

**THE BIOMEDICAL ROOTS OF THE QUEBEC ALZHEIMER PLAN:
A CRITICAL FRAME ANALYSIS**

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Abstract

The Biomedical Roots of the Quebec Alzheimer Plan: A Critical Frame Analysis Stephanie Doughty

Dementia is an increasingly prevalent health concern. To combat the global increase in people living with dementia, jurisdictions have begun implementing dementia health policies to better tackle the health concern. In Quebec, the local provincial government has implemented the Quebec Alzheimer Plan (2009), which has been sewn into the fabric of the Quebec healthcare system. Currently, the plan is in its third stage of implementation. To understand the QAP's problematization of and solution for dementia, this analysis employs Critical Frame Analysis (CFA) to assess the QAP policy text. This work explores how the policy has been framed, highlighting that elements of both the biomedical and social model of disability play roles in the framing of the policy, with the biomedical paradigm being the most dominant framing device in the text. The dominance of the biomedical paradigm hints at the power dynamic between medical professionals and patients and caregivers, suggesting that the former retain more authority and voice, resulting in the latter having diminished voice and agency.

Acknowledgments

A deep thank you and sense of gratitude to my thesis supervisors, Dr. Daniel Salée and Dr. Stephanie Paterson, for having taken the time and energy to help me along my journey.

A nod to the caregivers out there. Keep on fighting the good fight, but don't forget to re-light your flame lest you get sick, too.

Dedication

For dad: My self-defense-teaching, silly-walking-specialist, Inspector-Clouseau-watcher-outer, stargazing, canoe-tipper, duck-quacker, walking-up-the-mountain-backwards, green-bananas-only, protect-your-gut-microbiome, wobble-effect, Peter-Gabriel-loving, protector and rock.

I will remember for you.

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A Few Thoughts

“Pour des milliers de vieilles gens esseulés, sans personne pour les accompagner, tiennent présentement dans leurs mains des ordonnances et des renseignements sur des médicaments dont ils ne se souviennent plus de la raison ni de l’importance. Ils écoutent nos politiciens usés qui promettent un système de santé comme on se la souhaite au jour de l’An, la santé avec le paradis à la fin de nos jours. Ces solitaires et ces oubliés ont les mains qui tremblent. Au fond d’eux-mêmes, ils espèrent arriver au paradis avant de se retrouver dans un corridor ou dans un CHSLD.”¹
– Jacques Boulerice

“Hard time planet earth. Batten down the hatches.” – Dad

“The personal is political.” - Source unknown within the Feminist Movement

¹ Boulerice, 17

Note on Positionality

This project is borne out of my own lived experiences with dementia care and politics. More honestly, I can say that this thesis is a heartfelt re-membering (in the sense of ‘putting together’) of the last few years of both my father’s and my lives, particularly in light of how we struggled to make sense of the roles and situations we found ourselves in as people experiencing dementia. In providing this statement on positionality I hope to clarify a few things. This thesis is of personal significance to me. First and foremost because of the love I have for father, but equally because I have become my father’s legal caregiver. While this thesis remains committed to providing an unbiased evaluation of the QAP’s ideological framing, I feel that it is important to disclose my positionality in that I have gone through the dementia care system in a way that perhaps other dementia policy researchers have not. In some ways, it is impossible (and arguably undesirable) for me to separate myself and my experiences from an understanding of dementia problematization. On this note, the inclusion of auto-ethnographic vignettes in this thesis is not meant to sway the reader in a prejudicial fashion, but rather to provide a narrative arc and context to the dementia care landscape in Quebec. As the well-established auto-ethnographer Tony Adams suggests: all good stories are compelling.² Correspondingly, the inclusion of short vignettes based on my experiences affords me the ability to invite you into my world, colouring in some of the details of life for caregivers and people living with dementia in Quebec. Ultimately, in sharing these stories, I hope to have crafted a story that you will find to be compelling, fundamentally underscoring that the very most personal experiences of our lives are, in fact, deeply political and worthy of being explored.

² Adams, 2021

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CHAPTER 1: INTRODUCTION

1.1 THE UNWITTING BEGINING: THE STORY OF PETER PARKER

When most people hear the name Peter Parker they think of Spider-Man's everyday alias. Personally I knew Peter Parker to be a sweet, orange cat that belonged to my grandmother—my dad's mom. When my grandmother moved from her apartment to a senior's co-op, she was instructed that Peter Parker could not come with her. No cats allowed.

Not wanting to see the cat euthanized or fall into the hands of misfortune, I convinced my dad to let the cat come live with us. He was—to say the least—reluctant. Truth being told I knew he wouldn't be able to say no to my request. This was a man who, according to family lore, once pulled over to the side of a major road to rescue a stranded turtle. This was a man who took in a sick, elderly dog named Rocky simply to give him the best last months of life possible. This was the same man who, when I was a little girl, and—against all odds— I managed to catch a clam (yes, a clam!) at the end of my fishing hook, immediately put the clam back in the water and hoped that that was enough to keep him alive (the “fishing” I believe, was just an excuse to take the canoe out).

So, it goes without saying that Peter Parker came to live with us. My dad tended to his needs. Cleaned his litter. Fed him. Even plucked fleas from his back. Counter to my dad's “dad” rhetoric, he loved this cat. They bonded. A bromance was born.

This was all about 10 years ago now.

Perhaps two years after Peter Parker came to live with us, I had realized that there was some kind of problem between dad and me. I couldn't quite put my finger on what the problem was exactly, but I knew there was a problem. Was dad angry with me? No, that didn't make sense—dad and I never fought. We had the kind of easy, peaceful father-daughter dynamic that I am sure many people would be envious of. There was never any yelling. Not once. No fights. No ultimatums. We barely even disagreed—and when we did, it was almost always about something ridiculous like the earth being wobbly or who could do the most silly ‘silly walk’ (it was always him). When I think about this in retrospect, perhaps our lack of arguments could be attributed to our mutually calm natures. Or maybe we just got each other.

But now I could tell that something was off. Something had shifted, almost imperceptibly. I could see it in the little things. Dad was—out of nowhere—obsessed with Luminosity (you know, the brain quiz website). He kept saying that reading novels was becoming difficult. I remember asking him once: “What about Tommyknockers? You love Tommyknockers,” to which he ruefully replied: “Not even Tommyknockers.” And then there was the sudden issue about dad always being too busy to see me (which, considering that we would normally see each other a couple times a week, was very uncharacteristic of him). And when he would get around to seeing me, he'd make some kind of excuse and leave shortly thereafter, almost like my presence offended him. So after a while of this odd behaviour I became convinced that he was angry with me. Not that I could figure out why. I racked my brain. Was it something I said? Was it something I did? I told my family. I told my friends. No one seemed even mildly concerned. “It's probably nothing,” they overwhelmingly said.

Not too long after that, there was a small family dinner. I cannot tell you why we gathered. I cannot tell you what we ate. I can't even recall the season. All I know for sure is that dad was being very strange. Aggressive, even. As we sat around the table talking, I asked dad about what had been on my mind of late. And so I said: "Dad, where's Peter Parker? I haven't seen him around lately. I'm worried."

He replied, quite seriously: "I fed him to the foxes in Terracotta Park. He's gone."

Silence engulfed the table. *Fed the cat to the foxes?! WHAT!*

This was the moment I knew for sure that something was really wrong.

The shift from the calm, loving, dependable dad I had always known to this new person happened so much faster than I can still really fathom.

My dad was diagnosed with frontotemporal dementia (FTD) in 2020 at the age of 58, smack dab in the middle of the Covid-19 pandemic. He took the news of his diagnosis blithely. Over Zoom, the doctor said "Paul, you have dementia. That means you have problems with your memory."

Dad barely even looked at the screen, as unconcerned with the news as he was. "Ok, I have problems with my memory."

He was not upset. He was busy stirring the spoon in his mug of overly cool Earl Grey tea. He liked doing that. The doctor proceeded to inform us that dad's disease would likely be worse on us than on him. Many people with FTD at my dad's stage are incapable of what is medically referred to as 'insight' (the ability to know why you like something, or what you're doing). People living with FTD can be very repetitive in their actions. They might go for a four-hour walk around the same block. They might find themselves obsessively changing the channel on the television set. They might lose their ability to talk (as my dad was in the process of doing so). The doctor remarked that we might already recognize some of the symptoms in dad. Symptoms which had, up until then, been chalked up to a plethora of other explanations circulating around the family. Symptoms such as: apathy, changed behaviour, decreased linguistic capacity (which my teacher brain primed for language parsing long picked up on). Even my dad's newfound addiction to dumping heaving spoonfuls of honey into his tea could be explained away by my father's shrinking frontal and temporal lobes.

Oh yes, doc, we were already very familiar with these symptoms.

Perhaps it was of some comfort or validation to know that dad was legitimately sick—that some of the more severe behavioural changes, some of the unusual and unsavoury things he had done, could be neatly explained away by medical science. My sweet dad had not secretly become an insensitive, distracted, numbed, cat-killer. He was just really sick.

When I look back over the past few years of my dad's life, pausing to survey the damage done, I cannot help but remark the little injustices, the instances of dehumanization and the myriad of little tragedies along the way. Did things really need to transpire this way? Peter Parker lost his life in 2015 (though the exact date can never be confirmed). I knew then that something was very wrong, but it would never have occurred to me that it was dementia. My mountain-climbing, kale-and-green-banana eating, Scientific American-reading father living with dementia? Get out of here. Also, genetically it didn't make sense—both of his parents had made it to their late 90s in full cognitive health, with my spectacular grandmother in particular quoting Shakespeare and bible verses—in full—on her deathbed. These were Doughty genes. These were Thackway genes. These

genes didn't produce dementia. Dementia was never a consideration when it came to understanding what was going wrong with dad.

Considering my hubris in dad's genes—or naivete at life, as you might consider it—it's not really surprising that in the end it took a full five years, several police and court interactions, countless painful conversations, two bar-bannings, one home loss, one car loss, one court mandated alcohol-prevention program, along with a slew of other paper cut-sized traumas for the local medical community, as well for other people in my dad's entourage to agree that yes, there was some kind of medical problem going on here, and god help us all, it's called dementia.

1.2 THIS WORK

As you might have guessed from my introductory story, my thesis research does not come out of nowhere; I was violently thrown by the inertia of my life *into* this work. In many ways this thesis stems from a feeling of helplessness. My truest friend, my father, was getting sicker by the day and I could not make heads or tails of what was happening to him. I did not understand this new system I found myself navigating. I was lost.

One such instance in which I felt particularly lost and confused was when I found myself in attendance at a workshop held by the Montreal Alzheimer Society. I was the youngest person in the room by a solid three decades. In fact, when I showed up at the local library where the event was being held, the library staff mistook me for the person who was to give the lecture—which has to count as some kind of dark irony if you ask me. During the presentation we learned the official term for the dark cloud of grief that may descend upon you when your loved one has dementia—in the literature it is called *ambiguous loss*. According to the Alzheimer Society of Canada, ambiguous loss “is a type of loss you feel when a person with dementia is physically here, but may not be mentally or emotionally present in the same way as before.”³ As a consequence to this ambiguous loss, you might find yourself in your own sort of haze. You are grieving as if someone has died, but you don’t necessarily know you are grieving. You are angry (and in my case rageful) but you don’t know where to direct your anger. You are in a total muddle, but you fear no one notices because honestly how could they. You are heartbroken, but well-meaning people say things like *at least he’s still alive* and you try not to vocalize how you really feel out loud because there’s really no reason to go about telling people they know nothing. The dark cloud pestering you is a shapeshifter, but no matter what permutation it takes you find your energy dwindling, with life ticking on by, and you all the worse off because of it.

And so, it was in a spirit of trying to make sense of these experiences and this gnarly vortex of emotions that I embarked upon this thesis project. Without really knowing where I was going, I was going. I tried to understand not just the medical aspects of my dad’s disease, but the roles that we all had, and continue to have, in his welfare. For one thing, I learned that when someone gets dementia, like in the case of many diseases, it’s not just the afflicted that is impacted. Dementia is a communal disease. In dad’s case, doctors, nurses, police officers, social workers, neighbours, family members, community members, long lost friends and one very notable nut-shop owner are representative of just some of the people and institutions that helped, hindered, showed up for, or failed to show up for dad as he wound down in frontotemporal dementia path.

These very personal experiences invariably led me to wanting to know more about the politics involved in dementia care. Were there any policies in place pertaining to dementia? Surely there had to be something. My search brought me to discovering the Quebec Alzheimer Plan (QAP), equally known as “*The Quebec Alzheimer Plan: ‘Meeting the Challenge of Alzheimer’s Disease and Related Disorders: A Vision Focused on the Individual, Humanism, and Excellence’*” (2009). The QAP is a document of 137 pages, written and spearheaded by Dr. Howard Bergman and his team of medical experts (textually identifiable as the ‘Committee of Experts’) at the behest of the Quebec government.⁴ Initially, this policy had a prior life as a report commissioned in 2007

³ Alzheimer Society, June 2019

⁴ Bergman, 2009

by then Minister of Health Philippe Couillard (who, quite notably, was a practicing neurosurgeon in his former life).⁵ This report was subsequently adopted in its entirety as a health policy and written into the fabric of the Quebec healthcare system.⁶ In many ways, the QAP is the first of its ilk in Canada. It was the first Canadian policy to directly address dementia, those living with the disease, and how best to help them do so. Indeed, it outpaced all provincial and federal frameworks on dementia by several years, including the very recent federal framework *A Dementia Strategy for Canada: Together We Aspire* (2019).

As things stand, the QAP has been operating, albeit at varying stages of implementation, for well over 15 years. During this time, it has been the main policy instrument and lens through which neurocognitive diseases have been systematically detected, treated and clinically researched in the province of Quebec. By extension, the QAP is also the main policy instrument through which we might collectively imagine the ‘problem’ of dementia in the Quebec context. Given that the policy was crafted by medical professionals at the request of politicians, and given my own experiences, I became interested in understanding which ideas underpinned, shaped, and potentially dominated the policy. Was there just one, big idea hidden from my sight that was the guiding principle of this policy—or many? Would the policy speak to some of my lived experiences as a caregiver, or would this analysis reveal something else entirely?

⁵ Assemblée Nationale du Québec, Accessed: August 23rd, 2023

⁶ ROSA, Accessed: March 2023

1.3 RESEARCH QUESTION & RATIONALE

To tackle the notion of dominant ideas inherent in the QAP, I ask the following research question: *What are the main frames in the QAP?* The jumping off point in which I chose to go about answering this research question came in the form of Critical Frame Analysis (CFA) and my own lived experience. My up-until-then inkling was that there must be a dominant paradigm (or paradigms) in the medical field that was having some degree of an effect on Quebec dementia policy and policy outcomes, providing context as to why dementia care in Quebec is the way it is. Accordingly, I needed a tool to investigate the ideas inherent in the policy. The tool which I chose to optimally assess the Quebec Alzheimer Plan was Critical Frame Analysis (CFA). Critical Frame Analysis is a methodology whose objective is to reveal the stories or arguments that a policy tells, which includes the elucidation of how a given ‘problem’ is solved for. The stories that are baked into a policy are understood through policy frames, otherwise described as “interpretation scheme[s] that structure the meaning of reality.”⁷ CFA is ideal to conduct this research as it provides the requisite tools to deconstruct the QAP policy text and its frames in view of understanding its inherent policy ideas.

In this thesis project, I set out to establish how the Quebec Alzheimer Plan had been framed. Specifically, I sought to unveil the ideas that are embedded into the policy, or the notions which constitute dementia problematization to better understand the main foundational ideas (frames) that influence the policy text. In order to do this, I recalled the insight that policy frames are the stories that are inside a policy by which a version of reality can be interpreted.⁸ If it is understood that policy frames interpret reality, then the notion at the heart of this research fundamentally remains understanding how the story of Alzheimer and dementia problematization is told through the QAP policy text. This notion aligns with the ‘why?’ choose Critical Frame Analysis for this thesis. Because I came to this research on a quest to try to make sense of what I had experienced and seen as my father’s caregiver, the interest in asking how the QAP has been ideologically structured stems from a desire to unveil the dominant ideas inherent in the dementia policy landscape in Quebec.

A great part of my ‘why?’ can be traced to the perceived power imbalance I experienced as my father’s caregiver vis-à-vis the medical establishment. Indeed, it is fair to say that at many times during the past few years, it certainly felt like we were being shunted aside—as if our voices were less vital, and carried less authority, than the medical professionals (or adjacent) who we were communicating with, despite the fact that we were the ones who had to deal with the very real consequences of the disease in a day to day fashion. Accordingly, the ‘why?’ of this thesis can be framed by my interest in this power struggle, and in my determination to understand if the ideas underpinning the QAP are in some way responsible for this power struggle and the pushing aside of our legitimate voices and concerns.

Importantly, an understanding of the framing ideologies in the QAP grants insight into how dementia is constituted as a problem (how it is problematized), how it is solved for, and who has the responsibility to do something about the problem—all of which helps one academically parse ideas of dementia policy and care in Quebec, in addition to granting

⁷ Verloo and Lombardo, 32

⁸ Ibid

individuals like me a little bit of insight into the big ideas that dominate this policy landscape in this context.

I have endeavoured to understand this story by conducting a Critical Frame Analysis of the QAP policy text. Through the application of key sensitizing questions, this analysis has unveiled a story that relies heavily upon biomedical framing, albeit with notable elements of the social model of disability. Particular emphasis is directly and indirectly put on the biomedical model of knowledge, in part stemming from the fact that the policy was created by medical professionals who are steeped in this knowledge philosophy. As such, it is only logical that their proposed solutions reflect their own ideological origins.

More globally, the story of dementia problematization in Quebec demonstrates that although the problems and solutions to dementia care are mostly seen through the prism of biomedical knowledge, a significant degree of awareness about the structural difficulties people living with dementia and caregivers face signifies elements of the social model of disability. Indeed, the policy acknowledges the importance of confronting societal barriers that make life more difficult for these target groups. The policy also acknowledges the importance of dignity for those living with dementia, which suggests the influence of the social model of disability.

Ultimately, the biomedical lens through which the QAP is largely seen has lasting consequences on the policy instruments and solutions offered, effectively edging out alternative framing perspectives, such as the social model of disability. It is for this reason that when I consider the framing of this policy, I return to the ‘why?’ of this thesis; that is, why study the framing of the QAP? This work is greatly motivated by my own personal experiences with the Quebec dementia care landscape. My research bears out a larger theme that I have experienced in my own life: that the expertise and value of biomedical voices is often prioritized above the voices of people living with dementia and their caregivers. This work echoes my own experiences in demonstrating that the framing of the QAP as being predominantly biomedical has consequences for the different stakeholders involved in dementia problematization, frequently granting significant voice and authority in decision-making processes to medical professionals over people living with dementia and their family members.

CHAPTER 2: LITERATURE REVIEW

FRAMING KNOWLEDGES: THE MORAL, SOCIAL DISABILITY, BIOMEDICAL AND NEOLIBERAL MODELS

To set the stage for a clearer understanding of the Quebec Alzheimer Plan and its inherent framing devices, consider the key knowledges that are essential to understanding the current dementia policy landscape. These knowledges include, but are not limited to, the moral model of disability, the biomedical model, the social model of disability, the Marxist model, as well as the neoliberal or austerity model. These knowledges make it possible to understand how the problem of dementia can be constituted, thereby granting further clarity on how dementia policies, including the Quebec Alzheimer Plan, are framed.

Neurodegenerative diseases, including different forms of dementia and Alzheimer's disease, are by and large misunderstood and stigmatized diseases. Mythologized to a great extent⁹, the mere mention of the word 'dementia' tends to conjure images of suffering and genetic inevitability in the popular imagination.¹⁰ Despite these popular imaginings, recent scientific advances have uncovered that dementia is a much more nuanced disease than previously believed to be. The contemporary scientific consensus is that dementia is a neurodegenerative disease which "impairs memory, thinking, mood and problem solving"¹¹ over a period of several years. Risk factors for dementia may include, but are not limited to, poor nutrition, head trauma, social isolation, smoking, alcohol abuse, inflammation, stress¹², and genetic inheritance.¹³ While dementia is frequently presumed to be a disease of old age, it is now generally accepted that age is but one risk factor among many that is associated with the disease.¹⁴

Although it is now culturally and scientifically understood that dementia is an illness like any other, a historical look back at dementia reveals a murky past. Sadly, there is a dark history to disability and dementia ideologies which goes a long way in explaining the evolution of our contemporary framing knowledges, necessarily circumscribing how we have come to understand disabilities and illnesses. According to Stephen Bunbury, this legacy begins with the moral model of disability. The moral model demonstrates that, in the past, "disability [was seen as] a direct consequence of sin or fault."¹⁵ In other words, a person's moral inadequacy or failing provokes divine punishment in the form of disease. The logical corollary of this is that the burden of blame is placed squarely on the shoulders of the disabled.¹⁶ If disability is the result of some inherent personal fault, it thereby follows that the afflicted person is undeserving of help or support. Bunbury holds that this historical narrative contributes to the long-held and persistent legacy of negativity associated with disability.¹⁷ Although this paradigmatic model has largely fallen out of favour, it is worth noting that there are still some pockets of global society that maintain this

⁹Sherzai and Sherzai, 11

¹⁰ Sandberg and Ward, 2

¹¹ Sherzai and Sherzai, 19

¹² Sherzai and Sherzai, 18

¹³ Sherzai and Sherzai, 21

¹⁴ Sherzai and Sherzai, 27-28

¹⁵ Bunbury, 28, citing McTigue, 2010

¹⁶ Bunbury, 28

¹⁷ Ibid

perspective. By way of example, Marno Retief and Rantsoa Letšosa highlight the ways in which some contemporary interpretations of Christianity have left people with disabilities maligned and outcast in their respective communities and homes. According to the authors:

“The devastating influence of... the moral and/or religious model of disability... highlight[s] how some forms of Bible interpretation exclude PWDs [people with disabilities] by directly or indirectly equating “blindness”, “lameness”, “deafness”, “uncleanness” (chronic illness), mental illness (demonic possession), and other forms of disability . . . with human sin, evil, or spiritual ineptitude.”¹⁸

The notion that sin and disability are tied, and that a person with a disability is somehow deserving of their illness, is deleterious in that it places further strain on populations who are already vulnerable. This model exposes the stark reality that disabled people, due to their maligned status, can be relegated to the peripheries of society, thereby limiting their access to healthcare and support. In extreme cases, belief in this model can lead to tragic outcomes, such as abandonment and infanticide.¹⁹ Faith in this model necessarily creates obstacles for those living with dementia, singling them out as being deserving of their illness at a time when they are at their most vulnerable and in need of family and community support and care.

