la NGP ou le démantèlement progressif des services sociaux* (p. 148). St-Jérôme, QC.: MSSS.

Grenier, J., & Bourque, M. (2016). Les politiques et les pratiques managériales: impacts sur les pratiques du travail social, une profession à pratique prudentielle. *Forum*, *147*(1), 8–17.

Grenier, J., Bourque, M., & Boucher, Y. (2018). Défis pour les travailleuses sociales: participer au renouvellement des pratiques sociales dans un contexte de performance au travail. *Intervention*, *147*, 3–14.

Grenier, J., Bourque, M., & St-Amour, N. (2016). La souffrance psychique au travail: une affaire de gestion? *Intervention*, (144), 9–20.

Grosjean, S., & Bonneville, L. (2016). Technological change in organizations: from managing resistance to integrating employee creativity. In *Human Dignity and Managerial Responsibility: Diversity, Rights and Sustainability*. New York: Routledge.

Gruening, G. (2001). Origin and theoretical basis of New Public Management. *International Public Management Journal*, *4*, 1–25.

Guberman, N., & Lavoie, J.-P. (2010). Pas des superhéros: Des réalités et expériences des proches aidants. In *Vieillir au pluriel: perspectives sociales* (pp. 281–302). Montréal: Presses de l'Université du Québec.

Guberman, N., Lavoie, J.-P., Blein, L., & Olazabal, I. (2012). Baby boom caregivers: care in the age of individualization. *The Gerontologist*, *52*(2), 210–218.

Guberman, N., Lavoie, J.-P., Pepin, J., & Lauzon, S. (2006). Formal service practitioners' views of family caregiver's responsibilities and difficulties. *Canadian Journal on Aging*, *25*(1), 43–53.

Guberman, N., & Maheu, P. (2000). Conceptions of family caregivers: implications for professional practice. *Canadian Journal on Aging*, *21*(1), 27–37.

Gubrium, J. F. (2016). From the iron cage to everyday life. In, *Reimaging the human service relationship* (pp. 4–31). Columbia University Press.

Gubrium, J. F., Buckholdt, D. R., & Lynott, R. J. (1989). The descriptive tyranny of forms. *Perspectives on Social Problems*, *1*, 195–214.

Gubrium, J. F., & Jarvinen, M. (2014a). Troubles, problems, and clientization. In *Turning Troubles into Problems: Clientization in Human services* (p. 237). N.Y.: Routledge.

Gubrium, J. F., & Jarvinen, M. (2014b). *Turning Troubles into Problems: clientization in human services*. Routledge.

Hale, B., Barrett, P., & Gauld, R. (2010). *The age of supported independence. Voices of in-home care*. New Zealand: Springer.

Harlow, E. (2003). New managerialism, social service departments and social work practice today. *Practice*, *15*(2), 29–44.

Harlow, E. (2013). Neoliberalism, managerialism and the reconfiguring of social work in Sweden and the United Kingdom. *Organization*, *20*, 534–550.

Harrison, F., Low, L.-F., Barnett, A., Gresham, M., & Brodaty, H. (2014). *What do clients expect of community care and what are their needs? The community care for the elderly: Needs and service use study*.

Havighurst, A., R. (1961). Successful Aging. *The Gerontologist*, *1*(1), 8–13.

Hébert, G. (2017). *L'armée manquante au Québec: les services à domicile* (p. 16). Montréal: Institut de recherche et d'informations socioéconomiques (IRIS).

Hébert, R., Raîche, M., Dubois, M. F., Gueye, N. R., & Tousignant, M. (2012). Développement d'indicateurs pour valoriser des actions de prévention et de réadaptation de la perte d'autonomie des personnes âgées. *Révue d'Épidémiologie et e Santé Publique*, *60*, 463–472.

Hébert, R. (1982). L'évaluation de l'autonomie fonctionnelle des personnes âgées. *Can. Fam. Physician*, *28*, 754–762.

Hébert, R., Desrosiers, J., Dubuc, N., Tousignant, M., Guilbeault, J., & Pinsonnault, E. (2003). Le système de mesure de l'autonomie fonctionnelle (SMAF). The functional autonomy measurement system (SMAF). *La Revue de Gériatrie*, *28*(4), 323–336.

Hébert, R., Guilbault, J., Desrosiers, J., & Dubuc, N. (2001). The functional autonomy measurement system (SMAF): a clinical-based instrument for measuring disabilities and handicaps in older people. *Geriatrics Today*, *4*, 141–147.

Hébert, R., Tourigny, A., & Gagnon, M. (2004). *Intégrer les services pour le maintien de l'autonomie des personnes*. Quebec: Edisem.

Heneman, H. G., & Schwab, D. P. (1972). Evaluation of research on expectancy theory predictions of employee performance. *Psychological Bulletin*, *78*(1), 1–9.

Hertz, J. E., & Anschutz, A. A. (2002). Relationships among perceived enactment of autonomy, self-care and holistic health in community-dwelling older adults. *Journal of Holistic Nursing*, *20*(2), 166–186.

Higginbottom, G., Pillay, J. J., & Boadu, N. Y. (2013). Guidance on performing focused ethnographies with an emphasis on healthcare research. *The Qualitative Report*, *18*(17), 1–16.

Hillcoat-Nellétamby, S. (2014). The meaning of "independence" for older people in different residential settings. *Journals of Gerontology, Series B: Psychological and Social Sciences*, *69*(3), 419–430.

Hoeyer, K., & Hogle, L. F. (2014). Informed Consent: The politics of intent and practice in medical research ethics. *Annual Review of Anthropology*, *43*, 347–362.

Hofer, S. M., & Piccinin, A. M. (2010). Toward an Integrative Science of Life-Span Development and Aging. *Journal of Gerontology: Psychological Sciences and Social Sciences, Series B*, *65B(3)*, 269–278.

Hollander, M. J., Liu, G., & Chappell, N. L. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, *12*(2), 42–49.

Holmes, J. G. (2002). Interpersonal expectations as the building blocks of social cognition: An interdependence theory perspective. *Personal Relationships*, *9*, 1–26.

Holstein, M., & Minkler, M. (2003). Self, society and the "New Gerontology." *The Gerontologist*, *43*(6), 787–796.

Horowitz, A., Reinhardt, J. P., & Goodman, C. R. (2004). Congruence between disabled elders and their primary caregivers. *The Gerontologist*, *44*(4), 532–542.

Hunter, N. D. (2010). *Rights talk and patient subjectivity: The role of autonomy, equality, and participation norms*. Wake Forest Law Review.

Hurd, L. (1999). "We're not old!" Older women's negotiation of aging and oldness. *Journal of Aging Studies*, *13*(4), 419–439.

Hwang, H., Lin, H., Tung, Y., & Wu, H. (2006). Correlates of perceived autonomy among elders in a senior citizen home: A cross-sectional survey. *Journal of Nursing Studies*, *43*(4), 429–437.

Illich, I. (2003). Medical nemesis. *J Epidemial Community Health*, (57), 919–222.

Ipsos Reid. (2015). *Expectations of the health care system*. HealthCareCAN.

James, M. (2015). Situating a new voice in public relations: The application of positioning theory to research and practice. *Media International Australia*, *154*, 34–41.

Janlov, A.-C. (2006). Older persons' experience of being assessed for and receiving home help: Do they have any influence over it? *Health and Social Care in the Community*, *14*(1), 26–36.

Janzen, J. A., Silvius, J., Jacobs, S., Slaughter, S., Dalziel, W., & Drummond, N. (2006). What is a health expectation? Developing a pragmatic conceptual model from psychological theory. *Health Expectations*, *9*, 37–48.

Jessen, J. T. (2015). Public governance - constraints and challenges for social work practice. *Journal of Comparative Social Work*, *2*, 1–23.

Johansson, K. (2013). Have they done what they should? Moral reasoning in the context of translating older persons' everyday problems into eligible needs for home modification services. *Medical Anthropology Quarterly*, *27*(3), 414–433.

Johnson, R. A., & Bibbo, J. (2014). Relocation decisions and constructing the meaning of home: A phenomenological study of the transition into a nursing home. *Journal of Aging Studies*, *30*, 56–63.

Jones, R. L. (2006). "Older people" talking as if they are not older people: Positioning theory as an explanation. *Journal of Aging Studies*, *20*, 79–91. https://doi.org/10.1016/j.jaging.2004.12.003

Joosten, T., Bongers, I., & Janssen, R. (2009). Application of lean thinking to health care: issues and observations. *International Journal for Quality in Health Care*, *21*(5), 341–347.

Joseph Tham, S., & Letendre, M. C. (2014). Health care decision making: cross-cultural analysis of the shift from the autonomous to the relational staff. *The New Bioethics: A Multidisciplinary Journal of Biotechnology and the Body*, *20*(2), 174.

Kadushin, G. (1996). Elderly hospitalized patients' perceptions of the interaction with the social worker during discharge planning. *Social Work in Health Care*, *23*(1), 1–21.

Kahn, R. (2002). On "successful aging and well-being: Self-rated compared with Rowe and Kahn. *The Gerontologist*, *42*(6), 725–726.

Kane, A. R. (2016). Standardized assessments and measures in geriatric practice. In *The Oxford Handbook of Social Work in Health and Aging* (2nd ed.). New York: Oxford University Press.

Kasser, V., & Ryan, R. M. (1999). The relation of psychological needs for autonomy and relatedness to vitality, well-being, and morality in a nursing home. *Journal of Applied Social Psychology*, *29*(5), 935–954.

Katz, S. (1992). Alarmist demography: Power, knowledge, and the elderly population. *Journal of Aging Studies*, *6*(3), 203–225.

Katz, S. (2013). Active and successful aging: lifestyle as a Gerontological idea. *Recherches Sociologiques et Anthropologiques*, *1*.

Katz, S., & Calasanti, T. (2015). Critical perspectives on successful aging: Does it "appeal more that it illuminates"? *The Gerontologist*, *55*(1), 26–33.

Kearney, G. P., Johnstone, J. L., Hart, N. D., & Corman, M. K. (2018). Protocol: Exploring the objective structured clinical examination (OSCE) using institutional ethnography. *International Journal of Educational Research*, *88*, 42–47.

Keefe, J., Guberman, N., Fancey, P., Barylak, L., & Nahmiash, D. (2008). Caregivers' aspirations, realities and expectations: the CARE tool. *Journal of Applied Gerontology*, *27*(3), 286–308.

Kitwood, T. (1997). *Dementia Reconsidered: the person comes first*. Bristol. PA: Open University Press.

Knoblauch, H. (2005). Focused ethnography. *Forum: Qualitative Social Research*, *6*(3), 1–10.

Knottnerus, J. D. (1988). A critique of expectations states theory: Theoretical assumptions and models of social cognition. *Sociological Perspectives*, *31*(4), 420–445.

Kontos, P. C. (1998). Resisting institutionalization: Constructing old age and negotiating home. *Journal of Aging Studies*, *12*(2), 167–184.

Kukla, R. (2005). *Conscientious autonomy : displacing decisions in health care*. Hastings Centre Report 35, no 2.

Lamb, S. (2014). Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal of Aging Studies*, *29*, 41–52.

Lamb, S. (2017). *Successful aging as a contemporary obsession: Global perspectives*. Newark, N.J.: Rutgers University Press.

Larivière, C. (2010). *L'impact de la restructuration du réseau sur la pratique professionnelle* (p. 39). Québec: OTSTCFQ.

Larivière, C. (2012). Comment les travailleurs sociaux du Québec réagissent-ils à la transformation publique? *Intervention*, *136*, 30–40.

Laudy, D. (2008). Les enjeux éthiques du vieillissement : autonomie, solitude ou sollicitude? *Revue Internationale d'éthique Sociétale et Gouvernementale*, *10*(2), 1–14. https://doi.org/10.4000/ethiquepublique.1432

Lavalette, M. (2011). Social work in crisis during crisis: Whose side are we on? *Canadian Social Work Review*, *28*(1), 7–24.

Lavoie, J.-P., & Guberman, N. (2009). Le partenariat professionnel - famille dans les soins des personnes âgées. Un enjeu de reconnaissance. *Lien Social et Politiques*, *62*, 137–148.

Lavoie, J.-P., Guberman, N., & Marier, P. (2014). *La responsabilité des soins aux ainés au Québec : du secteur public au privé*. Institut de la recherche en politiques publiques.

Lavoie, J.-P., Guberman, N., Montejo, M.-E., Lauzon, S., & Pepin, J. (2003). Problématisations et pratiques des intervenantes: Des services à domicile auprès des aidantes familiales, quelques paradoxes. *Gérontologie et Société*, *1*(104), 195–211.

Lavoie, J.-P., & Rousseau, N. (2008). Pour le meilleur et pour le pire: transition au soin et identités conjugales. *Enfances Familles Générations*, *9*, 119–132.

Le Coadic, R. (2006). L'autonomie, illusion ou projet de société? *Cahiers Internationaux de Sociologie, Presses Universitaires de France*, *CXXI*, 317–340.

Leibing, A., Guberman, N., & Wiles, J. (2016). Liminal homes: Older people, loss of capacities and the present future of living spaces. *Journal of Aging Studies*, *37*, 10–19.

Leibing, Annette. (forthcoming). The vascularization of Alzheimer's disease – Making sense of prevention. In *Preventing Dementia? Critical perspectives on a new paradigm of preparing for old age*. New York/Oxford, UK.: Berghahn.

Leibing, Annette. (2006). Divided Gazes. Alzheimer's disease, the person within and death in life. In *Thinking about Dementia* (pp. 240–268). Rutgers University Press.

Leibing, Annette. (2017). Successful selves? Heroic tales of Alzheimer's disease and personhood in Brazil. In *Successful aging as a contemporary obsession: Global perspectives* (pp. 203–216). Newark, N.J.: Rutgers University Press.

Leibing, Annette. (2019). Dementia and humanism: Dementia and fallacies of care. *Journal of Aging Studies*, (Special issue: Fallacies of care). https://doi.org/10.1016/j.jaging.2019.100796

Leipzig, R. M., Wallenstein, S., & Cassel, C. K. (2002). Attitudes Toward Working on Interdisciplinary Healthcare Teams: A Comparison by Discipline. *J Am Geriatr Soc*, *50*, 1141–1148.

Leung, K. K., Silvius, J. L., Pimlott, N., Dalziel, W., & Drummond, N. (2009). Why health expectations and hopes are different: the development of a conceptual model. *Health Expectations*, *12*, 347–360.

Levasseur, M., Carrier, A., & Turcotte, P.-L. (2016). Réflexion sur l'utilisation de l'Outil d'évaluation Multiclientèle (OEMC) pour identifier les besoins de participation sociale des aînés ayant des incapacités. *Journal of Human Development, Disability and Social Change*, *22*(1), 1–33.

Lévesque, B. (2012). *Social Innovation and Governance in Public Management Systems: Limits of NPM and search for alternatives?* (Cahiers Du CRISES No. ET1116; p. 41). Montréal: Université de Québec à Montréal.

Lewis, H. (1984). Self-determination: The aged client's autonomy in service encounters. *Journal of Gerontological Social Work*, *7*(3), 51–63.

Liang, J., & Baozhen, L. (2012). Toward a discourse shift in social gerontology: from successful aging to harmonious aging. *Journal of Aging Studies*, *26*, 327–324.

Lilly, M. B., Robinson, C. A., Holtzman, S., & Bottorff, J. L. (2012). Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Colombia, Canada. *Health and Social Care in the Community*, *20*(1), 103–112.

Lowenstein, A. (2005). Developing an interdisciplinary innovative master of gerontology program. *The Gerontologist*, *45*(2), 255–261.

Lydahl, D. (2019). Standard tools for non-standard care: The values and scripts of a person-centered assessment protocol. *Health*, 1–18.

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlach, C. J. (2002). Caregiving as a dyadic process: perspectives from caregiver and receiver. *Journal of Gerontology: Psychological Sciences and Social Sciences, Series B*, *57B*(3), P195–P204.

Lysaught, M. T. (2004). Respect: Or, how respect for persons became respect for autonomy. *Journal of Medicine and Philosophy*, *29*(6), 665–680.

Lyttle, D. J., & Ryan, A. (2010). Factors influencing older patient's participation in care: A review of the literature. *International Journal of Older People Nursing*, *5*(4), 274–282.

Marshall, P. A. (1992). Anthropology and bioethics. *Medical Anthropology Quarterly*, *6*(1), 49–73.

MacDonald, J., & Nixon, K. (2016). La formation universitaire en travail social à l'épreuve du néo-libéralisme et de la nouvelle gestion publique: Introduction. *Canadian Social Work Review*, *33*(1), 111–114.

Mackenzie, C., & Stoljar, N. (2000). Introduction: Autonomy reconfigured. In *Relational Autonomy Feminist Perspectives on Autonomy, Agency and the Social Self* (pp. 3–31). New York: Oxford University Press.

MacLeod, H., & Stadnyk, R. L. (2015). Risk: 'I know it when I see it': how health and social practitioners defined and evaluated living at risk among community-dwelling older adults. *Health, Risk & Society*, *17*(1), 46–63.

Markham, A. (2014). *Creating lit reviews as arguments*. Retrieved from https://annettemarkham.com/2014/07/creatinglitreviewsasarguments

Marmol, E. (2016). The undemocratic effects and underlying racism of standardized testing in the United States. *Critical Intersections in Education*, *4*, 1–9.

Martin, D. (2017). LEAN in a cold fiscal climate: the public sector in an age of reduced resources. *Public Money and Management*, *38*(1), 29–36.

Martin, D. J., & Gillen, L. L. (2013). Revisiting gerontology's scrapbook: from Metchnikoff to the Spectrum model of aging. *The Gerontologist*, *54*(1), 51–58.

Martin, P., Kelly, N., Kahana, B., Kahana, E., Willcox, B. J., Willcox, D. C., & Poon, L. W. (2015). Defining successful aging: A tangible or elusive concept? *The Gerontologist*, *55*(1), 14–25.

