# Back to basics: everyday ethics and patient-centred care
## Bridging the concepts through Parkinson's disease patient perspectives

Natalie Alexandra Zizzo
Department of Experimental Medicine, Biomedical Ethics Unit
McGill University, Montreal

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Master of Science.

# TABLE OF CONTENTS

# LIST OF TABLES

# LISTS OF FIGURES AND BOXES

# LIST OF ABBREVIATIONS

PD: Parkinson’s disease
PCC: patient-centred care

# ABSTRACT

Research in bioethics has often focused on issues surrounding life and death. These more ‘dramatic’ ethical issues are considered ‘exciting’, are often tied to new technology and novel interventions, and can receive widespread media attention. Certainly, these issues are challenging and important to consider as they can have impactful consequences. However, there are many other ethical issues that arise within health care that have profound consequences. These issues are situated in the day-to-day experiences of healthcare practitioners, patients, caregivers, and researchers, and have sometimes been referred to as everyday ethics.

The work presented in this thesis is concerned with the everyday ethical issues that arise in the provision of care. In particular, this thesis focuses on everyday ethics for Parkinson’s disease patients in a patient-centred care clinic. The particular experience of Parkinson’s disease patients was considered likely to encounter everyday ethical issues. Furthermore, the context of patient-centred care provided an ideal paradigm from which to conduct this research, as it emphasizes the importance of patient perspectives in the provision of care.

We identified a particular knowledge gap in the understanding of Parkinson’s disease patient preferences for involvement in healthcare decision making. To fill this knowledge gap, qualitative research involving in-depth interviews with Parkinson’s patients was conducted. We found that overall, patients preferred shared decision making, although preferences for decisional control varied between individuals and depending on the decision, context, and relationships. Patient preferences for information were more stable, with most patients wanting information, although limits to provision of information were identified. The importance of the patient-physician relationship and communication was emphasized, and patients were found to support a relational approach to care.

We found that Parkinson’s patients described some issues in the provision of their care that could be considered everyday ethics. To unpack the concept of everyday ethics, we conducted a scoping review that reviewed how the term has been utilized in the literature, and identified its core features. To advance the concept further, we developed an integrative model of everyday ethics, drawing from various normative theories. We also conducted a scoping review of the Parkinson’s disease bioethics literature, to examine the extent to which everyday ethics is being discussed in this particular context, and found that everyday ethics makes up a minority of the discussions in this literature. This work highlighted the importance of everyday ethics, as well as the fact that everyday ethics remains under discussed.

The findings in this thesis point to the utility of patient perspectives for insight into everyday ethics and patient-centred care. Indeed, patient-centred care and everyday ethics are ideally suited to inform each other, and both can utilize patient perspectives to gain insight into theory and practice. Patient-centred care and everyday ethics are united in that they focus on the patient experience, and both aim to improve care by addressing ethical issues relevant to the patient. Increasing the focus of bioethics on everyday ethics and patient perspectives is recommended, as it can help us to address the most salient and pressing issues in health care and better promote respect for persons.

Keywords: bioethics, everyday ethics, patient-centred care, patient perspectives, patient preferences, Parkinson's disease

# RÉSUMÉ

La recherche en bioéthique a souvent été concentrée sur les questions de la vie et de la mort. Ces enjeux éthique « dramatiques » sont captivants, sont souvent liés aux nouvelles technologies et aux nouveaux traitements et peuvent faire l'objet des médias. Certes, ces enjeux éthiques peuvent avoir des conséquences percutantes, donc ils méritent considération et discussion. Cependant, il y a beaucoup d'autres enjeux éthiques qui ont aussi des conséquences profondes dans le contexte des soins de santé. Ces enjeux sont situés dans les expériences quotidiennes des professionnels de la santé, des patients, des aidants naturels et des chercheurs de la santé. Ce genre de problèmes est parfois nommé l'éthique du quotidien. Cette thèse s'attarde aux enjeux éthiques qui se produisent dans la prestation des soins quotidiens. En particulier, cette thèse se concentre sur l'éthique au quotidien pour les patients atteints de la maladie de Parkinson dans une clinique de soins centrés sur le patient. Nous nous intéressons à l'expérience des patients atteints de la maladie de Parkinson car il est fort probable de rencontrer des enjeux éthiques quotidiens dans les soins chroniques nécessaires pour leur maladie. De plus, une clinique de soins centrés sur le patient offre un contexte idéal pour mener cette recherche car elle met l'accent sur les perspectives des patients.

À cet égard, nous avons identifié une lacune en matière des connaissances quant à la compréhension des préférences des patients atteints de la maladie de Parkinson en ce qui a trait à leur participation dans la prise de décisions de santé. Pour combler cette lacune, nous avons mené une recherche qualitative basée sur des entrevues avec les patients atteints de la maladie de Parkinson. Nous avons constaté que ces patients préfèrent un modèle de prise de décision partagé. D'abord les préférences pour le contrôle décisionnel varient parmi les individus et selon la décision, le contexte ainsi que les relations interpersonnelles en cause. Les préférences des patients pour les informations au sujet de leur maladie sont plus établies; la plupart des patients veulent des informations, avec quelques limites. L'importance de la relation médecin-patient et de la communication a été soulignée de manière générale et les patients ont soutenu une approche relationnelle aux soins.

Nous avons remarqués que les patients ont décrit des enjeux éthiques dans la prestation de leurs soins que nous considérions relever de l'éthique du quotidien. Afin d'améliorer compréhension de ce concept d'éthique quotidienne, nous avons mené une revue de survol de la littérature (« scoping review »). Cette recherche a examiné la façon dont le terme «éthique au quotidien » a été utilisé dans la littérature, et a identifié ses caractéristiques fondamentales. Afin d’avancer le concept, nous nous avons servi de diverses théories normatives pour  développer un modèle intégré de l’éthique du quotidienne. Nous avons également mené une revue de survol de la littérature bioéthique associée à la maladie de Parkinson. Pour ce compte rendu, nous avons voulu examiner l’étendue de la littérature et voir si l’éthique du quotidien y est discutée. Nous avons trouvé que l'éthique du quotidien comprend une minorité des discussions dans cette littérature. Ce travail a mis en évidence l'importance de l'éthique du quotidien, ainsi que le fait que l'éthique du quotidien est peu discutée.

Les résultats discutés dans cette thèse soulignent l’utilité d’effectuer des recherches sur les perspectives des patients. Ces perspectives peuvent approfondir nos connaissances et notre compréhension des enjeux éthiques quotidiens et des soins centrés sur le patient. En effet, les soins centrés sur le patient et l'éthique du quotidien sont idéalement adaptés pour s’informer l’un l'autre, et les deux peuvent utiliser les perspectives des patients pour mieux comprendre la théorie et la pratique. Les soins centrés sur le patient et l'éthique du quotidien sont unis en tant que les deux mettent l'accent sur l'expérience du patient, et les deux visent à améliorer les soins en abordant les enjeux éthiques pertinents pour le patient. Mettre  davantage l'accent sur l'éthique du quotidien et les perspectives du patient dans le cadre de la bioéthique est recommandable. Ceci pourra nous aider à résoudre les problèmes les plus proéminents et les plus urgents dans le cadre des soins de santé et pourrait mieux promouvoir le respect des personnes.