While the moral model has existed for centuries, the most ubiquitous and transformative model of the last century is undoubtedly the biomedical model. This model finds its philosophical roots well over four hundred years ago, with ideas developed by the likes of René Descartes and Sir Isaac Newton.²⁰ Broadly speaking, biomedical knowledge is based upon science, medicine and solution finding. According to Mbh Jerome Tosam, the main tenets of the biomedical model can be characterized as such:

“All illnesses and all symptoms and signs arise from an underlying abnormality within the body...referred to as a disease; all diseases give rise to symptoms, eventually if not initially, and although other factors may influence the consequences of the disease, they are not related to its development or manifestations; health is the absence of disease; mental phenomena, such as emotional disturbance or delusions, are separate from and unrelated to other disturbances of bodily function; the patient is a victim of circumstance with little or no responsibility for the presence or cause of the illness; the patient is a passive recipient of treatment, although cooperation with treatment is expected.”²¹

This model has irrefutably concretized our modern understanding of what it means to be ill or to have a disease. Amongst other things, it has not only solidified how diseases are diagnosed, but it has equally outlined key power dynamics, circumscribing that the role of the doctor is active while the role of the patient is passive. Whereas the patient remains a victim of fate, the doctor is placed in a position of authority wherein “medical professionals... [are] tasked with the job of rectifying or curing the impairment.”²² While the biomedical model has been extraordinarily successful in helping medical science achieve spellbinding discoveries and scientific advancements, such as in

¹⁸ Retief and Lesosa, 2

¹⁹ Ibid

²⁰ Tosam, 132

²¹ T.D. Wade and P.W. Halligan, Mbh Jerome Tosam, 132

²² Bunbury, 28

the case of fighting infectious diseases,²³ where the biomedical model struggles is on the interpersonal front. Perhaps one of the biggest double-edged aspects of this model is that it encourages medical professionals to view the patient in mechanistic terms; it is the faulty ‘part’ that is treated, rather than the whole person (as a harmonious, interconnected system). This allows a doctor to zoom in on the problem area to great effect, though critics note that it encourages a dismissal of more holistic or all-encompassing perspectives, ones that acknowledge the vital role that emotional, psychological, cultural and environmental considerations have to play on disease.²⁴ Additionally, the propensity to overlook emotional and psychological considerations stems from how medical professionals are trained; the biomedical model fosters and rewards distanced assessments of patients. This metaphorical chasm that exists between a doctor and their patient can reinforce the mechanistic view of the patient, which has been shown to potentially limit a medical professional’s understanding of their patient’s illness, creating a passive, disengaged, disempowered agent out of the patient.²⁵ Despite the miraculous advancements this model has produced, it has not come without pitfalls. As pertaining to people living with disabilities, particularly in cases relating to their treatment and daily support, the biomedical knowledge standpoint can result in the “patroniz[ing] or pity[ing] [of] the disabled person,”²⁶ particularly given that biomedical knowledge seeks to solve *for* the disability, as opposed to working *with* the person living with the disability. The mechanistic aspect of this model results in a hyper-focused narrowing in on the problem, sometimes at the expense of the whole person, disregarding key aspects of the patient’s physical, emotional, psychological and even spiritual personhood. With respect to dementia, Ward and Sandberg note that the “biomedical paradigm continues to cast a long shadow over the field,”²⁷ blurring the epistemological considerations required for good health. They highlight how though it is taken for granted that biomedical knowledge “is cast as value-free, a medical fact that supposedly transcends time and place,”²⁸ this is empirically untrue. In fact, biomedicine can be associated with many values, the primary one, of course, being that the “dominant goal is cure... not care.”²⁹ Because value is placed on cure, dementia is rendered a “health responsibility” as opposed to a social or societal responsibility, thereby potentially leaving those with dementia “out of broader analyses of disability and ageing.”³⁰ Thus, if one subscribes to this knowledge model, the compounded effect is that dementia is something to be cured and medicated, and not something to live with, further devaluing the lived experiences of people with dementia, and equally limiting their care options.³¹ Additional criticisms of biomedicine point to the historical exclusion of voices in the biomedical model, with women and women’s knowledge consistently overlooked and excluded. Critics argue that this has resulted in a longstanding imbalanced approach to medicine.³² This exclusion further suggests that those who are tasked with treating people with dementia are operating in a more limited framework than previously thought.

²³ Hosein Abidi, 18

²⁴ Tosam, 133-134

²⁵ Hewa and Hetherington, 134

²⁶ Bunbury, 28

²⁷ Ward and Sandberg, 3

²⁸ Ward and Sandberg, 2

²⁹ Ibid

³⁰ Ibid

³¹ Grenier and Phillipson, 122

³² Mji, 75-76

The biomedical model also has implications for policy development. By virtue of a doctor's training, they are conferred with "a sense of correctness, authority and superiority in which 'the doctor knows best.'"³³ According to Patrick Marier, doctors are granted voice and power through the biomedical model. As he states, the biomedical model:

"Examines how human problems become medicalized and how this process represents a tool of social control, wherein the medical profession exerts paramount influence by organizing and delivering treatments, thereby defining the process known as medicalization or biomedicalization."³⁴

The power and influence that medical professionals exert also elevates their voices in the policy realm. Marier further explains that "the professional status of medicine confers a privileged space within the policy process to medical personnel... as opposed to community and social services [personnel]."³⁵ This favouring of the voices and paradigms upheld by medical professionals over community and social services and members, as well as over those living with dementia, has clear implications for policy development. In light of the fact that the biomedical trope is sewn into the very fabric of medical policies, it thus becomes imperative to measure for its impact.

Yet another vital framing knowledge to consider when assessing dementia policy is the social model of disability. This model emerged in the 1960s as a reaction to the biomedical model.³⁶ According to Uta Gerhardt, the social model of disability "focus[es] on the social determinants of health and illness."³⁷ It understands that people are not separate from their environments, and that a person's health has a symbiotic relationship with the environment in which they live. The social determinants of one's environment include factors such as: work-life balance, the health and strength of public institutions, social mores and practices, and environmental pollution.³⁸ Unlike the biomedical model in which the source of the problem is located within the individual's body,³⁹ the social model of disability "locates [the] problem in discriminatory social structures."⁴⁰ The source of any problematization is thus found in the inherent injustice within social structures which lead to particularly inequitable treatment of disabled people.

Disability can be a nebulous concept to define due to shifting scientific interpretations and public narratives. Nevertheless, a clear definition is required in order to understand just 'who' is disadvantaged by inherent injustices in social structures. Lisa I Iezzoni provides the simplest definition, in which she describes how people living with a disability "share one common element: persons with disabilities perform basic human functions—such as seeing, hearing, speaking, moving, thinking, and emoting—in different ways than do other persons."⁴¹ This demarcates the abled from the disabled in that their capacity to do something is somehow altered or limited. As

³³ Putsch and Joyce, quoted in Tosam, 142

³⁴ Marier, 34

³⁵ Marier, 36

³⁶ Bunbury, 29

³⁷ U. Gerhardt, 1989 as quoted in Hosein Abidi, 19

³⁸ Abidi, 19

³⁹ Mathews, 151

⁴⁰ Ibid

⁴¹ Iezzoni, 4

applied to people living with dementia, Tom Shakespeare explains that although “dementia and disability seem like ‘planets spinning on different axes’... these planets are aligned.”⁴² For those who are living with dementia, their ability to think, speak and emote can be limited or altered to varying degrees over the course of their lifetime, thereby placing them firmly in the category of ‘disabled.’ This labelling and often consequent discrimination has implications for the medical experiences of patients, including for people living with dementia (an undeniably medicalized disability).⁴³ One particular concern that this population faces is that they are “much more likely than others to experience sub-standard health care.”⁴⁴ This outcome can be attributed to poor communication between doctors and patients, as well as both physical and attitudinal barriers to health care access.⁴⁵ Another challenge, as explored by Pat Hobson, is the difficulty that people living with dementia have in receiving quality care. In evoking Kitwood’s work on Malignant Social Psychology (MSP), Hobson demonstrates how those who are living with dementia in assisted living facilities face a slew of behaviours that demean their personhood and agency. She equally demonstrates “the seriousness of malpractice in dementia care”⁴⁶ that can exist in care facilities. Some of the behaviours that are responsible for demeaning the core or essence of the humanness of the patient include ‘treachery’, ‘disempowerment’, ‘infantilization’, ‘withholding’, ‘objectification’ and ‘infantilization’.⁴⁷ Iezzoni suggests that this mistreatment can be partly explained by the fact that the disabled, and thereby those living with dementia, are not always viewed as complete humans; they can be perceived as lesser humans, or perhaps specters of their former selves.⁴⁸

Understandably, it is no wonder that adherents to the social model of disability strive to fight back against the dominant biomedical model. Recent activists have sought to change the conversation surrounding disability and dementia to mitigate discriminatory practices. Pia Matthews highlights how organizations such as the Alzheimer Society are attempting to change the tenor of the conversation to one which better supports those who are *living* with dementia.⁴⁹ Specifically, the hope is to shift the narrative to *living well with dementia* (as opposed to merely living), and in so doing “highlight the significance of human rights and dignity.”⁵⁰ The Alzheimer Society further remarks that with both governmental and institutional support, people living with dementia could easily lead fulfilling, happy lives.⁵¹ Karen A Hyman suggests that because the ‘psychosocial experience’ of dementia requires more social and environmental support than the biomedical perspective allows for,⁵² stances such as those taken by the Alzheimer Society are potentially much better suited to helping people live with dementia. In the same vein, activists such as Daithi Clayton aim to change the way society understands dementia. Daithi Clayton’s work specifically centers on the difficulty of attaining access to healthcare as a queer person living with dementia. Their work pinpoints the difficulties experienced in trying to find medical professionals

⁴² Shakespeare, Zeilig and Mitler, quoted in Matthews, 152

⁴³ Marier, 34

⁴⁴ Iezzoni, 11

⁴⁵ Iezzoni, 13-14

⁴⁶ Hobson, 5-7

⁴⁷ Hobson, 5-7

⁴⁸ Iezzoni, 4

⁴⁹ Matthews, 150

⁵⁰ Matthews, 163

⁵¹ Matthews, 154

⁵² Lyman, doi: 10.1093/geront/29.5.597

that are supportive of both their identity and of their illness.⁵³ Clayton furthermore highlights that their journey has been through ups and downs in the search of the kind of quality of care that they want as a queer, non-binary person who is also living with dementia, searching for the kind of care that resolutely keeps them in the role of “the orchestrator, not only of the end of my life, but my entire fabulous life.”⁵⁴ Clayton’s work reminds us that exercising agency over one’s own life is no small feat in a world which frequently equates disability with incapacity. Quite contrary to the biomedical model which would see a doctor taking “ownership of the ill body part in an attempt to cure it,”⁵⁵ the social model of disability engenders an awareness of the social injustices that create obstacles for the disabled person, and seeks to rectify both the injustices and the obstacles.⁵⁶

Another model to consider is the Marxist model. According to a Marxist approach, the notion that some people are identified as ‘normal’ and others are not, is further exacerbated by capitalism.⁵⁷ Due to the onset of industrialization, it was determined that if a disabled person could not partake in the modern economy, “they ha[d] no use in society.”⁵⁸ This commodification of the person further pushes disabled people into the peripheries of society, denying them any social or economic sense of utility. From a capitalistic perspective, this commodified-induced state can be resolved if some kind of ‘medical intervention’ is successfully pursued to remedy the person of their disability, subsequently allowing them to be reintroduced into the workforce.⁵⁹ Invariably, this paradigm demonstrates society’s obsession with ensuing cross-societal workforce productivity, pointing out that a capitalistic society places ultimate importance on human productivity.

Also related to the economy, the neoliberal (or austerity) model has a crucial role to play in how disability and dementia are viewed, including in the policy realm. Evidence suggests that the neoliberal model has had a significant impact on the development and curtailing of health outcomes for those with disabilities, including those with dementia. Jessica Polzer and Elaine Power outline how the responsabilization of health outcomes of the disabled mirrors a neoliberal turn in healthcare provision.⁶⁰ More specifically, they state: “neoliberal approaches to social policy favour a model of citizenship in which individuals are expected to demonstrate their duties to maintain their health through their own ‘free choices’ and ‘informed decisions.’”⁶¹ This amounts to shifting costs to the individual, making them responsible for contending with their health outcomes. For those living with dementia, this can have several implications. On the individual level, dementia activists like Helga Rohra note how her early diagnosis of Lewy Body dementia at age 54 illuminated how “there was no post-diagnosis support at all for people diagnosed at younger ages.”⁶² If structural care existed, it did so only for those whom were older and in need of more immediate care and intervention.⁶³ Steele et al. explain that the neoliberal context turns the

⁵³ Clayton, 16

⁵⁴ Clayton, 18

⁵⁵ Tosam, 137

⁵⁶ Matthews, 151

⁵⁷ Bunbury, 28-29, citing Terzi, 2004

⁵⁸ Ibid

⁵⁹ Bunbury, 29, citing Terzi, 2004

⁶⁰ Polzer and Power, 4

⁶¹ Ibid

⁶² Rohra, 32

⁶³ Ibid

bodies of disabled people into “sources of economic extraction.”⁶⁴ Care is structured around increasing corporate profits, a goal which does not necessarily overlap with helping disabled people live easier (more accessible, joyful) lives. On an individual level, it would seem that the cries of those with disabilities seeking structural aid go unheard in a neoliberal context. Activists like Rohra who live with dementia have seen her own pleas of “see me as a person!”⁶⁵ fall on deaf ears when profit is the major motivator under a neoliberal paradigm. On a macro level, the neoliberal model can lead to cost-cutting measures which “have resulted in a failure to recognize the personhood and rights of both people with dementia and their care partners.”⁶⁶ By way of example, consider how the Covid-19 pandemic illuminated the de-prioritization of people living with dementia in health systems, particularly in neoliberal socio-economic contexts. Dementia scholars highlight the ways in which the Covid-19 pandemic underscored the vulnerability of people living with dementia in a time of austerity, demonstrating how many of the deaths that occurred in the first year of the pandemic were attributable to people who had been living with dementia. Additionally, and most upsettingly, this population experienced other “privations” in the form of less social contact and being bottom tier with respect to triage care.⁶⁷ When looking at this model with clear eyes, it is no leap of logic to see how the neoliberal model has the potential to delimit who is worthy of medical services, who is worthy of contributing to society, and ultimately who is worthy of living and dying.

Altogether these knowledge models play a role in the development of any given dementia policy as they form the basis of knowledge upon which a ‘problem’ and its solutions might be understood and constructed. With respect to dementia policy development, the collective knowledge at the disposal of policy makers is the very same knowledge which has been built up over the past few hundred years, but with the particularly important developments in the form of biomedical and social disability paradigms over the last century or so. While ideas pertaining to disability and dementia have certainly changed significantly over time—beginning with disability being perceived as a moral failure, to today’s understanding of dementia being the combined result of several health risk factors, to biomedicalization’s notion of curing the malfunctioning part over treating the whole person in their environment—these ideas have contributed to the pool of knowledge which can be used to construct contemporary ideas of what it means to be living with dementia, and thereby equally how dementia is both problematized and solved for in policy making context.

⁶⁴ Steele, Phillipson, Swaffer and Fleming, 155

⁶⁵ Rohra, 32

⁶⁶ Ward and Sandberg, 6

⁶⁷ Ward and Sandberg, 1

CHAPTER 3: FRAMING AND RE-FRAMING: LITTLE OLD ME AND THE BIG, BAD NEPHROLOGIST

February 2024.

Sometimes understanding comes from the most unexpected of places. This is the story of how I unexpectantly, and quite viscerally, learned about the true impact of medical ideas on people. On me, to be more precise.

For someone who had spent months by this point thinking about policy framing, you might think I had a heretofore better understanding of what biomedical framing entails. Actually, maybe this isn't really me being fair to myself. I had understood what biomedicalization meant, what it implied, but I understood it in that academic way that we are trained to understand a concept. It is similar to how you understand that vegetables are good for you and fried Cheetos are bad for you, but you don't *really* get it until you're bent over the toilet bowl throwing up, regretting ever having had the cockamamy idea to deep fry Cheetos. Disclaimer: For the record and sake of levity, no Cheetos were harmed in the making of this thesis. But lots of food did make me very sick.

It was Saturday February 3rd, at 4:36 am when I really started to get what this paradigm can mean for us average, non-medical practitioner folk. Two days prior, quite unsuspectingly, I had gotten the news that I was sick. I had known that something was wrong—what with being unable to eat, body parts blowing up, and the instinctual urge to not even drink water lest I throw up again—but I didn't realize I was *sick* sick. I had actually thought that things were getting better, now that my also new thyroid condition was diagnosed and treated.

But February 1st was to be a horrible day no matter how I sliced it. On this day I placed my dad into his new forever home in the morning (which was not a particularly joyful experience), and then directly after that I had an appointment with a nephrologist of all things. I didn't even really know what the word meant until I had looked it up. But on this day, February 1st, more life challenging moments were to come my way. So it came to pass that not only were my health issues not improving, they were in fact getting worse. The first words that came out of this new doctor's mouth were actually: "Oui, vous avez une maladie néphrotique très sérieuse. Il faut régler ça tout suite." Quoi? Come again? *A what?* To say that my heart dropped into my stomach would be to underestimate how instantaneously heartbroken I was. Me? The girl who was never sick as a kid? Who spent her hours teaching germ-laden students and didn't catch their colds? The woman who never broke a leg, never fell out of a tree, never got scraped up gym class? The worst that had ever really happened was a really bad bout of strep throat once when I was finishing off grade 6, which required a round of antibiotics for a few weeks.

My gentle life experiences re health had left me a little too cavalier to understand the vastness of what was about to hit me.

He began his speech. No sugar coating. No fluff. Directly to the good stuff. Inject it right into my veins, why don't you.

Apparently my constellation of symptoms had led my nephrologist (a kidney specialist, for the lucky uninitiated) to confidently state that I had a serious kidney disease, and *do you have a*

wasn't eating because nothing would stay down.) Up until this point in his stats reading you still think you're getting out of this appointment with vitamins for your mystery syndrome. You don't know what you don't know yet. And then there's this major track shift. The doctor's body's language changes. His tone changes. You realize that the doctor has been building up to a punchline, that his secret-doctor-number-code reveals that apparently you have a grave kidney disease. Your situation has been upgraded from a nephrotic syndrome to a kidney disease. Joy.

At 4:37am real-time you understand that this doctor has spent his entire professional life speaking in this code. And later on—because you can no longer sleep—you look up his online ratings and have your perception validated by the countless commentators saying he's big on numbers, not so big on people.

Back in his office he stops talking to you. He picks up the phone. You still have questions. You wait until he's off the phone to ask your questions, to inquire if you should worry. Is it time to panic? Does one panic when diagnosed with a kidney disease? I'm new to diseases, help a woman out.

He hangs up the phone. With a nod, he says: "Good luck, la petite." [Read: get out of my office, little girl, I'm busy.]

There is no time for your questions. He does not make room—make space—for your questions.

You leave.

At 4:37am you understand that when academics talk about biomedical framing, the real, sick, bent-over-the-toilet-bowl-throwing-up-from-fried-Cheetos-come-to-Jesus moment reveals that when confronted with the stoutest of biomedical converts, you are not you; you are to be treated as a collection of symptoms and medical indicators that are in need of medical interventions. You're not a person, you're a puzzle that needs solving. You're just a fleshy Rubik's Cube. With this guy... well, even Doctor House has more charm than this guy. Forget human considerations. Take your vitamins. Go to the hospital. No bread. No cheese. No rice. No alcohol. No cigarettes. Ever. Again. You are told. No context. No humanity. You have your marching orders.

You belatedly wonder why you weren't asked...

... if you're stressed.

... if you're tired.

... if you're in need of help.

You're not asked anything remotely like this. You're not given the space to ask your own questions.

Good luck, la petite. Godspeed.

At 4:57 am you think you've exercised your biomedical demons enough and might be ready to get a few hours of shut eye before going back to see your specialist. Again. Hopefully this time he 'humans' a bit more.

In retrospect I can say that I didn't hold my breath.

CHAPTER 4: CANADIAN HEALTHCARE AND THE QAP

4.1: HEALTHCARE IN CANADA

Having reviewed some of the key knowledges associated with the problematization of dementia, let us now briefly turn our attention to understanding health care in the Canadian and Quebec contexts. Canada being a federal union, the division of authority is clearly outlined in *The Constitution Acts, 1867 to 1982*. Specifically, according to the constitutional division of powers, re section 92(7), it is stipulated that healthcare is a provincial responsibility; in other words, the policy sphere of healthcare is within provincial purview.⁶⁸ However, Canadian federalism being the ever-increasingly complex jurisdictional quagmire that it is, renders untangling who is, in practice, accountable for what less clearcut. Although in the context of medical care the provinces are the main jurisdictional authority, as André Picard explains, the federal government does nevertheless have a considerable role to play in this *enjeu*. This is particularly true in terms of the power of the purse. In point of fact, the federal government's funding capacity, as expressed through budgetary transfers such as the Canada Health Transfer, results in significant financial and legislative contributions to the healthcare outcomes of Canadians in all provinces. The Canada Health Transfer in particular accounts for 20% of federal spending,⁶⁹ or about the equivalent of about \$40 billion per year.⁷⁰ The proverbial catch, however, is that this funding hinges on provincial jurisdictions accepting a federally established criteria as outlined in the Canada Health Act (1984). This Act endeavours to maintain overarching standards or a guaranteed level of quality that the provinces must ensure in order to qualify for this federal transfer funding. Thus, to not accept these criteria is to forgo the financial support (thereby calling into question the jurisdictional authority of the provinces over healthcare). Nevertheless, the established criteria do serve a purpose, and they primarily focus on the following components: the transparency of public administration; accessibility; comprehensiveness; universality; and finally, portability.⁷¹ It is ultimately incumbent upon the provinces' to set up the more tailored and specific policies pertaining to healthcare that meet these criteria.