Martinson, M., & Berridge, C. (2015). Successful Aging and its Discontents: A systematic Review of the Social Gerontology Literature. *The Gerontologist*, *55*(1), 58–69.

Maslow, A. H. (1943). A Theory of Human Motivation. *Psychological Review*, *50*(4), 370–396.

Matsui, M., & Capezuti, E. (2007). Perceived autonomy and self-care resources among senior centre users. *Geriatric Nursing*, *29*(2), 141–147.

McCullough, L. B. (2011). Was bioethics founded on historical and conceptual mistakes about medical paternalism? *Bioethics*, *25*(2), 66–74.

McGraw, L. A., & Walker, A. J. (2004). Negotiating care: ties between aging mothers and their caregiving daughters. *Journal of Gerontology*, *59B*(6), S324–S332.

McGregor, S. (2001). Neoliberalism and health care. *International Journal of Consumer Studies*, *25*(2), 82–89.

McInnis-Dittrich, K. (2016). Comprehensive biopsychosocial assessments: the foundation of social work with older adults. In *The Oxford Handbook of Social Work in Health and Aging* (2nd ed., pp. 9–17). New York: Oxford University Press.

McLeod, C., & Sherwin, S. (2000). Relational autonomy, self-trust and health care for patients who are oppressed. In *Relational Autonomy Feminist Perspectives on Autonomy, Agency and the Social Self* (pp. 259–280). New York: Oxford University Press.

Ménoret, M. (2015). La prescription d’autonomie en médecine. *Anthropologie & Santé*, *10*, 1–15.

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Thousand Oaks, CA: Sage.

Ministère de la famille et des aînés. (2012). *Vieillir et vivre ensemble. Chez soi dans la communauté au Québec.* Québec.

Ministère de la Santé et des Services Sociaux. (2000). *Comité aviseur sur l’adoption d’un outil d’évaluation intégré des besoins des personnes en perte d’autonomie et de détermination des services requis notamment en institution ou à domicile*. Ministère de la Santé et des Services Sociaux.

Ministère de la santé et des services sociaux. (2003). *Chez soi: le premier choix. La politique du soutien à domicile*.

Mittelman, W. (1991). Maslow’s study of self-actualization: A reinterpretation. *Journal of Humanistic Psychology*, *31*(1), 114–135.

Molina, Y. (2014). Nouvelle gestion publique et recomposition professionnelle dans le secteur social. *Pensée Plurielle*, *2*(36), 55–66.

Molyneux, D. (2009). Should healthcare professionals respect autonomy just because it promotes welfare? *Journal of Medical Ethics*, *35*(4), 245–250.

Montgomery, R. J. V., & Kosloski, K. D. (2013). Pathways to a Caregiver Identity and Implications for Support Services. In *Caregiving Across the Lifespan: Research, Practice, Policy* (pp. 131–156). New York: Springer.

Montross, L. P., Depp, C., Daly, J., Reichstadt, J., Golshan, S., Moore, D., Jeste, D. V. (2006). Correlates of self-rated successful aging among community-dwelling older adults. *Am J Geriatric Psychiatry*, *14*(1), 43–51.

Morin, C. (2013). Libéralités et personnes âgées : entre autonomie et protection. *Revue de Droit de McGill*, *59*(1), 141–164.

Morin, E. (1981). Peut-on concevoir une science de l’autonomie? *Cahiers Internationale de Sociologie*, *71*, 257–266.

Morley, J. E. (2004). A brief history of geriatrics. *Journal of Gerontology*, *59A*(11), 1132–1152.

Morse, J. M. (2007). Does health research warrant the modification of qualitative methods? *Qualitative Health Research*, *17*(7), 863–865.

Muller, J. H. (1994). Anthropology, Bioethics, and Medicine: A Provocative Trilogy. *Medical Anthropology Quarterly, New Series*, *8*(4), 448–467.

Munhall, P. L. (2012). *Nursing Research: a qualitative perspective*. Mississauga On. Jones & Bartlett.

Muscadere, John, et al. (2016). Screening for frailty in Canada's health care system: A time for action. *Canadian Journal on Aging*, *35*(3), 281–297.

Naue, U. (2008). Self-care without a self: Alzheimer's disease and the concept of personal responsibility for health. *Medicine, Health Care and Philosophy*, *11*(3), 315–324.

Neufeld, A., & Harrison, M. J. (2003). Unfulfilled expectations and negative interactions: Non-support in the relationships of women caregivers. *Journal of Advanced Nursing*, *41*(4), 323–331.

Neuhouser, F. (2011). Jean-Jacques Rousseau and the origins of autonomy. *Inquiry*, *54*(5), 478–493.

O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, *21*, 165–174. https://doi.org/10.1016/j.jaging.2006.06.002

OEMC VS évaluation du fonctionnement social. (2016). Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec.

Olaison, A. (2016). Processing older persons as clients in elderly care: A study of micro-processes of care management practice. *Social Work in Health Care*, 1–21.

Olaison, A., & Cedersund, E. (2006). Assessment for home care: Negotiating solutions for individual needs. *Journal of Aging Studies*, *20*(4), 367–380.

Olaison, A., & Cedersund, E. (2008). Home care as a family matter? Discursive positioning, storylines and decision-making in assessment talk. *Communication & Medicine*, *5*(2), 145–158.

Olson, J. M., Roese, N. J., & Zanna, M. P. (1996). Expectancies. In *Social Psychology: Handbook of basic principles* (Edited by Tory Higgins and Arie W Kruglanski, pp. 211–238). New York: Guildford Press.

Ouwehand, C., de Ridder, D. T. D., & Bensing, J. M. (2007). A review of successful aging models: Proposing proactive coping as an important additional strategy. *Clinical Psychology Review*, *27*, 873–884.

Ozegovic, D., Carroll, L. J., & Holm, L. W. (2012). "Know" expectations? Refining the discussion of expectations and considerations and advancing understanding in health. *Disability, Community & Rehabilitation*, *11*(01), 1–9.

Pantzar, M., & Ruckenstein, M. (2017). Living the metrics: self-tracking and situated objectivity. *Digital Health*, *3*, 1–10.

Parazelli, M., & Ruelland, I. (2017). *Autorité et gestion de l'intervention sociale: entre servitude et actepouvoir*. Québec: Presses de l'Université du Québec.

Parmar, J., Torti, J., Brémault-Phillips, S., Charles, L., Chan, K., & Tian, P. G. (2018). Supporting family caregivers of seniors within acute and continuing care systems. *Canadian Geriatrics Journal*, *21*(4), 292–296.

Patton, C., & Balakrishnan, P. V. (Sundar). (2010). The impact of expectation of future negotiation interaction on bargaining processes. *Journal of Business Research*, *63*, 809–816.

Peek, M. K., Coward, R. T., Peek, C. W., & Lee, G. R. (1998). Are expectations for care related to the receipt of care? An analysis of Parent care amond disabled elders. *Journal of Gerontology: Psychological Sciences and Social Sciences, Series B*, *53B*(3), S127–S136.

Pelletier, C., & Beaulieu, M. (2016). Rôles et défis des travailleurs sociaux en gérontologie dans le réseau du Québec. *Intervention*, *143*, 135–146.

Perkinson, M. A., & Solimeo, S. L. (2013). Aging in Cultural Context and as Narrative Process: Conceptual Foundations of the Anthropology of Aging as Reflected in the Works of Margaret Clark and Sharon Kaufman. *The Gerontologist*, 1–7. https://doi.org/10.1093/geront/gnt128

Phelan, E. A., Anderson, L. A., LaCroix, A. Z., & Larson, E. B. (2004). Older adults views of "successful aging" - How do they compare with researchers' definitions? *J Am Geriatr Soc*, *52*, 211–216.

Pinsonnault, E. (2003). Functional autonomy measurement system: development of a social subscale. *Arch. Gerontol. Geriatr.*, *37*, 223–233.

Pinsonnault, Eugénie, Dubuc, N., Desrosiers, J., & Delli-Colli, N. (2009). Validation study of a social functioning scale: the social-SMAF (social-Functional Autonomy Measurement System). *Archives of Gerontology and Geriatrics*, *48*, 4044.

Pires, A. P. (1997). De quelques enjeux épistémologiques d'une méthodologie générale pour les sciences sociales. In *La recherche qualitative: Enjeux épistémologiques et méthodologiques* (pp. 3–52). Montréal: Gaetan Morin.

Plath, D. (2008). Independence in old age: the route to social exclusion? *British Journal of Social Work*, *38*, 1353–1369.

Poli, R. (2014). Anticipation: A new thread for the human and social sciences? *Cadmus*, *2*(3), 23–36.

Pols, J., Althoff, B., & Bransen, E. (2017). The limits of autonomy: Ideals in care for people with learning disabilities. *Medical Anthropology*, *36*(8), 772–785.

Poupart, J., Deslauriers, J.-P., Groulx, L.-H., Laperrière, A., Mayer, R., & Pires, A. P. (1997). *La recherche qualitative: enjeux épistémologiques et méthodologiques*. Montréal: Gaetan Morin.

Pyysiainen, J., Halpin, D., & Guilfoyle, A. (2017). Neoliberal governance and "responsibilization" of agents: reassessing the mechanisms of responsibility-shift in neoliberal discursive environments. *Distinktion: Journal of Social Theory*, *18*(2), 215–235.

Quinn, T. J., McArthur, K., Ellis, G., & Stott, D. J. (2011). Functional assessment in older people. *BMJ*, *343*, 1–6.

Reamy, A. M., Kyungmin, K., Zarit, S. H., & Whitlach, C. J. (2011). Understanding discrepancy in perceptions of values: individuals with mild to moderate dementia and their family caregivers. *The Gerontologist*, *51*(4), 473–483.

Reis, H. T., Sheldon, K. M., Gable, S. L., Roscoe, J., & Ryan, R. M. (2000). Daily Well-Being: The Role of Autonomy, Competence, and Relatedness. *Personality and Social Psychology Bulletin*, 419–435.

Renaud, M. (1977). Réforme ou illusion? Une analyse des interventions de l'état québécois dans le domaine de la santé. *La gestion de la Santé*, *9*(1), 126–152.

Rendtorff, J. D. (2008). The limitations and accomplishments of autonomy as a basic principle in bioethics and biolaw. In *Autonomy and Human Rights in Health Care, D. N. Weisstaub and G.D. Pintos (eds.)* (pp. 75–87). Springer.

Repkp, A. F. (2011). Defining interdisciplinary studies. In *Interdisciplinary research. Process and research.* (2nd ed. pp. 1–31). LA: Sage.

Ricard, L. (2013). L'autonomie relationnelle: un nouveau fondement pour les théories de la justice. *Philosophiques*, *40*(1), 139–169. https://doi.org/10.7202/1018381ar

Richard, S., & Gervais, R. (2018). Le travail social et l'art de se maintenir dans tous ses états. *Intervention*, *147*, 15–28.

Ridgeway, C. L. (2006). Expectations states theory and emotion. In *Handbook of the Sociology of Emotions* (pp. 347–367). Boston Ma. Springer.

Rosenberg, M. (2000). *The effects of population aging on the Canadian Health Care System* (No. SEDAP research paper no. 14; p. 45).

Rossiter, A., & Heron, B. (2011). Neoliberalism, competencies, and the devaluing of social work practice. *Canadian Social Work Review*, *28*(2), 305–309.

Roulston, K. (2010). *Reflective interviewing: A guide to theory and practice*. Thousand Oaks, CA: Sage publications.

Rowe, J. W., & Kahn, R. L. (1998). *Successful Aging*. New York: Dell.

Rowe, J. W., & Kahn, R. L. (2015). Successful aging 2.0 : Conceptual expansions for the 21st century. *Journals of Gerontology, Series B: Psychological and Social Sciences*, *70*(4), 593–596.

Roy, J. (1994). L'histoire du maintien à domicile ou les nouveaux apôtres de l'État. *Service Social*, *43*(1), 7–32.

Rubinstein, R. L., & de Medeiros, K. (2015). "Successful aging." Gerontological theory and neoliberalism: A qualitative critique. *The Gerontologist*, *55*(1), 34–42.

Ruckenstein, M., & Schull, N. D. (2017). The datafication of health. *Annual Review of Anthropology*, *46*, 261–278.

Ryan, R. M., & Deci, E. L. (2006). Self-regulation and the problem of human autonomy: does Psychology need choice, self-determination, and will? *Journal of Personality*, *74*(6), 1557–1585.

Saad, T. C. (208AD). The history of autonomy in medicine from antiquity to principlism. *Med Health and Care and Philos*, *21*, 125–137.

Sabat, S. R. (2003). Malignant positioning and the predicament of Alzheimer's disease. In *The Self and Others: Positioning individuals and groups in personal, political and cultural contexts* (p. 322). Westport Connecticut: Praeger.

Sabat, S. R., Johnson, A., Swarbrick, C., & Keady, J. (2011). The "demented other" or simply "a person"? Extending the philosophical discourse of Naue and Kroll through the situated self. *Nursing Philosophy*, *12*, 282–292.

Saint-Martin (de), C., Pilotti, A., & Valentim, S. (2014). La réflexivité chez le Doctorant-Praticien-Chercheur. Une situation de liminalité. *Interrogations*, 9 pages.

Salles, M. (2016a). Comment accéder à l'activité d'évaluation conduite par les travailleurs sociaux. *Recherches Qualitatives - Hors-Série*, *20*, 127–139.

Salles, M. (2016b). Évaluer l'autonomie fonctionnelle: l'activité clinique des travailleurs sociaux en soutien à domicile. *Vie et Vieillissement*, *13*(1), 25–31.

Salvador-Carulla, L., & Gasca, V. I. (2010). Defining disability functioning autonomy and dependency in person centered medicine and integrated care. *International Journal of Integrated Care*, 1–5.

Samuelsson, G., & Wister, A. (2000). Client expectations and satisfaction of quality in home care services. A consumer perspective. *Home Care Provider*, (December), 223–230.

Sandberg, M., Jakobsson, U., Midlov, P., & Kristensson, J. (2014). Case management for frail older people - a qualitative study of receivers' and providers' experiences of a complex intervention. *BMC Health Services Research*, *14*(14), 1–12.

Sarkisian, C. A., Hays, R. D., Berry, S. H., & Mangione, C. M. (2001). Expectations regarding aging among older adults and physicians who care for older adults. *Medical Care*, *39*(9), 1025–1036.

Schneewind, J. B. (1998). *The Invention of Autonomy: A History of Modern Moral Philosophy*. New York: Cambridge University Press.

Seematter-Bagnoud L, Fustinoni S, Meylan L, Monod S, & Junod A, Büla C, Santos-Eggimann B. (2012). *Le Resident Assessment Instrument (RAI) et autres instruments d'évaluation des personnes âgées.* (p. 64). Institut universitaire de médecine sociale et préventive, Lausanne, Suisse.: Centre d'Observation et d'Analyse du Vieillissement.

Selin, C. (2008). *The sociology of the future: tracing stories of technology and time*. *2*(6), 1878–1895.

Settersten, Jr., R. A. (2005). Linking the Two Ends of Life: What Gerontology Can Learn From Childhood Studies. *Journal of Gerontology: Social Sciences*, *60B*(4), S173–S180.

Sharon, T. (2017). Self-tracking for health and the quantified self: Re-articulating autonomy, solidarity and authenticity in an age of personalized healthcare. *Philos. Technol.*, *30*, 93–121.

Sheaff, R., Halliday, J., Byng, R., Ovretveit, J., Peckham, S., & Asthana, S. (2017). Bridging the discursive gap between lay and medical discourse in care coordination. *Sociology of Health and Illness*, (xx), 1–16.

Sherwin, S. (2008). Whither bioethics? How feminism can help reorient bioethics. *International Journal of Feminist Approaches to Bioethics*, *1*(1), 7–27.

Shield, R. R., & Aronson, S. M. (2003). *Aging in Today's World: Conversations between an Anthropologist and a Physician*. New York: Berghahn Books.

Simonet, D. (2014). Assessment of new public management in health care: the French case. *Health Research Policy and Systems*, *12*(57), 1–9.

Sims-Gould, J., & Martin-Matthers, A. (2010). We share the care: family caregivers' experiences of their older relative receiving home support services. *Health and Social Care in the Community*, *18*(4), 415–423.

Sirven, N. (2013). Frailty and preventing loss of autonomy: a health economics approach. *Questions d'économie de La Santé*, *184*, 1–6.

Sjostrand, M., Eriksson, S., Juth, N., & Helgesson, G. (2013). Paternalism in the name of autonomy. *Journal of Medicine and Philosophy*, *38*, 710–724.

Smith, P. R. (2014). A Historical Perspective in Aging and Gerontology. In *The Collective Spirit of Aging Across Cultures, International Perspectives on Aging* (H.F.O. Vakalahi eds., pp. 7–27). Springer.

Sneddon, A. (2013). *Autonomy*. New York: Bloomsbury Acedemic.

Sorenson, S., & Pinquart, M. (2001). Developing a measure of older adults preparation for future care needs. *International Journal of Aging and Human Development*, *53*(2), 137–165.

Sorrell, T. (2011). The limits of principlism and recourse to theory: the example of telecare. *Ethical Theory and Moral Practice*, *14*(4), 369–382.

Spolander, G., Engelbrecht, L., & Sansfaçon, A. (2015). Social work and macro-economic neoliberalism: beyond the social justice rhetoric. *European Journal of Social Work*, 1–16. https://doi.org/10.1080/13691457.2015.1066761

Stammers, T. (2015). The evolution of autonomy. *The New Bioethics*, *21*(2), 155–163.

St-Amour, N., Bourque, M., & Grenier, J. (2018). Austerity: The restructuring of social services and its impact on social work. *Pluralages*, *8*(1), 16–19.

Staniforth, B., Deane, K. L., & Beddoe, L. (2016). Comparing public perceptions of social work and social workers' expectations of the public view. *Quantitative Research*, *26*(1), 13–24.

Stebbins, R. A. (2001). What is exploration? In *Exploratory research in the social sciences* (pp. 2–17). Thousand Oaks: Sage publications.