Mots-clés : bioéthique, éthique au quotidien, soins centrés sur le patient, perspectives des patients, préférences des patients, maladie de Parkinson

# CONTRIBUTIONS OF AUTHORS

**Manuscript 1:** *What a patient wants: Examining Parkinson's disease patients' preferences for involvement in healthcare decision making in a patient-centred care clinic*
**Authors:** Natalie Zizzo, Emily Bell, Anne-Louise Lafontaine, Eric Racine
EB and ER conceptualized the project and were the main contributors to study design. NZ and ALL contributed to designing interview questions. NZ recruited patients and conducted all interviews. NZ led coding guide development with input from ER and EB. NZ was the primary coder, EB reviewed coding, and ER arbitrated disagreements in coding. NZ led content analysis with input from EB and ER. NZ prepared the first draft of the manuscript, including all tables and boxes. EB and ER contributed equally to the development of the manuscript, ALL gave critical input on later drafts of the manuscript. All authors agreed on the final version of the manuscript presented in this thesis.

**Manuscript 2:** *What is everyday ethics? A review and a proposal for an integrative concept*
**Authors:** Natalie Zizzo, Emily Bell, and Eric Racine
NZ led the scoping review and the writing for the first part of the manuscript ("What is everyday ethics" and "What is the significance of everyday ethics?"), and Table 4.1-1. ER led the writing for the second part ("Proposal: An integrative model of everyday ethics") and created a draft of Tables 4.1-2 and 4.1-3. NZ refined Table 4.1-2. NZ and EB developed Figure 4.1-1 together and refined Table 4.1-3. All authors contributed to the critical revision of the manuscript and agreed on the final version presented in this thesis.

**Manuscript 3:** *What do we talk about in bioethics? A characterization of the Parkinson's disease literature and an examination of everyday ethics*
**Authors:** Natalie Zizzo, Emily Bell, and Eric Racine
NZ led the scoping review and was the primary coder. ER reviewed all coding. NZ led content analysis, the writing of the manuscript and prepared all figures and tables. ER and EB contributed to content analysis and critical revision of the manuscript. All authors agreed on the final version presented in this thesis.

# ACKNOWLEDGMENTS

This thesis would not have been possible without the support of many exceptional individuals.

First and foremost, I would like to sincerely thank Dr. Eric Racine, for first taking me on as an undergraduate intern, and then supervising me as a graduate student. His guidance, support, and encouragement over the past two years have been invaluable.

I would also like to thank Dr. Emily Bell, who has not only contributed to the research and manuscripts presented in this thesis, but whose support and advice have been instrumental to the development of this thesis. She is a trusted sounding board whose guidance I appreciate greatly.

Additionally, I must thank my colleagues at the Neuroethics Research Unit, and in particular John Aspler, Dearbhail Bracken-Roche, and Victoria Saigle, who all generously provided editorial support for portions of this thesis.

My thesis committee members, Dr. Matthew Hunt, Dr. Anne-Louise Lafontaine, and Dr. Artur Kania, must be thanked for their advice and feedback on earlier stages of this work.

Moreover, I would like to thank the staff at the movement disorder clinic where participant recruitment took place, and most importantly the patients who generously shared their time, perspectives, and experiences with me. Without these individuals this work would not have been possible.

Finally, I would like to thank my family, friends, and Andrew Lingard, for their endless support in this endeavor, for tirelessly engaging me in my ideas and work, and for always encouraging me.

Financial support for the conduct of this research comes from the Canadian Institute of Health Research, a Master's award from the Fonds de la recherche en santé du Québec (in partnership with Unité SUPPORT du Québec), and an Institut de recherches cliniques de Montréal Joseph Paulin Scholarship.

# NOTE ON PRONOUNS

The singular pronoun “I” is used to describe research and work undertaken by Natalie Zizzo. The plural pronouns “we” and “our” are used to describe research and work undertaken by Natalie Zizzo and co-authors.

# INTRODUCTION

Research in bioethics has often focused on issues surrounding life and death. These more ‘dramatic’ ethical issues are considered ‘exciting’, are often tied to new technology and novel interventions, and can receive widespread media attention [1, 2]. Certainly, these issues are challenging and important to consider as they can have impactful consequences. However, there are many other ethical issues that arise within healthcare that have profound consequences, but that are under discussed and do not receive widespread attention [2-4]. These issues are often situated in the day-to-day experiences of healthcare practitioners, patients, caregivers, and researchers, and have sometimes been referred to as everyday ethics. The work presented in this thesis is concerned with these everyday ethical issues that arise in the provision of care. In particular, this thesis focuses on everyday ethics for Parkinson’s disease (PD) patients in a patient-centred care clinic. Patient-centred care is a model of care that has been endorsed specifically for PD populations [5]. It emphasizes treating patients as persons, considers the patient’s unique life experiences and perspectives, and engages patients in decision making. PD is a common neurodegenerative illness, requiring chronic care and regular interactions within the healthcare system. As a result, PD patients and those that care for them are likely to encounter everyday ethical issues.

This thesis explores how patient-centred care and everyday ethics can inform each other, and how both can utilize patient perspectives to gain insight into theory and practice. This is achieved through an examination of PD patients’ perspectives on decision-making processes, since engagement in decision-making is emphasized in patient-centred care and is a potential source of everyday ethical issues.

In Chapter 1, *Literature Review*, the concept of patient-centred care is unpacked. Definitions and models of patient-centred care are reviewed, and the key features of patient-centred care are extracted. Patient-centred care focuses on the patient’s experience in the delivery of care and has instrumental and moral value. Discussions of how to implement patient-centred care are examined, and the emphases on patient-centred communication, shared decision making, and relational autonomy are reviewed. Patient perspectives are central to patient-centred care, so patient preferences for care are investigated. Their preferences for involvement in healthcare decision making are of particular interest, given that engagement in decision-making is emphasized in patient-centred care and that the theoretical literature suggests shared decision making and relational autonomy are ideals in this model of care [6, 7]. Research in various populations suggests that there is variability in how patients want to be involved in making decisions about their care, but that most want to be informed [8, 9]. Nonetheless, there is a knowledge gap related to a lack of research on Parkinson's disease patient preferences for involvement in healthcare decision making. Research presented in this thesis aims to address this gap. We recognize the potential for everyday ethical issues to surrounding decision-making processes, and thus view an investigation into preferences for these processes as a window into enhancing understanding of both patient-centred care and everyday ethics.

In Chapter 2, *Methods*, our epistemological background and main research goals are described. This thesis includes three manuscripts, and the methodologies for each are reported. Manuscript 1 investigates PD patients' preferences for involvement in healthcare decisions using qualitative research methods. Manuscript 2 explores the concept of everyday ethics; the first half of the manuscript details the results of a scoping review, and the second is a conceptual exploration of everyday ethics. Manuscript 3 characterizes the PD bioethics literature to examine if everyday ethics is discussed, also using scoping review techniques. The reasoning for and details of these methodologies and their limitations are included in this chapter.

In Chapter 3, *Exploring Parkinson's Disease Patient Preferences*, Manuscript 1 is presented. This manuscript, entitled *What a patient wants: Examining Parkinson's disease patients' preferences for involvement in healthcare decision making in a patient-centred care clinic* presents the results of qualitative research with a sample of Parkinson's disease patients. The main findings of this research are that patients prefer shared decision making, although preferences for decisional control vary between individuals and are decision-, context-, and relation- dependent. We examine patient perspectives on the patient-physician relationship, identifying important interpersonal skills for the physician and responsibilities for the patient, and find that communication is regarded as central to the therapeutic relationship by patients. We find that most patients want information in decision-making processes, and investigate patients' most utilized sources of information and the types of information they sought from those sources. Limits to the types and amounts of information patients want are also explored. The manuscript concludes with an examination of how patient perspectives can expand our understanding of healthcare decision making, and finds support for relational autonomy in patient-centred care.