With respect to dementia policy, both the federal government and several provincial jurisdictions have developed pertinent policies. The federal government, for instance, proposed an umbrella strategy on dementia in 2019 entitled *A Dementia Strategy for Canada: Together We Aspire*. This policy aims to improve the quality of life for those living with dementia by:

“Prioritiz[ing] quality of life for people living with dementia and caregivers... respect[ing] the human rights of people living with dementia...engag[ing] in evidence-informed decision making, taking a broad approach to gathering and sharing best available knowledge and data.”⁷²

According to André Picard, this strategy is theoretically top notch, but as he suggests it still remains to be seen whether it will be given the requisite funding and political support required to

⁶⁸ Government of Canada, access date: November 5th, 2023, URL: <https://laws-lois.justice.gc.ca/eng/const/page-3.html#h-19>

⁶⁹ Picard, 63

⁷⁰ Picard, 173

⁷¹ Picard, 38-39

⁷²Public Health Agency of Canada, X

really bring it to life.⁷³ Notably, while this strategy acts as more of an overarching guideline, providing “broad guidance to dementia research and care and support funding, the main work [is to] be done by the provinces and territories.”⁷⁴ In other words, given the federal nature of Canada, it is the provinces that are expected to deliver on the concrete actions required to effect dementia care planning. Some of the more dynamic existing provincial plans include, but are not limited to: *The Provincial Guide to Dementia Care in British Columbia (2016)*; *Ontario’s Investments in Dementia Care in the Community (2018)*; and Quebec’s *Meeting the Challenge of Alzheimer’s Disease and Related Disorders A Vision Focused on the Individual, Humanism, and Excellence*⁷⁵ (2009 expert report).⁷⁶

In contextualizing how federalism impacts healthcare delivery, it is clear to see that while the federal government contributes both financially and in terms of establishing standardization criteria for health standards, the provinces nevertheless have both the authority and a significant amount of leeway in conducting legislative affairs as they see fit. In the next section, we will see how this applies in the Quebec context.

⁷³ Picard, 177

⁷⁴ British Columbia Law Institute, accessed: April 21st, 2023. URL: <https://www.bcli.org/an-overview-of-the-national-dementia-strategy/>

⁷⁵ Public Health Agency of Canada, 45

⁷⁶ Hereafter referred to as the Bergman Report, its alternate name.

4.2: DEMENTIA POLICIES AND QUEBEC

Globally, dementia is on the rise. According to the WHO, it is estimated that there are currently 55 million people worldwide living with dementia. Even more shockingly, about 10 million people are diagnosed with dementia each year.⁷⁷ In Canada, there are currently “more than 419, 000 Canadians aged 65 and older diagnosed with dementia, [not accounting for] those under the age of 65 with a diagnosis.”⁷⁸ This number is projected to increase twofold by 2030.⁷⁹ It is estimated that dementia care costs about \$604 billion dollars worldwide.⁸⁰ In Canada, the cost associated with dementia care reaches upwards of \$10.4 billion a year.⁸¹

Accordingly, jurisdictions have begun implementing policies to contend with the increasing number of citizens affected by this disease. In the Quebec context, the provincial government has implemented the Quebec Alzheimer Plan (QAP) to meet the diagnosis and care needs of citizens living with this illness. The QAP, implemented in 2009, is the main policy instrument through which neurocognitive diseases are to be detected, treated, researched and thought of.

Zooming in on the dementia context in Quebec, it is generally acknowledged that the province has been, and continues to be, a Canadian leader in developing and enacting dementia policy. According to Chow et al., a concrete dementia plans strives to “provide appropriate medical care for people with dementia. A government dementia plan is a policy whereby the national government holds itself accountable to carry out its state specific objectives and policy changes.”⁸² In this case, the Quebec government has chosen to pursue this task by implementing the Quebec Alzheimer Plan. This policy is of fundamental practical, academic and policy importance in that it touches broad swaths of society. Finding its genesis well over a decade before many of its Canadian counterparts,⁸³ in 2009 the Quebec government commissioned a group of doctors, spearheaded by Dr. Howard Bergman, to report on the status of the ‘problem’ of dementia. The resultant report that was produced would then go on to become the exact basis for Quebec’s current dementia plan. As pertaining to the backstory of this report, one must return to 2007. In that year, former Health and Social Services Minister (MSSS) Philippe Couillard brought forth a plan to invest more money and resources into dementia research and care. Couillard, formerly a neurosurgeon in both Quebec and abroad, oversaw many changes to the Quebec health policy context during his tenure as health minister and premier.⁸⁴ According to records found in the

⁷⁷ WHO, accessed: April 11th, 2023, URL: <https://www.who.int/news-room/fact-sheets/detail/dementia>

⁷⁸ Public Health Agency of Canada, accessed: April 11th, 2023, URL: https://www.canada.ca/content/dam/phac-aspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy_ENG.pdf, VI.

⁷⁹ Alzheimer Society, accessed: April 11th, 2023, URL: <https://alzheimer.ca/en/about-dementia/what-dementia/dementia-numbers-canada>

⁸⁰ Sherzai, 2-3

⁸¹ Alzheimer Society, accessed: April 11th, 2023, URL: <https://alzheimer.ca/en/about-dementia/what-dementia/dementia-numbers-canada>

⁸² Chow, Chow, Lam, Taylor, Bonin, Rowbottom, Lam, DeAbgelis and Herman, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6028171/>

⁸³ That is, well before the WHO policy (2017), the Canadian federal policy (2021), as well as the other Canadian provincial dementia policies.

⁸⁴ Assemblée Nationale du Québec, Accessed : August 23rd, 2023, <https://www.assnat.qc.ca/fr/deputes/couillard-philippe-5811/biographie.html>

(2007) Quebec Hansard (Journal des débats), Couillard proceeded to announce a plan which would benefit those living with dementia. In a press briefing he noted that two upcoming changes would take place: one would be increased funding for Baluchon Alzheimer, an organization which provides support to help families coping with the fallout of a dementia diagnosis; the second would be the development of a dementia policy, headed by the well-known Quebec geriatric specialist Dr. Howard Bergman and his team or “groupe d’action”.⁸⁵ Their objective would be to determine the ideal path for dementia testing, care, treatment and research.⁸⁶ According to records, this policy decision was made some time after dementia awareness month, at which prior point the government had insisted that there was enough care for those with dementia through pre-existing seniors’ plans. When a reporter inquired as to the sudden change in policy, Minister of Health Philippe Couillard responded:

“I would say it’s an increased degree of personal awareness... not because one member of my family is touched by the problem. It’s just because I have seen and heard so many testimonies of people affected directly or indirectly by this problem... and I recognize that, while we have I think a very good plan in general for dependent seniors, we must put a special emphasis on this question, and then other countries have done this... take France for example... M. Sarkozy announced that it would be his personal theme.”⁸⁷

While not definitive, this suggests that dementia was put on the agenda due to a change in opinion. Patrik Marier, in citing Cobb, Keith-Ross and Ross, explains that for a policy issue to be put onto the agenda “a problem must (1) garner significant attention, (2) be understood to require some sort of action, and (3) be on the radar of governmental officials.”⁸⁸ This government discourse suggests that some variation of these three requirements took place, leading to a change in policy interest. Or, in other words, that Couillard’s invigorated interest in dementia care prompted a policy shift.

Two years after this initial press briefing, the Bergman Report (May 2009)⁸⁹ was subsequently implemented into the fabric of the Quebec healthcare system under the name of the Quebec Alzheimer Plan (QAP).⁹⁰ Although the report offers much more specificity on what actions ought to be pursued in the form of seven priority actions and 24 recommendations,⁹¹ the government’s initial central focus since implementation has been on Priority Action 2: “provid[ing] access to personalized, coordinated assessment and treatment services for people with Alzheimer’s and their family/informal caregivers.”⁹² This action is based on the collaborative care model, in which doctors “are responsible for detecting, assessing, and following people living with dementia in a family medicine group.”⁹³ Other health professionals in the Family Medicine Group (FMG/GMF), including nurses, pharmacists and social workers, are equally involved in the

⁸⁵ Later in the text referred to as the “Committee of Experts”.

⁸⁶ Assemblée Nationale du Québec, Accessed : August 2023, <https://www.assnat.qc.ca/en/actualites-salle-presse/conferences-points-presse/ConferencePointPresse-3317.html>

⁸⁷ Ibid

⁸⁸ Cobb, Keith-Ross and Ross cited in Marier, 52

⁸⁹ Bergman, 2009

⁹⁰ ROSA, accessed March 2023, URL: https://www.healthcareexcellence.ca/media/doeexyox/final-5-policy-brief-format-long_en-final-ua.pdf

⁹¹ Healthcare Excellence Canada, 1

⁹² Ibid

⁹³ Ibid

distribution of care coordination under this policy.⁹⁴ Of note, in practice, less initial focus had been paid to the other priority actions, such as the “promot[ion of] quality of life and provi[sion of] access to home support services and a choice of high-quality alternative living facilities... treat[ing] family/ informal caregivers as partners who need support... [and] raising awareness, inform[ing] and mobiliz[ing].”⁹⁵ According to Arsenault-Lapierre et al., in 2011 this was updated when the MSSS decided to put all priority actions into effect, now that the initial focus on fast access to evaluation and personalized primary care had been concretized and set into motion.⁹⁶

In a span of four years, the Quebec government had nominated specialists to tackle the problematization of dementia, had agreed to the findings and pathways laid out in the expert report published by Dr. Howard Bergman and his team, and had begun implementing the priority actions found within the QAP. While the initial focus had been on providing evaluation and diagnosis within the primary care sector of the FMGs, as of 2011 all priority actions have been put into effect to some degree of overall operability.

⁹⁴ Healthcare Excellence Canada, 2

⁹⁵ Ibid

⁹⁶ Arsenault-Lapierre, Godard-Sebillotte, Sourial et al., URL: <https://www.cairn.info/revue-sante-publique-2020-4-page-375.html>

4.3: THE QAP POLICY: THE NITTY GRITTY

The Quebec Alzheimer Plan, or “Meeting the Challenge of Alzheimer’s Disease and Related Disorders: A Vision Focused on the Individual, Humanism, and Excellence” is a document of 137 pages, written and spearheaded by Dr. Howard Bergman, co-written with his team of ‘Committee of Experts’, at the behest of the Quebec government.⁹⁷ Initially, this policy was a report commissioned in 2007 by then Minister of Health, Philippe Couillard.⁹⁸ This report was subsequently adopted in its entirety as a health policy and written into the fabric of the Quebec healthcare system.⁹⁹

The policy can be broken down into constituent units. The most concerning for this thesis analysis includes the following: the Foreword; the Executive Summary; Section 1: Alzheimer’s Disease and Related Disorders: A Major Public Health Problem; Section 2: Major Achievements and Challenges for Quebec; Section 3: A Societal Approach Centered on the Individual, Humanism, and Excellence; Section 4: Priority Action 1 Raise awareness, inform, and mobilize; Priority Action 2: Provide access to personalized, coordinated assessment and treatment services for people with Alzheimer’s and their family/informal caregivers; Priority Action 3: In the advanced stages of Alzheimer’s, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities; Priority Action 4: Promote high-quality, therapeutically appropriate end-of-life care that respects people’s wishes, dignity, and comfort; Priority Action 5: Treat family/informal caregivers as partners who need support; Priority Action 6: Develop and support training programs; Priority Action 7: Mobilize all members of the university, public, and private sectors for an unprecedented research effort; and finally, the Conclusion.¹⁰⁰

The *Foreword* of this document outlines the main players and objectives of the policy. The first highlight of this section outlines that the plan was established at the behest of the Quebec Ministry of Health and Social Services (MSSS) in 2007 to have a group of experts convene to discuss a plan of action for caring for people with various forms of dementia throughout Quebec.¹⁰¹ This committee was given the specific mandate to “cover all aspects of this subject, from research and prevention to end-of life care.”¹⁰² Aside from committee members, relevant specialists, organizations and individuals with dementia and ageing expertise were consulted.¹⁰³ The Foreword also acknowledges the importance of “forging ties” with experts in different political jurisdictions which have undertaken the task of working on dementia policies.¹⁰⁴

Section 1: Alzheimer’s Disease and Related Disorders: A Major Public Health Problem outlines foundational information about dementia and how it pertains to the Quebec context. It

⁹⁷ Bergman, 2009

⁹⁸ Assemblée Nationale du Québec, Accessed August 23rd, 2023, <https://www.assnat.qc.ca/fr/deputes/couillard-philippe-5811/biographie.html>

⁹⁹ ROSA, Accessed: March 2023

¹⁰⁰ Bergman, iii

¹⁰¹ Bergman, iv

¹⁰² Ibid

¹⁰³ Ibid

¹⁰⁴ Ibid

clarifies that dementia is a type of neurodegenerative disease, of which Alzheimer's is but one subtype.¹⁰⁵ It further explains that dementia is increasingly a source of anxiety for many Canadians, but that dementia remains vastly stigmatized and misunderstood.¹⁰⁶ Moreover, it is estimated that 20% of baby boomers will develop Alzheimer's. Nevertheless, the authors caution that dementia is not an inevitable or so-called normal aspect of ageing.¹⁰⁷ Another important theme of this chapter is that of the impact that neurodegenerative diseases have on society. Alzheimer's is recognized as "one of the main causes of disability among elderly people in high-income countries."¹⁰⁸ Relatedly, the impact on their families is heavily felt. Families bear the brunt of caregiving, with "women, most of them elderly, act[ing] as informal (nonprofessional) caregivers."¹⁰⁹ Consequently, caring for a loved one with dementia is often "a major source of psychological and social exhaustion. It has major effects on caregivers' health and financial status."¹¹⁰ Additionally, Alzheimer's and related dementias puts "tremendous pressure on the health care system and on society, [with] ... up to 80% of the people living in Québec's residential and long-term care centres (CHSLDs) hav[ing] Alzheimer's."¹¹¹ The cost associated with dementia in Canada was estimated to be 5.5 billion in 2000, not accounting for "the considerable indirect costs, particularly in the form of lost income for family caregivers, who often have to shorten their work weeks or use vacation days to care for their loved ones who have Alzheimer's."¹¹² Finally, this chapter emphasizes that dementia is a growing concern both domestically and internationally, requiring immediate attention, funding and action.¹¹³

Section 2: Alzheimer's Disease and Related Disorders: Major Achievements and Challenges for Québec begins by underscoring recent achievements related to dementia in Quebec, particularly with respect to some "innovative solutions" that have been enacted, including pilot projects for people with cognitive difficulties in some health and social service centers (CSSSs); the opening of special outreach clinics; and the expansion of coverage of key community organizations, such as the Alzheimer society, in providing much needed services like respite and daycare services.¹¹⁴ This section also notes that Quebec has made considerable progress vis-a-vis "research into age-related cognitive impairment, and particularly into Alzheimer's disease and related disorders, represents one of the 'poles of excellence' of health research in Québec."¹¹⁵ However, Quebec still faces a few particular challenges en route to developing access and quality of care for people living with dementia, specifically with respect to carrying out "structural initiatives" related to the stigmatization of Alzheimer's; improving access to coordinated health services; improving overall quality of care in and out of long-term care facilities; training; and research.¹¹⁶

¹⁰⁵ Bergman, 1

¹⁰⁶ Bergman, 1-2

¹⁰⁷ Bergman, 2

¹⁰⁸ Bergman, 3

¹⁰⁹ Ibid

¹¹⁰ Ibid

¹¹¹ Bergman, 4

¹¹² Ibid

¹¹³ Bergman, 5-6

¹¹⁴ Bergman, 7

¹¹⁵ Bergman, 8

¹¹⁶ Bergman, 9

Section 3: A Societal Approach Centered on the Individual, Humanism, and Excellence emphasizes that the committee bases all their recommendations on a philosophical approach that is cemented in humanistic values and excellence, of which dignity is of the utmost concern.¹¹⁷ To ensure this, the committee emphasizes that it is imperative to base their work on academic research, coupled with involving key “players and resources includ[ing] the public health and social services system, private resources, not-for-profit organizations, advocacy and service organizations, universities (including university research settings), and private businesses.”¹¹⁸

Section 4: Priority Actions outline the main goals and recommendations of the Quebec Alzheimer Policy. The objective of this section of the policy is to clearly relate expert-identified trouble zones associated with dementia care in Quebec and provide innovative solutions in the form of recommendations.

Priority Action 1: Raise awareness, inform, and mobilize is designed to demonstrate where the information gaps in dementia awareness are and how to resolve them. First order of business is tackling societal ambivalence and the stigmatization of Alzheimer’s and dementia in the general population, particularly in terms of addressing:

“Defeatist attitudes regarding Alzheimer’s disease [which] are common among professionals as well as the general public. This is especially so with regard to assessment, treatment, and approaches to helping people with Alzheimer’s and their families.”¹¹⁹

Thus, the first objective of this section is to promote individual, institutional and societal understanding of dementia and its impacts on those living with the disease and their family members, in addition to raising awareness about dementia prevention. Accordingly, the policy recommends that the Quebec Ministry of Health and Social Services, in conjunction with the Quebec Alzheimer Society, other key ministries, academic institutions, and the private sector “develop and implement a strategy for raising awareness, disseminating information, and mobilizing resources to meet the challenges posed by Alzheimer’s disease.”¹²⁰ Furthermore, the policy also recommends the Quebec Public Health Service develop a plan to increase the public’s awareness over dementia prevention and risk factors.¹²¹

Priority Action 2: Provide access to personalized, coordinated assessment and treatment services for people with Alzheimer’s and their family and/or informal caregivers is, in many ways, the most instrumental element of the QAP. This section acknowledges that one of the major issues that people living with dementia, and accordingly their families, face is accessing the kind of care required for helping someone living with dementia to live with dignity. Limited access applies particularly to receiving appropriate clinical services, including diagnosis, as well as a limited access to “interventions for treatment and management of the behavioural and psychological symptoms of dementia (BPSD).”¹²² The policy also notes limited access in the forms of psychosocial and crisis services, which are of the utmost importance to both patients and their

¹¹⁷ Bergman, 10

¹¹⁸ Bergman, 11

¹¹⁹ Bergman, 12

¹²⁰ Bergman, 13

¹²¹ Bergman, 14

¹²² Bergman, 16

caregivers.¹²³ Contributing factors to these limited services include stigma over dementia, the complexity of the disease, inadequate training of health professionals, inflexible healthcare infrastructures, lack of coordination of services, and a lack of specialized services, particularly in non-urban regions.¹²⁴ Accordingly, this section of the policy seeks to rectify these limitations by restructuring how healthcare is delivered to dementia patients and their caregivers by empowering medical professionals in Family Medicine Groups (FMGs) through the collaborative care model. The main prongs of this approach include coordination between doctors, nurses, patients and family members in diagnosing dementia and delivering care and services over a sustained period time. Moreover, a designated nurse will act as a care navigator, following up with family and patient to ensure all is running smoothly.¹²⁵ This chapter also places a role for cognition clinics and integrated university health networks to improve through a variety of institutional, organizational, research and funding tweaks.¹²⁶

Priority Action 3: In the advanced stages of Alzheimer's, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities asserts that quality of life is the utmost priority when aiming to support patients living with dementia in the end stages of their battle, be it in the form of home support or in alternative living environments. The main problems faced by caregivers and patients stem from limited resources for assistance and the complexity of the illness. As a result, many caregivers face burnout.¹²⁷ As such, the recommendations offered include supporting caregivers in their efforts to care for their loved ones either at home or in another living environment through the improvement of available services; enhanced training for health professionals; and increased information awareness campaigns for caregivers.¹²⁸

Priority Action 4: Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity, and comfort is designed to provide solutions for dignity at the end of a dementia patient's life. While acknowledging that "Alzheimer's disease and related disorders are certainly among the main causes of death in the elderly, [they] often are not identified as such in the death certificates issued by physicians."¹²⁹ Accordingly, this section of the policy seeks to enable ways Quebecers can have more agency and dignity at end of life. Policy suggestions include: the development of an integrative end-of-life plan by the government¹³⁰; that medical institutions provide caregivers with requisite end-of-life information¹³¹; that all medical professionals receive appropriate end-of-life training¹³²; that all medical institutions conduct an evaluation of the quality of their existing end-of-life practices; and finally that all CHSLDs have a clinical-pharmacological care committee charged with evaluating appropriateness of the prescriptions residents receive.¹³³ The goal of these recommendations is to ensure that those living

¹²³ Bergman, 17

¹²⁴ Bergman, 17-18

¹²⁵ Bergman, 21

¹²⁶ Bergman, 26-27

¹²⁷ Bergman, 31

¹²⁸ Bergman, 35-37

¹²⁹ Bergman, 38

¹³⁰ Bergman, 42

¹³¹ Bergman, 43

¹³² Bergman, 43

¹³³ Ibid

with dementia are afforded the dignity they are due and that their family members are not caught off guard when difficult and painful decisions need to be made. These suggestions ensure a measure of ethical integrity for end-of-life care.

Priority Action 5: Treat family/informal caregivers as partners who need support underscores the importance of recognizing the very important work that caregivers—who are largely female family members—play in caring for a loved one with dementia. Virtually, the policy outlines that they are to be treated as partners potentially in need of support and services to alleviate their tasks, emotional burden and any physical ailments that might result from the stress of caregiving.¹³⁴ Accordingly, the QAP recommends that once a loved one is diagnosed with dementia, a health and social service file should be opened on the caregiver. This ought to be done so as to better provide family members with crucial services that might be of value in their role as active caregivers.¹³⁵ The policy emphasizes that caregivers must have access to “flexible and supportive-care services”¹³⁶ and that in order to best take advantage of a range of services, that the “Government of Québec make social and financial support programs for family/informal caregivers stronger and more flexible, and inform caregivers about these programs.”¹³⁷ Priority Action 5 thus seeks to establish and strengthen programs to support caregivers, acknowledging that without caregivers the lives of those living with dementia would not be as dignified, and that caregivers themselves need support during potentially trying times.