Stephens, C. (2016). From success to capability for healthy ageing: shifting the lens to include all older people. *Critical Public Health*, 1–8. https://doi.org/10.1080/09581596.2016.1192583

Stevens, M., Sharpe, E., Moriary, J., Manthorpe, J., Hussein, S., Orme, J., Cavagnah, K. (2010). Helping Others or a Rewarding Career? Investigating student motivations to train as social workers in England. *Journal of Social Work*, *0*(0), 1–21.

Stowe, J. D., & Clooney, T. M. (2015). Examining Rowe and Kahn's concept of successful aging: Importance of taking a life course perspective. *The Gerontologist*, *55*(1), 43–50.

Takala, T. (2001). What is wrong with global bioethics? On the limitations of the four principles approach. *Cambridge Quarterly of Healthcare Ethics*, *10*(1), 72–77.

Tate, R. B., Swift, A. U., & Bayomi, D. J. (2013). Older men's definitions of successful aging over time: the Manitoba follow-up study. *International Journal of Aging and Human Development*, *76*(4), 297–322.

Tate, R., Leedine, L., & Cuddy, T. E. (2003). Definition of successful aging by elderly Canadian males: The Manitoba follow-up study. *The Gerontologist*, *43*(5), 735–744.

Tauber, A. L. (2001). Historical and Philosophical Reflections on Patient Autonomy. *Health Care Analysis*, *9*, 299–319.

Taylor, B. (2012). Developing an integrated assessment tool for the health and social care of older people. *British Journal of Social Work*, *42*, 1293–1314.

Thielke, S., Harniss, M., Thompson, H., Patel, S., Demiris, G., & Johnson, K. (2012). Maslow's hierarchy of human needs and the adoption of health-related technologies for older people. *Ageing Int*, *37*, 470–488.

Thomas, R., & Davies, A. (2005). Theorizing the micro-politics of resistance: New public management and managerial identities in the UK public services. *Organization Studies*, *26*(5), 683–706.

Thompson, A. G., & Sunol, R. (1995). Expectations as determinants of patient satisfaction: Concepts, theory and evidence. *International Journal for Quality in Health Care*, *7*(2), 127–141.

Timmermann, C. (2014). Standards, scales and chronic illness: A brief introduction. *Chronic Illness*, *10*(1), 3–4.

Timmermans, S., & Almeling, R. (2009). Objectification, standardization and commodification in health care: A conceptual readjustment. *Social Science & Medicine*, *69*, 21–27.

Timmermans, S., & Epstein, S. (2010). A world of standards but not a standard world: toward a sociology of standards and standardization. *Annu. Rev. Sociol.*, *36*, 69–89.

Tirado, F., & Galvez, A. (2007). Positioning theory and discourse analysis: Some tools for social interaction analysis. *Forum: Qualitative Social Research*, *8*(2), 1–21.

Tousignant, M., Hébert, R., Dubuc, N., & Colombe, C. (2003). *Détermination du profil d'autonomie fonctionnelle et du taux de réponse aux besoins de la clientèle long terme du programme soutien à domicile des CLSC de la Montérégie* (p. 10). Centre de recherche sur le vieillissement.

Traphagan, J. W. (2013). *Rethinking autonomy: A critique of principlism in biomedical ethics*. Albany, N.Y.: SUNY.

Trocmé, N. (2016). Still in critical demand? *Canadian Social Work Review*, *33*(1), 141–146.

Tuckett, A. G. (2006). On Paternalism, autonomy and best interests: Telling the (competent) aged-care resident what they want to know. *International Journal of Nursing Practice*, *12*(3), 166–173.

Turgeon, J., Jacob, R., & Denis, J.-L. (2011). Québec: cinquante ans d'évolution au prisme des réformes (1961-1920). *Presses de Sciences Po*, (30), 57–85.

Turner, L. (2009). Anthropological and Sociological Critiques of Bioethics. *Journal of Bioethical Inquiry*, *6*(1), 83–98.

Twigg, J. (1989). Models of carers: How do social care agencies conceptualise their relationship with informal carers? *Journal of Social Policy*, *18*(1), 53–66.

Unger, D. (2011). *The Canadian Bioethics Companion*. Retrieved from http://canadianbioethicscompanion.ca

Van Dijck, J. (2014). Datafication, dataism and dataveillance: big data between scientific paradigm and ideology. *Surveillance & Society*, *12*(2), 197–208.

Van Eerde, W., & Thierry, H. (1996). Vroom's expectancy models and work-related criteria: A Meta-analysis. *Journal of Applied Psychology*, *81*(5), 575–586.

Van Lente, H. (2012). Navigating foresight in a sea of expectations: Lessons from the sociology of expectations. *Technology Analysis & Strategic Management*, *24*(8), 769–782.

Van Pevenage, I. (2015). Les sens de l'autonomie: regards d'enfants sur leur mère âgée. In *Les baby-boomers, une histoire de familles. Une comparison Québec-France. Sous la direction de Catherine Bonvalet, Ignace Olazabal et Michel Oris*. Montréal: Presses de l'université du Québec.

Vanneste, D., De Almeida Mello, J., Macq, J., Van Audenhove, C., & Declercq, A. (2015). Incomplete assessments: Towards a better understanding of causes and solutions. The case of the interRAI home care assessments in Belgium. *PLOS ONE - Open Access*. https://doi.org/10.1371/journal.pone.0123760

Varelius, J. (2006). The value of autonomy in medical ethics. *Medicine, Health Care and Philosophy*, *9*, 377–388.

Vézina, A. (2003). Le fonctionnement familial perçu en contexte de soutien à domicile d'un parent âgé. *Canadian Social Work Review*, *20*(2), 203–226.

Vroom, V. H. (2005). On the origins of expectancy theory. In *Great Minds in Management: The process of theory development* (pp. 239–258). Oxford: Oxford University Press.

Wagner, C. S., Roessner, J. D., Bobb, K., Klein, J. T., Boyack, K. W., Keyton, J., … Bôrner, K. (2011). Approaches to understanding and measuring interdisciplinary scientific research (IDR): A review of the literature. *Journal of Informetrics*, *165*, 14–26.

Wall, S. (2015). Focused ethnography: a methodological adaptation for social research in emerging contexts. *Forum: Qualitative Social Research*, *16*(1), 1–11.

Wallace, J., & Pease, B. (2011). Neoliberalism and Australian social work: Accommodation or resistance? *Journal of Social Work*, *11*(2), 132–142.

Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: Partners in care? *Advances in Nursing Science*, *22*(3), 89–103.

Wardrope, A. (2015). Liberal individualism, relational autonomy and the social dimension of respect. *International Journal of Feminist Approaches to Bioethics*, *8*(1), 37–66.

Webb, S. A. (2000). The politics of social work: power and subjectivity. *Critical Social Work*, *1*(2), 1–7.

Welch IV, J. (2011). The emergence of interdisciplinarity from epistemological thought. *Issues in Integrative Studies*, *29*, 1–39.

Welford, C., Kazer, M., Murphy, K., & Casey, D. (2010). A concept analysis of autonomy for older people in residential care. *Journal of Clinical Nursing*, *19*(9–10), 1226–1235.

Wentzel, K. R., Russell, S., & Baker, S. (2016). Emotional support and expectations from parents, teachers, and peers predict adolescent competence at school. *Journal of Educational Psychology*, *108*(2), 242–255.

White, S., Hall, C., & Peckover, S. (2009). The descriptive tyranny of the common assessment framework: technologies of categorization and professional practice in child welfare. *British Journal of Social Work*, *39*, 1197–1217.

Wiles, J., Leibing, A., Guberman, N., Reeve, J., & Allen, R. (2012). The meaning of "Aging in Place" to older people. *The Gerontologist*, *52*(3), 357–366.

Wiles, Janine. (2003). Informal caregivers' experience of formal support in a changing context. *Health and Social Care in the Community*, *11*(3), 189–207.

Will, J. (2011). A brief and theoretical perspective on patient autonomy and medical decision making. Part I The beneficence model. *Chest*, *139*(3), 669–673.

Will, J. F. (2011). A brief and theoretical perspective on patient autonomy and medical decision making. Part II The autonomy model. *Chest*, 1491–1497.

Wolf, Z. R. (2012). Ethnography: the method. In *Nursing Research: a qualitative perspective* (pp. 283–335). Mississauga On. Jones & Bartlett.

Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Intern Med*, 372–379. https://doi.org/10:1001/jamainternmed.2015.7664

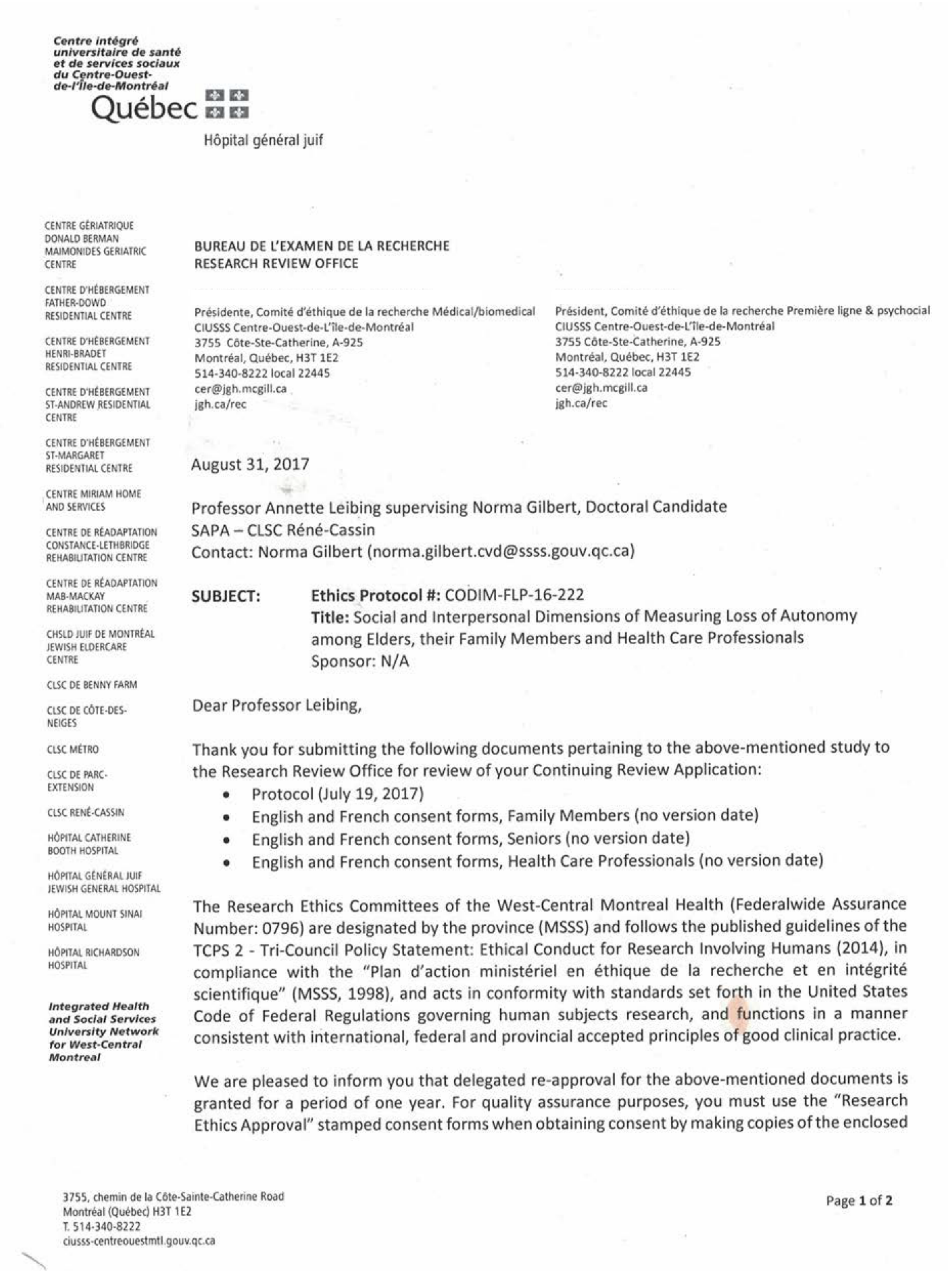
Wright, J., Williams, R., & Wilkinson, J. R. (1998). Development and importance of health needs assessment. *BMJ*, *316*, 1310–1315.

Yuval-Davis, N. (2010). Theorizing identity: beyond the "us" and "them" dichotomy. *Patterns of Prejudice*, *44:3*, 261–280.

Zielinski, A. (2009). Le libre choix de l'autonomie rêvée à l'attention aux capacités. *Gérontologie et Société*, *4*(131), 11–24. https://doi.org/10.3917/GS.131.0011

ANNEXES

ANNEX 1 – ETHICS APPROVAL CODIM 2017 (RENEWAL)



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BUREAU DE L'EXAMEN DE LA RECHERCHE
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August 31, 2017

Professor Annette Leibing supervising Norma Gilbert, Doctoral Candidate
SAPA – CLSC Réné-Cassin
Contact: Norma Gilbert (norma.gilbert.cvd@ssss.gouv.qc.ca)

SUBJECT: **Ethics Protocol #:** CODIM-FLP-16-222
Title: Social and Interpersonal Dimensions of Measuring Loss of Autonomy among Elders, their Family Members and Health Care Professionals
Sponsor: N/A

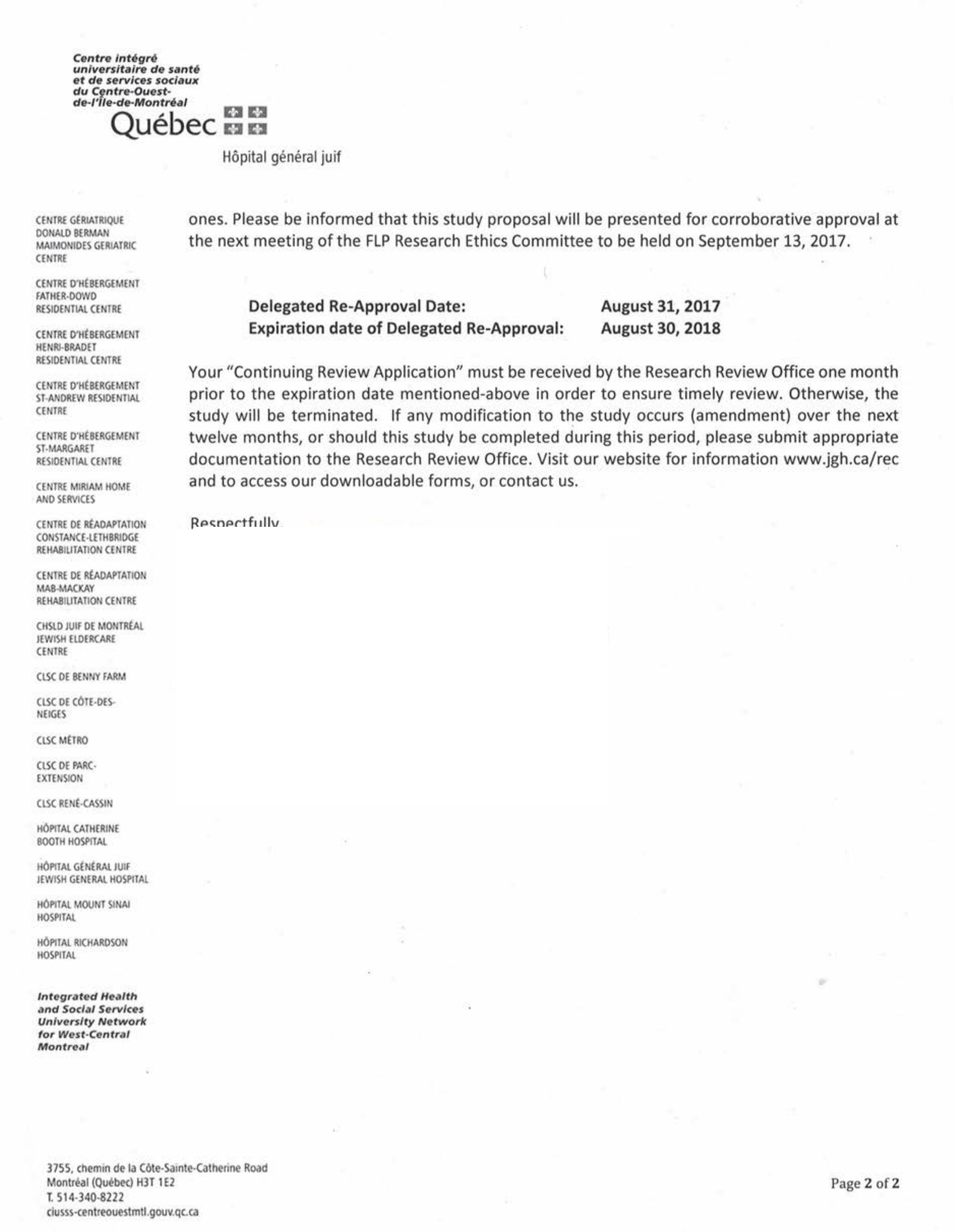
Dear Professor Leibing,

Thank you for submitting the following documents pertaining to the above-mentioned study to the Research Review Office for review of your Continuing Review Application:

- Protocol (July 19, 2017)
- English and French consent forms, Family Members (no version date)
- English and French consent forms, Seniors (no version date)
- English and French consent forms, Health Care Professionals (no version date)

The Research Ethics Committees of the West-Central Montreal Health (Federalwide Assurance Number: 0796) are designated by the province (MSSS) and follows the published guidelines of the TCPS 2 - Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2014), in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998), and acts in conformity with standards set forth in the United States Code of Federal Regulations governing human subjects research, and functions in a manner consistent with international, federal and provincial accepted principles of good clinical practice.

We are pleased to inform you that delegated re-approval for the above-mentioned documents is granted for a period of one year. For quality assurance purposes, you must use the "Research Ethics Approval" stamped consent forms when obtaining consent by making copies of the enclosed



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ones. Please be informed that this study proposal will be presented for corroborative approval at the next meeting of the FLP Research Ethics Committee to be held on September 13, 2017.