Chapter 4, *Exploring Everyday Ethics,* is divided into two parts. In Part One, Manuscript 2, *What is everyday ethics? A review and a proposal for an integrative concept,* is presented. This manuscript reviews the existing literature on everyday ethics and finds diverse definitions and descriptions of the term, and identifies four core features of everyday ethics. The significance of everyday ethics is explored and a normative imperative to investigate everyday ethics is described. Finally, we make a proposal for an integrative model of everyday ethics that draws from multiple normative theories. This model helps to shed light on everyday ethical issues in bioethics and clinical practice, and has theoretical, methodological, practical and pedagogical implications.

In Part Two, Manuscript 3, *What do we talk about in bioethics? A characterization of the Parkinson's disease literature and an examination of everyday ethics,* is presented. This manuscript characterizes the Parkinson's disease bioethics literature and classifies it based on the context in which it discusses bioethics. It corroborates claims that everyday ethics is under-discussed in bioethics and finds that dramatic ethics dominates discussions in the PD bioethics literature. This manuscript identifies a potential wealth of topics that could be explored in bioethics relevant to Parkinson's disease, and raises questions as to why everyday ethics is under-discussed.

Finally, Chapter 5, *Discussion and Conclusion,* connects the concepts of everyday ethics and patient-centred care. Both are identified as being informed by patient perspectives. In particular, patient perspectives can provide insight into patient-centred care theory and practice. For everyday ethics, investigations into patient perspectives can reveal specific issues. The overlap between the implications of everyday ethics and patient-centred care practice is discussed, and everyday ethics and patient-centred care are viewed as being able to inform each other.

Thus, this thesis covers a number of topics, including patient-centred care, patient perspectives and everyday ethics. These topics are united in that they focus on the patient experience, and all aim to improve care by addressing ethical issues relevant to the patient. Patient-centred care can provide an ideal platform for researching everyday ethics. Increasing the focus of bioethics on everyday ethics and patient perspectives can help us to address the most salient and pressing issues in healthcare for key stakeholders and improve the ethical provision of care.

# CHAPTER 1: LITERATURE REVIEW

## Introduction

Parkinson's disease (PD) is a common neurological disorder that affects approximately 100,000 Canadians [10] and 7-10 million individuals worldwide [11]. This degenerative disease causes progressive motor impairments as well as possible psychiatric and cognitive co-morbidities as it advances. Recently, there has been a call for PD treatment to be delivered within a patient-centred model of care [5]. Patient-centred care is respectful of and responsive to patients' wants, needs, and values, and aims to have patient preferences guide clinical decision-making [12]. However, implementing patient-centred care can be challenging, especially given the current lack of understanding on PD patients' perspectives, values, and care preferences [13-16]. In particular, how patients want to be involved in decision-making processes remains unclear [9, 17, 18].

In this chapter, I examine what patient-centred care is, reviewing its various definitions and key elements, and consider why it should be implemented, exploring its moral and instrumental value. I look at how patient-centred care can be operationalized, and in particular examine its implications for communication, autonomy, and decision making processes. Furthermore, given the central role of patient preferences in patient-centred care, I review the literature investigating patient preferences for decision-making processes and communication of information. Finally, I examine the particular push for patient-centred care in the context of Parkinson's disease, and look at the specific evidence on PD patient preferences. This chapter concludes with the identification of a knowledge gap in understanding PD patient preferences for involvement in decision-making.

## What is patient-centred care?

The concept of patient-centred care was first introduced in the 1950s by Balint [19] and was characterized by its emphasis on understanding the patient as a unique human being [20]. McWhinney (1989) also gave a broad description of patient-centred care, describing it as entering the patient's world and seeing the illness through the patient's eyes [21]. Similarly, Gerteis et al. (1993) highlighted patient-centred care as being consistent with, and responsive to, patients' wants, needs, and preferences [22].

One of the most comprehensive and frequently cited descriptions of patient-centred care comes from Stewart et al. (2003). These authors viewed patient-centred care as (1) exploring both the disease and the experience of having the illness; (2) seeking an integrated understanding of the patient's world at the individual, relational and contextual levels; (3) finding common ground regarding the health problem and its management; (4) incorporating prevention and health promotion; (5) enhancing the patient-physician relationship; and (6) addressing realistic personal limitations, such as availability of time and resources [23].

The Institute of Medicine (2001) also adopted a more comprehensive model of patient-centred care, one originally developed by Gerteis et al. (1993). This model includes: (1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) effective education of and communication to patients, where trustworthy information is delivered in a manner that is attentive, responsive, and tailored to an individual's needs; (4) provision of physical comfort that is timely and adapted to each patient's needs; (5) provision of emotional support, to help alleviate fear and anxiety, and to care for the patient; and (6) involvement of family and friends, in recognition of the important role these relationships play in the lives of patients [12, 22].

As its name suggests, patient-centred care focuses on keeping the patient *central* to care, and it shifts the focus from disease to person. In fact, patient-centred care has been viewed as an attempt to change the tendency for health care to be too disease-, system- and/or staff-centred [24], and it has been contrasted to biomedical models of care [25]. A biomedical model of care does not dedicate time to examine a patient's experience of their illness, but instead reduces their illness to a set of signs and symptoms that can be investigated, interpreted, diagnosed, and treated, thus curing the patient and solving the problem [25]. In contrast, patient-centred care calls for a view of illness from the biopsychosocial perspective. This perspective views disorders as existing at different levels that interact with each other (biological, psychological, and social) and does not view illness (i.e., the experience of being unwell) and disease (i.e., the pathology that can cause illness) as coterminous [25].

Importantly, patient-centred care has been juxtaposed to biomedical models of care in five specific ways: (1) patient-centred care calls on healthcare practitioners to view patients from a biopsychosocial perspective; (2) it stresses the importance of the patient-as-person, underscoring the need to understand the patient as "an experiencing individual rather than the object of some disease entity" [25, p. 1089]; (3) it involves the clinician sharing power and responsibility with patients, encouraging patients to have increased involvement in their care; (4)

it emphasises a “therapeutic alliance”, signalling a need to develop a relationship between clinician and patient, and requires a common understanding of the goals and requirements of treatment; and, finally, (5) it notes the importance of recognizing the doctor as person, and that the doctor and the patient influence each other. These points dispel suggestions from the biomedical model of care that there is no theoretical reason why equally trained doctors are not interchangeable, and makes room for considering the roles of subjectivity, context, and relationships in patient-centred care.

Thus, in patient-centred care, the patient is not viewed as merely an object experiencing various signs and symptoms but as a fully formed person with a personal history, relationships, and contextual factors that influence how they experience illness and disease. In this way, patient-centred care shifts the focus of healthcare from treatment of disease to treatment of persons. Patient-centred care underscores the unique life and illness experience of the individual, and focuses on providing care that honours this individuality. This need to adapt care to individual patients requires the development of relationships between practitioners and patient. These descriptions make it apparent that the central idea of patient-centred care is the treatment of patients as persons.

## Why patient-centred care?

Patient-centred care has been endorsed by the Canadian Medical Association [26], the United States’ Institute of Medicine [12], and has been recognized internationally by bodies such as the World Health Organization [27]. In fact, patient-centred care has been described as “the cornerstone of good medical practice” [26, p. 1] and the Institute of Medicine has called it a key element to improving the quality of healthcare [12]. Thus, it is clear that patient-centred care is broadly supported, but the value of patient-centred care remains unclear. To understand the justification of patient-centred care, its instrumental benefits and moral value can be explored.