Priority Action 6: Develop and support training programs emphasizes that one of the major problems in dealing with patients with Alzheimer’s and related dementias is that these diseases remain “relatively neglected” in the broad medical sense.¹³⁸ As a result, a significant lack of energy has been devoted to “developing and transferring knowledge about this disease to professionals and support staff,”¹³⁹ which results in inferior quality of care for these patients.¹⁴⁰ This policy supports the development of more post-secondary training courses pertaining to:

“... Education on aging, and more specifically on Alzheimer’s disease, at all colleges and universities in Québec. The curriculum and programs that these institutions implement to provide academic training at the bachelor’s, master’s and doctoral levels, as well as continuing professional development, will enable professionals and other people working in this field to gradually upgrade their skills and keep them up to date hereafter.”¹⁴¹

Moreover, this section of the policy also recommends cooperation between universities and health and social services centres (CSSSs) to “develop an Alzheimer’s disease training program for support staff in community agencies, in public and private alternative living facilities, and in residential and long-term care centres (CHSLD).”¹⁴² Finally, the policy also recommends

¹³⁴ Bergman, 44

¹³⁵ Bergman, 46

¹³⁶ Bergman, 48

¹³⁷ Ibid

¹³⁸ Bergman, 49

¹³⁹ Ibid

¹⁴⁰ Ibid

¹⁴¹ Bergman, 51

¹⁴² Bergman, 53

increasing awareness about dementia-care training to decisionmakers.¹⁴³ Taken all together, this segment of the policy seeks to encourage training by developing key policy solutions to meet this need, in conjunction with improving the opportunities for training, as well as mobilizing key decisionmakers through awareness campaigns.

Priority Action 7: Mobilize all members of the university, public, and private sectors for an unprecedented research effort highlights that although there are many instances of excellent research amongst individuals and institutions in Quebec, there is still much work to be done, particularly with becoming “a major source of new knowledge that can in turn generate new clinical practices and new ways of delivering health and social services, both nationally and internationally. Québec Alzheimer’s research can thus rightly aspire to a leading role on the world stage.”¹⁴⁴ To meet this challenge, the Committee of Experts proposes that: a research consortium on dementia be established in Quebec¹⁴⁵; that the consortium support research through research grants¹⁴⁶; and that medical infrastructures be instituted, such as biological banks and a clinical research registry.¹⁴⁷ The Committee of Experts also emphasizes the importance of amending Article 21 of the Civil Code of Quebec so that a “person’s spouse or close relative or someone who has demonstrated a special interest in him or her to give consent” so that they might become a research participant.¹⁴⁸ By implementing these changes, the Committee of Experts hopes to see research on Alzheimer’s disease and related dementias become more of a priority in the Quebec healthcare system.

Finally, the *Conclusion* of the QAP underscores that dementia remains an immense challenge for the medical and social fabric of Quebec society. As long as it remains a poorly understood and stigmatized disease, the consequences for both people living with dementia and their family members will remain unexamined and unaided to a certain degree.¹⁴⁹ Accordingly, the Committee of Experts urges that for the best outcome vis-a-vis dementia care in Quebec, all concerned parties must vigorously participate in the effort. As they state: “one condition is vital: this effort must involve all parties concerned—in the public health and social services system, in associations such as the Federation of Quebec Alzheimer Societies, in community organizations, in the private sector, and in academia.”¹⁵⁰ In other words, broad support from all key stakeholders is essential to the advancement of dementia cure, care and policy development in Quebec.

Taken in its entirety, the Quebec Alzheimer Plan is a treatise on how best to view, treat and tackle dementia treatment and care within the Quebec healthcare context. Multi-pronged and vastly researched, the policy’s initial position as a set of comprehensive recommendations translates neatly into its application as Quebec’s main protocol for healthcare vis-a-vis dementia. Initially set to be fully integrated into the healthcare system by 2020, but postponed to 2022 due to the

¹⁴³ Ibid

¹⁴⁴ Bergman, 54

¹⁴⁵ Bergman, 56

¹⁴⁶ Bergman 57

¹⁴⁷ Bergman, 58

¹⁴⁸ Ibid

¹⁴⁹ Bergman, 65

¹⁵⁰ Bergman, 65

pandemic,¹⁵¹ the policy currently finds itself in its third stage of implementation, formally known as *Phase III: consolidation and expansion*.¹⁵² This final phase entails the full application of the recommendations described herein, particularly relating to the implementation of recommendations pertaining to primary care clinicians in Family Medicine Groups (FMGs).

¹⁵¹ MSSS, Accessed February 16, 2024. <https://www.msss.gouv.qc.ca/professionnels/maladies-chroniques/alzheimer-et-autres-troubles-neurocognitifs-majeurs/>.

¹⁵² ROSA, Accessed: February 14th, 2024, URL: https://www.healthcareexcellence.ca/media/0p1jhwug/final-2-policy-brief-format-court_en-final-ua.pdf

4.4: FINDINGS ON THE QAP'S EFFECTIVENESS: A BEGINNING

Up till this point in time, there has been minimal scholarly work conducted on the effectiveness of the QAP as a policy. However, of the research conducted on the topic, findings signal that the policy is succeeding and failing in different areas. For instance, one study conducted by Vedel et al. in 2019 suggests that since the QAP has been implemented, “the detection of neurocognitive disorders in patients aged 75 years or more improved... [with] the intensity and quality of management of patients in this age group with neurocognitive disorders also improved.”¹⁵³ Another study from 2021 by Khanassov et al. sought to establish how the QAP is having an effect on the ground level. Although limited in the number of available participants for study, as well as limited by the constraints of the Covid-19 pandemic, this study has revealed:

“The participants were satisfied with access to care, and medical services in primary practices... [although] persons living with dementia and their caregivers need a contact person, a clear explanation of their dementia diagnosis, a care plan, written information on available services, and support for the caregivers.”¹⁵⁴

Some participants in the same study also highlighted how there was, at times, a lack of doctor-patient follow-up. Some families noted that their loved one had undergone cognitive testing, but that they never received any feedback with respect to the results of the testing.¹⁵⁵ Furthermore, participants also noted that they frequently “did not receive timely access to the community services when required, [and] it was not tailored to their specific expectations and needs.”¹⁵⁶¹⁵⁷ Similarly, Arsenault-Lapierre et al., underscore that although the overall quality of care has improved for both patients with dementia and their caregivers, this effectively only applies to people who have doctors within a GMF. According to their research, in 2017 only 54% of Quebeckers had a doctor that belonged to a GMF; as of 2020 that number should have reached 85%.¹⁵⁸ As a result, while care has improved, it has only done so for those who have a family doctor within a GMF. Although more research is required to better substantiate this claim, this is to say nothing of the 800 000 people in Quebec without a family doctor,¹⁵⁹ amongst whom assuredly include some people who are yet to be diagnosed with and/or are already living with dementia. Additionally, a more recent study hoping to establish whether evaluative dashboard indicators might act as a useful analytical tool for the implementation the QAP cross-regionally, supports that such a tool “increase[s] the monitoring capacity for the QAP and ... contribute[s] to the emergence of a learning health care system culture.”¹⁶⁰ This tool could potentiate proper implementation of the plan. A 2024 study by Lemay-Compagnat et al. follows up on some of the formerly noted concerns, proposing that the QAP as practiced could benefit from further reforms

¹⁵³ Vedel et al, Accessed May 27th, 2023, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6579653/>

¹⁵⁴ Vladimir Khanassov, Rojas-Rozo, Sourial, et al., 2021

¹⁵⁵ Khanassov et al., 6

¹⁵⁶ Khanassov et al., 7

¹⁵⁷ Side note: From my own point of view, I can say this is reflective of my experience. We had a particularly challenging time finding available community services, none of which were directed to us by my father's doctor, none of which provided any support, let alone timely support.

¹⁵⁸ Arsenault-Lapierre et al., 378

¹⁵⁹ Ha, 2022

¹⁶⁰ Arsenault-Lapierre, Lemay-Compagnat, Guilette, Couturier, Massamba, Dufour, Mauert, Fournier, Denis, Morin, and Isabelle, 2024

or updates.¹⁶¹ According to the authors, the first problem to revisit is the existence of ‘gray areas’ or voids in implementation wherein patients are “left somewhat on their own; either there are waiting lists, or people do not communicate with each other.”¹⁶² These ‘gray areas’ leave patients in vulnerable positions, in which they remain uncertain as to how to proceed to address their care options. Secondly, and along similar lines, participants in the study also call for improved medical access to their primary care doctors, or any family doctor (should they not have a doctor of their own).¹⁶³ Given that the policy is centered around the family medicine groups and primary care physicians, it is alarming that patients have difficulty in accessing crucial appointments. A third, and cardinal suggestion, is to inform caregivers of all care decisions affecting their loved one.¹⁶⁴ This criticism is poignant, as the findings demonstrate that these care partners “are not adequately considered in the healthcare and social system, and they need to be fully heard.”¹⁶⁵ While it might seem evident that caregivers should be involved in all decision-making processes, the stark reality is that much information is often simply not communicated to them, or decisions are made without their prior knowledge.

Collectively, these findings suggest that there have been continued implementation issues with the QAP, particularly in terms of doctor-patient-caregiver communication and access to care appointments. While it is certainly true that, overall, the evidence suggests that the QAP is moving the needle in the right direction, increasing detection of the disease, providing much needed medical support, and offering evaluative frameworks to ensure the continued improvement of the implementation process, there is still refinement to be had, particularly with respect to providing in-community services for people living with dementia and their caregivers, and additionally with providing the kind of directional support that patients and caregivers desperately need when trying to navigate a disease which can cause serious changes in lifestyle.

¹⁶¹ Lemay-Compagnat, Cetin-Sahin, Rojas-Rozo, Arsenault-Lapierre, Couturier, Bergman, Vedel and COVID-ROSA Research Team, 2

¹⁶² Lemay-Compagnat et al., 5

¹⁶³ Lemay-Compagnat, 6

¹⁶⁴ Lemay-Compagnat, 8

¹⁶⁵ Ibid

4.5: DRAWING THE THEORETICAL AND THE PRACTICAL TOGETHER: WHERE DOES THAT LEAVE US?

Dementia is a pressing health policy concern in Quebec, Canada and internationally. With a projected 1 million people to be living with dementia in Canada by 2030,¹⁶⁶ many of whom will be residents of Quebec, evaluating ongoing dementia policies becomes more and more important from a policy perspective. Correspondingly, understanding how dementia policies can be framed becomes imperative to better understanding this brand of health policy. As it has been demonstrated, potential ways in which dementia policies can be framed include, but are not limited to, biomedical, social disability and neoliberal models. These knowledges subsequently form the basis upon which policymakers frame or constitute the problem of dementia. In the Canadian context, federalism renders healthcare a provincial responsibility.¹⁶⁷ Necessarily then, both federal and provincial jurisdictions have developed dementia policies. In Quebec, the QAP has been the major policy of import on this front. This policy seeks to provide diagnosis, support and care to people living with dementia through primary care physicians, employing the collaborative care model to best support these patients and their caregivers.¹⁶⁸ While the policy has undergone some recent policy evaluations, given that it is still relatively new and still in the process of being integrated,¹⁶⁹ further research is needed to assess its ability to support Quebecers living with dementia. Of the studies that have been conducted, there is evidence to suggest that the policy is effective in some fundamental ways, such as in diagnosing and caring for patients in primary care settings.¹⁷⁰ Nevertheless, some studies reveal that both people living with dementia and their caregivers still need further information and support navigating the trajectory and realities of the disease.¹⁷¹

Invariably, more research is required to assess the policy's overall comprehensiveness. With this view in mind, this thesis fills this gap by assessing how the QAP has been framed. Understanding the framing of the QAP is essential to best ascertain how dementia has been problematized in Quebec. Dombos et al. explain that policy frames can be seen as “organizing principles that transform fragmentary or incidental information into a structure and meaningful problem, in which a solution is implicitly or explicitly included.”¹⁷² If policy frames organize what a problem is and how it is to be solved, it then becomes instructive to understand how the QAP has been framed, as this understanding grants insight into the ideas and paradigms which have constructed ‘dementia’ in the Quebec context. Thus, without a comprehensive understanding of how the QAP has been framed, this remains a gap in our collective knowledge about this policy, as well as other health policies within the greater Canadian healthcare policy realm.

¹⁶⁶ Alzheimer Society, Accessed: April 11th, 2023, URL: <https://alzheimer.ca/en/about-dementia/what-dementia/dementia-numbers-canada>

¹⁶⁷ Government of Canada, Accessed: November 5th, 2023, URL: <https://laws-lois.justice.gc.ca/eng/const/page-3.html#h-19>

¹⁶⁸ ROSA. Accessed: March 2023, URL: https://www.healthcareexcellence.ca/media/doeexyox/final-5-policy-brief-format-long_en-final-ua.pdf

¹⁶⁹ In the sense that it is a policy which has several stages of implementation and is only now in its final stage (despite the entire process having begun in 2007).

¹⁷⁰ Vedel et al, accessed May 27th, 2023, URL: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6579653/>

¹⁷¹ Khanassov et al., 6-7

¹⁷² Dombos, Krizsan, Verloo and Zentai, 5

This project evaluates the framing of dementia in the QAP by applying Critical Frame Analysis to assess dementia problematization. This work hopes to contribute to a growing body of literature about dementia policies and the role they play in the health policy context in Canada. As a leader in the Canadian healthcare context vis-à-vis dementia policies, Quebec's plan needs to be thoroughly understood and evaluated to determine what, if anything, needs changing to provide the best quality of care to people living with dementia in Quebec. In a spirit similar to André Picard's notion that healthcare improvement requires for us to, above all else, "give life to our values,"¹⁷³ this work searches for dignity in dementia policy, particularly in order to understand the role of the different players in dementia care.

¹⁷³ Picard, 179

CHAPTER 5: METHODOLOGY

5.1 METHODOLOGICAL EXPLANATION

The objective of this thesis is to ask the following research question: *What are the main frames in the QAP?* In order to answer this question, I have employed Critical Frame Analysis to uncover what ideas are inherent in the QAP. The principal idea is that once one has revealed which ingredients make up the QAP, one will then have a clearer picture of which ideas constitute the policy. In so doing, this project assesses which paradigmatic frameworks are dominant in the Quebec Alzheimer Policy. This undertaking represents a beginning step toward better understanding the theoretical underpinnings of the policy, thereby opening the door for further discursive research in the field. This analysis is guided by a feminist research ethic that pays heed to epistemological concerns, notions of inclusion, exclusion and power, as well as the ‘situatedness’ of the researcher.¹⁷⁴

Understanding which ingredients make up dementia problematization is of increasing importance in our society. Considering that this neurodegenerative disease is on the rise in Canada, it has become all the more pressing to address multiple angles of the policy issue.¹⁷⁵ In view of this task, it is crucial to first operationalize a key concept: public policy. Broadly speaking, public policy is that which impacts our everyday lives. Public policies are, by their very nature, ideas which have captured the public’s attention or imagination in some manner. According to Dye, public policy is “anything a government chooses to do or not to do.”¹⁷⁶ Similarly, Anderson notes that public policy is “a purposive course of action followed by an actor or a set of actors in dealing with a problem or matter of concern.”¹⁷⁷ In the case of dementia policy in Quebec, the government’s purposive action is the application of the QAP, which acts as a guiding framework by which various members of society, including medical professionals and those working in both public and private institutions, are to diagnose, treat and coordinate the care of people living with dementia, support caregivers, and, more generally, improve societal understanding of dementia in the Quebec context.

In conducting this policy evaluation, this work turns to Critical Frame Analysis (CFA). This methodology is connected to what is often called the “argumentative turn of public policy.”¹⁷⁸ Fischer and Gottweis highlight how the argumentative turn has “called for a new direction in planning and policy analysis... [one which] turns away from the dominant empirical approach of policy inquiry to make way for the recognition of language and argumentation as fundamental aspects of both theory and analysis in policy-making and planning.”¹⁷⁹ Many methodologies, including frame analysis, were a part of the approaches that arose out of this argumentative turn.¹⁸⁰ Narrowing in on one form of frame analysis, Critical Frame Analysis, is a methodology which

¹⁷⁴ Ackerly and True, 2014

¹⁷⁵ Alzheimer Society, Accessed: April 11th, 2023, URL: <https://alzheimer.ca/en/about-dementia/what-dementia/dementia-numbers-canada>

¹⁷⁶ Dye, 2

¹⁷⁷ Anderson, 1984

¹⁷⁸ Paterson, 488

¹⁷⁹ Fisher and Gottweis, 425

¹⁸⁰ Ibid

strives to understand the stories or arguments that a given policy presents, which includes a comprehensive analysis of how any given problem is to be solved for. The stories or arguments that are baked into a policy are understood through policy frames, otherwise described as “interpretation scheme[s] that structure the meaning of reality.”¹⁸¹ According to Stavroula Sant-Geronikolou, Critical Frame Analysis offers an ideal tool “for rigorous and systematic policy analysis useful for comparing dissimilar public policies, identifying, describing and comparing frames, meaning how people communicate their interpretation of reality.”¹⁸² This work thus employs CFA in order to both uncover and describe the existing frames in the QAP. Furthermore, knowing that policy frames can be broken down into three constituent types of frame analysis, including ‘issue frame’ analysis, ‘document frame’ analysis, and ‘meta-frame’ analysis,¹⁸³ this work employs a ‘document frame’ type of analysis, which entails revealing “how a particular document or actor constructs the issue.”¹⁸⁴ Or, in other words, pulling back the veil on which ideas dominate a policy.

When assessing frames, according to the Critical Frame Analysis theory, logical inquiry begins with the understanding that there could be a multiplicity of intellectual paradigms ‘framing’ a problem, though often policy actors will choose a dominant frame which aligns with their policy vision.¹⁸⁵ Recent research by Rianne Dekker argues that frames are “much less coherent and unitary with regard to problem definition and proposed policy actions than what theory so far suggests.”¹⁸⁶ Or, in other words, there can be a mismatch between different vectors of the policy text. This is crucial to keep in mind considering that policy visions are important to examine as they can “have concrete and material consequences that set the conditions for future actions and realities.”¹⁸⁷ Consequently, illuminating how a policy has been framed, or understanding the framers’ intent (and potential blind spots), can benefit those for whom the policy was constructed by highlighting what the original goals for the policy were. This is because, as Haar and Verloo contend, inherent within the policy argument is “an implicit or explicit representation of a problem (diagnosis), connected to an implicit or explicit solution (prognosis) and a call for action.”¹⁸⁸ Moreover, Hans-Georg Gadamer’s work highlights the importance of uncovering hidden (i.e. unconscious) policymaker prejudices “that make us [read: them] deaf to the voice of a text.”¹⁸⁹ This renders CFA an ideal analytical tool for this type of evaluative work because “CFA does not assume or impose meanings in advance, [but] seeks to uncover meanings embedded in policy texts”¹⁹⁰ Thus, Critical Frame Analysis helps the researcher unmask how a given policy defines, solves and calls for action to address a policy problem. Evidently, framing can “generate completely different solutions” to a perceived problem,¹⁹¹ much of which is dependent upon who is doing the framing and their respective goals for policy development. The utility of Critical Frame Analysis then is that through analysis one can determine how an issue has been seen and solved

¹⁸¹ Verloo and Lombardo, 32

¹⁸² Sant-Geronikolou, 19.

¹⁸³ Dombos et al, 6

¹⁸⁴ Ibid

¹⁸⁵ Verloo and Lombardo, 31

¹⁸⁶ Dekker, 129

¹⁸⁷ Verloo and Lombardo, 32

¹⁸⁸ Van der Haar and Verloo, 2

¹⁸⁹ Gadamer 137, cited in Verloo and Lombardo, 32

¹⁹⁰ Paterson, 489

¹⁹¹ Verloo and Lombardo, 35

for, as well as whether the problematization and solutions that are presented are best suited to solving the problem.¹⁹²

¹⁹² Ibid

5.2 CONDUCTING CRITICAL FRAME ANALYSIS IN THIS PROJECT

To get to the heart of whether a policy solution matches its problematization according to a Critical Frame Analysis perspective, a series of ‘sensitizing questions’ are applied to a given policy and any of its concordant documents. As Tamas Dombos et al. outline in their work on Critical Frame Analysis for the QUING Project, sensitizing questions serve to “provide a certain interpretative tool when reading policy document[s] in search for policy frames... [from which] issues can be identified and/or constructed by searching for similarities and difference in what documents say about these questions.”¹⁹³ As can be seen in the table below, the sensitizing questions cover a range of themes, including: voice, diagnosis, attribution of roles in diagnosis, prognosis, attribution of roles in prognosis, normativity and balance. These themes aim to help a researcher better ascertain how the problem is constructed, by whom and to what specific and overall effects.¹⁹⁴

As a method to uncover the main framing devices that are found in the QAP, a series of sensitizing questions, as modeled by and taken from the list of sensitizing questions found in the QUING Project, were accordingly applied to the QAP policy text. By asking these sensitizing questions about this policy text, I have been able to interpret and orient an understanding of the inherent framing devices in the text. Consider the sensitizing questions in Table 1 for further clarification as to which questions were asked of the QAP policy text.