Delegated Re-Approval Date:	**August 31, 2017**
Expiration date of Delegated Re-Approval:	**August 30, 2018**

Your "Continuing Review Application" must be received by the Research Review Office one month prior to the expiration date mentioned-above in order to ensure timely review. Otherwise, the study will be terminated. If any modification to the study occurs (amendment) over the next twelve months, or should this study be completed during this period, please submit appropriate documentation to the Research Review Office. Visit our website for information www.jgh.ca/rec and to access our downloadable forms, or contact us.

Respectfully

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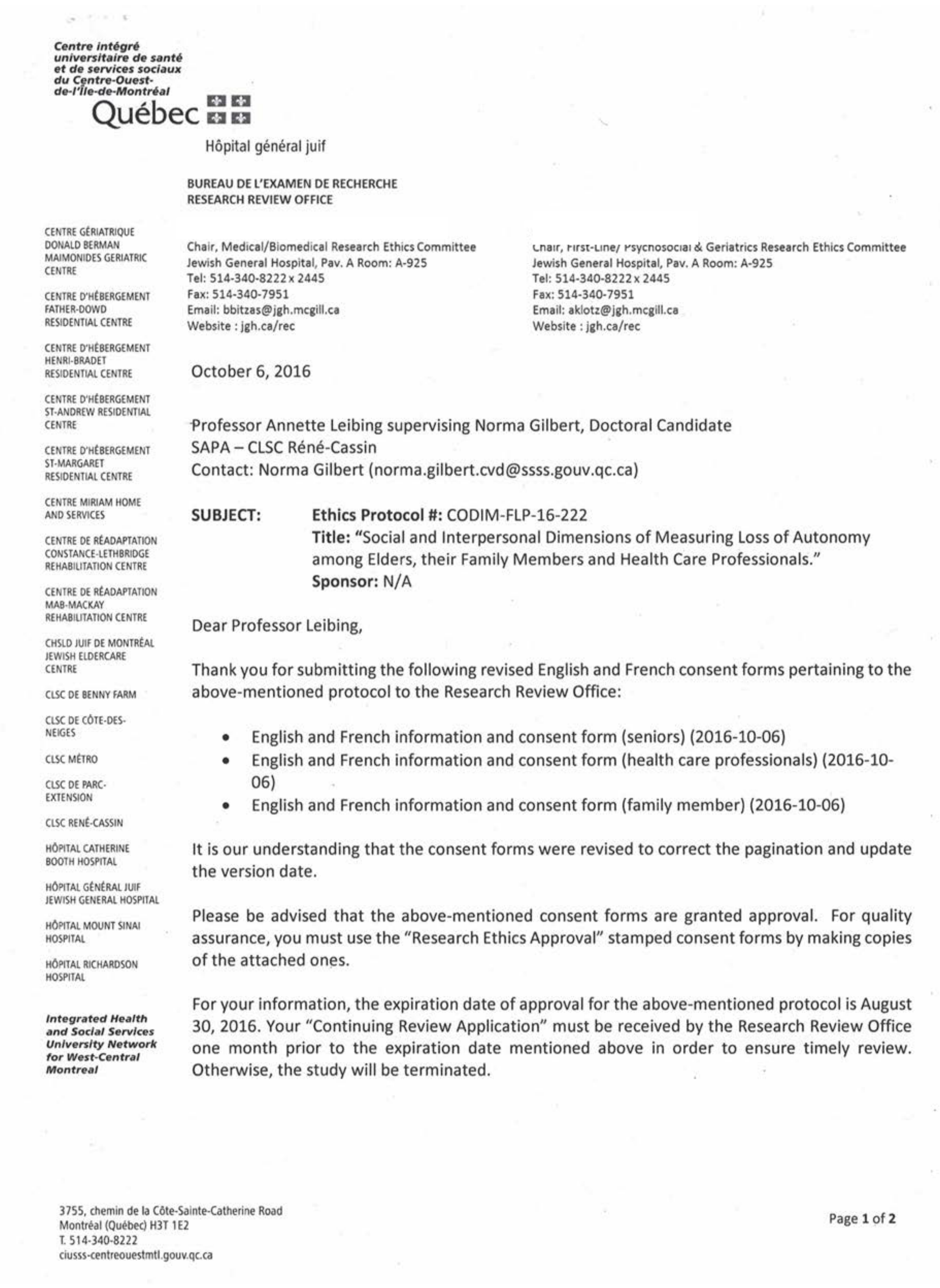
ANNEX 2 – ETHICS APPROVAL CODIM 2016



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Tel: 514-340-8222 x 2445
Fax: 514-340-7951
Email: aklotz@jgh.mcgill.ca
Website : jgh.ca/rec

October 6, 2016

Professor Annette Leibing supervising Norma Gilbert, Doctoral Candidate
SAPA – CLSC Réné-Cassin
Contact: Norma Gilbert (norma.gilbert.cvd@ssss.gouv.qc.ca)

SUBJECT: **Ethics Protocol #:** CODIM-FLP-16-222
Title: **"**Social and Interpersonal Dimensions of Measuring Loss of Autonomy among Elders, their Family Members and Health Care Professionals."
Sponsor: N/A

Dear Professor Leibing,

Thank you for submitting the following revised English and French consent forms pertaining to the above-mentioned protocol to the Research Review Office:

- English and French information and consent form (seniors) (2016-10-06)
- English and French information and consent form (health care professionals) (2016-10-06)
- English and French information and consent form (family member) (2016-10-06)

It is our understanding that the consent forms were revised to correct the pagination and update the version date.

Please be advised that the above-mentioned consent forms are granted approval. For quality assurance, you must use the "Research Ethics Approval" stamped consent forms by making copies of the attached ones.

For your information, the expiration date of approval for the above-mentioned protocol is August 30, 2016. Your "Continuing Review Application" must be received by the Research Review Office one month prior to the expiration date mentioned above in order to ensure timely review. Otherwise, the study will be terminated.

CENTRE GÉRIATRIQUE DONALD BERMAN MAIMONIDES GERIATRIC CENTRE

CENTRE D'HÉBERGEMENT FATHER-DOWD RESIDENTIAL CENTRE

CENTRE D'HÉBERGEMENT HENRI-BRADET RESIDENTIAL CENTRE

CENTRE D'HÉBERGEMENT ST-ANDREW RESIDENTIAL CENTRE

CENTRE D'HÉBERGEMENT ST-MARGARET RESIDENTIAL CENTRE

CENTRE MIRIAM HOME AND SERVICES

CENTRE DE RÉADAPTATION CONSTANCE-LETHBRIDGE REHABILITATION CENTRE

CENTRE DE RÉADAPTATION MAB-MACKAY REHABILITATION CENTRE

CHSLD JUIF DE MONTRÉAL JEWISH ELDERCARE CENTRE

CLSC DE BENNY FARM

CLSC DE CÔTE-DES-NEIGES

CLSC MÉTRO

CLSC DE PARC-EXTENSION

CLSC RENÉ-CASSIN

HÔPITAL CATHERINE BOOTH HOSPITAL

HÔPITAL GÉNÉRAL JUIF JEWISH GENERAL HOSPITAL

HÔPITAL MOUNT SINAI HOSPITAL

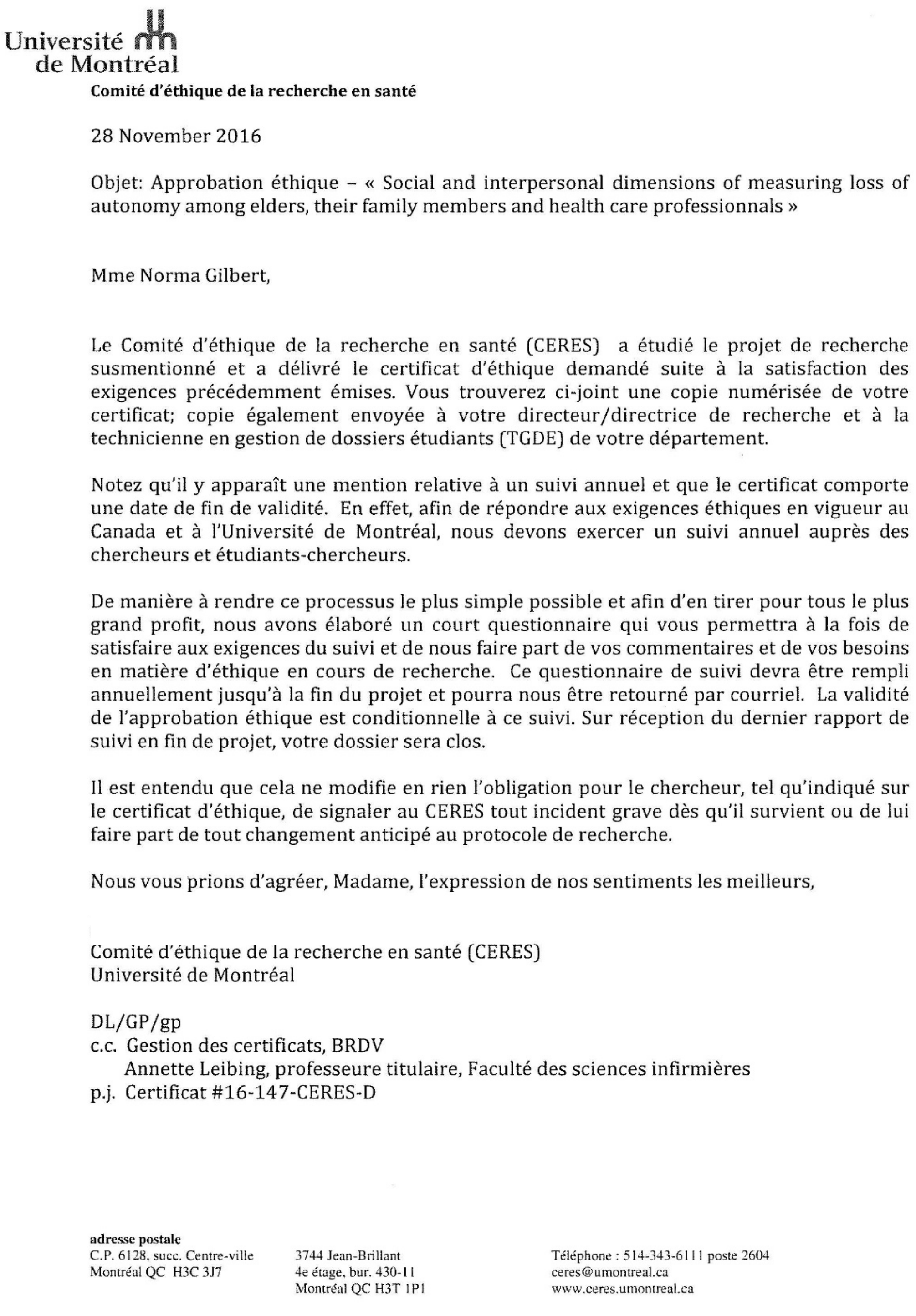
HÔPITAL RICHARDSON HOSPITAL

Integrated Health and Social Services University Network for West-Central Montreal

Respectfully,

[redacted]

ANNEX 3 – ETHICS APPROVAL CERES 2016



Université de Montréal
Comité d'éthique de la recherche en santé

28 November 2016

Objet: Approbation éthique – « Social and interpersonal dimensions of measuring loss of autonomy among elders, their family members and health care professionnals »

Mme Norma Gilbert,

Le Comité d'éthique de la recherche en santé (CERES) a étudié le projet de recherche susmentionné et a délivré le certificat d'éthique demandé suite à la satisfaction des exigences précédemment émises. Vous trouverez ci-joint une copie numérisée de votre certificat; copie également envoyée à votre directeur/directrice de recherche et à la technicienne en gestion de dossiers étudiants (TGDE) de votre département.

Notez qu'il y apparaît une mention relative à un suivi annuel et que le certificat comporte une date de fin de validité. En effet, afin de répondre aux exigences éthiques en vigueur au Canada et à l'Université de Montréal, nous devons exercer un suivi annuel auprès des chercheurs et étudiants-chercheurs.

De manière à rendre ce processus le plus simple possible et afin d'en tirer pour tous le plus grand profit, nous avons élaboré un court questionnaire qui vous permettra à la fois de satisfaire aux exigences du suivi et de nous faire part de vos commentaires et de vos besoins en matière d'éthique en cours de recherche. Ce questionnaire de suivi devra être rempli annuellement jusqu'à la fin du projet et pourra nous être retourné par courriel. La validité de l'approbation éthique est conditionnelle à ce suivi. Sur réception du dernier rapport de suivi en fin de projet, votre dossier sera clos.

Il est entendu que cela ne modifie en rien l'obligation pour le chercheur, tel qu'indiqué sur le certificat d'éthique, de signaler au CERES tout incident grave dès qu'il survient ou de lui faire part de tout changement anticipé au protocole de recherche.

Nous vous prions d'agréer, Madame, l'expression de nos sentiments les meilleurs,

Comité d'éthique de la recherche en santé (CERES)
Université de Montréal

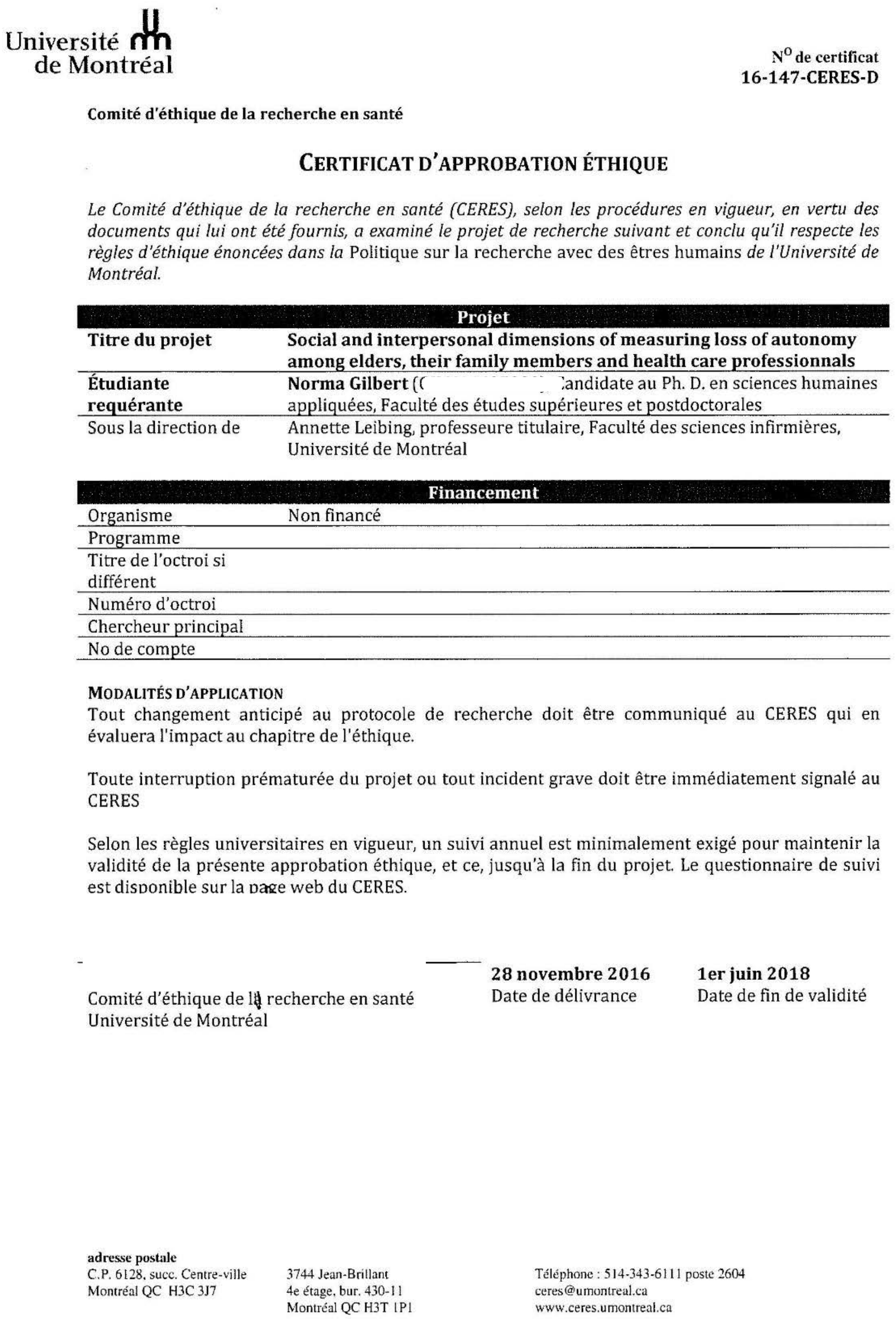
DL/GP/gp
c.c. Gestion des certificats, BRDV
Annette Leibing, professeure titulaire, Faculté des sciences infirmières
p.j. Certificat #16-147-CERES-D

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

3744 Jean-Brillant
4e étage, bur. 430-11
Montréal QC H3T 1P1

Téléphone : 514-343-6111 poste 2604
ceres@umontreal.ca
www.ceres.umontreal.ca

ANNEX 4 – ETHICS CERTIFICATE CERES



Université de Montréal

N^O de certificat
16-147-CERES-D

Comité d'éthique de la recherche en santé

CERTIFICAT D'APPROBATION ÉTHIQUE

Le Comité d'éthique de la recherche en santé (CERES), selon les procédures en vigueur, en vertu des documents qui lui ont été fournis, a examiné le projet de recherche suivant et conclu qu'il respecte les règles d'éthique énoncées dans la Politique sur la recherche avec des êtres humains *de l'Université de Montréal.*

Projet	
Titre du projet	**Social and interpersonal dimensions of measuring loss of autonomy among elders, their family members and health care professionnals**
Étudiante requérante	**Norma Gilbert** ([redacted] andidate au Ph. D. en sciences humaines appliquées, Faculté des études supérieures et postdoctorales
Sous la direction de	Annette Leibing, professeure titulaire, Faculté des sciences infirmières, Université de Montréal

Financement	
Organisme	Non financé
Programme	
Titre de l'octroi si différent	
Numéro d'octroi	
Chercheur principal	
No de compte	

MODALITÉS D'APPLICATION

Tout changement anticipé au protocole de recherche doit être communiqué au CERES qui en évaluera l'impact au chapitre de l'éthique.