Studies of patient-centred care have found that it can lead to increased patient and healthcare provider satisfaction [28], improved patient adherence to treatment, improved health outcomes, improved self-reported health and physiological status [29, 30], and decreased healthcare costs [31, 32]. Furthermore, a Cochrane review has found that interventions to promote patient-centred care in clinical contexts can have beneficial effects on patients’ health behaviour and health status [19]. Consequently, patient-centred care has many instrumental benefits; these alone could be sufficient to justify patient-centred care. However, patient-centred care also has clear ethical value; it has been described as a moral concept, leading some to view it as normative or prescriptive model of care [24, 33]. In particular, Duggan et al. looked at the moral value of patient-centred care from consequentialist, deontological, and virtue ethics perspectives [33]. Versions of these arguments are presented below.

From a consequentialist perspective, it is necessary that the outcomes of an action be predominantly good in order to consider that action moral [33]. The empirical evidence discussed above clearly demonstrates that patient-centredness leads to better outcomes for patients and healthcare systems, and so patient-centred care can be ethically justified on the basis of consequentialism.

In comparison, a deontological framework does not view outcomes as important, but rather the action in and of itself is judged. If an action possesses some intrinsic property of “rightness”, deontology holds that it ought to be pursued as a matter of duty [33]. Additionally, deontology requires the treatment of persons as ends in themselves and calls for respect for persons. Respect for persons recognizes the inherent dignity of persons, as well as respects the individual’s experience and capacity to feel and think. Since the overarching theme of patient-centred care is to not merely treat the patient’s disease, but to treat the person that is a patient, patient-centred care adheres to the ethical principle of respect for persons. Similarly, by empowering patients and seeking to involve them in their own care, patient-centred care also upholds the bioethics principle of respect for autonomy. Moreover, some feminist scholars have ascribed a priori value to relationships [34, 35], such that respect for relationships could be considered an ethical duty. Since patient-centred care places an emphasis and value on the physician-patient relationship and promotes respect for the patient’s other relationships, it clearly upholds this ethical duty. Patient-centred care thus upholds ethical norms and principles, and has inherently valuable features. As a result, patient-centred care may need to be pursued as a matter of duty.

Lastly, we can evaluate patient-centred care from a virtue ethics perspective, which focuses on fostering attitudes and character traits deemed virtuous. In virtue ethics, an action is deemed morally acceptable if and only if it is what a person with these virtuous attitudes and traits would do in the given circumstances [36]. For patient-centred care to be justified by virtue ethics, it must call for physicians to embody virtuous characteristics and attitudes. And indeed, patient-centred care does just that: it calls on physicians to be attentive to their patient's needs and wants, and to recognize their responsibility to secure the patient's holistic well-being. Patient-centred care requires physicians to embody virtues such as respect for the individual, commitment to the patient and to their relationship with that patient, compassion, empathy and loyalty. Thus, by encouraging physicians to practice virtues that are deemed morally good, patient-centred care is supported by virtue ethics.

In sum, by promoting positive outcomes, upholding ethical principles, and promoting virtuous characteristics, patient-centred care is morally desirable. It is not just an instrumental model of care, but it is an inherently moral concept that can be viewed as prescriptive or normative [24, 33]. Advocates of patient-centred care assert that this model should be sought after as the ideal form of care [24, 33], and given its instrumental and moral value, it is clear why patient-centred care is endorsed.

## Putting patient-centred care into practice

There is a clear emphasis in patient-centred care on recognizing relational and contextual factors, and on using the patient's preferences to guide care. Accordingly, there is a need to learn how to communicate in a patient-centred way, to reflect on how best to understand patient autonomy, and to examine how patients ought to be involved in decision making.

### *Patient-centred communication*

Many authors have emphasized the importance of communication in patient-centred care (e.g., [12, 19, 22, 37, 38]). However, guidance on how to communicate in a patient-centred way is more limited. The most prominent description of patient-centred communication comes from Epstein et al. (2007). They defined patient-centred communication as (1) eliciting, understanding, and validating patient perspectives; (2) understanding the patient within their psychosocial context; (3) developing a shared understanding of the patient's problem and its treatment; and (4) sharing power with the patient by offering them meaningful involvement for healthcare decision making [37]. They stressed that effective communication requires cooperation, coordination, discovery, negotiation, and reconciliation to achieve mutual understanding, and that communication is a collaborative process, requiring interactions between clinician, patient, and family members. They also underscored the role that context plays in communication (e.g. disease factors, family and social environment, cultural and/or religious context, media environments, health care system and societal factors), and that it can be a powerful mediator of patient-centred communication processes and outcomes. In sum, patient-centred communication places an importance on understanding the patient's context and relationships, and on enabling the patient to participate in their care. This requires health care practitioners to develop communication and interpersonal skills that can help the elicitation of patient preferences.

### *Patient-centred care and relational autonomy*

Patient-centred care stems from ideas of respect for persons and for autonomy [33]. Respect for autonomy emphasizes the patient's freedom of choice and respects her capacity to choose based on her values and preferences [39]. However, this principle has been critiqued as it has led to an overwhelming focus on the individual's *capacity* to choose, to the detriment of exploring other factors that can influence choice, such as one's relationships and social context [40]. Furthermore, healthcare providers sometimes interpret the idea that autonomous choices must be informed and free from external factors as a need to inform patients without 'interfering' with their decision (i.e., they abstain from providing a recommendation or opinion on the decision, and restrict communication to providing information about the various options) [24]. Accordingly, healthcare providers may neglect the important role of the physician-patient relationship in decision-making [24]. In contrast, patient-centred care acknowledges the therapeutic aspect of the patient-physician relationship [25] and notes the need to support the patient in decision-making. As a result, patient-centred care needs to adopt a model of autonomy that promotes patient involvement but does not leave them without support, as isolating patients in their decision making would run counter to patient-centred approaches [7]. Furthermore, patient-centred care recognizes the patient as person, and thus requires a model of autonomy that acknowledges that patients are complex social beings with interdependencies and interconnections that can influence decision-making.

Relational autonomy has been endorsed as the model of autonomy that ought to be adopted in patient-centred care [7, 24]. This form of autonomy recognizes the social nature of people's lives; it acknowledges that a person's identity and values are formed within social contexts and particular environments. It recognizes that relationships and social context matter in the development of skills, capacities and preferences for decision-making, and requires clinicians to treat patients as whole-persons. Relational autonomy goes beyond simply upholding the patient's right to informed choices, which can occur in an individualistic autonomy paradigm, and acknowledges the dynamic nature of patient's lives and the multiple factors that can affect their choices. Indeed, relational autonomy recognizes that collaboration of others is necessary in decision-making, and that choices are not made in isolation. In this way, relational autonomy recognizes the person making decisions, and its focus on the person makes it congruent with patient-centred care.

Moreover, relational autonomy can be considered an essential component of patient-centred care [7]. Currently, discussions of patient-centred care have avoided explicit discussion of autonomy. Explicit adoption of relational autonomy fills this obvious bioethical gap, and can inform the operationalization of patient-centred care. Moreover, as relational autonomy reinforces supportive relationships and the active guiding role of the patient, it strengthens patient-centred care [7].

### *Patient-centred care and decision-making processes*

Within healthcare, there are three main decision-making models: paternalism, informed choice, and shared decision making. Each of these decision-making models can occur over three analytical stages: (1) information exchange, (2) deliberation, and (3) decision [41]. Stage one, information exchange, includes the types and amounts of information communicated between physician and patient; stage two, deliberation, refers to the process of expressing and discussing treatment preferences, including weighing the risks and benefits; and stage three, decision, involves making a decision on which treatment to implement. The degree to which the physician or patient participates in each of these stages determines the decision-making model. Within patient-centred care, shared decision making has been proposed as the ideal decision-making model [6] and it is often placed as a middle ground between paternalism and informed choice [42].