Table 1-MAGEEQ Methodology of Critical Frame Analysis SUPER TEXT TEMPLATE¹⁹⁵

SENSITIZING QUESTIONS	Voice SUMMARY • Voice(s) speaking: • Perspective: • References: words/concepts (and where they come from) • References: actors • References: documents
Diagnosis SUMMARY • What is represented as the problem? • Why is it seen as a problem? • Causality (what is seen as a cause of what?) • Dimensions of gender (social categories/identity/behavior/norms & symbols/institutions) • Intersectionality • Mechanisms (resources/norms & interpretations/legitimization of violence) • Form (argumentation/style/conviction techniques/dichotomies/ metaphors/contrasts) • Location (organization of labor/organization of intimacy/organization of citizenship)	Attribution of roles in diagnosis SUMMARY • Causality (who is seen to have made the problem?) • Responsibility (who is seen as responsible for the problem?) • Problem holders (whose problem is it seen to be?) • Normativity (what is a norm group if there is a problem group?) • Active/passive roles (perpetrators/victims, etc.) • Legitimization of non-problem(s)
Prognosis	Attribution of roles in prognosis

¹⁹³ Dombos, Krizsan, Verloo and Zentai, 7

¹⁹⁴ Verloo and Lombardo, 47-49 (Annex 1)

¹⁹⁵ Ibid

SUMMARY • What to do? • Hierarchy/priority in goals: • How to achieve goals (strategy/means/instruments)? • Dimensions of gender (social categories/identity/behavior/norms & symbols/institutions) • Intersectionality • Mechanisms (resources/norms & interpretations/violence) • Form (argumentation/style/conviction techniques/dichotomies/metaphors) • Location (organization of labor/intimacy/citizenship)	SUMMARY • Call for action and non-action (who should [not] do what?): • Who has voice in suggesting suitable course of action? • Who is acted upon? (target groups) • Boundaries set to action • Legitimization of (non)action
Normativity SUMMARY • What is seen as good? • What is seen as bad? • Location of norms in the text (diagnosis/prognosis/elsewhere)	Balance SUMMARY • Emphasis on different dimensions/elements • Frictions or contradictions within dimensions/elements

These exact questions were used to analyze the Quebec Alzheimer's Plan. To collect data for this thesis, the major questions in each of these interpretative categories were applied in a systematic fashion to the QAP policy report. Specifically, these questions were applied to each of the following sections of the policy text: the Foreword; the Executive Summary; Section 1: Alzheimer's Disease and Related Disorders: A Major Public Health Problem; Section 2: Major Achievements and Challenges for Quebec; Section 3: A Societal Approach Centered on the Individual, Humanism, and Excellence; Section 4: Priority Action 1 Raise awareness, inform, and mobilize; Priority Action 2: Provide access to personalized, coordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers; Priority Action 3: In the advanced stages of Alzheimer's, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities; Priority Action 4: Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity, and comfort; Priority Action 5: Treat family/informal caregivers as partners who need support; Priority Action 6: Develop and support training programs; Priority Action 7: Mobilize all members of the university, public, and private sectors for an unprecedented research effort; and finally, the Conclusion.¹⁹⁶ These sections are the pool from which base data was drawn to conduct all coding analyses.

To aggregate my data, I applied these interpretative sensitizing questions to each of the aforementioned sections. Data was recorded by noting the section name, the question, and the response (what I will also call 'code' hereafter). Once responses were recorded, they were tabulated to determine the most repeated words found throughout the collection of results. This was done by using a datasheet to keep track of which words were the most frequently repeated throughout the document. This datasheet outlined the frequency of responses to key criteria, including 'actors voice', 'problem holders,' 'what is the problem to be solved?,' 'who is affected

¹⁹⁶ Bergman, iii

by it?,' 'what needs to be done?', and 'who should do it?.'¹⁹⁷ A particular emphasis was placed on actors, voice, problematization, and solutions for this analysis. Focused analysis results, i.e. 'codes', were subsequently interpreted in light of the policy text with the view of gaining a comprehensive understanding of the policy document. By way of demonstration, consider the following example: *Committee of Experts* was marked as an important code, appearing in the analysis results 39 times in response to the sensitizing questions, such as '*who has voice in suggesting suitable course of action?*' From there, I used the code *Committee of Experts* to recontextualize my understanding of what was being said in the policy, which in this case pertained to who has 'voice' in the policy text, and to what degree compared to other actors. From there, connections were made between the coding results and framing knowledges that most related to the code of *Committee of Experts*, granting a clearer understanding of how the code is framed. Thus, dominant ideological frames stem from key words and ideas of repeated frequency in the text, which were then re-contextualized and subsequently extrapolated into larger or broad connective policy paradigms. This ultimate jump to larger policy paradigms helps shed light on larger trends in the dementia policy realm context.

¹⁹⁷ Note: a selective choice was made not to code all revealed elements of the text, as that would have resulted in a far larger project, one which equally falls outside of the scope of this current project.

CHAPTER 6: ANALYSIS RESULTS & DISCUSSION

6.1 INTRODUCTION

This section outlines the results of my methodological approach. Having applied the sensitizing questions in a systematic fashion to answer the question *What are the frames of the Quebec Alzheimer Plan?* this Critical Frame Analysis exercise has revealed valuable results pertaining to actor(s) voice, problem holder(s), problem(s), target(s) of the problem, solution(s), and solution provider(s), notably unveiling the philosophical dominance of the biomedical model across different vectors of the policy text. Although the social model of disability is represented in the policy framing, it invariably plays second fiddle to an almost overpowering biomedical perspective.

These framing results suggest an inherent tension between the stakeholders that represent and/or benefit from the upholding of their preferred framing model. In broad terms, the key stakeholders of the biomedical model are medical professionals, and they are textually represented by codes such as *Committee of Experts*. The social model of disability is represented by codes such as *people with Alzheimer's and dementia, caregivers, and family members*. The tension between these stakeholders is mirrored by the tension in the text between the biomedical and social disability paradigms in that in this instance, the stakeholders of the social model of disability paradigm are also overpowered by the sheer dominance of those who represented and uphold the biomedical perspective. This has key implications for the kinds of solutions offered, which facets of dementia problematization are given top priority, who has voice to effect change, and so forth.

6.2 ACTOR VOICE

In response to the first coding theme, corresponding with the sensitizing questions about Actor(s) Voice, or: *who has a dominant voice in the text?* (found in Table 1, category ‘Voice’) the results in Bar Graph 1 demonstrate the codes that arose most frequently in response to the application of the sensitizing questions. Notably, the top three actors with voice that are most represented in the QAP text include *people with dementia and Alzheimer’s*, *caregivers*, and the *Committee of Experts*. The code *people with dementia and Alzheimer’s* in particular is 50% more prevalent than the other leading codes, and about 16 times more frequent in occurrence than the least frequently revealed code *Family Medicine Groups (FMGs)*.

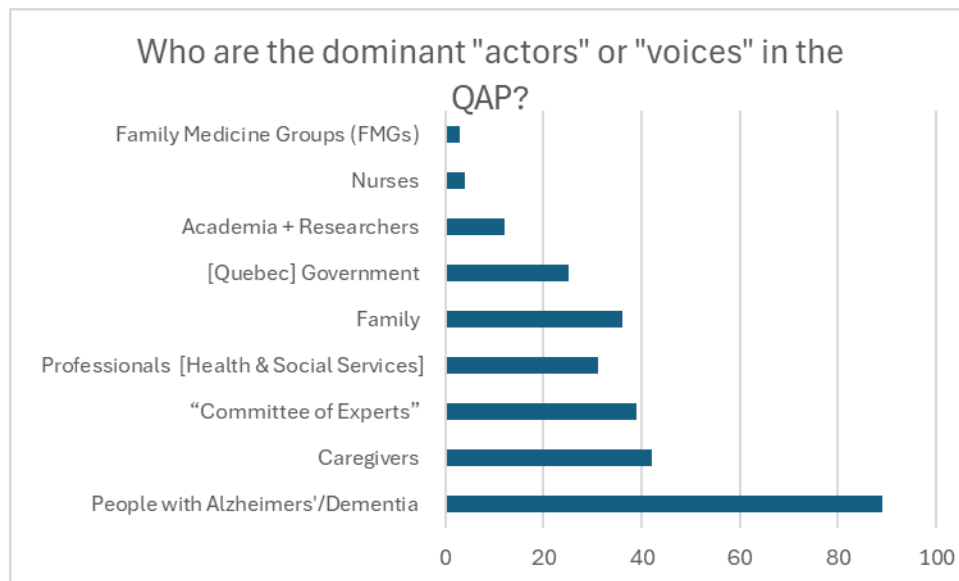


Figure 1

While the codes *people with Alzheimer’s and dementia*, *caregivers* and the *Committee of Experts* are the most prevalent in the analysis results, it is noteworthy to mention that the other results are similar in nature in that they represent overlapping themes. For example, the code *family* overlaps with *caregivers*, the code *professionals [Health & Social Services]* overlaps to some degree with the codes *Committee of Experts*, *nurses*, and *FMGs*, all of which taken together suggests that the top three codes are even more representative of the variety of actors with voice revealed in the coding analysis.

In linking these codes to larger theoretical paradigms, clear patterns emerge demonstrating the QAP’s dominant theoretical underpinnings. Beginning with *people with Alzheimer’s and dementia*, there are many references to this group of actors throughout the policy text. Indeed, their dominant inclusion in the text suggests that the policy is first and foremost made for and conceived with this target demographic in mind. Most pertinently, the coding language here—by highlighting the voice of *people with Alzheimer’s and dementia*—suggests elements of the social model of disability, the model which, according to Hosein Abidi, is best known for encapsulating the notion that it is the inherent injustices and discriminatory practices in one’s immediate environment which potentiate disability or illness in the

individual.¹⁹⁸ The fact that the voice of *people with Alzheimer's and dementia* is textually recognized as a group for whom giving voice is imperative aligns neatly with the social model of disability in that this model seeks to embolden the voices of the disabled, who notably have less of a voice due to societal barriers. Textually, one of the first indications of this paradigm at work can be found in the dedication. The authors of the QAP note that the document is “dedicate[d to]... first and foremost to people who have Alzheimer's disease or related disorders, to whom we owe respect, dignity, excellent care, and humaneness in all circumstances.”¹⁹⁹ The acknowledgement that people with dementia are due respect, dignity and excellence in care is important in that it raises their voice and agendas to the foreground, but also in that it affirms their rights as differently abled people. These facets suggest an understanding of the societal barriers, as well as the potential lack of agency they might experience as a result of these barriers.

Further evidence demonstrating a commitment to the social model of disability can be shown in passages such as the following:

“The committee members met with many individuals and organizations that deal with Alzheimer's and related disorders. Committee members held discussions not only with managers and professionals from Quebec's health and social services institutions and Ministry of Health and Social Services, but also with associations such as the Federation of Quebec Alzheimer Societies, foundations and other organizations such as the Québec Seniors' Council (Conseil des aînés du Québec), and with many representatives of community organizations, the private sector, and the research community.”²⁰⁰

Amongst the people implicated in the development of the QAP, it was not only medical professionals who had been included. Indeed, as the text clarifies, those living with different forms of dementia were included in the policy development process. From a social disability perspective, their inclusion diversifies the voices opined to speak on how best to address any structural inequities or imbalances that people living with dementia in Quebec face, and consequently how best to address the ‘problem.’ This is crucial, especially considering research by academics such as Lisa Iezzoni reveal that people with disabilities are “much more likely than others to experience sub-standard health care.”²⁰¹ It thereby becomes all the more vital to include the voices and knowledge of people living with dementia in order to develop superior, integrated problem-solving vis-a-vis dementia problematization. Ultimately, this hints at a degree of sensitivity towards understanding that there are more perspectives than the biomedical perspective at play in addressing dementia problematization.

Similarly, the text also models notions of justice that are crucial to the social model of disability. This is noticeable in the degree of emphasis put on the humanistic philosophy which underpins the QAP. As the Committee of Experts note in the policy document:

“The approach proposed by the Committee of Experts is centered on the individual, grounded in humanistic values, and based on excellence in all respects. Hence this

¹⁹⁸ Abidi, 19

¹⁹⁹ Bergman, ii

²⁰⁰ Bergman, iv

²⁰¹ Iezzoni, 11

approach places the dignity of people with Alzheimer's disease and respect for their choices front and centre."²⁰²

It is remarkable that the text takes special consideration of the voice of people with dementia. That it is textually stipulated that people living with dementia do require dignity, and that they equally deserve the right to be heard and make choices that they feel are appropriate for their own lives is a clear demonstration of respect for their agency and 'voice.' This is particularly notable in a societal context where medicalization and medical professionals are afforded a status with considerably more dominance.

The second element that comes through in the analysis is the coding result: *caregivers*. 'Caregivers' are mentioned throughout the policy text. Quite so, two of the priority actions directly reference *caregivers*, i.e: "Priority Action 2: Provide access to personalized, co-ordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers"; and "Priority Action 5: Treat family/informal caregivers as partners who need support". It is certainly also the case that the authors of the QAP go through some trouble in detailing the realities that dementia *caregivers* experience. This detailing has the compounded effect of further elevating their 'voice' in the policy document. Notable passages indicate the potential severity of impact on caregivers, stressing that "the vast majority of whom are elderly women."²⁰³ In point of fact, the authors note that "Alzheimer's disease is a major source of psychological and social exhaustion. It has major effects on caregivers' health and financial status."²⁰⁴ Additionally, caregivers experience a significant dent in their pocketbooks because of their caregiving responsibilities, leading to their inability or unavailability to participate in paid work within the greater market economy. This is a net loss for both society and the individual.²⁰⁵ It is for these reasons that it is so consequential that both priority actions 1 and 5 strive to underscore the importance of including caregivers in the policy solution equation; they are fundamental players in solving the 'problem' of dementia, and hearing their 'voice' is one piece of addressing the problem. Thus, the elevation of the 'voice' of *caregivers* suggests that elements of the social model of disability are also included in the framing of the policy. Particularly, as Pia Matthews clarifies, there are obstacles that caregivers face which can be aligned with the social model of disability's philosophy of sourcing 'the problem' of disability in unjust social structures as opposed to in the body of the person with the disability.²⁰⁶ In this case, the fact that caregivers are mentioned in the text points to an understanding that caregivers must confront the unjust social structures that make life challenging for the person whom they are caring for. Furthermore, the policy text's interest and care for *caregivers* would suggest that this policy has given thought to the voice of caregivers in that they are a part of the system or network of people that look after people with dementia, and as a corollary function of their efforts, are equally in need of caring and support. The QAP policy therefore considers that caregivers might be facing social structures which are potentially harmful to their health, financial status, and ability to act as caregivers. Hence, an indirect emphasis is put on assessing the structures and tools in place to help people living with dementia in Quebec.

The third element revealed in the coding analysis is *the Committee of Experts*. The prevalence of their 'voice' in the text is notable. To be sure, their 'voice' is repeatedly outlined

²⁰² Bergman, 10

²⁰³ Bergman, v

²⁰⁴ Bergman, 3

²⁰⁵ Bergman, 4

²⁰⁶ Mathews, 151

by the clear demonstration of the priorities, preoccupations and responsibilities of the committee. *The Committee of Experts* code represents the professionals chosen to advise the government on how best to tackle dementia problematization in Quebec. In point of fact, the policy document thoroughly explores their role, first and foremost, by clarifying their *raison d'être* in the policy text. Their mandate—as assigned by the government of Quebec—is to craft a policy that meets the needs of Quebecers with dementia.²⁰⁷ This is otherwise explained accordingly:

“To cover all aspects of this subject, from research and prevention to end-of-life care... the committee then set about defining the main problems that had to be considered with respect to Alzheimer’s disease and related disorders. By determining the causes of these problems, the committee was able to better assess possible solutions that could be translated into priority actions.”²⁰⁸

In other words, their goal is to define and solve for dementia problematization in the QAP and thereby shaping dementia policy in the greater Quebec policy landscape. Their voice, above all others, is the primary mouthpiece for dementia problematization—despite them being the third most prevalent code in this section of the analysis.

The voice of the *Committee of Experts* can be defined by their desire to achieve “excellence in all respects.”²⁰⁹ Notably, this includes putting an emphasis on evidence-based solutions, wherein “the solutions to be implemented under this approach must not be improvised... they must be grounded in evidence-based findings from clinical and other research conducted in Quebec, elsewhere in Canada, and abroad.”²¹⁰ Philosophically, the *Committee of Experts* are concerned with finding superior medical solutions that integrate evidence-based findings, uphold a person’s dignity, and support excellence in tackling dementia care in Quebec. This philosophy and explanation of mandate suggest that the major paradigmatic framing to keep in mind while assessing the role of *The Committee of Experts*’ ‘voice’ is the biomedical paradigm. Recall that the biomedical model holds a preferential position of authority in our era, and particularly amongst the medical establishment. This model is interested in approaching diseases as if they are puzzles to be solved, wherein medical professionals first determine the cause of the problem, and then through (bio)medical intervention, aim to cure or treat the malfunctioning body part(s). Under this model, the ultimate good and goal is cure, not care.²¹¹ The biomedical paradigm, due to its roots in science and evidence-based methodologies, is viewed “as value-free, a medical fact that [sic] transcends time and place,”²¹² though many scholars disagree with the neutrality aspect of the model, arguing instead that the almost exclusive emphasis on cure can have negative consequences for people living with diseases. In the case of those living with dementia, the biomedical paradigm can have the effect of leaving this population out of larger policy and societal discussions about ageing and health.²¹³ Thus, in evaluating the ‘voice’ of the *Committee of Experts*, it is important to consider that their ‘voice’, by virtue of how the medical establishment trains health professionals, places more authority in the hands of doctors than civilians.²¹⁴ Tosam’s argument is aligned with Patrik Marier’s

²⁰⁷ Bergman, vi

²⁰⁸ Bergman, iv

²⁰⁹ Bergman, 10

²¹⁰ Ibid

²¹¹ Ward and Sandberg, 2

²¹² Ibid

²¹³ Ward and Sandberg, 2-3

²¹⁴ Tosam, 132

comment on how the professional status of medicine privileges medical personnel above other actors.²¹⁵ This professional status necessarily elevates the ‘voice’ of the *Committee of Experts* above *people living with Alzheimer’s or dementia* and *caregivers* by virtue of their professional status. In elevating the ‘voice’ of medical professionals, sometimes at the expense of other key voices like dementia activists like Helga Rohra, (bio)medical voices and advocates maintain more pull in policymaking arenas. As Patrick Marier explains, “[The biomedical paradigm] examines how human problems become medicalized and how this process represents a tool of social control, wherein the medical profession exerts paramount influence by organizing and delivering treatments.”²¹⁶ This form of social controls extends into the policymaking venue, in which it is seen that “the professional status of medicine confers a privileged space within the policy process to medical personnel... as opposed to community [members] and social services,”²¹⁷ suggesting that the biomedical model is granted more power and authority to act over other models in the policymaking sphere. Knowing that medical professionals are accorded more gravitas in policymaking accordingly implies that *the Committee of Experts* have a privileged and arguably biased role to play in the framing of ‘voice’ in the QAP.

In summation, the theoretical underpinnings revealed from the evaluation of ‘voice’ in the QAP suggests framing elements reflective of both the social model of disability and the biomedical model. While the codes *people with Alzheimer’s disease and dementia* and *caregivers* are statistically more prevalent than the third code, *the Committee of Experts*, one caveat is necessary to consider: that is, there is a significant difference between being referred to and being the actor who is doing the referring. While the codes *people with Alzheimer’s disease and dementia* and *caregivers* do indeed suggest elements of the social model of disability in the framing of ‘voice’, the code *Committee of Experts*, and thereby the biomedical model, arguably has a more direct impact on ‘voice’ in the policy than the other two groups simply because it was the Committee that wrote the policy. Extrapolating from this, it is important to consider that the degree of influence that biomedical knowledge has had on this policy’s development is potentially more powerful than the social model of disability when referring to ‘voice’ considering that the shapers of the policy are medical professionals deeply implicated in the biomedical paradigm. Even though the committee has shown an interest in hearing the ‘voice’ of caregivers and people living with dementia, these latter groups did not have pen to paper writing the final QAP policy text. This entails that it is all very well possible that some of the inherent biases of the biomedical model, such as an overemphasis on medical interventions, seeped their way into the policy despite the framers’ intention. Ultimately this points to a tension between the stakeholders that represent the biomedical paradigm and the stakeholders that represent the social model of disability in terms of ‘voice’ in that although the policy text is very much aimed at patients and caregivers, the authority of the Committee to write the policy and define its innerworkings, muffles the voice of patients and caregivers. This finding thematically mirrors my own lived experience as my father’s caregiver, in which my own ‘voice’ in addressing concerns pertaining to my father’s care were often secondary, or simply not applicable, when communicating with medical experts; they had information to communicate, often pertaining to disease progression, but had very little to offer by way of social support or pathways.

²¹⁵ Marier, 36

²¹⁶ Marier, 34

²¹⁷ Marier, 36

6.3 PROBLEM HOLDERS

In response to the sensitizing question answers vis-a-vis problem holders, i.e. who holds/receive the problems that dementia presents in the Quebec context (see Bar Graph 2 for all responses), the top three most prevalent codes that came out of the analysis are: *People with Alzheimer's and dementia*, *caregivers*, and *family*. While the *Quebec government* and *hospitals* are also prevalent responses, these codes occur in a far lesser measure than the top three coded responses. One nuance in the coding results is a response similar in nature to *caregivers*: that is, there is a second code called *women caregivers* that appears in a separate coding response. This finding modulates the notion that not only are caregivers one of the biggest problem holders, but that these caregivers are typically women.

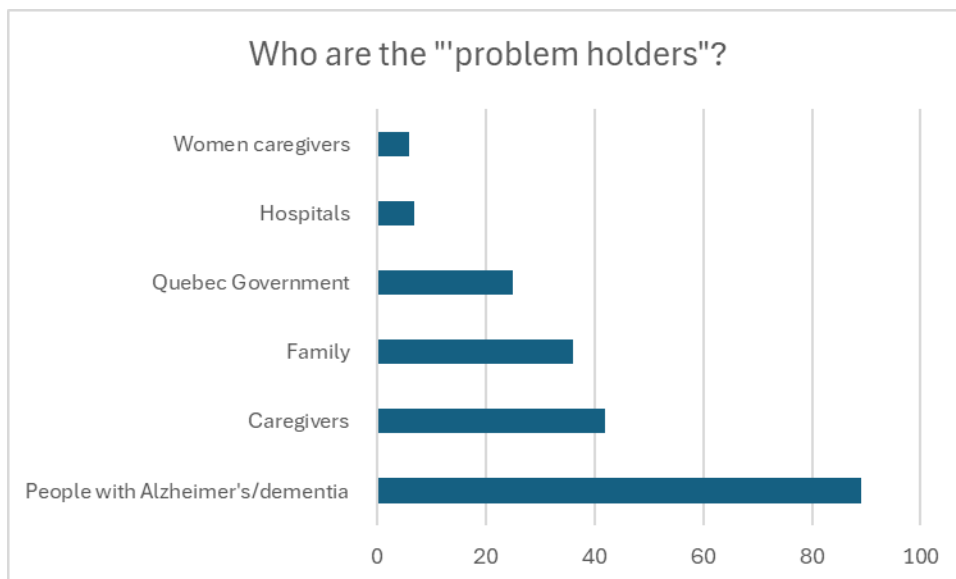


Figure 2

These analysis results pertaining to who holds the ‘problem’ of dementia in Quebec clarify that it is *people with Alzheimer's and dementia*, *caregivers* and, *family* that are largely tasked with holding, or experiencing, the ‘problem’; these are the groups of people who must deal with the day-to-day realities associated with dementia. As problem holders, these three groups play a passive role in that they receive the problem (as opposed to being actors causing the problem). Problem holders of a lesser degree include the Government of Quebec and hospitals.