Toute interruption prématurée du projet ou tout incident grave doit être immédiatement signalé au CERES

Selon les règles universitaires en vigueur, un suivi annuel est minimalement exigé pour maintenir la validité de la présente approbation éthique, et ce, jusqu'à la fin du projet. Le questionnaire de suivi est disponible sur la page web du CERES.

Comité d'éthique de la recherche en santé
Université de Montréal

28 novembre 2016
Date de délivrance

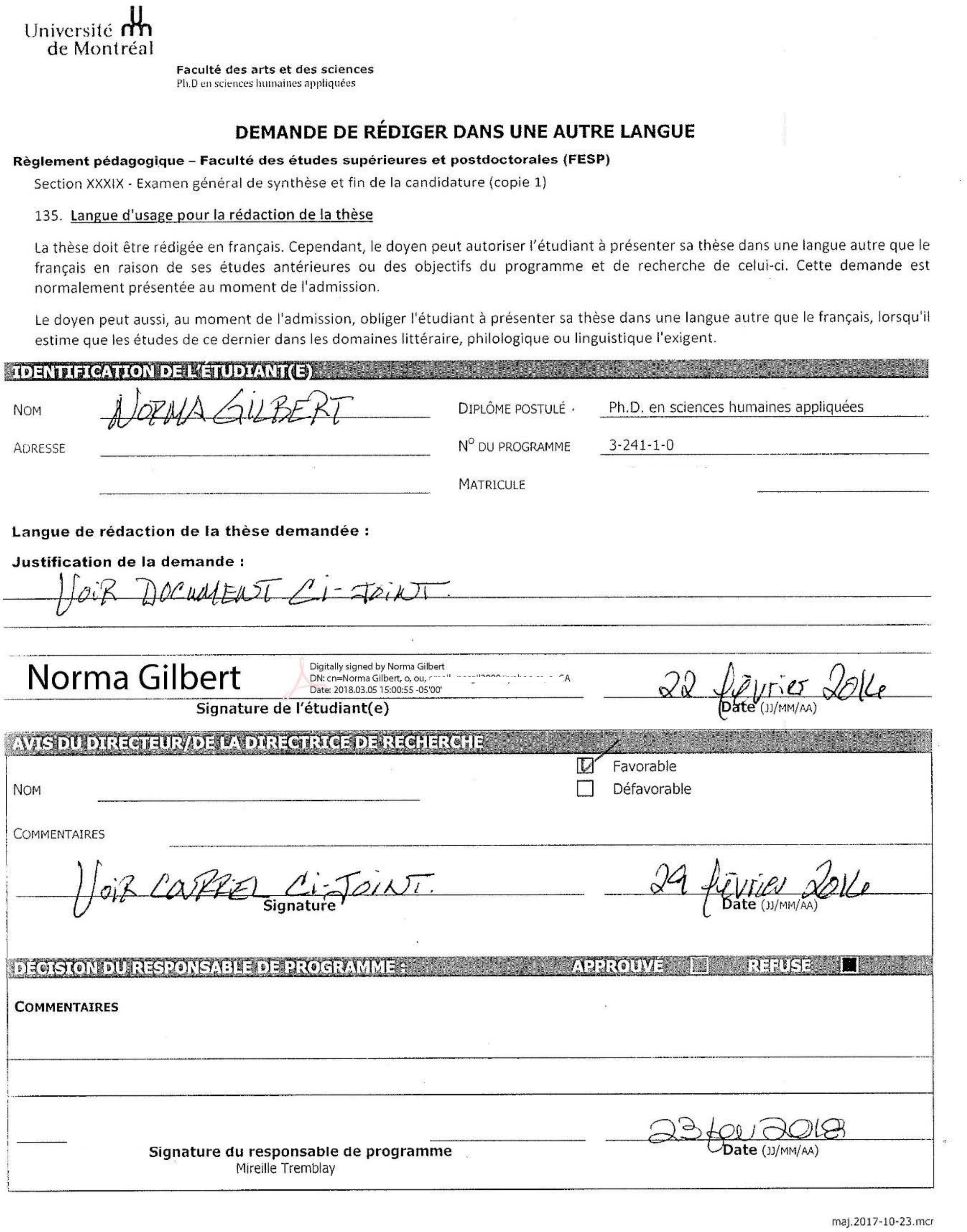
1er juin 2018
Date de fin de validité

adresse postale
C.P. 6128, succ. Centre-ville
Montréal QC H3C 3J7

3744 Jean-Brillant
4e étage, bur. 430-11
Montréal QC H3T 1P1

Téléphone : 514-343-6111 poste 2604
ceres@umontreal.ca
www.ceres.umontreal.ca

ANNEX 5 – DEMANDE DE RÉDIGER DANS UNE AUTRE LANGUE



Université de Montréal

Faculté des arts et des sciences
Ph.D en sciences humaines appliquées

DEMANDE DE RÉDIGER DANS UNE AUTRE LANGUE

Règlement pédagogique – Faculté des études supérieures et postdoctorales (FESP)

Section XXXIX - Examen général de synthèse et fin de la candidature (copie 1)

135. Langue d'usage pour la rédaction de la thèse

La thèse doit être rédigée en français. Cependant, le doyen peut autoriser l'étudiant à présenter sa thèse dans une langue autre que le français en raison de ses études antérieures ou des objectifs du programme et de recherche de celui-ci. Cette demande est normalement présentée au moment de l'admission.

Le doyen peut aussi, au moment de l'admission, obliger l'étudiant à présenter sa thèse dans une langue autre que le français, lorsqu'il estime que les études de ce dernier dans les domaines littéraire, philologique ou linguistique l'exigent.

IDENTIFICATION DE L'ÉTUDIANT(E)

NOM NORMA GILBERT

DIPLÔME POSTULÉ Ph.D. en sciences humaines appliquées

ADRESSE

N° DU PROGRAMME 3-241-1-0

MATRICULE

Langue de rédaction de la thèse demandée :

Justification de la demande :

VOIR DOCUMENT CI-JOINT.

Norma Gilbert
Digitally signed by Norma Gilbert
DN: cn=Norma Gilbert, o, ou, [redacted] CA
Date: 2018.03.05 15:00:55 -05'00'

Signature de l'étudiant(e)

22 février 2016
Date (JJ/MM/AA)

AVIS DU DIRECTEUR/DE LA DIRECTRICE DE RECHERCHE

☑ Favorable
☐ Défavorable

NOM

COMMENTAIRES

VOIR COURRIEL CI-JOINT.
Signature

24 février 2016
Date (JJ/MM/AA)

DÉCISION DU RESPONSABLE DE PROGRAMME : **APPROUVÉ** ☐ **REFUSÉ** ■

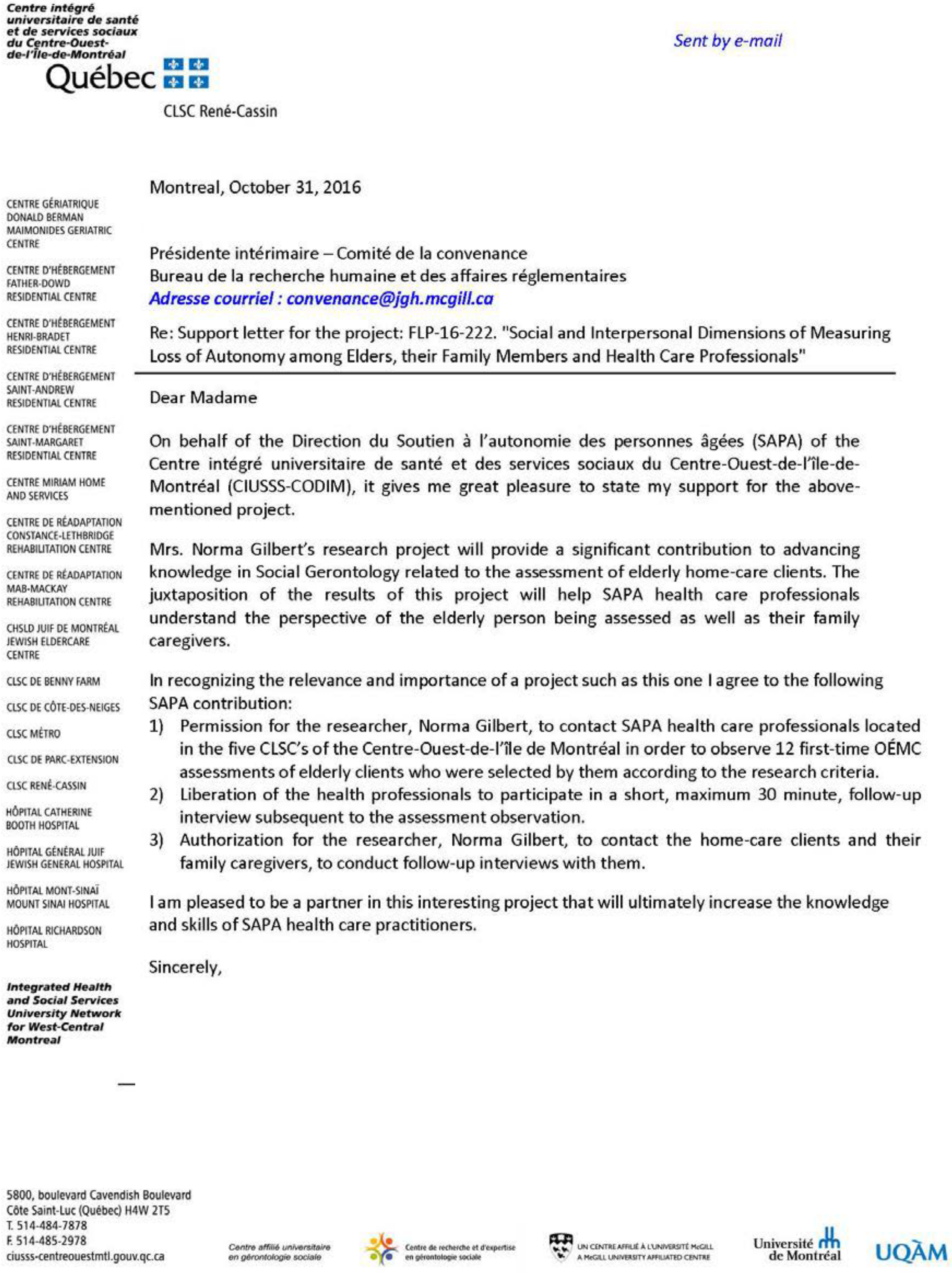
COMMENTAIRES

Signature du responsable de programme
Mireille Tremblay

23 fev 2018
Date (JJ/MM/AA)

maj.2017-10-23.mcr

ANNEX 6 – LETTER OF SUPPORT



Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'Île-de-Montréal
Québec
CLSC René-Cassin

Sent by e-mail

CENTRE GÉRIATRIQUE DONALD BERMAN MAIMONIDES GERIATRIC CENTRE
CENTRE D'HÉBERGEMENT FATHER-DOWD RESIDENTIAL CENTRE
CENTRE D'HÉBERGEMENT HENRI-BRADET RESIDENTIAL CENTRE
CENTRE D'HÉBERGEMENT SAINT-ANDREW RESIDENTIAL CENTRE
CENTRE D'HÉBERGEMENT SAINT-MARGARET RESIDENTIAL CENTRE
CENTRE MIRIAM HOME AND SERVICES
CENTRE DE RÉADAPTATION CONSTANCE-LETHBRIDGE REHABILITATION CENTRE
CENTRE DE RÉADAPTATION MAB-MACKAY REHABILITATION CENTRE
CHSLD JUIF DE MONTRÉAL JEWISH ELDERCARE CENTRE
CLSC DE BENNY FARM
CLSC DE CÔTE-DES-NEIGES
CLSC MÉTRO
CLSC DE PARC-EXTENSION
CLSC RENÉ-CASSIN
HÔPITAL CATHERINE BOOTH HOSPITAL
HÔPITAL GÉNÉRAL JUIF JEWISH GENERAL HOSPITAL
HÔPITAL MONT-SINAÏ MOUNT SINAI HOSPITAL
HÔPITAL RICHARDSON HOSPITAL

Integrated Health and Social Services University Network for West-Central Montreal

Montreal, October 31, 2016

Présidente intérimaire – Comité de la convenance
Bureau de la recherche humaine et des affaires réglementaires
Adresse courriel : convenance@jgh.mcgill.ca

Re: Support letter for the project: FLP-16-222. "Social and Interpersonal Dimensions of Measuring Loss of Autonomy among Elders, their Family Members and Health Care Professionals"

Dear Madame

On behalf of the Direction du Soutien à l'autonomie des personnes âgées (SAPA) of the Centre intégré universitaire de santé et des services sociaux du Centre-Ouest-de-l'île-de-Montréal (CIUSSS-CODIM), it gives me great pleasure to state my support for the above-mentioned project.

Mrs. Norma Gilbert's research project will provide a significant contribution to advancing knowledge in Social Gerontology related to the assessment of elderly home-care clients. The juxtaposition of the results of this project will help SAPA health care professionals understand the perspective of the elderly person being assessed as well as their family caregivers.

In recognizing the relevance and importance of a project such as this one I agree to the following SAPA contribution:

1) Permission for the researcher, Norma Gilbert, to contact SAPA health care professionals located in the five CLSC's of the Centre-Ouest-de-l'île de Montréal in order to observe 12 first-time OÉMC assessments of elderly clients who were selected by them according to the research criteria.
2) Liberation of the health professionals to participate in a short, maximum 30 minute, follow-up interview subsequent to the assessment observation.
3) Authorization for the researcher, Norma Gilbert, to contact the home-care clients and their family caregivers, to conduct follow-up interviews with them.

I am pleased to be a partner in this interesting project that will ultimately increase the knowledge and skills of SAPA health care practitioners.

Sincerely,

5800, boulevard Cavendish Boulevard
Côte Saint-Luc (Québec) H4W 2T5
T. 514-484-7878
F. 514-485-2978
ciusss-centreouestmtl.gouv.qc.ca

Centre affilié universitaire en gérontologie sociale
Centre de recherche et d'expertise en gérontologie sociale
UN CENTRE AFFILIÉ À L'UNIVERSITÉ McGILL A McGILL UNIVERSITY AFFILIATED CENTRE
Université de Montréal
UQÀM

ANNEX 7 – INFORMATION AND CONSENT FORM (SOCIAL WORKER)

INFORMATION AND CONSENT FORM (SOCIAL WORKER)

RESEARCH PROJECT TITLE

Social and Interpersonal Dimensions of Measuring Loss of Autonomy: Expectations among Family Caregivers and Social Workers in Quebec

RESEARCH DIRECTOR

Annette Leibing Researcher	Professor, Medical Anthropology, Faculté des sciences infirmières, Université de Montréal Centre de recherche et d'expertise en gérontologie sociale (CREGÉS), West-Central Montreal Health

RESEARCHER

Norma Gilbert Doctoral Candidate	Applied Human Sciences, Université de Montréal Centre de recherche et d'expertise en gérontologie sociale (CREGÉS), West-Central Montreal Health

FUNDING AGENCIES

None

INTRODUCTION

You have been invited to participate in a research project. Before accepting, please take the time to read this document which presents the conditions for participation. If you have any questions, please don't hesitate to ask the person presenting this document. You have been selected because as a Social Worker or Social Work Technician of the CIUSSS Centre de Ouest de l'ile de Montréal you perform home care evaluations on seniors using the *Outil d'évaluation muliclientele.(OEMC).*

Please feel free to ask the researcher any questions you have or to have any information or words that are not clear explained to you.

DESCRIPTION AND PURPOSE OF THE RESEARCH PROJECT

The purpose of the research project is to examine the intersection and influence of expectations between social workers and family caregivers in the context of loss of autonomy assessment of elderly clients in home care services in some CLSC's of the CIUSSS Centre de Ouest de l'ile de Montréal. We will be recruiting Social Workers or Social Work Technicians who perform assessments on seniors using the *Outil d'évaluation muliclientele.(OEMC).* As well family caregivers of the seniors will also be interviewed to obtain their perception and expectations of the assessment as well as the state of autonomy of their relative..

The results of the interviews with social workers and caregivers will provide a double perspective on the assessment which will be compared and contrasted to each other.

The goal of this study is to advance knowledge in the area of loss of autonomy assessment of elderly home care clients in order to better understand the importance of the concept of expectations in elder care.

PROCEDURE

Your participation consists of acquiring the permission of a family caregiver to be contacted by the researcher by telephone to explain the project and to be interviewed. As well, there will be a 90 – 120 minute interview scheduled with you in person, at your convenience. There may be follow-up questions by telephone. For transcription purposes, we will request your permission to record the interview on an audio device.

POTENTIAL INCONVENIENCES OF PARTICIPATING IN THE RESEARCH PROJECT

There is no particular risk to you in participating in the project. Nevertheless, if any questions make you uncomfortable you can refuse to answer at any time or even end the interview.

POTENTIAL BENEFITS OF PARTICIPATING IN THE RESEARCH PROJECT

You could derive personal benefits from taking part in this research project, but we cannot guarantee it. Your participation will however contribute to a better understanding of how expectations can affect the assessment of older people by the healthcare system.

VOLUNTARY PARTICIPATION AND FREEDOM TO WITHDRAW

Your participation in this project is completely voluntary and you can withdraw at any time with no consequences simply by advising us and there is no need to justify your decision. If you should decide to withdraw please contact the researcher at the number indicated below.