The paternalistic model assumes that there are objective criteria for determining what is best for the patient, and that the physician, as medical expert, is ideally positioned to make decisions on treatments that will best promote the patient's health and well-being [43]. Under this model, it is not necessary to include patients in decision making or to inform them about their condition or treatment options. At most, information exchange involves a unidirectional flow of medical information from physician to patient, the physician alone deliberates, and it is the physician that makes the decision. As a result, paternalism excludes patients from the decision-making process, assumes that their values and preferences matter less than the objective criteria determined by the physician, and reduces the concept of patient autonomy to one where the patient merely assents [43, 44].

Directly contrasted to paternalism is the informed choice model, where the purpose of the patient-physician interaction is for the physician to give the patient all the relevant information, and allow the patient to decide on the treatment she wants. Under this model, information exchange is mostly limited to a one-way flow of medical information from physician to patient, but the patient undertakes deliberation and it is the patient that retains final decisional control. Hence, informed choice views the physician as a provider of technical expertise and her role in the decision-making process is limited to one of information transfer; the patient is then left to make the decision independently [43, 44]. This model is sometimes seen as being in line with individualistic notions of autonomy. However, this model of decision making can leave patients feeling unsupported and isolated in their care [24].

Both the paternalistic and informed choice decision making models have important drawbacks that render them incongruous with patient-centred care. Patient-centred care values patient and provider perspectives as well as the “therapeutic alliance” they forge [25]; it calls for a decision making model that is consistent with its valuation of communication between patient and provider, and that promotes the development of a shared understanding. Yet the paternalistic model fails to incorporate patient perspectives into decision making, and the informed choice model fails to incorporate physician perspectives [44], so neither models are conducive to patient-centre care. Instead, shared decision making, which involves discussions where the knowledge, concerns and perspectives of all parties are considered [45], has been put forth as the ideal in patient-centred care.

While there is no one accepted definition of shared decision making [42], the most frequently cited descriptions come from Charles et al. [41, 44], who identified four key characteristics. First, they described shared decision making as involving at least two participants, the physician and patient, although they recognized that family members or friends can also play a role in decision making. Second, they emphasized the need for both parties to take steps to participate in the process of treatment decision-making. For the physician, this would involve establishing an atmosphere where the patient's views are valued and needed, eliciting the patient's preferences, transferring the technical information to the patient, helping the patient weigh the risks and benefits, and finally sharing treatment recommendation with the patient. For the patient, this would involve being engaged in the decision-making process, disclosing their preferences, asking questions, deliberating on treatment options, and formulating a treatment preference. Third, they viewed information sharing as a prerequisite to shared decision-making. And fourth, Charles et al. claimed that both parties must agree to the decision. They noted that both parties did not have to view the decision as optimal, but rather endorse it for the situation at hand; this mutual acceptance could then be taken to mean that both parties share responsibility for the final decision.

Thus, shared decision making involves bidirectional information exchange, with a discussion of all the relevant medical and personal information. The deliberation stage would include both physician and patient, and potentially others, to discuss the patient's values, the physician's recommendations, and deliberate over options. Finally, the decision stage would involve both physician and patient. However, there is some debate over the extent to which the final decision must be shared in order for the process to be considered shared decision making [46]. Some view the decision stage as being necessarily shared, where an agreement has to be reached in order for the process to be considered shared decision-making [41]. Others have suggested that mutual agreement is ideal in shared decision making, but not necessary [42]. They view it as acceptable for the patient to delegate control over the final decision to the physician, if this is in line with their preferences and if they have been involved in the information exchange and deliberation stages [47].

Overall, shared decision making is in line with patient-centred care because it puts an emphasis on sharing the decisional process between physician and patient, and requires an examination of the preferences, needs and values of the patient. However, patient-centred care also means taking into account the patient's desire for sharing decisions and information, and responding appropriately [32]. Thus, while shared decision making with mutual agreement may be ideal for patient-centred care, sharing *all* information and decisions with patients may not be necessary, so long as this is in line with the patient's preference. In a patient-centred care practice, patients can choose to participate in decision making to the extent that they desire; they can delegate control over the final decision to their physician or they can retain control themselves. Therefore, patient-centred care calls for a broader model of shared decision making, where there is bidirectional communication and aspiration towards mutual agreement, but participation in decision making is directed by the patient. As a result, patient preferences play a clear role in decision making and care, and an exploration of patient preferences is merited.

## Exploring patient preferences

In light of the apparent theoretical relevance of communication, relational autonomy, and shared decision making to patient-centred care, we might wonder if these concepts are in fact in line with patient preferences. Patient preferences are, most simply, “what patients want from their healthcare” [48, p. 168]. These preferences can be investigated in a broad sense by looking at patients’ general beliefs, values and desire to be involved in care, or more narrowly by looking at specific situations or events (e.g., preferences for a treatment plan, deciding on a particular care provider) [48]. The focus in this thesis is on patient preferences more broadly, as this can give better insight into key aspects of patient-centred care. In particular, this review looks at patient preferences for involvement in medical decision-making processes, including communication of information, and perspectives on the patient-physician relationship.

### *Patient preferences for decision-making processes*

Research has shown that physicians perform poorly when assessing their patients’ preferences for involvement in decision making [9], and that they judge patient preferences for treatment to be different from what they actually are (“preference misdiagnosis”) [17]. Moreover, there is a pervasive mismatch between patient’s preferred and actual roles in decision making [49]. In particular, patients generally want to participate more than they do in practice [49].

Reviews on patient preferences for involvement in decision making show variability in how patients want to be involved [8, 9]. For instance, a study using a representative sample of the American population found that nearly all respondents preferred to be offered choices and be asked their opinions, though half of respondents preferred to leave final treatment decisions to their physicians [50]. Similarly, a study of patients in a primary care setting found that patients preferred decisions to be made by their physician [51]. In contrast, a study of patients with advanced cancer found that two thirds of patients wished to participate actively in decision-making [52], while a separate study of primary care patients found that 36% of patients wanted to participate to some degree in decision-making, and up to 40% of patients wanted to participate fully [53]. Adding to these mixed findings, studies of patients in chronic care [54] and with coronary heart disease [55] found substantial variability between patients' preferences for decision-making participation, with specific groups preferring more active roles.

Interestingly, while many of these studies found variation in preferences for decision making participation, there was consistency in regards to preferences for information. Most studies found that, at minimum, patients want to be informed of their illness and treatment options [51, 52, 54, 55]. Indeed, research indicates that patients report wanting as much information as is available, although patient preferences for receiving different types of information can change across the disease continuum, over time, and with their healthcare system interactions [48, 56]. Importantly, patients' desire for information may not necessarily correspond with their information-seeking behaviours in healthcare interactions (i.e., they may want information, but not actively seek it in clinical encounters) [22, 57], which indicates a need for clinicians to better elicit and respond to patient preferences.

It is important to note that these studies focused on a variety of populations, and that preferences may vary between populations and disease experiences. Additionally, the majority of studies on patient preferences for involvement in decision making have been quantitative and relied on surveys and structured interviews to elicit patient preferences [8]. Quantitative research on preferences may not be wholly telling; notably, a mixed methods study found that patient's responses to quantitative surveys varied from preferences elicited in qualitative interviews [58]. This finding is in line with research that indicates the measures used to determine patient preferences can influence reported preferred decisions roles [48, 59]. Thus, there is a need for more refined approaches to understanding patient preferences.

The limited qualitative research that has been conducted has illuminated decision-making processes. It has shown that participation in decision making is a developmental process, enhanced by information, development of personal expertise, and a relationship with the healthcare professional [60]. Qualitative research has also identified barriers to patient involvement in decision making (e.g., lack of information, lack of understanding of the potential role in participation, anxiety/fear of making a 'wrong' decision, time and resource pressures, poor interactive relationships), as have factors that facilitate involvement in decision making (e.g. access to information, assertiveness/desire for responsibility over one's own body, education, good interactive relationships with healthcare providers, encouragement form healthcare providers) [61, 62].