Based on these codes and textual evidence, the concept of problem holders is underpinned by elements of the social model of disability. To begin with, the first code revealed in the analysis, *people with Alzheimer's and dementia*, necessarily acknowledges that this is a problem primarily experienced by the target group, i.e. people living with forms of dementia. As such, social disability knowledge is fundamental. Those living with disabilities must face challenges in the social structures of society which make living their lives more difficult.²¹⁸ According to the policy text, some of the obstacles that people with dementia in Quebec face include:

²¹⁸ Matthews, 151

“Shortcomings in services provided... Access is still limited to intensive assistance measures to help keep people at home in the advanced stages of Alzheimer’s disease. The number of hours of service offered is limited. There is little flexibility in the nature and modalities of help and respite services.”²¹⁹

This suggests elements of the social model of disability in that the policy text directly addresses the difficulties that *people with Alzheimer’s and dementia* explicitly face when trying to access care, acknowledging how the available infrastructures are insufficient and too slow to address their needs. Similarly, for *caregivers* and *family* problem holders, these groups also face obstacles in the social structure that render their lives more difficult. The QAP notes that:

“Family/informal caregivers receive little support and gradually become exhausted. They often face crises: social crises, intense BSPD, medical emergencies, and so on. These situations demand a fast, appropriate response, but in reality, the response is often very hard to obtain and inappropriate when it does come.”²²⁰

Here the authors explain that the types of crises caregivers and family members are liable to encounter are situations which are challenging, requiring timely, decisive action. That family members and caregivers are more often than not confronted with either facing the crisis or temporarily managing the crisis while waiting for professional support speaks to the structural hardships they face. This calls to attention how these groups of people find themselves in a position where they must witness a loved one being in a state of sickness or crisis, while they simultaneously might be finding themselves in the precarious emotional or physical health situation. Given this, the repeated acknowledgement of the hardships or even burdens faced by family and caregivers in the QAP policy text underscore an appreciation for the social model of disability, specifically in that the text understands that family members and caregivers are, in many ways, the first line of support and defense for people living with dementia, and that it is them who are tasked with navigating the vagaries of the their societal infrastructure (healthcare systems, financial systems, etc.). This aligns with Hosein Abidi’s understanding that the social disability model “focus[es] on the social determinants of health and illness,”²²¹ in that it confirms that the obstacles a person faces can have a significant effect on their health outcomes. This is particularly true in the case of caregivers, wherein while they are providing care for their family member, they themselves can become over-exhausted or ill in the process, especially considering, as the QAP notes, that caregivers often do not receive adequate and timely support.²²² Hence, an awareness of the structural inadequacy of offered support services suggests social disability framing in this context.

The acknowledgement of the difficulties caregivers and family members face as problem holders, and its paradigmatic connection to the social model of disability, also relates to another notion highlighted in the QAP: that is, the importance of affording dignity to all people living with Alzheimer’s and dementia.²²³ The notion of dignity equally reflects contemporary social disability attitudes in dementia discourse which strive to shift the language surrounding disability. As Pia Matthew’s recounts, there is a very real possibility for people with dementia to do more than simply survive; the possibility of living a good life with dementia, especially with the provision of adequate governmental and social support, is achievable. This nods to the social

²¹⁹ Bergman, 31

²²⁰ Ibid

²²¹ Gerhardt, 19

²²² Bergman, 31

²²³ Bergman, ii

model of disability's concern of fighting the structural social inequities that lead to negative health outcomes.²²⁴ In fact, the QAP outlines many ways in which it is concerned with dignity for all three problem holding groups (*people with Alzheimer's and dementia, caregivers, and family*). This is evidenced by many key tenants throughout the policy, which ultimately seek to "support resources, services for people with Alzheimer's and their family/informal caregivers."²²⁵ This being said, the noted lack of resources and support systems leaves problem holders in difficult positions, negating the QAP's aspirational tone of "act[ing] with respect for the dignity and choices of people with Alzheimer's and their families."²²⁶

In summation, when considering the notion of 'problem holders' it is evident that the social model of disability has a crucial role to play in defining who holds the problem of dementia as defined by the Quebec Alzheimer Plan. Social disability knowledge is fundamental in that it acknowledges that *people with Alzheimer's and dementia, caregivers, and family* face societal barriers and inequities that need addressing in order for them to live as well as possible while coping with dementia.

²²⁴ Matthews, 151

²²⁵ Bergman, 14

²²⁶ Bergman, 10

6.4 WHAT IS THE PROBLEM TO RESOLVE?

Analysis results pertaining to what problem the QAP seeks to resolve indicates that the top three problem priorities of the QAP are: *Alzheimer's and dementias* (that is, the diseases themselves), *enhancing quality of life and care* (for people with Alzheimer's and dementia), and *accessing diagnosis, psychological and other medical services* (for people with Alzheimer's and dementia) (See Bar Graph 3). Thus, while this policy outlines that many problems pertaining to dementia care and treatment are essential for problem resolution, it is the illness itself that must be addressed first, followed by improving quality of care and access to care and treatment. Some of the additional codes that came out of this analysis section, such as addressing the stigmatization around dementia, are thematically similar to the top three analysis results in that they support the overall goal of improving treatment, diagnosis and care. In ascertaining what the problems found in the QAP are, all three of these top priorities are circumscribed by largely biomedical and social disability interventions.

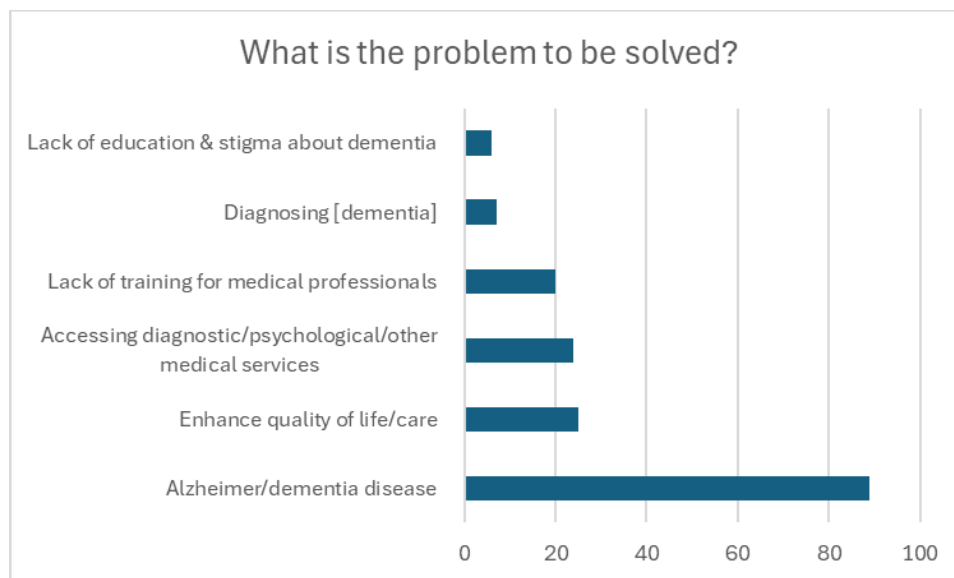


Figure 3

With respect to the first problem, evidence suggests that the ‘problem’ of *Alzheimer’s and dementia* is associated with a biomedical perspective. The policy text is replete with examples of dementia being the foremost problem to be solved. Indeed, defining this problem is primarily conveyed through an interest in improving knowledge pertaining to these neurological conditions, as well as improving access to varied services for both people living with dementia and their caregivers.²²⁷ The text outlines how these objectives are achieved by breaking down tasks into smaller targets. One of these fundamental targets that is mentioned is acting on dementia as a major health problem that needs medical definition. The authors outline the issue at hand in strikingly biomedical terms:

“The nature of Alzheimer’s disease and related disorders are degenerative brain conditions manifested by the progressive, irreversible deterioration of cognition. Individuals generally present with memory loss and diminished reasoning skills, leading

²²⁷ Bergman, 9

to the gradual loss of their ability to perform the tasks of daily living. As the disease progresses, cognitive deficits are accompanied by behavioural and psychological symptoms of dementia (BPSD) that disturb both these individuals and the people around them.”²²⁸

Textual evidence like this sets the tone for describing the problem in medical terms, as opposed to societal terms, nodding to the medical symptoms, physiological changes, and behavioural shifts that present with the disease, rendering societal challenges or biases an afterthought. This definition falls in line with work by other authors, such as Sherzai and Sherzai, who define dementia in biomedical terms as a condition which “impairs memory, thinking, mood and problem solving”²²⁹, equally attributing causation to largely biomedical factors, including poor nutrition, head trauma, smoking, alcohol abuse, inflammation, stress²³⁰, and genetic inheritance.²³¹²³²

This biomedical framing is important to keep in mind for a variety of reasons when addressing the question of the problem to be solved. One of these reasons surrounds the taboo nature of neurocognitive diseases. The Committee of Experts thoughtfully asks us to consider and accept that we live in “a society that is concerned but ambivalent about Alzheimer’s disease,”²³³ with the clear implication being that the populace is concerned about the effects of dementia on their own minds, perhaps particularly even more so knowing that these types of neurological disorders are becoming more prevalent.²³⁴ Because the framing of the problem is set in largely biomedical terms, this lays bare the path for biomedical solutions. Undeniably then, the problem of *Alzheimer’s and dementia* is described in clear biomedical terms, tied into notions of measurement and scientific description that are the bastion of the biomedical model.²³⁵ Philosophically, unveiling the framing of *what is the problem to be solved?* means starting with a particular lens which will structure everything that comes after. Recalling the work of Verloo and Lombardo, the way in which a policy is framed or imagined can “have concrete and material consequences that set the conditions for future actions and realities.”²³⁶ This entails that understanding the problem of *Alzheimer’s and dementia* as being biomedical in nature does not only craft our understanding of the disease as a problem, but defines, to a certain extent, the type of future actions to remedy the problem.

In considering the second problem, *Enhancing quality of life and care*, this problem is more closely related to the social model of disability. Consistent textual evidence supports the notion that this particular problem has social disability philosophical underpinnings. In fact, many key tenets in the policy text explore how fundamental quality of care (and its improvement) is. Some of the ways in which quality of care can and must be improved include: “enhanc[ing] quality of life and quality of care in alternative living facilities; enhanc[ing] quality of life and quality of care at end of life; enhanc[ing] quality of life and quality of care for

²²⁸ Bergman, 1

²²⁹ Sherzai and Sherzai, 19

²³⁰ Sherzai and Sherzai, 18

²³¹ Sherzai and Sherzai, 21

²³² Though they also consider social isolation to be a risk factor for dementia, which would suggest an understanding of the social environments which can precipitate disease.

²³³ Bergman, 1

²³⁴ Bergman, 2

²³⁵ Wade and Halligan, 132

²³⁶ Verloo and Lombardo, 32

family/informal caregivers.”²³⁷ Indisputably, quality of care is valued in the text, putting a focus on providing high level care from the moment a person is diagnosed to the very end stages of the disease. This suggests an understanding of how policy can affect the lived experiences of patients, which in turn thematically points to an understanding of the social elements that help or hinder one’s health—which ultimately is the purview and interest of the social model of disability.²³⁸

With respect to the third problem revealed in the coding, *Accessing diagnosis, psychological and other medical services*, this problem is underpinned by biomedical knowledge. This is evidenced throughout the text in its problem definition, and particularly in instances like the following, in which the text outlines the struggles people living with the disease have in accessing (and understanding the availability of) medical services:

“People with Alzheimer’s disease and their families often have difficulty in accessing the health care and support services that they need. Health and social services professionals often are not fully aware of the range of care and services available and do not know how to guide individuals and their families to them. The results are strong feelings of frustration and a failure to make optimal use of the care and services that are in fact available.”²³⁹

Quite reasonably, the text’s emphasis is on accessing medical care and support services, as this is a fundamental objective required for diagnosis, treatment, and long-term care. In this instance, access to dementia care services is presented as a problem which requires largely biomedical interventions. More specifically, it places the medical professionals in the position of authority. This can be problematic if those professionals are somehow limited or biased in their understanding of what people living with dementia and their family members might require from their access to diagnostic, psychological, and other medical services. This echoes one of the major critiques brought forth by proponents of the social model of disability, such as Ward and Sandberg, in that it highlights how many people with dementia get left “out of broader analyses of disability and ageing”²⁴⁰ when the social and environmental contexts are not properly considered. When the biomedical model is the main lens through which dementia problematization is assessed, it becomes quite possible that many of the services people living with dementia require go unnoticed as the problem is seen through the vector of the biomedical, resulting in a full range of social and societal considerations being potential left unconsidered. Fundamentally, because the goal of the biomedical model remains cure over care, ensuring a more inclusive understanding of patient needs remains an uphill battle.²⁴¹

In summation, elements of both the biomedical and social model of disability define the problems of major problems in the QAP, namely *Alzheimer’s and dementias, enhancing quality of life and care*, and *accessing diagnosis, psychological and other medical services*. This suggests the requirement of biomedical and social disability interventions to describe the problem to be solved in the QAP. While the problems are outlined in primarily biomedical terms, there are some elements of acknowledgement towards the social model of disability, especially when one zeroes in on the importance of mitigating societal barriers to enhancing quality of life and care for people living with dementia and their caregivers.

²³⁷ Bergman, 2

²³⁸ U. Gerhardt, cited in Hosein, 19

²³⁹ Bergman, 16

²⁴⁰ Ward and Sandberg, 2

²⁴¹ Ibid

6.5 WHO IS AFFECTED BY THE PROBLEM?

With respect to who is mainly affected by the problem of dementia in Quebec as determined by the QAP, the analysis results are fairly conclusive and straightforward: *people with Alzheimer's/dementia, caregivers* and or *family* members are those who are significantly impacted by the 'problem' of dementia in the Quebec context (See Bar Graph 4). The analysis results are clear in that only these three groups demonstrated any statistical significance whatsoever in the coding analysis responses to the sensitizing questions pertaining to 'who is affected by the problem'.

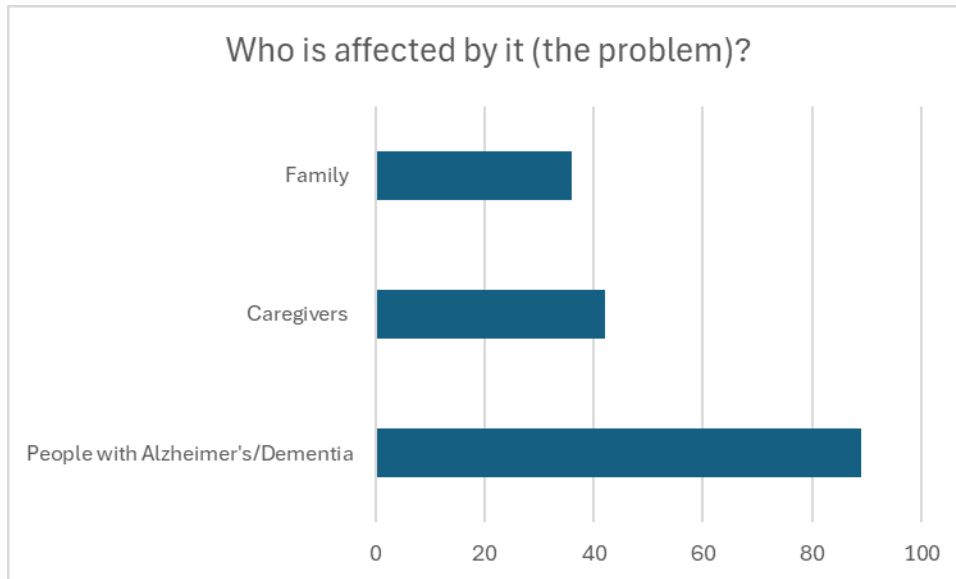


Figure 4

Given that the 'problems' of the QAP, i.e.: *Alzheimer's and dementias, enhancing quality of life and care, and accessing diagnosis, psychological and other medical services* pertain to the people who are affected by it, we can determine that the main paradigmatic connections to be made are equally based upon biomedical and social disability foundations. *People with Alzheimer's and dementias, caregivers* and *family* live in the same policy context which can, at times, result in a dichotomy between the biomedical imperatives of defining and solving for dementia problematization and the equally important social structures and barriers that need to be addressed in order to contend with social disparities and injustices that lead to negative or vastly diminished health outcomes. As Karen A Hyman suggests, this dichotomy exists because the 'psychosocial experience' of dementia requires more social and environmental support than the biomedical perspective allows for.²⁴² In line with this thinking, the policy text outlines some of the structural challenges around public and professional awareness pertaining to dementia and dementia care that exist when only the biomedical model is taken into account—challenges which are absorbed by *people with Alzheimer's and dementias, caregivers* and *family*. According to the policy text:

²⁴² Lyman, 1989, doi: 10.1093/geront/29.5.597

“Health professionals and the general public continue to know very little about the risk factors for Alzheimer’s disease or the protective factors that can delay its negative effects. The same is true for the appearance of symptoms of depression and stress in family/informal caregivers. In this regard, very little is being done as yet to apply and to disseminate information about best practices for prevention and health promotion. But if the knowledge already available were properly applied, it could help delay the onset of the disease, possibly slow its progression, and also ensure a better quality of life for caregivers.”²⁴³

In this, the authors of the QAP acknowledge the extent to which the public and medical professionals are unaware of the physical, emotional and financial factors that could delay or mitigate damage caused in the lives of people living with dementia, as well as in the lives of family members and caregivers. While on the one hand, it could be argued that this points to a social disability framing of who is affected by the problem, the excerpt only points to the medical consequences of a lack of medical awareness and knowledge.

Similarly, the text explores how there are not enough “tools for assessing the [health] status of family/informal caregivers.”²⁴⁴ Knowing that the burden of care that family members and caregivers experience demonstrably impacts their health, especially regarding their psychological and physical health,²⁴⁵ the QAP goes so far as to confirm that “these caregivers thus constitute an “at-risk” group within the healthcare system.”²⁴⁶ Once again, this intimates that who is being affected by the problem is framed in medical terms, explaining how they are at risk for health problems that could require significant medical intervention. Accordingly, *caregivers* and *family* are thus directly affected by all three of the QAP’s top problems (*Alzheimer’s and dementias*, *enhancing quality of life and care*, and *accessing diagnosis, psychological and other medical services*), increasing their chances of requiring medical services.

The sensitizing question pertaining to the framing of who is affected by the problems presented in the QAP demonstrates that these problems are largely framed by the biomedical model, with some elements of the social model of disability. Because *access* remains one of the fundamental challenges described in the policy, the burden falls on the shoulders of *people with Alzheimer’s and dementias*, *caregivers* and *family*. While this is framed as a biomedical issue (as in, getting access to these medical services), a social disability framing would allow for better understanding of the challenges in society that are preventing access. Additionally, although evidence is not found for this particular model in the text in this instance, the continued inability of these groups to access services suggests the defacto existence of elements of the neoliberal model, particularly in that vulnerable citizens are left to their own devices to find healthcare support when services are otherwise limited.²⁴⁷ In a way, this demonstrates that it is once again the same stakeholders, i.e.: *people with Alzheimer’s and dementias*, *caregivers* and *family*, that are up against the medical system as they struggle to access much needed care and treatment in an overly competitive environment.

²⁴³ Bergman, 12

²⁴⁴ Bergman, 44

²⁴⁵ Ibid

²⁴⁶ Ibid

²⁴⁷ Polzer and Power, 4

6.6 WHAT NEEDS TO BE DONE TO SOLVE THE PROBLEM?

In terms of assessing how best to solve the problematization of dementia, the answers are more varied. The coding reveals that the greatest priority is *access to diagnostic/ psychosocial/ other medical services* (See Bar Graph 5). Coming in closely behind this, significant emphasis is put on *providing/improving training* for health professionals to better meet the needs of people living with various forms of dementia. The third greatest priorities are to *help/support family caregivers* to better shoulder the onus of care and the QAP's *Action Plan*. The authors of the policy emphasize that to solve the problem of dementia in Quebec, it is instrumental to follow the steps laid out in their "Action Plan", which is otherwise understood as the core tenants of the QAP policy. These tenets, as described earlier in this work, cover a broad spectrum of ideas and actionable policy decisions.

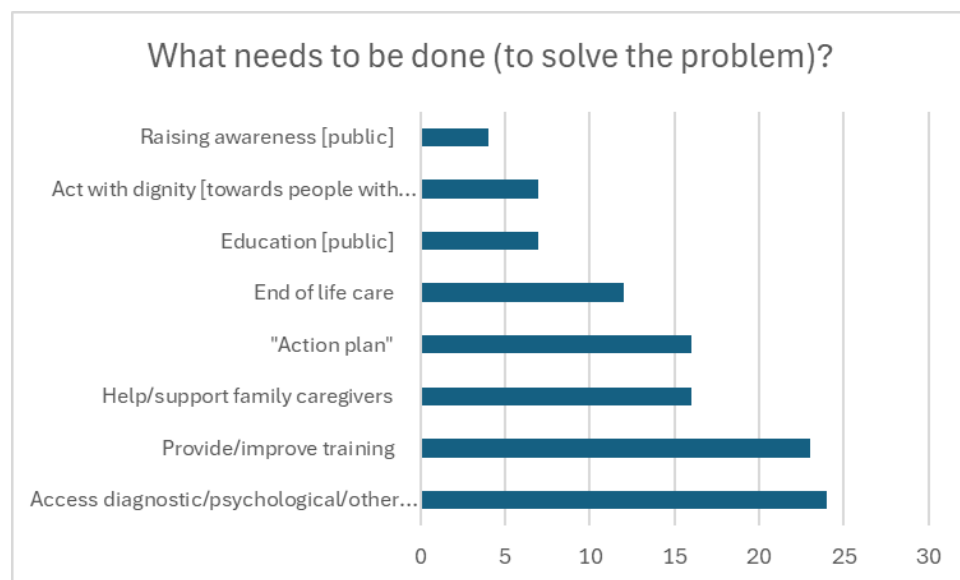


Figure 5

With respect to the question of *what needs to be done to solve the problem?* recall that this question is guided by its inherent sub-questions: What is to be done in order to solve the problem?; What is the hierarchy or priority of goals?; and: How to go about achieving these goals (strategies/means/instruments)? (See Table 1). Accordingly, the coding analysis in this section revealed that the top four codes, *Access diagnosis/psychological/other health services*; *provide/improve training*; and *help/support family caregivers*, *Action Plan*, indicate that dementia problematization is represented by biomedical and social disability frames.