CONFIDENTIALITY

In the course of your participation in this project, the principal investigator will collect information concerning you and keep it in a research file. Only information needed to meet the scientific objectives of the project will be gathered. Your research file could also include other information such as your name, gender, and age.

All information gathered will remain strictly confidential within the limits of the law. To protect your identity and the confidentiality of the information, you will be identified only by a file number. The code linking your name to your research file will be kept by the principal investigator. The principal investigator will use the data for research purposes to meet the scientific objectives of the project described in this information and consent form. Your personal information will be kept for 5 years by the principal investigator under lock in her office. Computer records will be irreversibly erased numerically (Shred-it) and paper format shredded. Though the results could be published in specialized journals or be the subject of scientific discussions, it will be impossible to identify you.

For your protection, particularly for the purpose of contacting you rapidly, your name, your contact information and the start and end dates of your participation in the project will be kept for one year from the end of the project in a separate research file stored by the principal investigator or the institution.

CONTACT PERSON

If you have any questions regarding the research project or if a problem arises that you believe is connected to your participation in the project, you can contact Norma Gilbert.

SUPERVISION OF THE ETHICAL ASPECTS OF THE RESEARCH PROJECT

The Research Ethics Committee of the Jewish General Hospital is responsible for monitoring this research project. In addition, any changes to the information and consent form or to the research protocol must first be approved by the Committee.

If you have any questions regarding your rights as a research participant or if you would like to file a complaint or make a comment regarding the project, you can contact the local service quality and complaints commissioner of West-Central Montreal Health.

This research study has been approved by the following ethics committees:

The Jewish General Hospital Research Ethics Committee: CODIM-FLP-16-222, October 6, 2016, renewed, August 13 2017.

Comité d’éthique en recherché, Université de Montréal, 16-147-CERES, le 28 novembre 2016

CONSENT FORM

PARTICIPANT'S COPY (SOCIAL WORKER)

Social and Interpersonal Dimensions of Measuring Loss of Autonomy: Expectations among Family Caregivers and Social Workers in Quebec

CONSENT

Participant's consent

I have read this information and consent form. I acknowledge that the research project has been described to me, that my questions have been answered to my satisfaction and that I was given all the time I needed to make a decision.

- I understand that I can take my time to reflect before agreeing to participate in the research.
- I understand I can ask the research team any questions until I feel satisfied with the answer.
- As a research participant I understand that I do not renounce my rights or release the researchers from their responsibilities.
- I understand this information form and the research project and I agree to participate.

____

Name and signature of participant Date

Researcher's commitment

I have explained to the participant all the conditions for participation in this research project. I have responded to the best of my ability to all questions and I believe the participant completely understands everything. I agree to respect everything that is included in this information and consent form.

____

Name and signature of researcher Date

ANNEX 8 – INFORMATION AND CONSENT FORM (FAMILY CAREGIVER)

INFORMATION AND CONSENT FORM (FAMILY CAREGIVER)

TITLE OF RESEARCH PROJECT

Social and Interpersonal Dimensions of Measuring Loss of Autonomy: Expectations among Family Caregivers and Social Workers in Quebec

RESEARCH DIRECTOR

Annette Leibing Researcher	Professor, Medical Anthropology, Faculté des sciences infirmières, Université de Montréal Centre de recherche et d'expertise en gérontologie sociale (CREGÉS), West-Central Montreal Health

RESEARCHER

Norma Gilbert Doctoral Candidate	Applied Human Sciences, Université de Montréal Centre de recherche et d'expertise en gérontologie sociale (CREGÉS), West-Central Montreal Health

FUNDING AGENCIES

None

INTRODUCTION

We would like to invite you to participate in a research project. You have been selected because you are a caregiver to a family member and have been referred by your social worker. We are interested in knowing about your experience and expectations of the assessment of your family member that was done by the social worker of the CLSC.

Before agreeing to participate and signing this form, please take the time to read, understand and carefully consider the following information. Please feel free to ask the researcher any questions you have or to have any information or words that are not clear explained to you.

DESCRIPTION AND PURPOSE OF THE RESEARCH PROJECT

When an older person experiences changes in their health and independence that effects their home situation they are often referred for support services from their local CLSC. When this happens they are usually met by a health care worker who interviews the person and their family to find out what services may be needed to keep the elderly person safe and secure in their home. How the family understands and perceives this assessment process as well as their expectations could have an impact on how the interview is done and the results. The purpose of the research project is to understand how the perspectives the family members and the health care professional may play a role in the assessment of elderly clients in home care services of the CLSC's of the CIUSSS Centre de Ouest de l'île de Montréal.

Through the CLSC's we will be recruiting caregivers whose relative has been assessed by a social workers using the *Multi-clientele evaluation instrument.* The interviews will in no way influence or interfere with the health professional's official evaluation that determines support services.

In this way we hope to advance knowledge in the area of loss of autonomy assessment of elderly home care clients and to be able to transfer our insights into the improvement of home care intervention programs.

PROCEDURE

Your participation consists of agreeing to an interview with the researcher who will ask you questions about the assessment process and what your expectations are of the healthcare system. For transcription purposes the interview will be recorded on an audio device with your permission. The duration of the follow-up interview will be about 60 to 90 minutes with a possibility of follow-up questions in person or by telephone. The location of the interview will be set at your convenience and availability.

POTENTIAL INCONVENIENCES OF PARTICIPATING IN THE RESEARCH PROJECT

There is no anticipated risk to you in participating in the project. Nevertheless, if any questions make you uncomfortable you can refuse to answer at any time or even end the interview.

POTENTIAL BENEFITS OF PARTICIPATING IN THE RESEARCH PROJECT

Your participation in this project will offer you the chance to share your knowledge and to contribute to a better understanding of how older people and their family members manage changes in their health and independence and how it is assessed by the health care system.

VOLUNTARY PARTICIPATION AND FREEDOM TO WITHDRAW

Your participation in this research project is entirely voluntary and you are free to refuse to take part in it. Moreover, if you do agree to take part, you may withdraw at any time, with no need to provide a reason, by simply notifying the researcher.
Refusing to participate in or withdrawing from the project will have no impact on the health care and services you are entitled to or on your relationship with the principal investigator or with any other healthcare professionals.

CONFIDENTIALITY

In the course of your participation in this project, the principal investigator will collect information concerning you and keep it in a research file. Only information needed to meet the scientific objectives of the project will be gathered. Your research file could also include other information such as your name, gender and age.

All information gathered will remain strictly confidential within the limits of the law. To protect your identity and the confidentiality of the information, you will be identified only by a file number. The code linking your name to your research file will be kept by the principal investigator. The principal investigator will use the data for research purposes to meet the scientific objectives of the project described in this information and consent form. Your personal information will be kept for 5 years by the principal investigator under lock in her office in at the CREGÉS. Computer records will be irreversibly erased numerically (Shred-it) and paper format shredded. Though the results could be published in specialized journals or be the subject of scientific discussions, it will be impossible to identify you.

For your protection, particularly for the purpose of contacting you rapidly, your name, your contact information and the start and end dates of your participation in the project will be kept for one year from the end of the project in a separate research file stored by the principal investigator or the institution.

CONTACT PERSON

If you have any questions regarding the research project or if a problem arises that you believe is connected to your participation in the project, you can contact Norma Gilbert.

SUPERVISION OF THE ETHICAL ASPECTS OF THE RESEARCH PROJECT

The Research Ethics Committee of the Jewish General Hospital has approved and is responsible for monitoring this research project. In addition, any changes to the information and consent form or to the research protocol must first be approved by the Committee.

If you have any questions regarding your rights as a research participant or if you would like to file a complaint or make a comment regarding the project, you can contact the local service quality and complaints commissioner of West-Central Montreal Health.

This research study has been approved by the following ethics committees:

The Jewish General Hospital Research Ethics Committee: CODIM-FLP-16-222, October 6, 2016, renewed, August 13 2017.

Comité d’éthique en recherché, Université de Montréal, 16-147-CERES, le 28 novembre 2016.

CONSENT FORM (FAMILY CAREGIVER)

Social and Interpersonal Dimensions of Measuring Loss of Autonomy:
Expectations among Family Caregivers and Social Workers in Quebec

CONSENT

Participant's consent

I have read this information and consent form. I acknowledge that the research project has been described to me, that my questions have been answered to my satisfaction and that I was given all the time I needed to make a decision.

- I understand that I can take my time to reflect before agreeing to participate in the research.
- I understand I can ask the research team any questions until I feel satisfied with the answer.
- As a research participant I understand that I do not renounce my rights or release the researchers from their responsibilities.
- I understand this information form and the research project and I agree to participate.

____

Name and signature of participant Date

Researcher's commitment

I have explained to the participant all the conditions for participation in this research project. I have responded to the best of my ability to all questions and I believe the participant completely understands everything. I agree to respect everything that is included in this information and consent form.

____

Name and signature of researcher Date

ANNEX 9 – RECRUITMENT POSTER SOCIAL WORKERS

Doctoral Research Study
Norma Gilbert, Doctorante, Université de Montréal
Annette Leibing, Research Supervisor, Université de Montréal

Project title: The Social and Interpersonal Dimensions of Measuring Loss of Autonomy in Elders, their Family Members and Social Workers: Expectations and Interactions

Objectives:
This project aims to examine the intersection of three perspectives (Social Worker, SAPA client and family member) during initial assessment of elderly SAPA clients in regards to their service expectations.

Requirements:
At the initial contact with the client, the Social Worker or Technienne en travail sociale will request the authorization from the elder client or family member to be contacted by the researcher to explain the project and gain their permission to observe the initial assessment (OEMC) meeting and perform follow-up interviews at their convenience. They will then inform the researcher (Norma Gilbert) who will telephone to provide additional details. No client will be contacted until the health professional has obtained their permission.

Profile:
First time home assessment (OEMC) in French or English of a SAPA client with caregiver family member (spouse or adult child) present. The client and family member should be capable of actively participating in the assessment and provide consent to participate in the research which consists of observation and follow-up interviews.

Method:
The process will include observation of ten first-time assessments of elderly home care clients by Social Workers and Social Work technicians and follow-up interviews with the health professionals, the elderly person and their family caregivers. The follow up interview with the professional will take about 15 minutes and about one hour with the senior and the family member.

Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'Île-de-Montréal
Québec

Centre de recherche et d'expertise
en gérontologie sociale

ANNEX 10 – RECRUITMENT POSTER CAREGIVERS

Doctoral Research Study
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Project title: The Social and Interpersonal Dimensions of Measuring Loss of Autonomy in Elders, their Family Members and Social Workers: Expectations and Interactions

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Recruitment for the caregiver discussion group

Objective:
The objective of this group is to discuss, in an informal manner, caregiver expectations of support and care services from their health institution. The focus will be on how expectations may have changed or altered from the beginning of your caregiver role until today.

Requirements:
The person could be a present caregiver or a former caregiver to a family member. They should already be receiving some services from the CIUSSS west-central Montreal

Method:
The discussion will take place over the period of about one hour. It will be audio-recorded and each participant will be asked to sign a consent form. All information gathered is confidential and it will in no way impact the services you are receiving.

Thank you for your participation.

ANNEX 11 - INTERVIEW GRID - SOCIAL WORKERS

Social Workers Interviews

Interview code: SW #______________

Date:	
Location:	
Time:	
Gender:	
Years of experience:	
Duration of interview:	

Introduction:

The purpose of this interview is to explore with you some of the underlying ideas for the evaluation of loss of autonomy in the elderly. More specifically, we are looking at the instrument itself, the OEMC, and what you expect and think about it as a tool for measuring loss of autonomy in your clients and how it effects your work. Also, in the second part I'd like to ask you some questions about what you expect from the family caregivers you meet and who are often present during your assessment.

Theme #1 – Opinion of the OEMC

A. **OEMC - general**
   a. Can you give me your thoughts, just off the top of your head, about the OEMC?
      i. What about the length, the time it takes to complete?
      ii. Do you bring the laptop or the paper version with you when you go to the home to do an assessment?
      iii. Does it ever happen that the score that comes out doesn't really represent the true situation of the client in your judgement?
      iv. What, if anything, would you change about the OEMC if you could?

B. OEMC process

a. How would you typically describe to the older person or the family member the reason for doing the assessment?
   i. What other things do you take into account besides what is in the assessment?
   ii. How do the family members participate in the evaluation?
   iii. How do you include the family caregiver into the assessment?
   iv. When there is a caregiver present does that effect the assessment in any way?
   v. Does the caregiver ever contradict what the elderly person is saying?
   vi. How do you negotiate that to make a proper assessment, who do you believe?
   vii. What do you do if that happens?

C. OEMC results

a. Does it ever happen that the score that comes out doesn’t really represent the true situation of the client in your judgement?
   i. If allocation of services is determined by a score, how does the social worker obtain services when the score and the psychosocial evaluation don’t coincide?
   ii. After doing the assessment and you go back to the client and family does it ever happen that they don’t agree or accept the results?
   iii. How would you explain things to them?

D. Closure

a. Do you have anything you would like to add about working with the OEMC?

Theme #2 – Expectations of caregiver

A. General expectations

a. In the context of your assessment of the client and subsequent interventions, how would you describe your expectations of the caregiver?

B. Communicating expectations

- a. Do you have any particular way you let the caregiver know what your expectations of them are?
    - i. How do the family members usually let you know what their expectations are?
    - ii. When the family members participate in the assessment, are you able to detect their expectations as well?
- b. Since we have an expectation of caregivers as a resource, how do you respond if they start expressing their own needs?
    - i. How do you know the caregiver is capable of being the resource and compensator?
    - ii. Is an assessment of the caregiver included in the overall evaluation?
    - iii. Do you find them generally well informed?

C. Closure

- a. Is there anything else you would like to add about the exchange of expectations between yourself and caregivers?

Theme #3 – Management expectations of social workers

A. General expectations

- a. So how would you describe the role of Social Workers …I'm hearing about lot of different hats you wear.
    - i. What about expectations on you, as a professional, from the system?
    - ii. Do you feel supported?

B. Workload expectations

- a. So I'm hearing you say that the expectations of the management and the system on the workers are not realistic…?
    - i. Have you talked to your colleagues about this?
    - ii. What are people saying about it?
- b. What other expectations are put on you in terms of time, caseload, etc.?
    - i. What can you describe in terms of time constraints?
    - ii. How many clients a day are you expected to see?
    - iii. How are you and others handling all the paperwork?

c. I’ve been hearing it’s hard because of time, even time to do the psychosocial evaluation that’s mandated by the Order?
    i. Why do you think people are having a problem with completing it?
    ii. What are the repercussions if it’s not done?
d. So looking at the expectations, would you say that the organization and the government are placing unrealistic expectations on the workers?

C. Closure

a. Is there anything else you’d like to say that we may not have covered in terms of assessment, expectations and working climate?

ANNEX 12 – INTERVIEW GRID – FAMILY CAREGIVERS

Individual caregiver interviews and caregiver group discussion

Interview code: CG #______________

Date:	
Location:	
Time:	
Gender:	
Years of caregiving:	
Duration of interview:	

Introduction:

This study is looking at caregivers expectations for homecare services from the CLSC in the context of loss of autonomy assessment by social workers. I'd like to get your general thoughts about what you thought of the process itself and if you had any particular expectations for services. This is an informal process and entirely confidential, so please feel free to say whatever you want to. *Note:* The icebreaker questions were only asked at the start of the individual interviews. By contrast, the first question put to the discussion group was: *"Have all of you, at some time, had some kind of assessment of your husband or wife that you remember?"* The reason for the difference was related to time management. My experience has taught me that asking a group of twelve caregivers to speak about their caregiving experience would have been very time consuming. However, during the discussion their individual stories were spontaneously revealed by them. The other questions were put to them in more or less the same sequence.

Theme #1 – Caregiver experience

A. Can you tell me a little bit about your experience as a caregiver?
  a. Who are you caring for?
    i. How long has it been?
    ii. When did you first realize that you were an official caregiver?
  b. What is your present situation?

        i. Are you getting any assistance from the CLSC right now?

Theme #2 - Loss of autonomy assessment

B. The assessment process

  a. Do you remember when the social worker came to the home to do the assessment of your ___________________?
    i. How did it go?
    ii. Did __________________ take part in it?
    iii. How was the process explained to you?
  b. Can you tell me what the result was?
    i. Were the results what you expected?
    ii. Were you offered any services?