Overall, reviews of the patient preferences literature indicate that patients generally have a desire to be highly informed, and that there are a number of influences on patient's preferences for involvement in medical decisions [8]. Demographic factors, such as age, education, and sex, or previous experience of illness and medical care, seem to be connected to patients' desire for involvement. The type of decision to be made, trust in healthcare professionals, and previous interactions with health professionals can also affect patient desire for involvement in decision-making [8]. Indeed, four broad contextual domains within which patient preferences may be formed have been identified, including (1) cultural; (2) social; (3) the media information environment; and (4) economic [48]. Thus, it is clear patient preferences for involvement in decision making are complex, and "range from the very clear, specific, and intractable, to the elusive, vague and unstable" [48, p. 168]. Interestingly, a systematic review identified a time trend for patient preferences; prior to 2000, only 50% of patients preferred sharing decisions, compared to 71% after this period. This indicates that desire for active involvement in decision-making is growing [59].

### *Patient perspective on clinical communication*

In general, patients prefer physicians who display a patient-centred approach [63]; this approach is preferred because it involves working with them, respecting their opinions, and exploring what they want [64]. Patients described excellent clinical communication as involving respect, empathy and an interest in the patient's perspective, as well as a willingness to accept the patient's desire to share decisions. The ability to provide information that is clear and adequate to the needs and education of patients is also key [65]. Developing the clinician-patient (-family) relationship is key, and communication during the clinical encounter is central to the elicitation, clarification and construction of patients' preferences for care [48].

*Operationalizing patient preferences*

It has been suggested that patients' role preferences (i.e., how they want to be involved in decision-making) should be assessed prior to or early in the clinician-patient consultation [48]. Given that role preferences are dynamic and can vary during decision-making, regular clinical assessment to meet patients' expectations may be necessary [49]. Importantly, it should not be assumed that if patients state they have low preferences for involvement in decision making that they need not participate in this process [9]. These statements may instead reflect patient's lack of understanding of the different components of the decision-making process and the actual benefits of active participation in the consultation. Furthermore patients may be ill-informed about the extent to which doctors understand their preferences, and their expressed preference may reflect their past experiences of health care, where they were not involved in the decision-making process [9]. Indeed, it has been postulated that most patients prefer to take on an active role, but that they need and want physicians to take on the "problem solving" aspect of decision-making [66]. Problem solving requires a certain set of skills and a specific knowledge base and entails the diagnosis and identification of treatment options. Once patients understand the choices available and their associated trade-offs, they are more likely to want to participate in decision making [66].

It should also be noted that the behaviour of others may in fact limit patients' ability to be involved. In a study of diabetes patients, it was found that many patients wanted to be involved but that practitioners frequently discounted their experiential knowledge and did not provide the resources necessary to allow the patient to make an informed decision [67]. Thus, in order to foster decision-making participation, the experiential knowledge of the patient must be recognized [67], information has to be presented in a way that is appropriate to the patient [68], and information on the available alternatives, their potential outcomes, and the costs, risks and benefits of each must be communicated [66].

The clinician-patient relationship is central to determining how preferences are revealed, constructed, and enacted [48]. There is a need for clinician to acknowledge the range of patient preferences that exist, and to offer patients the opportunity to participate in their treatment by sharing decision making. This necessarily involves assessing the patient's preferences and is in line with ideals of patient-centred care [69]. Indeed, matching care to the patient's preferences has been associated with greater satisfaction with care and less psychological distress or decisional conflict [70]. Patient’s preferences should be studied as highly contextualized, as potentially varying within specific situations, relationships and problems to be solved, and investigations of patient preferences should not assume that preferences are stable or fixed [48]. Assessing patient preferences in this way is in line with patient-centred care as it recognizes the important context of the individual and honours their wants and needs.

The research reviewed so far gives us important insight into patient preferences, and shows the utility in assessing those preferences for informing the implementation of patient-centred care. However, given the highly contextual nature of patient preferences, research within specific populations may not be generalizable to others. Notably, patient preferences can vary depending on the health condition, and the progression or severity of the condition [48]. It is thus important to look at the specific literature on PD patient preferences.

## **Patient-centred care and Parkinson’s disease patients**

Patient-centred care is a model of care that has been particularly endorsed for PD patients [5]. Markedly, PD patients and their caregiving relatives have requested this patient-centred approach [16], and there have been calls for their increased involvement in decision-making and disease management [14]. This is in line with ideas that increased patient involvement can improve perceived quality of life [16] and health outcomes [71] for PD patients. However, for patient-centred care to be implemented in the context of PD, an examination of PD patient perspectives is needed.

There have been limited studies examining the different facets of PD patients’ experiences, with most studies focusing on the lived experience of PD patients’ expectations of care. Studies investigating PD patient’s experiences include Wressle et al.’s 2007 study where they examined the consequences of day-to-day life with PD for both patients and their caregivers [16]. They found that the effects of PD permeated daily living, and that living with PD placed restrictions on both household and leisure activities, required habit changes, and resulted in decreased socialisation. Abudi et al. (1997) also focused on patient’s experiences, looking at their perceptions of their symptoms and how this compared to specialists’ perspectives [13]. They found that patients judged some symptoms as less disturbing than the specialists expected, while other symptoms were found to be more alarming. This indicates a discord between patient and healthcare provider perspectives on PD experiences. Nisenzon et al. (2011) focused on PD patients' expectations of treatment and their criteria for successful outcomes [15]. Their results also indicated a discrepancy between patient and physician goals for treatment. These findings highlight the importance of dialogue between patients and healthcare providers, particularly as it relates to treating the symptoms perceived as most pressing to the patient and meeting patient expectations for care. Furthermore, given the apparent relevance of dialogue, it should be noted that a study of specialty physicians found that specialists demonstrated a limited range of communication skills and used a more doctor-centred style that allowed for little patient participation [65]. This is particularly important to note as PD patients regularly see a specialist (general neurologist or movement disorder specialist) for the management of their PD.

Overall, there has been recognition of the importance of PD patient perspectives on the assessment of their health needs, as their views and feelings have implications for clinical practice and health policy [14]. However, while the described studies provide valuable information on the lived experiences of PD patients, there is still a lack of understanding on the perspectives and values of PD patients. Multiple studies report the need for further investigation of PD patient preferences and perspectives [13-16]. Notably, research on PD patients and decision-making has mostly revolved around PD patient's ability to participate in decision-making, rather than their perspectives on participation [72]. No studies were found that specifically examined PD patient preferences for involvement in decision-making, pointing to an important knowledge gap.

## **Summary and conclusion**

Patient-centred care is a model of care that focuses on treating patients as persons, and recognizes the importance of the patient's context, values, needs, and preferences. It is both morally and instrumentally valuable. The implementation of patient-centred care requires the development of the clinician-patient relationship and strong communication skills. Patient-centred care can be strengthened by the explicit adoption of relational autonomy, and it is line with shared decision-making models.

Most importantly, patient-centred care seeks to use patient preferences to improve care, and in particular it utilizes patient preferences to guide decision-making processes. Currently, patient desire for involvement in decision-making is not well understood, and in particular there is a significant knowledge gap in the understanding of PD patient preferences for involvement in decision-making.

This thesis aims to fill this knowledge gap by examining PD patient preferences for involvement in the decision-making process. We specifically investigate patient preferences for involvement in medical decision-making, preferences for communication of information, and perspectives on the patient-physician relationship. Subsequently, we identify issues related to decision-making as everyday ethical issues, and examine this concept of everyday ethics more closely. Broader review of the Parkinson’s disease bioethics and everyday ethics literatures demonstrates that everyday ethics is under discussed in the PD bioethics literature, and that there is an ethical imperative to investigate these issues more closely. The connection between everyday ethics and patient-centred care is further explored in the discussion.