As per the first code, *access [to] diagnosis/psychological/other health services*, a clear connection can be made to biomedical framing. The importance of the biomedical paradigm is evident throughout the text, including in Priority Action 2 (Provide access to personalized, coordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers)²⁴⁸; Priority Action 3 (In the advanced stages of Alzheimer's, promote quality of life and provide access to home-support services and a choice of high-quality

²⁴⁸ Bergman, 16

alternative living facilities)²⁴⁹; and Priority Action 4 (Promote high-quality, therapeutically appropriate end-of-life care that respects people’s wishes, dignity, and comfort).²⁵⁰ These textual examples demonstrate the policy’s commitment to solving this part of dementia problematization through biomedical means. In this case, access to medical services is imperative and arguably represents the most important element in the entire QAP policy text. Quite so, Priority Action 2 relies upon the collaborative care model to help properly diagnose people with dementia.²⁵¹ This is, in many ways, the bedrock of the policy—everything flows from the family medicine group setting. This evokes the biomedical model in that the doctor (and the practitioners within the family medicine group) become the centre of the dementia care universe. As Tosam argues, the biomedical model places decision-making authority in the hand of the medical expert, while “the patient is a passive recipient of treatment, although cooperation with treatment is expected.”²⁵² This aligns with Priority Action 2 in that the patient is receiving treatment, guidance and support mostly through medical means and perspectives. Although the policy text does note that psychosocial needs should be taken into consideration in tandem with pharmacological and medical needs,²⁵³ this does not negate the arrangement that the collaborative care model necessitates “a physician-and-nurse partnership with patients and their families,”²⁵⁴ which invariably reinforce the anchoring of power in the hands of medical practitioners. This kernel at the centre of solving for dementia problematization necessarily relies upon a biomedical framework as it pertains to medicine, diagnosis, and science above all else. While other knowledges might play a role, in terms of this vector of problematization, none can compete with the biomedical model.

With respect to the second code, *provide/improve training*, there is a multiplicity of textual references pertaining to solving dementia problematization through the provision and improvement of training. One of the most notable examples of this is Priority Action 6 (develop and support training programs). In noting that dementia remains a “neglected disease... [having] received scant attention or energy from the health and social service system,”²⁵⁵ it is communicated through Priority Action 6 that much more intensity and energy is required to develop professional training and staff knowledge about dementia.²⁵⁶ Objectives in the QAP underscore the importance of relying on biomedical ideas and structures, such as “linking training to clinical guidelines”²⁵⁷ and the mobilization of academic institutions to further training and study.²⁵⁸ On this point, the text explicates ways in which training and academic institutions can work cohesively to improve medical knowledge. One recommendation highlights how all Quebec post-secondary institutions ought “to provide education on aging, and more specifically on Alzheimer’s disease.”²⁵⁹ Similarly, the text also outlines the way in which the medical, educational, and pharmaceutical communities can harmoniously contribute to improved training:

²⁴⁹ Bergman, 31

²⁵⁰ Bergman, 38

²⁵¹ Healthcare Excellence Canada, 1

²⁵² Tosam, 132

²⁵³ Bergman, 20

²⁵⁴ Bergman, 21

²⁵⁵ Bergman, 49

²⁵⁶ Ibid

²⁵⁷ Bergman, 51

²⁵⁸ Ibid

²⁵⁹ Bergman, 51

“We recommend that the MSSS mobilize universities, 11 professional associations and colleges, the pharmaceutical industry, and the Alzheimer Society to pool their expertise and resources in a coherent, collective effort to establish an extensive continuing professional development operation aimed at the main health professionals who provide care to Alzheimer’s patients.”²⁶⁰

The continued refrain of the importance of training and the exacting selection of medical industries and expertise further supports the notion that the ‘solving’ of dementia problematization involves the medical establishment and its philosophies to an extended degree. This suggests that Ward and Sandberg’s critique of the “long shadow” cast by the biomedical paradigm in the medical field²⁶¹ equally applies to the QAP, wherein medical knowledge and personnel are activated to solve for dementia problematization.

For the third code, *help/support family caregivers*, a clear argument can be made that this solution was guided with a view to addressing the social impacts of dementia on family caregivers, implicating the social model of disability. By way of evidence, consider the most striking example found in the policy text, i.e. Priority Action 5 (Treat family/informal caregivers as partners who need support). This priority action is entirely about defining the problems that family caregivers experience and then finding actionable solutions for said problems. Of the proposed solutions, one notes 1) the creation of a file on the caregiver to keep tabs on their needs as they continue to act as caregivers; 2) supporting local Alzheimer’s support centres, and/or creating them if need be²⁶²; 3) providing respite services²⁶³; and 4) improving upon access and awareness to governmental, social, and financial support programs for caregivers.²⁶⁴ These solutions speak to the social model of disability, highlighting certain injustices or gaps inherent in society’s social fabric that require improvement so as to best support people living with dementia. Given that the social model of disability understands the problem of disability and illness to be found in social structures, as opposed to within the individual,²⁶⁵ these solutions suggest a deep awareness of the struggles that caregivers face vis-a-vis the mental, physical, social and financial trials that may stem from their role as caregiver. Moreover, this intimates a further acknowledgement that both governmental and non-governmental institutions have a role to play in mitigating the deleterious consequences that caregivers face, thereby further compounding the argument that social disability knowledge played a role in the framing of the *help/support family caregiver* solution.

Finally, the fourth code, *action plan* (i.e.: the plan devised by the Committee of Experts to address dementia problematization in Quebec) implicates the biomedical paradigm by virtue of the role that the Committee of Experts played in its creation. In this instance, the ‘solution’ to dementia problematization makes significant room—and deeply relies upon—the vision established in the *action plan*. This plan, which includes the priority actions and recommendations established by the Committee of Experts, does not originate from a theoretical vacuum. Rather, one cannot deny the fact that medical professionals are steeped in biomedical traditions by virtue of their training, which implies that this part of the ‘solution’ has ties to

²⁶⁰ Bergman, 52

²⁶¹ Ward and Sandberg, 3

²⁶² Bergman, 46

²⁶³ Bergman, 47

²⁶⁴ Bergman, 48

²⁶⁵ Matthews, 151

biomedical knowledge. While of course it is important to note that this should not brand the Committee as being pure acolytes of biomedicine, it does follow that biomedicine is an important—if not the most important—element of their medical ethos.

One way in which it is important to explore the connection between biomedicine and the Committee is in acknowledging the privileged status that the Committee had in devising this *action plan*. This calls to mind Patrick Marier's comments about how a special status is granted to medical professionals in the policy making realm; a privileged rank which subsequently squeezes out other actors in the community, including those with different ideological stances who might have valuable insights for policy development.²⁶⁶ While the biomedical framing of dementia problematization and its solutions are important in that they allow for the expansion of medical knowledge and understanding, the other side of the coin demonstrates that medical professionals can at times wear blinders as to their own privileged status, biases and ideational preferences in the policy making arena. On more of a street level, doctors in the family medicine groups might find themselves acting blind through their inability to see the faults in the biomedical paradigm. One such concern is the propensity to underestimate the effect of putting a patient in a passive role in their health journey, which can diminish the patient's sense of agency. Furthermore, as argued by Hewa and Hetherington, a doctor's biomedical viewpoint might lead to assessing the patient in terms of their dysfunctional body part, as opposed to a whole person who has a multiplicity of needs, requiring different analytical viewpoints.²⁶⁷ It is thus important to consider the very real possibility that the Committee, in devising this *action plan*, might not have considered this blind spot inherent in this paradigm.

Summing up, in answering the question of *what needs to be done to solve the problem?* to address dementia problematization in the Quebec context, the philosophical framing of the provided solutions are largely biomedical, with some room granted to ideas that can be associated with the social model of disability of knowledge. This suggests that the stakeholders that represent the biomedical paradigm—medical professionals—have much more of a connection to the ideas surrounding solving dementia problematization than those groups which are more represented by the social model of disability—namely people living with dementia, family members and caregivers. In drawing this conclusion, the concern is that the ideas behind what needs to be done to solve for dementia problematization are overly influenced by biomedical stakeholders who, aside from treating patients, do not have to live with the day to day realities of living with or caring for one with dementia, and hence might not be inclined or primed to think outside of their usual perspective to solve for dementia problematization.

²⁶⁶ Marier, 36

²⁶⁷ Hewa and Hetherington, 134

6.7 WHO SHOULD SOLVE THE PROBLEM?

When addressing the question of who should solve the problem of ‘dementia’, the clearest answer revealed in the coding results is the *Committee of Experts*. This response is followed relatively closely by [health and social service] *professionals*, and then the *Government of Quebec* (See Bar Graph 6). These coding responses, as seen in Bar Graph 6, suggest a strong focus on medical professionals and elected officials [representing policy makers and enactors] charged with problem resolution.

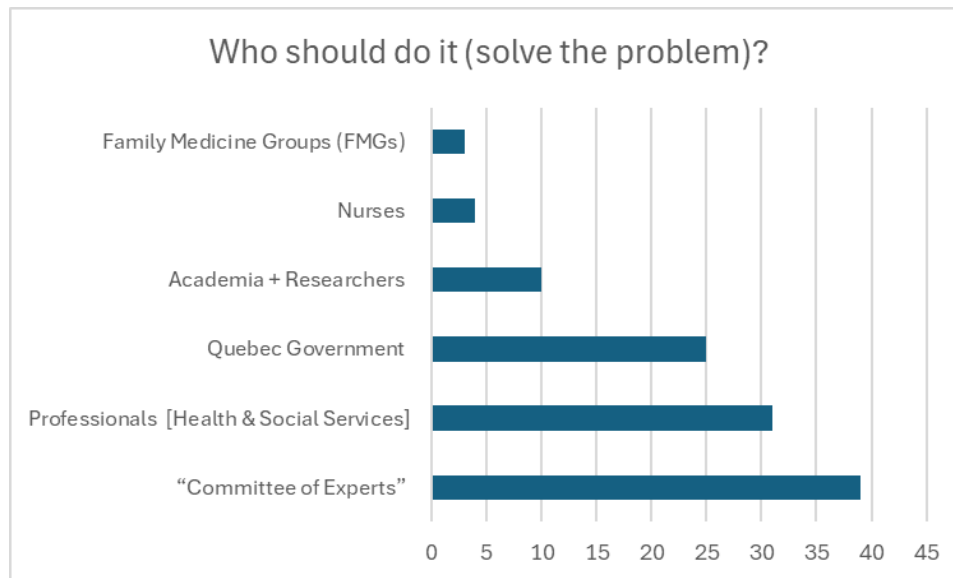


Figure 6

With respect to the second code, [health and social service] *professionals*, the importance is put on providing agency to the key players in society that help deliver medical and social services to people living with Alzheimer’s and dementia. This carries with it a biomedical framing, as, once again, actors that are within the biomedical sphere are empowered to act in lieu of—or with more frequency than—other members of society. Granted, while this code also applies to those in the social service sectors, such as social workers, their work in this domain often carries with it clerical work which relates to the application of biomedical policies (such as a social worker who helps a person living with dementia receive CLSC medical care services). The QAP repeatedly demonstrates its orientation to help medical professionals act in service of people living with dementia. For example, the policy text underscores how crucial it is to “help policymakers, managers, professionals, and other staff in the health-care system to develop their skills in dealing with Alzheimer’s, and support for the definition of optimal care practices;”²⁶⁸ or how important it is to “train physicians, nursing staff, and other professionals in ethical reasoning, palliative end-of-life interventions in cases of Alzheimer’s disease, and the importance of giving families good support and keeping them well informed.”²⁶⁹ While these two examples are different in what they aim to achieve, what they both have in common is the underlying notion that doctors and other medical professionals are the nucleus of all action, and

²⁶⁸ Bergman, 13

²⁶⁹ Bergman, 42

as such, they must be up to speed on their training and practice in order to deliver the best quality of care possible to people living with dementia. Indisputably, providing adequate training to medical professionals in these contexts is a net positive. However, what is perhaps all the more interesting to consider in this instance is how the text — albeit in the service of people living with dementia and their caregivers—reinforces that the medical establishment is the locus of power. This in turn echoes Tossam’s argument that medical professionals are automatically placed in a position of authority over other members of the community, without the guarantee of a discussion on the appropriateness of this conferral of power ever being had.²⁷⁰

Arguably, the more interesting and noteworthy biomedical framing element is found when one considers the other two codes: the *Committee of Experts* and the *Government of Quebec*. As a matter of fact, an interesting connection exists between these two coding results. While technically independent, the *Government of Quebec* code is defensibly based upon biomedical foundations as well when understood that the QAP policy was produced at the behest of the Quebec government with the understanding that medical professionals would compile a strong, actionable policy for dementia care and treatment. In other words, the biomedical connection to the *Government of Quebec* is based on the assertion that in this instance policymakers opted to have the policy defined and designed by medical experts, and that the government subsequently implemented the QAP in its entirety, without alteration or intervention from governmental policymakers.²⁷¹ Furthermore, textual evidence demonstrating the connection between these two codes is abundant. Consider some of the recommendations made by the Committee of Experts. Noteworthy passages include language which demonstrate the authority that the *Committee of Experts* was endowed with by the *Government of Quebec*. These include textual excerpts such as:

“We [the Committee of Experts] recommend that the Ministry of Health and Social Services (MSSS) respond rapidly to the report of the Committee of Experts, define a strategy for implementing its recommendations, and allocate the funding needed to carry this strategy out gradually over the coming six years (through 2015)”;²⁷²

and

“We [the Committee of Experts] recommend that the Ministry of Health and Social Services create a strategic ministerial team to implement, monitor, and follow up on the future ministerial action plan”;²⁷³

and

“We [the Committee of Experts] recommend that the Ministry of Health and Social Services make Alzheimer’s disease a priority challenge for the health and social services system and recognize Alzheimer’s as a chronic disease. The Ministry of Health and Social Services should incorporate its future ministerial action plan into: - the 2010-2015 strategic action plan; - the Québec plan for managing chronic diseases; - the Québec public health program.”²⁷⁴

²⁷⁰ Tossam, 142

²⁷¹ ROSA, Accessed: March 2023. URL: https://www.healthcareexcellence.ca/media/doeexyox/final-5-policy-brief-format-long_en-final-ua.pdf

²⁷² Bergman, 61

²⁷³ Bergman, 62

²⁷⁴ Bergman, 61

These textual examples demonstrate that the *Committee of Experts* is tasked with guiding the policy conversation. Hence, if it is the case that the Committee is directing the government in its policy decisions vis-a-vis dementia, then it is also clear that the framing for both codes is based, to varying degrees, on biomedical imperatives, bearing in mind that the biomedical model is the primary model to which the QAP and its framers subscribe to.

In answering the question of who is endowed with the power to act to solve for dementia problematization in Quebec, these codes demonstrate that the QAP once again has a strong commitment to biomedical knowledge framing. The fact that it is the *Committee of Experts*, [health and social service] *professionals* and the *Quebec Government* that are the most empowered and encouraged to act, in addition to the fact that these actors are mostly relying on biomedical perspectives, is significant for framing outcomes. This is particularly noteworthy to retain when addressing who has the power to act, as the biomedical model necessitates that medical voices remain in a position of authority over the voices of other people in the community, including the very people who are living with dementia. Indeed, it is consequential that in responding to the question of who has agency to act in the fight against dementia, the very people who are living with the illness are not included in the battle as problem solvers. This again echoes the criticism that, according to the biomedical model, people living with an illness are but victims of fate, unable to do anything to help improve their health outcomes except accepting medical advice. In this scenario, they remain passive actors, as opposed to individuals who may have a significant role to play in fighting their disease.²⁷⁵ This fundamentally speaks to a lack of understanding of the human experience of being ‘ill’, and an overlooking of the value of human life at any stage of illness. Thus while activists such as Daithi Clayton remind us of the importance of living a vivid and thriving life despite a dementia diagnosis, the QAP’s framing of who ought to solve dementia denies them the opportunity to participate on equal footing with biomedical practitioners—the latter of which underscores the recurrent dynamic tension inherent in this policy between biomedical stakeholders and social disability stakeholders. While it would be of great use to have more people living with dementia have an active role to play in solving for dementia, the role remains largely in the hands of biomedical experts who potentially lack the firsthand knowledge garnered through experience. Of course, there is significant reason to having biomedical experts speak to dementia problematization (such as their expertise and scientific understanding of disease). The comment being made is that a more balanced perspective on who gets to solve the ‘problem’ of dementia might increase the real agency of people living with dementia to be, where possible, masters of their own destiny.

²⁷⁵ Hewa and Hetherington, 134

6.8 SUMMING UP

After applying the sensitizing questions to address the research question of *How has the QAP been framed?* this Critical Frame Analysis has revealed key insights pertaining to actor(s), voice, problem holder(s), problem(s), target(s) of the problem, solution(s), and solution provider(s). The purpose of the discussion section has been to demonstrate how different vectors of dementia problematization in the QAP have been framed, or what knowledges significantly underpin the way the QAP has been conceptualized. As Rianne Dekker proposes, policy frames in practice are nowhere near as ‘coherent’ as theory would suggest.²⁷⁶ This notion is relevant to this study as the analysis results demonstrate that there are more than one knowledges framing different elements of the policy. According to this analysis, the main framing knowledges are, as ranked in order of importance determined by prevalence: the biomedical model and the social model of disability model.²⁷⁷

This snapshot of the policy text demonstrates that these knowledges have a crucial role to play in how actors’ ‘voice’, ‘problem holders’ ‘problem’, ‘solution’ ‘affected target of the problem’ and the empowered ‘actor’ or ‘solution provider’ are framed. Overall, the main influence on these themes is biomedical in nature. More specifically, this policy evaluation has unveiled that with respect to ‘voice’, the framing has elements of social disability and biomedical knowledges; pertaining to ‘problem holders’, there are clear elements of the social model of disability; ‘problem’ definition according to the QAP is largely underpinned by biomedical and social disability knowledges; the provided ‘solutions’, interestingly is mostly founded on biomedical framing; the ‘affected target’ of the problem is framed by biomedical and social disability knowledges; and finally the role of empowered ‘actor’ demonstrates the QAP’s strong commitment to biomedical framing.

It is interesting to note that the biomedical model, being the dominant framing model to come out of this analysis of the QAP, resonates with pre-existing literature in dementia studies. In acknowledging that the biomedical model has a big role to play in the framing of the QAP, it is also important to acknowledge the inherent power struggle between the main actors of the biomedical model and the social model of disability. Clearly, the important dynamic at play is how the framing empowers some actors at the expense of others; that is, because the biomedical model empowers medical professionals, those who are represented by the social model of disability, namely those living with dementia and their caregivers, are disempowered in some key ways. This is particularly demonstrable when considering ‘voice’, wherein the Committee of Experts retain most voice in addressing dementia problematization; in ‘problem’ definition, wherein the Committee of Experts are tasked with defining the problem of dementia in the Quebec context; and in the problem ‘solution’, wherein the majority of solutions provided by the Committee of Experts are biomedical in nature. Ultimately this amounts to medical professionals having more of a say in charting the path of dementia procedures than the very people who are living with the experience of dementia. It is worth mentioning that this power dynamic echoes my own lived experience, in which I often found my voice at odds with those of medical professionals. Hence, in summing up, it is relevant to retain that the power struggle between

²⁷⁶ Dekker, 129

²⁷⁷ Note: This does not take into account all framing paradigms unveiled from this analysis. Indeed, one framing knowledge, the neoliberal framing paradigm, does play a role in the QAP to a minor extend, but was comparatively statistically less relevant. A more in-depth analysis, I am confident, would provide more context to the neoliberal elements in the policy text.

these two groups, and how the policy's framing can effect the lived outcomes of people living with dementia and their caregivers. Additionally, while the frame analysis shows the good intentions of the Committee of Experts to create a solid policy to support people experiencing dementia, as biomedical practitioners they ultimately (perhaps inadvertently) are more interested in traditional biomedical solutions that revolve around cure and treatment, as opposed to taking an overview of the whole systemic environment of dementia disease, which necessarily also includes non-medical interventions as foundational solutions in dementia care.

CHAPTER 7: GENETIC TESTING: A CLOSE APPROXIMATION OF HOW THINGS WENT DOWN

Fall, 2020.

As if being cooped up in my apartment alone all the time because of covid restrictions wasn't bad enough, it was then brought to my attention that frontotemporal dementia CAN BE GENETIC.

A flurry of forwarded emails volleyed back and forth, with me CC'd in each message.

RE: Genetic Testing for Paul

RE: Genetic Counselling

RE: Zoom Appointment Scheduling

Ugggggh.

Because I was not upset enough at the time, I also had to find it within myself to not yell at random genetic counsellors via email. Nor at my mom, who apparently had information I didn't have.

"We need to see if your dad's dementia is genetic."

"We need to what?"

"We need to see if it's genetic."

"Wait."

"No, we need to see."

"Wait. I don't want to know."

"Of course you want to know. It's not going to be genetic. I'm positive."

"I'm not so sure about that. If it is positive, it'll just ruin the rest of my life."

"No, I know you, you want to know."

"I don't want to know or do any of this."

"Steph."

What followed was surely a temper tantrum, a stream of expletives and hisses, and the strange kind of keening noise that escapes a person's mouth when they really can't voice their emotions anymore but the pain needs to escape somehow. Rarely have I ever been so scared in my

life. If dad had one of the genes they were looking for, it meant that I could have the gene too. If I had the gene... then what?