Theme #3 - Expectations for care

C. Caregiver’s expectations

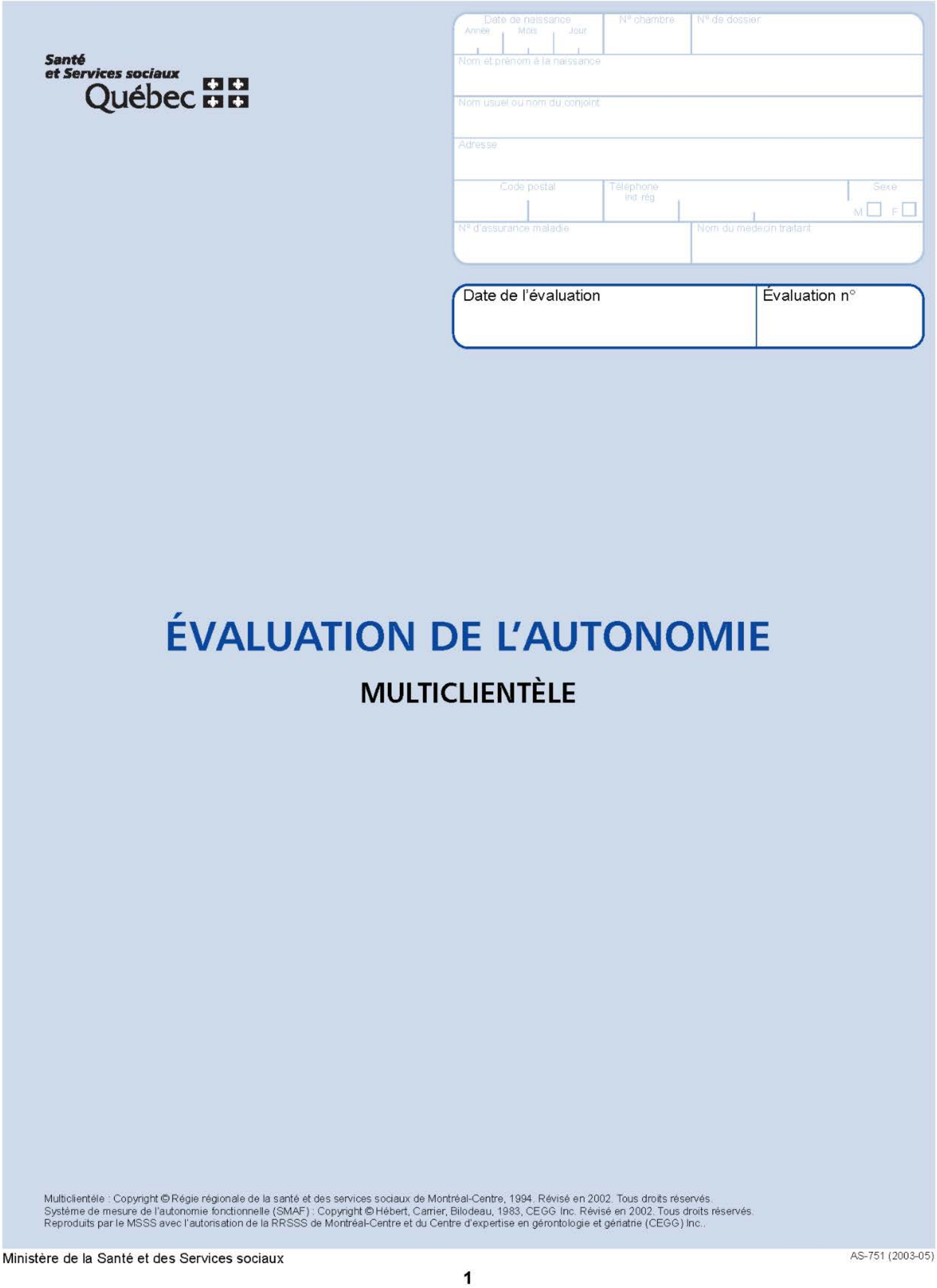
  c. What are your expectations for services from the healthcare system?
    i. Should they also help the family caregivers?
    ii. How did you learn about healthcare services?
    iii. How did you let the social worker know what you were expecting from the visit?
    iv. Do you feel that your expectations have been met by the healthcare system?

Theme #4 – Loss of autonomy

D. Meaning of loss of autonomy

  a. If I say the term ‘loss of autonomy’ what meaning does that have for you?
    i. How has it effected your life and relationship with ___________?
    ii. Are you and your _______________ in agreement about how autonomous they are?

ANNEX 13 – L'OUTIL D'ÉVALUATION MULTICLIENTÈLE (OÉMC) (20 P.)



Santé
et Services sociaux
Québec

Date de naissance Année Mois Jour	N° chambre	N° de dossier
Nom et prénom à la naissance		
Nom usuel ou nom du conjoint		
Adresse		
Code postal	Téléphone ind. rég.	Sexe M ☐ F ☐
N° d'assurance maladie	Nom du médecin traitant	

Date de l'évaluation	Évaluation n°

ÉVALUATION DE L'AUTONOMIE

MULTICLIENTÈLE

Ministère de la Santé et des Services sociaux

AS-751 (2003-05)

ÉVALUATION DE L'AUTONOMIE

N° de dossier

Préciser, s'il y a lieu, la source d'information : **U**sager – **P**roche – **É**valuateur — **Problème**

ÉTAT DE SANTÉ

1. HISTOIRE DE SANTÉ PERSONNELLE ET FAMILIALE, ET DIAGNOSTICS ACTUELS

(maladies physiques et mentales – incluant maladies ou problèmes chroniques ou stabilisés –, anomalies congénitales, hospitalisations, chirurgies, traumatismes)

Allergies (médicament, alimentation, environnement) : ____________________

2. SANTÉ PHYSIQUE

Difficultés éprouvées ou observations spécifiques	Non	Oui
• Fonction **digestive** (douleur, nausées, vomissements, diarrhée, constipation, gaz, dysphagie, etc.)	☐	☐
Si oui, préciser : ____________________		
• Fonction **respiratoire** (douleur, toux, expectorations, difficultés respiratoires, etc.)	☐	☐
Si oui, préciser : ____________________		
• Fonction **cardiovasculaire** (douleur, palpitations, stimulateur cardiaque, etc.)	☐	☐
Si oui, préciser : ____________________		
• Fonction **génito-urinaire** (douleur, problème urinaire, problème gynécologique ou génital, etc.)	☐	☐
Si oui, préciser : ____________________		
• Fonction **motrice** (douleur, déformation, limitation des mouvements, force, coordination, tremblements, équilibre, endurance physique, etc.)	☐	☐
Si oui, préciser : ____________________		
• Fonction **sensorielle** : yeux, oreilles, nez, bouche, toucher (douleur, écoulement, inflammation, sensibilité, etc.)	☐	☐
Si oui, préciser : ____________________		
• Condition de la **peau** (plaie, rougeur, œdème, écoulement, etc.)	☐	☐
Si oui, préciser : ____________________		
• Autres informations	☐	☐
Si oui, préciser : ____________________		

Taille : ________ Poids : ________ Gain ou perte de poids : ________ Si pertinent : ________ T.A. ________ Pouls ________ Resp. ________ T°

Commentaires : ____________________

Problème identifié **Non** — N **Oui** — O

N° de dossier

ÉVALUATION DE L'AUTONOMIE

Préciser, s'il y a lieu, la source d'information : Usager – Proche – Évaluateur **Problème**

3. SANTÉ PSYCHIQUE (état dépressif, idée suicidaire, idée paranoïde, délire, comportement violent, manie, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non

☐ Oui, préciser :

Commentaires :

Problème identifié
Non N
Oui O

4. SOINS PARTICULIERS (soins que nécessite l'état de l'usager : pansement, soins de cathéters divers, oxygène, aspiration des sécrétions, drainage postural, dialyse péritonéale, etc., et ceux faisant l'objet de la demande de services)

☐ Non

☐ Oui, description, fréquence et par qui :

Commentaires :

Problème identifié
Non N
Oui O

5. MÉDICATION (prescrite ou non)

Nom de la pharmacie :

Ind. rég. Téléphone

Ind. rég. Télécopieur

Courriel

Nom du médicament	Dose et fréquence	Pour quelle raison, selon l'usager	Nom du médecin qui le prescrit	Prescrit	
				Oui	Non

Effets secondaires : ☐ Non ☐ Oui

Médication suivie : ☐ Non ☐ Oui

Commentaires :

Problème identifié
Non N
Oui O

N° de dossier

ÉVALUATION DE L'AUTONOMIE

Préciser, s'il y a lieu, la source d'information : Usager – Proche – Évaluateur **Problème**

6. SERVICES DE SANTÉ (services médicaux, réadaptation, médecine douce, psychologie, podiatrie, etc.)

Suivi médical régulier : ☐ Non ☐ Oui

Médecin de famille : ______

Ind. rég. | N° de téléphone | N° de poste Ind. rég. | N° de télécopieur Courriel

Médecin spécialiste : ______

Ind. rég. | N° de téléphone | N° de poste Ind. rég. | N° de télécopieur Courriel

Médecin spécialiste : ______

Ind. rég. | N° de téléphone | N° de poste Ind. rég. | N° de télécopieur Courriel

Autre : ______

Ind. rég. | N° de téléphone | N° de poste Ind. rég. | N° de télécopieur Courriel

Commentaires (préciser les services requis non comblés) : ______

Problème identifié **Non** ☐ N **Oui** ☐ O

HABITUDES DE VIE

1. ALIMENTATION

Régime alimentaire quotidien :

Lait et produits laitiers : ☐ Oui ☐ Non Viande et substituts : ☐ Oui ☐ Non

Fruits et légumes : ☐ Oui ☐ Non Pain et céréales : ☐ Oui ☐ Non

Quantité de liquide : ______ tasses ou verres

Diète : ☐ Non ☐ Oui, préciser : ______

Prescrite : ☐ Oui ☐ Non Suivie : ☐ Oui ☐ Non

Alimentation pour dysphagique : ☐ Oui ☐ Non

Autres observations (heure et endroit des repas, mange avec qui, appétit, etc.) :

Difficultés éprouvées ou observations spécifiques : ☐ Non

☐ Oui, préciser : ______

Actuellement, les habitudes alimentaires sont satisfaisantes pour l'usager : ☐ Oui ☐ Non

Dentition (douleur, difficulté à mastiquer, prothèse, etc.) :

Difficultés éprouvées ou observations spécifiques : ☐ Non

☐ Oui, préciser : ______

Commentaires : ______

Problème identifié **Non** ☐ N **Oui** ☐ O

N° de dossier

ÉVALUATION DE L'AUTONOMIE

Préciser, s'il y a lieu, la source d'information : Usager – Proche – Évaluateur **Problème**

2. SOMMEIL (insomnie, se lève et pourquoi, peur, agitation, médicament, heures du lever et du coucher, sieste, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non
☐ Oui, préciser : ______

Actuellement, les habitudes de sommeil sont satisfaisantes pour l'usager : ☐ Oui ☐ Non

Commentaires : ______

Problème identifié **Non** N **Oui** O

3. CONSOMMATION DE TABAC (genre de consommation, quantité, surveillance à apporter, motivation à cesser de fumer, etc.)

Fume : ☐ Non
☐ Oui, préciser : ______

Actuellement, cette habitude pose un problème pour l'usager : ☐ Oui ☐ Non

Commentaires : ______

Problème identifié **Non** N **Oui** O

4. CONSOMMATION D'ALCOOL ET DE DROGUE (odeur éthylique, indicateurs extérieurs, genre de consommation, quantité, fréquence, surveillance à apporter, motivation à changer d'habitude, etc.)

Consomme de l'alcool ou de la drogue : ☐ Non
☐ Oui, préciser : ______

Actuellement, cette habitude pose un problème pour l'usager : ☐ Oui ☐ Non

Commentaires : ______

Problème identifié **Non** N **Oui** O

5. ACTIVITÉS PERSONNELLES ET DE LOISIRS (intégration au travail, aux études ou aux loisirs, activités usuelles, activités souhaitées, empêchements, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non
☐ Oui, préciser : ______

Actuellement, les activités personnelles et de loisirs sont satisfaisantes pour l'usager : ☐ Oui ☐ Non

Commentaires : ______

Problème identifié **Non** N **Oui** O

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ	HANDICAP

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

A. ACTIVITÉS DE LA VIE QUOTIDIENNE (AVQ)

1. SE NOURRIR

0 Se nourrit seul

-0,5 Avec difficulté

-1 Se nourrit seul mais requiert de la stimulation ou de la surveillance OU on doit couper ou mettre en purée sa nourriture au préalable

-2 A besoin d'une aide partielle pour se nourrir OU qu'on lui présente les plats un à un

-3 Doit être nourri entièrement par une autre personne OU porte une sonde naso-gastrique ou une gastrostomie

☐ sonde naso-gastrique ☐ gastrostomie

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

⊟ ⊞ ⊡

Commentaires (aide technique utilisée, par exemple) : ______________________________

____

____

2. SE LAVER

0 Se lave seul (incluant entrer ou sortir de la baignoire ou de la douche)

-0,5 Avec difficulté

-1 Se lave seul mais doit être stimulé OU nécessite une surveillance pour le faire OU qu'on lui prépare le nécessaire OU a besoin d'aide pour un bain complet hebdomadaire seulement (incluant pieds et cheveux)

-2 A besoin d'aide pour se laver (toilette quotidienne) mais participe activement

-3 Nécessite d'être lavé par une autre personne

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

⊟ ⊞ ⊡

Commentaires (habitudes et fréquence : bain, douche et lavage des cheveux, équipement utilisé, aide pour les transferts, etc.) :

____

____

____

3. S'HABILLER (toutes saisons)

0 S'habille seul

-0,5 Avec difficulté

-1 S'habille seul mais doit être stimulé OU a besoin d'une surveillance pour le faire OU on doit lui sortir et lui présenter ses vêtements OU on doit apporter certaines touches finales (boutons, lacets, bas de soutien)

-2 Nécessite de l'aide pour s'habiller

-3 Doit être habillé par une autre personne

☐ bas de soutien

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

⊟ ⊞ ⊡

Commentaires (tenue vestimentaire habituelle, aide technique utilisée, etc.) : ______________________________

____

____

* **Ressources : 0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : ⊟ diminuent, ⊞ augmentent, ⊡ restent stables ou ne s'appliquent pas.

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ	HANDICAP

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

4. ENTRETENIR SA PERSONNE (se brosser les dents ou se peigner ou se faire la barbe ou couper ses ongles ou se maquiller)

0 Entretient sa personne seul

-0,5 Avec difficulté

-1 A besoin de stimulation
OU nécessite de la surveillance pour entretenir sa personne

-2 A besoin d'une aide partielle pour entretenir sa personne

-3 Ne participe pas à l'entretien de sa personne

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ___ ___ ___

⊟ ⊞ ⊡

Commentaires (aide technique utilisée, par exemple) : ____________________

____

____

5. FONCTION VÉSICALE

0 Miction normale

-1 Incontinence occasionnelle
OU en goutte à goutte
OU une autre personne doit lui faire penser souvent d'uriner pour éviter les incontinences

-2 Incontinence urinaire fréquente

-3 Incontinence urinaire totale et habituelle
OU porte une culotte d'incontinence ou une sonde à demeure ou un condom urinaire

☐ culotte d'incontinence ○ incontinence nocturne
☐ condom urinaire ○ incontinence diurne
☐ sonde à demeure

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ___ ___ ___

⊟ ⊞ ⊡

Commentaires : ____________________

____

____

6. FONCTION INTESTINALE

0 Défécation normale

-1 Incontinence fécale occasionnelle
OU nécessite un lavement évacuant occasionnel

-2 Incontinence fécale fréquente
OU nécessite un lavement évacuant régulier

-3 Incontinence fécale totale et habituelle
OU porte une culotte d'incontinence ou une stomie

☐ culotte d'incontinence ○ incontinence nocturne
☐ stomie ○ incontinence diurne

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ___ ___ ___

⊟ ⊞ ⊡

Commentaires : ____________________

____

____

* **Ressources : 0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : ⊟ diminuent, ⊞ augmentent, ⊡ restent stables ou ne s'applique pas.

N° de dossier

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ	HANDICAP

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

7. UTILISER LES TOILETTES

0 Utilise seul les toilettes
(incluant s'asseoir, s'essuyer, s'habiller et se relever)

-0,5 Avec difficulté

-1 Nécessite de la surveillance pour utiliser les toilettes
OU utilise seul une chaise d'aisance, un urinal ou une bassine

-2 A besoin de l'aide d'une autre personne pour aller aux toilettes
ou utiliser la chaise d'aisance, la bassine ou l'urinal

-3 N'utilise pas les toilettes, la chaise d'aisance, la bassine ou l'urinal

☐ chaise d'aisance ☐ bassine ☐ urinal

Actuellement, l'usager a les ressources humaines
(aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

− + •

Commentaires (fréquence, équipement utilisé, aide de combien de personnes, etc.) : ____________________

____

____

B. MOBILITÉ

1. TRANSFERTS (du lit vers le fauteuil et la position debout et vice versa)

0 Se lève, s'assoit et se couche seul

-0,5 Avec difficulté

-1 Se lève, s'assoit et se couche seul mais doit être stimulé
ou surveillé ou guidé dans ses mouvements

préciser : ____________________

-2 A besoin d'aide pour se lever, s'asseoir et se coucher

préciser : ____________________

-3 Grabataire (doit être levé et couché en bloc)

☐ positionnement particulier

☐ lève-personne ☐ planche de transfert

Actuellement, l'usager a les ressources humaines
(aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

− + •

Commentaires (aide de combien de personnes, mobilité au lit, précision du positionnement, etc.) : ____________________

____

____

2. MARCHER À L'INTÉRIEUR (incluant dans l'immeuble et se rendre à l'ascenseur) [1]

0 Circule seul (avec ou sans canne, prothèse, orthèse, marchette)

-0,5 Avec difficulté

-1 Circule seul mais nécessite qu'on le guide, stimule ou surveille
dans certaines circonstances
OU démarche non sécuritaire

-2 A besoin de l'aide d'une autre personne

-3 Ne marche pas

☐ canne simple ☐ tripode ☐ quadripode ☐ marchette

[1] Distance d'au moins 10 mètres

Actuellement, l'usager a les ressources humaines
(aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

− + •

Commentaires (aire de déplacement, par exemple) : ____________________

____

____

* **Ressources :** **0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Prépose.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : − diminuent, + augmentent, • restent stables ou ne s'applique pas.

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ | **HANDICAP**

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

3. INSTALLER PROTHÈSE OU ORTHÈSE

0 Ne porte pas de prothèse ou d'orthèse

-1 Installe seul sa prothèse ou son orthèse

-1,5 Avec difficulté

-2 A besoin qu'on vérifie l'installation de sa prothèse ou de son orthèse OU a besoin d'une aide partielle

-3 La prothèse ou l'orthèse doit être installée par une autre personne

Type de prothèse ou d'orthèse : ______________________

____

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ___ ___ ___

⊟ ⊞ ⊡

Commentaires : ______________________

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4. SE DÉPLACER EN FAUTEUIL ROULANT À L'INTÉRIEUR

0 N'a pas besoin de fauteuil roulant pour se déplacer

-1 Se déplace seul en fauteuil roulant

-1,5 Avec difficulté

-2 Nécessite qu'une personne pousse le fauteuil roulant

-3 Ne peut utiliser un fauteuil roulant (doit être transporté en civière)

☐ fauteuil roulant simple

☐ fauteuil roulant à conduite unilatérale

☐ fauteuil roulant motorisé

☐ triporteur

☐ quadriporteur

- Le logement où habite l'usager permet la circulation en fauteuil roulant

☐ Oui → 0

☐ Non ↓

- Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ___ ___ ___

⊟ ⊞ ⊡

Commentaires : ______________________

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5. UTILISER LES ESCALIERS

0 Monte et descend les escaliers seul

-0,5 Avec difficulté

-1 Monte et descend les escaliers mais nécessite qu'on le guide, stimule ou surveille OU monte et descend les escaliers de façon non sécuritaire

-2 Monte et descend les escaliers avec l'aide d'une autre personne

-3 N'utilise pas les escaliers

L'usager doit utiliser un escalier

☐ Non → 0

☐ Oui ↓

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ___ ___ ___

⊟ ⊞ ⊡

Commentaires : ______________________

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* **Ressources :** **0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : ⊟ diminuent, ⊞ augmentent, ⊡ restent stables ou ne s'applique pas.