# CHAPTER 2: Methods

# BACKGROUND

## Epistemology:

Our research is conducted within the field of bioethics, a practical field that supports interactive methodologies and that has been considered by many to be a form of naturalism [73]. As a result, the research approach taken in this thesis is one based off a philosophy of moderate (pragmatic) naturalism [74]. Moderate pragmatic naturalism considers knowledge to be a dynamic and interactive process between observer and the observed phenomenon [73]. Consequently, in this thesis, we adopt an inductive orientation with a constructivist approach to knowledge.

Furthermore, a pragmatic perspective holds that bioethics inquiries are conducted with the purpose of creating knowledge that can make purposeful change in practice [75]. Pragmatism supports both conceptual and empirical work in the development and identification of ethical norms, viewing ethical norms as rules created by human social activity [74]. From a conceptual standpoint, pragmatism allows us to draw from multiple normative theories to enhance our understanding of ethics. From an empirical standpoint, this epistemology calls on us to investigate stakeholder perspectives, with a need to capture everyday experiences.

## Project goals:

One of the overarching goals of our research project was to draw attention to ethical issues that may arise in the provision of healthcare; in particular we aimed to develop an understanding of the ‘everyday’ issues patients may face, hoping to develop knowledge that could be applied to patient-centred care practice. In line with this aim, we conducted empirical research with a PD population receiving treatment in a patient-centred care clinic. In particular, we investigated an important knowledge gap related to the lack of understanding about PD patient preferences for involvement in medical decision-making (Manuscript 1, Chapter 3). We also conducted literature reviews and conceptual research on the concept of everyday ethics to enhance understanding of this concept and inform how it can be utilized in bioethics (Manuscripts 2 and 3, Chapter 4). The links between patient-centred care and everyday ethics are identified and explored in Chapter 5.

## MANUSCRIPT 1 METHODS: "What a patient wants: A look at Parkinson's disease patients' preferences for involvement in healthcare decision making in a patient-centred care clinic"

### Research goals and questions:

Our goal in this study was to improve understanding of Parkinson's disease (PD) patient preferences for involvement in the medical decision-making process. We aimed to acquire knowledge that was informative for the patient-centred clinic in which these patients receive care, but also to inform patient-centred care more broadly. Specifically, we aimed to answer the following questions:

- What are PD patient preferences for involvement in decision-making processes, including:
    - Preferences for participatory involvement in medical decision-making
    - Perspectives on the patient-physician relationship and values important to care
    - Preferences for communication of information relevant to decision-making

### Methodology:

In line with a naturalistic epistemological orientation, we employed interpretive description as our qualitative research methodology [76]. Interpretive description is particularly useful in clinical descriptions with an explanatory component and in investigations of a clinical phenomenon where the purpose is to develop knowledge that will inform clinical practice [77].

We did not adopt an explicit theoretical framework for this study because variability in patient preferences for involvement in decision-making, particularly in PD, are poorly understood and so no a priori theoretical understanding can adequately address the phenomenon under study [76]. Furthermore, an a priori theory would risk constraining our analysis, and instead our pragmatic approach allows us to draw from the literature that is the most informative to our goals. Consequently, we acknowledged the available evidence suggesting that there is variability in patient preferences and understanding of decision-making processes.

**Research design:** This research project is part of a broader mixed-methods research study that includes (1) an initial investigation into PD patient preferences for autonomy using a validated quantitative survey of PD patients; (2) follow-up qualitative semi-structured interviews with a selection of these patients to enrich our understanding of their preferences for decision-making; and (3) a knowledge transfer component to identify strategies for the translation of results into clinical practice. The focus of this thesis is on the qualitative component of this study, which is most telling for the development of an understanding of patient preferences and identification of ethics issues relevant to patients.

**Data collection:** Data was derived from audio-recorded, cross-sectional, face-to-face, semi-structured interviews, transcribed *verbatim*.

**Research ethics:** The investigators' institutional research ethics boards approved the research protocol, and participants gave their free and informed consent. See Appendix 2-1 for an English version of the consent form.

**Participant selection:** Interview participants were early stage PD patients in a patient-centred movement disorder clinic at a university tertiary and quaternary care centre. Established collaborations with the healthcare team and director of this program made this a practical sample of participants to select from. Exclusion criteria included if patients were not proficient in English or French (the languages in which care is offered in the clinic), or if they had cognitive deficits, based on validated cognitive tests on file (Montreal Cognitive Assessment, or MoCA), as this could impact their ability to be involved in decision making. All appropriate candidates, as identified by medical staff at the clinic, were approached for participation.

To select our participants, we used maximum variation sampling [78], a form of purposeful sampling that is encouraged in interpretive description and that increases diversity of data [76, 77]. Participants were purposefully selected based on the results from a previously administered validated quantitative survey. This survey collected demographic data that enabled us to select an even proportion of male and female participants with an expected age range of approximately 50-70 years old. A mix of Anglophone and Francophone patients, and patients with a variety of education background were selected. Such a variety of participants increased maximum diversity in perspectives and information gathered.

Patients were given the option to include their partner or caregiver in the interview if this individual normally attended medical appointments with them. Allowing informal caregivers to take part in the interview gave us a more natural representation of the decision-making process, and allowed us to acquire realistic and ecologically valuable data. Thus, interviews were conducted individually (i.e., with the PD patient) or in groups (i.e., PD patient + caregiver). When the patient's partner or caregiver was present for the interview, interview questions were modified so as to include their perspective.

We aimed to interview 20 patients. This N was selected as it was feasible given the number of patients at the clinic, and it was likely to lead to saturation. In line with interpretive description, we borrowed the idea of saturation from grounded theory, and take it to be the point at which the data is sufficiently dense [77]. We believed an N of 20 was likely to be sufficient since comparable qualitative studies examining PD patient perspectives previously used an N of 16 [16] while other qualitative studies investigating patient preferences for decision-making used an N of 20 [58, 79]. If, after 20 interviews, the data did not seem sufficiently dense, we agreed to continue data collection until an N of 25, due to feasibility constraints.

**Interview structure:** Interviews were semi-structured and included open-ended questions. Questions were developed through internal team discussions and some questions were derived from the literature [80]. The healthcare team at the movement disorder clinic provided feedback on the interview grid to enrich it with questions that were pertinent to their practice. The initial interview grid was piloted in three interviews, and refined upon team review of the transcripts from these interviews.

Interviews consisted of three main sets of questions aimed at:

1) Understanding the patient experience and the types of information patients want to receive about PD and when.
2) Understanding patient preferences for involvement in decision making and autonomy in the medical encounter.
3) Understanding patient expectations about a patient-centred care program for PD.

For part one, we sought to understand patients' experiences of diagnosis and how they became patients at the movement disorder clinic. We investigated what information they wanted at the time of their diagnosis, and what types of information were now important to them as well as how they sought this type of information. We asked about any potential limits to information and investigated if there was information that they did not want to receive.

For part two, we investigated patient preferences for involvement in medical decision-making processes by asking questions about their perspectives on the patient-physician relationship and their preferences for the involvement of physician and patient in decision-making. Our questions on participation preferences did not specify the type of healthcare decisions, which allowed patients to interpret the question to the types of decisions most salient in their mind. We asked patients to explain why they expressed these preferences, and we inquired about two hypothetical situations: one in which there is a conflict between patient and physician, and one in which the patient might be excluded from decision-making. When patients' caregiver or spouse was present, questions were modified to include their input and specific questions probed the relationships between the caregiver/spouse and patient, and the caregiver/spouse and physician.