[As an aside, I will say this: Despite now knowing that my dad does not have one of the genes they know to be associated with FTD, that doesn't mean that my brain doesn't automatically do the math every time I think of ageing. Dad is 62 now. He was diagnosed at 58. I saw symptoms of something—then not knowing what it was—in 2015, when dad would have been 54 years old. At the time, I would have been 27. In 2020 I was 32. The thought process follows accordingly: *Do I only have a solid 20 years left? Less?! Disease sets in before the symptoms are visible to the eye.* If I had the gene, would I be tormented for the next 20 years, waiting for my brain to start turning on me, making me into someone my loved ones don't recognize? Wait, what if I had a young child -oh god, would she have to deal with this, too?! And repeat.]

Anyway, a genetic counsellor associated with the Neuro/MUHC wanted to get dad's genes tested so that they could then be sent off to some head honcho down in the States at this place that deals with FTD, so that they could collate the data for some larger project (of which was never explained to me), to try to determine ... something sciencey. The bitter part of me says that this is typical. Whenever someone gets sick—forgive me—before their user manual says they are supposed to, people get interested. Inquiring minds want to know. I still don't know the exact steps of how this all transpired. Who contacted who? What was the first step?

Back to my inbox.

Before me were all these messages about getting dad's blood and setting up Zoom appointments and getting him to use this placebo inhaler and and and... I was flummoxed.

Stop the carousel, I want to get off, as dad's mom—grandma—used to say.

While they were going on about genes and testing and things far beyond me, I just wanted to tell them to stuff it.

By this point in time I had had enough of these shiny doctors. No, there's no help for your dad. Sorry. Hey, can your dad be a part of our test group—we're trying to see if this medication helps improve mood for dementia patients. Please come to this appointment in the middle of the work week at a super inconvenient time, wait for me in the lobby, and then when you try to ask a question—because I'm a big fancy doctor who works at a big, fancy research institute—I will shush you and hold up my hand to stop you from talking when you try to talk. Imagine that, being shushed as an adult. Is it my round face that gives off the impression that I am someone who can be *shushed*, or is this just standard protocol? Ok, so I'm still upset and a smidge resentful. But in my defense, it did feel like they were using my dad like a guinea pig and I had questions. I had insight. I had to protect dad.

Fast forward a couple of weeks, a blood test, and enough time to conduct the genetic analysis, and poof—dad doesn't have any of the genes associated with the disease. At least none of the ones they know of, yet.

Shortly thereafter I had a zoom call with the genetic counsellor.

My appointment with her remains somewhat of a blur to me. Did we speak only the once—or was it twice? What did we talk about? I know she told me dad didn't have the genes they were looking for, but I somehow have lost account of most of our conversation. My dominant memories revolve around her calming me down because I couldn't keep myself together. By then, I had gotten to a place where tears just came out of me equally on a random Tuesday as to when anyone asked me anything about dad. And so, when I muse on the purpose of the meeting, part of me wonders if it was intended to be a mental health check or if that was that just this particular geneticist's personal touch? We talked about disease and what causes it—and about her own personal conviction that sometimes nature and nurture combine to create a perfect storm and people end up sick. I remember telling her that dad was an anomaly to me. His dad lived to 94. University professor. Sharp till the very end. His mom was still with us at the time, 96, quoting Shakespearean soliloquies every time she got the chance. Those wartime Brits. Greatest Generation. No dementia was going get them alright.

And this wonderful genetic counsellor. I remember telling her:

"I *don't* get it," I said.

She nodded. "It doesn't always make sense."

In an ideal situation, when something doesn't make sense, someone or something guides you through it. A loved one. A teacher. Some sort of spiritual guide. A belief system. A doctor. A counsellor. A friend.

If, in my capacity as caregiver, I have had over 100 interactions with all kinds of people, civil servants, police officers, medical professionals, social workers, community aid groups, lawyers, judges, business owners, neighbours, bankers, family members and other people who aren't coming to mind at the moment—all on behalf of or related to something to do with my father—I would say that my interaction with this genetic counsellor was exceptional. It was exceptional in that, despite my huffing and puffing and temper-tantrum-let's-blow-the-house-down behaviour, she really took the time to assuage my pain and fear. She listened. Frankly, she did more than her job description asked of her. She was human with me.

When I think of dementia care in this province, I think of these kinds of things. I think of these things and I hope that other people are having better experiences than some of our more harrowing ones. I hope that if they aren't, that things will change for the better.

A political science professor once told me that hope is the last refuge of the foolish. I suppose I've been thinking about this for the better part of a decade now. I never quite bought it to be honest, but now I believe it to be the total bunk. Hope is not for the foolish; hope is for those who dare to imagine a world in which things might be just a bit brighter, for those who will get their hands dirty, knowing that they will probably get kicked a lot until something—anything—changes. This genetic counsellor gave me hope. She allowed me to believe that someone in the system could be empathic enough to understand that I was suffering because of my dad's condition. She understood that the caregiver and dementia landscape can be cold and isolating. She

understood that a touch of humanity could go a long way in making the caregiving and grieving process less frightening.

CHAPTER 8: CONCLUSION

This exercise in framing has sought to unveil the ideologies inherent in the Quebec Alzheimer Plan with the view of understanding how the text has been constituted. The analysis results clearly demonstrate that the policy is framed in largely biomedical terms, with some grace given to the social model of disability. While this frame analysis does validate the good intentions established in the policy to help people living with dementia, the Committee of Experts and their biomedical framing of the text ultimately reinforce the notion of cure above systemic change which would break down societal barriers to better health.

When zooming in on the specifics of the policy, it is undeniable that the notion of ‘voice’ is framed in mostly biomedical terms, making medical professionals, particularly the Committee of Experts, the most dominant voice in the policy. This framing has the knock-on effect of edging out the voices of people living with dementia, as well as their loved ones, from the greater (dementia) policy conversation. The framing of ‘problem holders’ retains clear elements of the social model of disability, indicating that the text understands that people living with dementia, caregivers, and family members are the true holders of the problem. The framing of ‘problem’ definition in the QAP is largely underpinned by biomedical and social disability knowledges, suggesting that dementia and access to care are defined in biomedical terms, whereas quality of care is defined in terms that speak to the social model of disability. The provided ‘solutions’ to solving these problems have mostly biomedical framing, especially for improving access to health services and revamping medical training in addition to following the Expert advice as prescribed in the QAP’s *Action Plan*. The ‘affected target’ of the problem is framed by biomedical and social disability knowledges, once again speaking to an understanding of both the biomedical and societal hurdles people living with dementia and caregivers face in coping with neurocognitive diseases. Finally, the role of empowered ‘actor’ to solve the problem demonstrates the QAP’s strong commitment to biomedical framing, particularly in that medical practitioners and the Committee of Experts are offered up as the ideal contributors to addressing dementia problematization in the dementia landscape of Quebec.

These analysis results echo a reality that can be seen from a macro-historical perspective of healthcare policy, one which tells the story of biomedical dominance over the past few centuries. With respect to this thesis, the framing analysis results herein demonstrate the brewing dynamic between the stakeholders that are representative of the biomedical model and those that are more aligned with the social model of disability. As the coding results objectively demonstrate, the QAP policy text reinforces the dominance of the biomedical model in that its framing consistently places voice and agency in the hands of medical professionals over the very people who are supposed to benefit from this policy. This conclusion does not entail that the policy’s authors have made some sort of malignant attempt to disempower non-medical voices, but rather it indicates that an inadvertent biomedical hijacking of the QAP has skewed the range of heard voices and power players in the policy text, resulting in a power struggle between these two camps.

This thesis found its genesis in my own frustration and sadness over dealing with my father’s dementia. In many ways, for a while it felt like I was meeting a dead-end at every turn in trying to look after my dad. Perhaps save for the exceptional encounter I had with the particularly empathetic geneticist, a significant portion of my experiences as acting caregiver to my father have left much to be desired. While I imagine grief of this nature is always clumsy and painful, I am still surprised by how markedly confused, heartbroken, offended, infantilized and even punished some of these experiences made me feel. And in the thick of all of this, I often

found myself wondering about my role as caregiver and how I could best advocate for dad. When it came to speaking on his behalf, I knew that sometimes my voice—my wishes—were heard and respected; at other points I was pretty confident that no one wanted to hear my take, and that my speaking up was actually a hindrance to work getting done; and sometimes I believe my voice was just lost amongst the endless medical paperwork, or maybe drowning at the bottom of a long waiting list.

These deeply personal experiences in conjunction with the framing analysis bring me to an intersection of sorts when it comes to thinking about the Quebec Alzheimer Plan. While I do not mean to suggest a necessary causal link between my experiences and the QAP, what I have seen does leave me critical of the dementia policy landscape in Quebec. With respect to the QAP itself, I am left with a bittersweet taste in my mouth. On the one hand, I am deeply encouraged that experts have taken the time to thoughtfully craft a policy that—at least on paper—redresses inadequacies in dementia care in Quebec. On the other hand—and this is the bitter part—I fear that the text’s overwhelming devotion to the biomedical model ultimately does a disservice to people living with dementia by unintentionally undermining some of the genuinely caring intentions itemized in the plan. Accordingly, I have some scruples about the dementia landscape in Quebec—scruples which I would like to connect to the ideas found in the policy text.

First on the docket: On the ideational front, all framing models are not given the same latitude. This is in great part because the biomedical model is ranked as first among equals in our society. For over centuries now—but particularly over the last 150 years—the biomedical model has found itself in a dominant position in the realm of medicine. The disciplined focus on the minutia of disease, and the scientific application of study to cure and provide disease management has saved countless lives, truly launching the world into a hitherto unseen era of medical advancement. Yet there is more to disease than cure and management. When a person gets sick, they need more than a doctor who will tell them what is wrong with them. Of course, a person will require medical oversight; they will also need nurses to perform checkups, and pharmacists to properly place pills into blister packs; they will need bi-annual rendezvous to monitor the progression of their disease. Without a doubt, all of these elements of treatment are essential. Nevertheless, the more pressing needs of people living with dementia tend to be of a more day-to-day nature. They need someone to sit with them as they uncontrollably panic and cry because their condition has rendered them muddled. They need someone to roll them out of bed when they are depressed and no longer have the will to do so themselves. They need someone who will talk to them like a normal human being when their family members are otherwise occupied with their own lives. They need places to go where they can feel safe and needed, where a warm smile greets them at the door. They need people who will help them when they lose their agency and are confused or frightened. They need people and society to see them as complete human beings, not vestiges of their former selves, or some taboo boogeyman that could get them one day as well. The list could go on. So while the biomedical model is in many ways a modern miracle, it is *not* everything. The biomedical model, in its prioritization of cure above daily care, is not well suited for framing of the quotidian needs of people living with dementia. Knowing this, and knowing that the QAP is centered around family medicine groups delivering medical support for patients, I maintain that this framing will produce a gap with respect to some of the much needed social, psychological, emotional, and economic needs of caregivers and people living with dementia.

As a consequence of the biomedical model being so dominant in the policy text, I also fear that the ‘voice’ of those affected by dementia is lost in some ways. While it is true that the policy text does go to some pains to elaborate the importance of listening to people with dementia and

their caregivers in order to support them through their journey, these examples pale in comparison to the textual references that indicate biomedical framing. It is particularly significant that the QAP has more textual references suggesting the biomedical model in that this shifts the balance of power in terms of who has ‘voice’ in the policy. As it has been demonstrated, the impersonal nature of biomedicine, which prioritizes the voice of the medical professional and a distanced relationship between doctor and patient, might directly or indirectly strip a patient’s voice in medical interactions.²⁷⁸ While this is not ideal for any patient, I fear that it could potentially cause more damage for people who are possibly already losing some of the power of their voice.

A similar issue applies on the policy level. Because the biomedical model places power and authority in the hands of medical professionals (as conferred by the status of their profession)²⁷⁹, the domino effect is that patients, caregivers and other community and social service members are left out of key decision or policy making opportunities. Non-medical persons are simply not accorded the same level of importance, and thus access, to the people and places where decisions are made.²⁸⁰ By not having a seat at the decision-making table, these groups effectively see their ‘voice’ diminished, unfortunately leaving a significant gap in what kinds of issues are brought to the table when it comes to dementia policy-making.

Another scruple pertains to the ease of access of care for dementia patients—or perhaps the more apt way to say that would be ‘the difficulty of access of care’. Because there is a communication chasm between doctor and patient²⁸¹, it is worrisome to consider the impact this has on access to different avenues of care. If the biomedical model is the dominant paradigm in the policy, and if the doctor in the Family Medicine Group is the centre of the Quebec Alzheimer Plan, then I worry about how this will affect the lived experience of people with dementia. Studies on the QAP’s effectiveness are now beginning to report that patients and family members are facing obstacles in receiving different forms of care, specifically due to a lack of communication from health professionals, mainly doctors.²⁸² This is all the more problematic when you consider that this medical hub (FMG) is also responsible for educating and providing patients with information for further social, psychological and medical support. This is a shortcoming to be noted, as it speaks to a key flaw in the biomedical model: that is, training doctors to focus exclusively on scientific, measurable aspects of disease at the expense of other considerations, such as doctor-patient communication, which would include guiding a person through their illness. Certainly, disease management requires an all-hands-on deck approach, one which includes practices that are in line with both the biomedical and social disability framing models. On this point, I recall quite clearly how my own father received his frontotemporal dementia diagnosis through an iPad screen. The doctor explained the scientific aspects of my dad’s condition. He told us how long my dad had to live. I do not recall there being any discussion as to appropriate services that might be of use, or any suggestion as to what our next step should be. This reflection gives me cause for concern when thinking about the QAP because if it is the medical professionals in the family medicine group that are supposed to be directing the show... why did no one direct us when it came to my father’s own diagnosis and treatment? It is easy for me mentally extrapolate how other people, who are potentially in much more trying and vulnerable situations, have

²⁷⁸ Hewa and Hetherington, 134

²⁷⁹ Putsch and Joyce, quoted in Tosam, 142

²⁸⁰ Marier, 36

²⁸¹ Iezzoni, 13-14

²⁸² Khanassov et al., 6-7

similarly found themselves lost and confused and not getting the help they so desperately need. So once again, while I do not interpret this as being a sign of neglect on behalf of the doctor, I do believe that this is indicative of a dominant biomedical framing and its de-prioritization of some of the more human aspects of caring for a patient. In the case of my father's diagnosis via iPad, the doctor was simply doing what he had been trained to do.

Another issue worth addressing is reflective of the relative power of the biomedical model over other framing models. Because the biomedical model is the flashiest of all the paradigms pertaining to health found within the policy text (and also in the context of recent history), I equally worry that the elements of the text that do favour the social model of disability (and provide some paradigmatic balance to the policy text) will not—and do not—get as much traction because they are less politically and societally attractive. There is simply less buzz and interest in addressing social inequities that lead to unwanted health outcomes than there is for finding miracle cures and drugs that treat Alzheimer's and dementia. So although the policy vision laid out in the QAP includes elements of both paradigms, my faith in the power of the social model of disability to match or overcome the sheer might of biomedical model in practice wavers.

In an ironic sort of way, the largely biomedical framing of the QAP reminds me of that joke about a couple of fish swimming around in a fishbowl. One fish says to the other: "How's the water today?" and the second fish replies "What's water?" Expressed differently, it can be very difficult to see a thing for what it is when you are stuck in the thick of it, unable to get a sense of what you are looking at—let alone to start to be able to come to some conclusions as to what elements are involved. I believe this to be the case with the involvement of biomedical framing in the QAP; biomedicine is ubiquitous in the policy text.

In this thesis I have purposefully applied Critical Frame Analysis to the QAP policy text in order to flesh out the ideas and elements that underlie the very structure of the policy. The conclusion that I have ultimately drawn being that the QAP has been hijacked, although not maliciously so, by the idea that the biomedical paradigm and its accordant strengths and tools is the best approach to address the bulk of dementia problematization in the Quebec policy landscape. In many ways, this hijacking-lite does not surprise me. History is replete with examples of dominant ideas shaping policy outcomes, and thereby the everyday lived experience of average people. When studying the history of medicine and health policy, one can trace a direct line going back to when Descartes and his contemporaries first developed the philosophical and theoretical basis for what would become the biomedical tradition. This brought on an era in which the body began to be viewed in dualistic, mechanistic terms²⁸³, wherein a "rising demand for a calculable and predictable interpretation of the world,"²⁸⁴ was expected, setting the foundation for a scientific understanding where the biomedical model would come to shape the modern narrative, rules, techniques and institutions around health policy. While a diversity of ideas tends to strengthen discourse and policy, unfortunately in the instance of biomedicine this shaping has often been done at the expense of other ideas and forms of knowledge. Quite so, one significant critique of the biomedical philosophy highlights its lack of diversity and liberal exchange with other models. This critique stems from academics who point to the historical suppression and exclusion of women and women's knowledge in the biomedical model; women as healers and holders of knowledge were systematically excluded from foraying into the formal medical realm throughout much of the

²⁸³ Soma and Hetherington, 130

²⁸⁴ Ibid

biomedical era, with their knowledge and viewpoints dismissed, usurped, or otherwise misconstrued.²⁸⁵ Over the long run, this has resulted in what Gubela Mji sees as an “absence of balance in these institutions [which] has perpetrated a crisis that now extends alarmingly through all levels of health: from the health of cells, tissues, the mind and relationships to the health of the environment upon which life itself is dependent.”²⁸⁶ Mji’s remark is joined by a growing chorus of voices, such as those of Ward and Sandberg, who see that the long shadow that the biomedical model has cast is not entirely benign.²⁸⁷

So where does that leave the QAP as a policy, and what implications are there for people living with dementia in Quebec? A good *point de repère* to begin this meditation can be found in the dedication of the QAP. As the Committee of Experts explain:

“Throughout our work on this action plan, we never forgot for whose sake we were developing it: people with Alzheimer’s disease and related disorders and their families. The members of the Committee of Experts devote a significant portion of their professional practices to these individuals, so it is no exaggeration to say that this disease affects us too, and all the more so because we are recommending a profoundly humanistic approach focused on the individual and on excellence in care”²⁸⁸

From the very initial stages of this policy, the intention of developing the plan has been to support modes of care and treatment that reflect humanistic values, thereby supporting those whose lives are directly impacted by dementia in Quebec. While this ethos is remarkably humane, it is at odds with the overpowering elements of the biomedical model in the policy text. Though the biomedical model in itself can produce extraordinarily positive results for patients, its almost autocratic displacement of other framing devices can lead to negative consequences for the very people the Committee of Experts aim to help. As such, in answering the question *where do we go from here?* I contend that more awareness around the pitfalls of the biomedical model as applied to the QAP policy text is required. Although beyond the scope of this thesis, further work ought to consider how to protect the non-biomedical elements of the policy text from being overtaken by the priorities and sway of the biomedical priorities.

The QAP remains an important policy text. It aims to help a vulnerable population process a very difficult life event. The text covers the full range of policy considerations that need to be made to improve living conditions for people with dementia, from broad notions that tackle the stigmatization of dementia, to the institutional action required to facilitate life for those living with dementia, to key medical interventions needed for diagnosis and care.

The QAP being a first of its kind in the Canadian context sets the blueprint for what a domestic dementia policy could look like. As such, this thesis has sought to understand the key ideas that are in the very fabric of the policy. Understanding the foundational building blocks of this policy allow us to deconstruct the power players and paradigms that are most represented in this text. This analysis has shown that the main players and paradigms found in this policy text are medical professionals and people living with dementia, respectively represented by the biomedical

²⁸⁵ Mji, 75-76

²⁸⁶ Mji, 75

²⁸⁷ Ward and Sandberg, 3

²⁸⁸ Bergman, ii

and social disability paradigms. Largely speaking, these stakeholders can be separated into two groups, with the medical professionals aligning more closely with the biomedical perspective and people living with dementia and their caregivers aligning more with the social model of disability. Notably, there is an inherent tension between these stakeholders. While medical professionals, according to the biomedical model they are so deeply entrenched in, are tasked with curing or treating symptoms, the people actually experiencing dementia in one way or another are confronted with the more arduous task of getting on while living with dementia. The latter is no small feat, and often the needs of these people would be better spoken for in social disability terms. Hence, the trick going forward will be to acknowledge the role that the biomedical model plays in the framing of the policy and its inherent strategies for tackling dementia care, and to subsequently find a way to balance the biomedical model with some of the other models inherent in the text, primarily the social model of disability. This is particularly true when considering the impact on the main stakeholders affected by dementia problematization, dementia patients and caregivers, who would benefit from having their voice heard more clearly. In many ways, this thesis represents a reclaiming of my voice as a caregiver; I could only wish the same for anyone else going through this process.

This thesis has also considered the notion of dignity in the QAP. This evaluation has shown that dignity is an important concern in the QAP policy text. The story of the QAP is ultimately one which hopes to, through biomedical and social disability interventions, improve outcomes for people living with dementia. I have sought to bring forth the notion of dignity through this policy evaluation and in telling the story of my own lived experiences. Future research might build upon the frames inherent in this policy in conjunction with the stories of people who have intimate experience with the QAP to determine further possible connections and elucidations between the two. Similarly, future work might also investigate how the QAP's framing has affected people's lived health outcomes. A final area of future research might be to investigate how the framing of the QAP interacts with structural and resource realities in the province. An intriguing point of departure might be the juncture where framing and lack of resources meet. Particularly, it would be fruitful to investigate how the framing of the problem of dementia as a largely biomedical issue to be solved by biomedical interventions (such as diagnosis through family medicine doctors) interacts with the structural reality that more and more Quebeckers do not have a family doctor.

LIMITATIONS OF THIS WORK

This work has sought to investigate the framing inherent in the Quebec Alzheimer Plan through a Critical Frame Analysis methodology. While I have managed to achieve a broad framing analysis, with broad codes, this work is limited in that more specific framing codes could not be assessed due to time and resource limitations.

Moreover, this work is also limited in that it is a single study, as opposed to a comparative study. The QAP policy text in of itself is quite substantial. As a result, there were limits in terms of what I could evaluate on my own, as a solitary investigator, in a constrained time period. While this does mean that a thorough evaluation of the document has been conducted, this work is limited by a lack of comparative analysis that might have shed more light on the overall dementia healthcare policy context. For example, it would have been very informative to be able to compare the QAP with other dementia plans, such as the federal framework on dementia. This might have resulted in a more comprehensive understanding of the similarities and differences in framing ideologies that underpin these documents, thereby granting a more concrete understanding of how Canada conceptualizes dementia as a problem, and its concordant solutions.

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