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ	HANDICAP

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

6. CIRCULER À L'EXTÉRIEUR

0 Circule seul en marchant (avec ou sans canne, prothèse, orthèse, marchette) [2]

-0,5 Avec difficulté

-1 Utilise seul un fauteuil roulant ou un triporteur/quadriporteur **

-1,5 F.R. avec difficulté

OU circule seul en marchant mais nécessite qu'on le guide, stimule ou surveille dans certaines circonstances
OU démarche non sécuritaire [2]

-2 A besoin de l'aide d'une autre personne pour marcher [2]
OU utiliser un fauteuil roulant **

-3 Ne peut circuler à l'extérieur (doit être transporté sur civière)

[2] Distance d'au moins 20 mètres

** L'environnement extérieur où habite l'usager permet l'accès et la circulation en fauteuil roulant ou triporteur/quadriporteur

☐ Oui → 0

☐ Non

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

− + •

Commentaires (aire de déplacement, par exemple) : ____________________

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C. COMMUNICATION

1. VOIR

0 Voit de façon adéquate avec ou sans verres correcteurs

-1 Troubles de vision mais voit suffisamment pour accomplir les activités quotidiennes

-2 Ne voit que le contour des objets et nécessite d'être guidé dans les activités quotidiennes

-3 Aveugle

☐ verres correcteurs ☐ loupe

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

− + •

Commentaires (quel œil, par exemple) : ____________________

____

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2. ENTENDRE

0 Entend convenablement avec ou sans appareil auditif

-1 Entend ce qu'on lui dit à la condition de parler fort
OU nécessite qu'on lui installe son appareil auditif

-2 N'entend que les cris ou que certains mots
OU lit sur les lèvres
OU comprend par gestes

-3 Surdité complète et incapacité de comprendre ce qu'on veut lui communiquer

☐ appareil auditif

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui → 0

☐ Non → -1 -2 -3

Ressources* : ☐ ☐ ☐

− + •

Commentaires (quelle oreille, dispositif installé sur le téléphone et autre aide technique, etc.) : ____________________

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* **Ressources : 0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : − diminuent, + augmentent, • restent stables ou ne s'applique pas.

ÉVALUATION DE L'AUTONOMIE

N° de dossier

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ | **HANDICAP**

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

3. PARLER

	INCAPACITÉ	HANDICAP		
0	Parle normalement			
-1	A une difficulté de langage mais réussit à exprimer sa pensée	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	− + •
-2	A une difficulté grave de langage mais peut communiquer certains besoins primaires OU répondre à des questions simples (oui, non) OU utilise le langage gestuel	☐ Oui ☐ Non	-1 -2 -3	
-3	Ne communique pas Aide technique : ☐ ordinateur ☐ tableau de communication	Ressources* : ___ ___ ___		

Commentaires (type de compensation, par exemple) : ______________________________

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Compréhension et expression écrite : ______________________________

____

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D. FONCTIONS MENTALES

Pour chaque élément, préciser depuis quand existe l'incapacité et la réaction de l'usager à cette incapacité

1. MÉMOIRE

	INCAPACITÉ	HANDICAP		
0	Mémoire normale			
-1	Oublie des faits récents (nom de personne, rendez-vous, etc.) mais se souvient des faits importants	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	− + •
-2	Oublie régulièrement des choses de la vie courante (fermer cuisinière, avoir pris ses médicaments, rangement des effets personnels, avoir pris un repas, ses visiteurs, etc.)	☐ Oui ☐ Non	-1 -2 -3	
-3	Amnésie quasi totale	Ressources* : ___ ___ ___		

Commentaires : ______________________________

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2. ORIENTATION

	INCAPACITÉ	HANDICAP		
0	Bien orienté par rapport au temps, à l'espace et aux personnes			
-1	Est quelques fois désorienté par rapport au temps, à l'espace et aux personnes	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	− + •
-2	Est orienté seulement dans la courte durée (temps de la journée), le petit espace (environnement immédiat habituel) et par rapport aux personnes familières	☐ Oui ☐ Non	-1 -2 -3	
-3	Désorientation complète	Ressources* : ___ ___ ___		

Commentaires : ______________________________

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* **Ressources :** **0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : − diminuent, + augmentent, • restent stables ou ne s'applique pas.

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ	HANDICAP

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

3. COMPRÉHENSION

0 Comprend bien ce qu'on lui explique ou lui demande

-1 Est lent à saisir des explications ou des demandes

-2 Ne comprend que partiellement, même après des explications répétées OU est incapable de faire des apprentissages

-3 Ne comprend pas ce qui se passe autour de lui

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui — 0

☐ Non — -1 -2 -3

Ressources* : ☐ ☐ ☐

⊟ ⊞ ⊡

Commentaires : ______________________________

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4. JUGEMENT

0 Évalue les situations et prend des décisions sensées

-1 Évalue les situations et nécessite des conseils pour prendre des décisions sensées

-2 Évalue mal les situations et ne prend des décisions sensées que si une autre personne les lui suggère

-3 N'évalue pas les situations et une autre personne doit prendre les décisions à sa place

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui — 0

☐ Non — -1 -2 -3

Ressources* : ☐ ☐ ☐

⊟ ⊞ ⊡

Commentaires : ______________________________

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5. COMPORTEMENT

0 Comportement adéquat

-1 Troubles de comportement mineurs (jérémiades, labilité émotive, entêtement, apathie) qui nécessitent une surveillance occasionnelle ou un rappel à l'ordre ou une stimulation

-2 Troubles de comportement qui nécessitent une surveillance plus soutenue (agressivité envers lui-même ou les autres, dérange les autres, errance, cris constants)

-3 Dangereux, nécessite des contentions OU essaie de blesser les autres ou de se blesser OU tente de se sauver

Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité

☐ Oui — 0

☐ Non — -1 -2 -3

Ressources* : ☐ ☐ ☐

⊟ ⊞ ⊡

Commentaires : ______________________________

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* **Ressources : 0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : ⊟ diminuent, ⊞ augmentent, ⊡ restent stables ou ne s'applique pas.

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

INCAPACITÉ	HANDICAP

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

E. TÂCHES DOMESTIQUES (activités de la vie domestique)

1. ENTRETENIR LA MAISON

0	Entretient seul la maison (incluant entretien quotidien et travaux occasionnels) -0,5 Avec difficulté			
-1	Entretient la maison (incluant laver la vaisselle) mais requiert surveillance ou stimulation pour maintenir un niveau de propreté convenable OU nécessite de l'aide pour des travaux occasionnels (laver les planchers, doubles fenêtres, peinture, gazon, déneigement, etc.)	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité ☐ Oui ☐ Non	0 -1 -2 -3	− + •
-2	A besoin d'aide pour l'entretien quotidien de la maison			
-3	N'entretient pas la maison	Ressources* : ☐ ☐ ☐		

Commentaires : ______________________________

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2. PRÉPARER LES REPAS

0	Prépare seul ses repas -0,5 Avec difficulté			
-1	Prépare ses repas mais nécessite qu'on le stimule pour maintenir une alimentation convenable	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité ☐ Oui ☐ Non	0 -1 -2 -3	− + •
-2	Ne prépare que des repas légers OU réchauffe des repas déjà préparés (incluant la manutention des plats)			
-3	Ne prépare pas ses repas	Ressources* : ☐ ☐ ☐		

Commentaires : ______________________________

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3. FAIRE LES COURSES

0	Planifie et fait seul les courses (nourriture, vêtements, etc.) -0,5 Avec difficulté			
-1	Planifie et fait seul les courses mais nécessite qu'on lui livre	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité ☐ Oui ☐ Non	0 -1 -2 -3	− + •
-2	A besoin d'aide pour planifier ou faire les courses			
-3	Ne fait pas les courses	Ressources* : ☐ ☐ ☐		

Commentaires (préciser les activités pour lesquelles l'usager a une incapacité) : ______________________________

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* **Ressources : 0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : − diminuent, + augmentent, • restent stables ou ne s'applique pas.

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

	INCAPACITÉ	HANDICAP		

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

4. FAIRE LA LESSIVE

0	Fait toute la lessive seul			
	-0,5 Avec difficulté			
-1	Fait la lessive seul mais nécessite une stimulation ou une surveillance pour maintenir un niveau de propreté convenable	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	−
-2	A besoin d'aide pour faire la lessive	☐ Oui		+
-3	Ne fait pas la lessive	☐ Non	-1 -2 -3	•
		Ressources* : ☐ ☐ ☐		

Commentaires : ______________________________

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5. UTILISER LE TÉLÉPHONE

0	Se sert seul du téléphone (incluant la recherche d'un numéro dans le bottin)			
	-0,5 Avec difficulté			
-1	Répond au téléphone mais ne compose que quelques numéros qu'il a mémorisés ou des numéros en cas d'urgence	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	−
-2	Parle au téléphone mais ne compose pas de numéros ou ne décroche pas le récepteur	☐ Oui		+
-3	Ne se sert pas du téléphone	☐ Non	-1 -2 -3	•
		Ressources* : ☐ ☐ ☐		

Commentaires (appareil spécial, par exemple) : ______________________________

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6. UTILISER LES MOYENS DE TRANSPORT

0	Utilise seul un moyen de transport (automobile, véhicule adapté, taxi, autobus, etc.)			
	-0,5 Avec difficulté			
-1	Doit être accompagné pour utiliser un moyen de transport OU utilise seul le transport adapté	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	−
-2	N'utilise que l'automobile ou le transport adapté à la condition d'être accompagné et aidé pour monter et descendre	☐ Oui		+
-3	Doit être transporté sur civière	☐ Non	-1 -2 -3	•
		Ressources* : ☐ ☐ ☐		

Commentaires : ______________________________

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* **Ressources : 0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Prépose.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : − diminuent, + augmentent, • restent stables ou ne s'applique pas.

N° de dossier

ÉVALUATION DE L'AUTONOMIE

STABILITÉ DE LA RESSOURCE ■

	INCAPACITÉ	HANDICAP		

Préciser, s'il y a lieu, la cause, la déficience responsable de l'incapacité et la réaction de l'usager à cette incapacité

7. PRENDRE SES MÉDICAMENTS

0	Prend seul ses médicaments de façon adéquate OU ne prend pas de médicament			
	-0,5 Avec difficulté			
-1	A besoin de surveillance (incluant la surveillance à distance) pour prendre convenablement ses médicaments OU utilise un pilulier hebdomadaire (préparé par une autre personne)	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	−
		☐ Oui		+
-2	Prend ses médicaments s'ils sont préparés quotidiennement	☐ Non	-1	•
-3	On doit lui apporter ses médicaments en temps opportun		-2	
	☐ pilulier	Ressources* : ☐ ☐ ☐	-3	

Commentaires : ____________________

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8. GÉRER SON BUDGET

0	Gère seul son budget (incluant gestion bancaire)			
	-0,5 Avec difficulté			
-1	A besoin d'aide pour effectuer certaines transactions complexes	Actuellement, l'usager a les ressources humaines (aide ou surveillance) pour combler cette incapacité	0	−
-2	A besoin d'aide pour effectuer des transactions simples (encaisser un chèque, payer des comptes) mais utilise à bon escient l'argent de poche qu'on lui remet	☐ Oui		+
		☐ Non	-1	•
-3	Ne gère pas son budget		-2	
		Ressources* : ☐ ☐ ☐	-3	

Commentaires (procuration bancaire, par exemple) : ____________________

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* **Ressources : 0.** Usager lui-même, **1.** Famille, **2.** Voisin, **3.** Employé(e), **4.** Auxiliaire familial(e), **5.** Infirmier(ère), **6.** Bénévole, **7.** Autre, **8.** Préposé.

■ **Stabilité :** dans les 3 à 4 semaines qui viennent, il est prévisible que ces ressources : − diminuent, + augmentent, • restent stables ou ne s'applique pas.

ÉVALUATION DE L'AUTONOMIE

N° de dossier

Préciser, s'il y a lieu, la source d'information : Usager – Proche – Évaluateur | **Problème**

SITUATION PSYCHOSOCIALE

1. HISTOIRE SOCIALE (occupation, mariage, divorce, deuil, scolarité, immigration, déménagement, autres événements importants, etc.)

Commentaires :

Problème identifié
Non N
Oui O

2. MILIEU FAMILIAL

Composition de la famille (âge, sexe, lieu de résidence ou génogramme) :

Dynamique familiale (interactions de l'usager avec sa famille et des membres de la famille entre eux ; satisfaction de l'usager au regard de sa situation familiale ; comment la famille réagit ou est affectée par la situation de l'usager ; indices d'abus, de violence ou de négligence, etc.) :

Commentaires :

Problème identifié
Non N
Oui O

3. AIDANTS PRINCIPAUX (implication, épuisement, perception de leur situation, attentes, volonté de s'impliquer, etc.)

Commentaires :

Problème identifié
Non N
Oui O

N° de dossier

ÉVALUATION DE L'AUTONOMIE

Préciser, s'il y a lieu, la source d'information : Usager – Proche – Évaluateur **Problème**

4. RÉSEAU SOCIAL (incluant le milieu scolaire et le milieu de travail)

Personnes significatives (amis, voisins, collègues, enseignants, etc.) :

Dynamique des relations (interaction de l'usager avec les membres de son réseau social ; satisfaction de l'usager au regard de ses relations avec les membres de ce réseau ; comment les membres de ce réseau réagissent ou sont affectés par la situation de l'usager ; indices d'abus, de violence ou de négligence, etc.) :

Commentaires :

Problème identifié **Non** N **Oui** O

5. RESSOURCES COMMUNAUTAIRES, PUBLIQUES ET PRIVÉES (bénévoles, associations, centre de jour, transport adapté, services inscrits dans le bail, etc.)

Préciser le type de services, la fréquence de ces services, les interactions de l'usager avec ces ressources :

Commentaires (services requis non comblés) :

Problème identifié **Non** N **Oui** O

6. ÉTAT AFFECTIF (humeur, estime de soi, sentiment d'utilité ou de solitude, anxiété, etc.)

Commentaires :

Problème identifié **Non** N **Oui** O

N° de dossier

ÉVALUATION DE L'AUTONOMIE

Préciser, s'il y a lieu, la source d'information : **U**sager – **P**roche – **É**valuateur | Problème

7. PERCEPTION DE L'USAGER (comment il perçoit sa situation, y réagit ou s'y adapte, motivation, solutions envisagées, etc.)

Commentaires :

Problème identifié **Non** N **Oui** O

8. SEXUALITÉ (satisfaction de l'usager, préoccupation, comportement socialement inacceptable, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non

☐ Oui, préciser :

Commentaires :

Problème identifié **Non** N **Oui** O

9. CROYANCES ET VALEURS PERSONNELLES, CULTURELLES ET SPIRITUELLES (expression, par exemple)

Difficultés éprouvées ou observations spécifiques : ☐ Non

☐ Oui, préciser :

Commentaires :

Problème identifié **Non** N **Oui** O

CONDITIONS ÉCONOMIQUES

CAPACITÉ DE FAIRE FACE À SES OBLIGATIONS SELON SES REVENUS ACTUELS (loyer, nourriture, habillement, médicaments, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non

☐ Oui, préciser :

Est-ce que l'usager bénéficie d'un des programmes suivants : supplément de revenu garanti, régime de rentes du Québec, programme d'accès au logis, rente d'invalidité, sécurité du revenu, allocation familiale spéciale, autre : ☐ Non ☐ Oui

Si oui, préciser :

Commentaires :

Problème identifié **Non** N **Oui** O

N° de dossier

ÉVALUATION DE L'AUTONOMIE

Préciser, s'il y a lieu, la source d'information : Usager – Proche – Évaluateur **Problème**

ENVIRONNEMENT PHYSIQUE

1. CONDITIONS DU LOGEMENT (salubrité, espace, satisfaction, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non
☐ Oui, préciser : ______

☐ Propriétaire ☐ Locataire ☐ Pensionnaire ☐ Adresse inconnue Habite ce logement depuis : ______

Logement situé au : ______ étage Nombre de pièces : ______

Accès : ☐ ascenseur ☐ escalier intérieur, nombre de marches ______ ☐ escalier extérieur, nombre de marches ______

Commentaires : ______

Problème identifié **Non** N **Oui** O

2. SÉCURITÉ PERSONNELLE ET ENVIRONNEMENTALE (risque de chute, incendie, fugue, système téléphonique d'urgence, avertisseurs lumineux, télésurveillance, système de contrôle à distance, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non
☐ Oui, préciser : ______

Commentaires (besoins non comblés) : ______

Problème identifié **Non** N **Oui** O

3. ACCESSIBILITÉ (barrières architecturales, emplacement des appareils, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non
☐ Oui, préciser : ______

Commentaires (besoins non comblés) : ______

Problème identifié **Non** N **Oui** O

4. PROXIMITÉ DES SERVICES (épicerie, banque, église, buanderie, etc.)

Difficultés éprouvées ou observations spécifiques : ☐ Non
☐ Oui, préciser : ______

Commentaires : ______

Problème identifié **Non** N **Oui** O

N° de dossier

SYNTHÈSE (contexte de l'évaluation, problèmes prioritaires décelés, attentes de l'usager, facteurs de risque, orientations suggérées)

Année Mois Jour

Signature

Titre

Date