For part three, we investigated patient experiences with members of the healthcare team, inquiring about their expectations for each of these different roles and the contributions they perceive they receive from different healthcare practitioners. We looked at patients' values for provision of care more broadly and the gaps they perceive in their care. See appendix 2-2 for an English version of the final interview grid.

**Data analysis:** Given that existing research literature on this topic is limited and our goal was to understand and provide an interpretive description of PD patient preferences for decision-making, we used thematic qualitative content analysis [81]. Using the interview grid and an initial analysis of a diversified sample of interviews eliciting key thoughts and concepts, the initial coding guide was developed [81]. This coding guide was piloted on a diversified sample of interviews (N=5, 25% of sample), and definitions and rules for the application of each code were developed to ensure rigor and thoroughness. This coding guide was then applied to the remainder of the sample. If during coding, new themes or concepts emerged, additions and changes to the coding guide were allowed. These changes were constantly compared with previous coding to ensure that the material was analyzed with rigor and exhaustiveness. This act of constant comparison is associated with grounded theory, and can be used in interpretive description [77]. Coding and data analysis was conducted using the QSR NVivo 9 qualitative software package.

The piloting of the coding involved full team (reflexive) discussions to diminish subjective biases of the primary coder. Upon completion of coding, results were reviewed and some nodes were further analyzed. Natalie Zizzo was the primary coder, and a senior team member, Emily Bell, systematically reviewed all coding. Disagreements between the coder and the reviewer were discussed to achieve consensus, and Eric Racine arbitrated outstanding disagreements. See Appendix 2-3 for a copy of the final coding guide.

## Limitations:

Limitations include the common limitations of qualitative research, such as unknown generalizability and uncertain external validity, as well as the possibility of the researcher's subjective input into study design, questions, and data analysis.

## MANUSCRIPT 2: "What is everyday ethics? A review and a proposal for an integrative concept"

### Research goals and questions:

We considered issues related to involvement in medical decision making as potential everyday ethical issues for PD patients. However, the concept of 'everyday ethics', though named in the literature, is unclear. Consequently, we aimed to improve understanding of the concept. We asked:

- How has everyday ethics been defined and utilized in the academic literature?
- In what ways do different ethical theories inform the concept of everyday ethics?

### Methodology

In order to address our first research question (i.e., to better understand how everyday ethics has been defined and utilized in the academic literature), we performed a scoping review of all articles that used the term everyday ethics. Scoping reviews are appropriate when the goal is to map the key concepts of a research area [82]. Furthermore, scoping reviews are encouraged when an area has not been reviewed comprehensively before [82]. This is the case for everyday ethics, since no reviews on this concept were found.

We used the search term "everyday ethic*" on PubMed and MedLine Proquest. This search yielded a total of 88 results (excluding duplicates); 27 of these were excluded because they had no abstract and were inaccessible, while 61 results were included and analyzed (two had abstracts but full versions were inaccessible, 59 results were fully accessible). All results were fully read; specific definitions of everyday ethics were extracted, and common themes were noted. We explored the different aspects of everyday ethics as described in the literature and identified its core features.

In order to address our second research question, we used different normative theories as lenses [83] to enrich current descriptions of everyday ethics. This is in line with our pragmatic orientation, where there is no commitment to a single, foundational perspective, and where we can draw from multiple normative theories to enhance our understanding of ethics. Indeed, multiple ethical theories address the concept of everyday ethics, although they do not name it as such. Reflection and team discussion between the co-authors enabled us to consider the theoretical and practical contributions of each ethical theory to the concept of everyday ethics, and we identified questions that can be operationalized by clinicians to enhance their attention to everyday ethics.

## Limitations

Scoping reviews give us insight into the research that currently exists, but do not appraise the quality of the research [84]. A scoping study provides a narrative or descriptive account of the literature, but does not consider the weight of the evidence or the influence of the research examined [84]. As such, compared to systematic reviews, scoping reviews are limited in their ability to tell us about the weight or quality of the research reviewed.

## MANUSCRIPT METHODS 3: “What do we talk about in bioethics? A characterization of the Parkinson’s disease literature and an examination of everyday ethics”

### Research goal and question:

Given the lack of discussion on issues surrounding decision-making in Parkinson’s disease that was noted in Chapter 1, we aimed to aimed to characterize the PD bioethics literature see if the types of issues most PD patients are likely to face, or everyday ethics, were being discussed. This research was viewed as complementary to our conceptual research on everyday ethics (manuscript 2), where we observed claims that everyday ethics is under-discussed. Consequently, we asked:

- What are the major contexts in which ethics is discussed in the Parkinson’s disease bioethics literature?

### Methodology:

To answer our research question, we conducted a scoping review. Scoping reviews can be used to examine the extent, range and nature of research activity, and to identify research gaps in the literature [84]. This enabled us to map the field of study and to draw some conclusions as to the overall state of research within bioethics as it relates to PD [84].

For this review, we performed a search on PubMed using the search terms “Parkinson’s disease” AND (“ethic*” OR “bioethic*”) (N=333). Exclusion factors included low relevance to ethics and/or Parkinson’s disease (N=135), non-academic sources (N=8), no abstract with an article in a language other than English (N=13), no abstract and inability to access the full article (N=28), and duplicates (N=3) (see Appendix 2-4 for detailed exclusion factors). Abstracts of included results (N=146) were analyzed and classified based on the context in which they discussed ethics. These contexts were derived inductively based on a pilot sample (N=50), refined based on team consensus, and then applied systematically to the remainder of the sample. If in this process new contexts were identified, the whole sample was revisited and classified accordingly.  Articles with no abstracts were analyzed based on the first 1-3 paragraphs. Broad topics of discussion (e.g., issues related to informed consent) were also identified in each context. Natalie Zizzo did the primary classification, and the senior team member, Eric Racine, systematically reviewed this analysis. Disagreements were resolved through discussion. Articles falling within the “general healthcare” context, which was considered most directly connected to everyday ethics, were fully read to further identify in detail the types of ethical issues discussed. See Appendix 2-5 for a detailed coding guide including inductively derived contexts and topics of discussion.

## **Limitations:**

See limitations for scoping reviews detailed in Manuscript 2 Methods (above).

# CHAPTER 3: EXPLORING PARKINSON’S DISEASE PATIENT PREFERENCES

Manuscript 1

# MANUSCRIPT 1

# CONTEXT OF MANUSCRIPT 1

An understanding of patient preferences is essential for the implementation of patient-centred care that is truly respectful of and responsive to patient wants, needs, and values. Moreover, a pragmatic approach calls on us to investigate stakeholder perspectives and holds that these can inform ethical theory. Given the push for patient-centred care in Canadian healthcare systems [1] and the particular advocacy for patient-centred care in PD care [2], investigations of PD patient preferences for care are needed. In particular, Chapter 1 identified a knowledge gap in understanding PD patients’ preferences for involvement in decision making.

PD patients require chronic care, typically from a neurologist or a movement disorder specialist. As part of this care, patients are required to consider many different decisions. For instance, there are decisions to be made about medication, which can be complex as there are many approaches possible based on efficacy and side-effect profiles. Other decisions to be made are more relevant to the patient’s personal values (e.g., when to disclose the diagnosis to family and to work), while some relate more to patient’s lifestyle (e.g., what types of lifestyle changes to adopt with the goal of slowing progression of the disease, when to accept disability, when to make adaptations to the home). Many of these decisions must be made with great uncertainty about the future as PD has an unpredictable rate of progression and significant variability in terms of disability between patients. Furthermore, later stages of the disease can involve dementia and incapacity, requiring a surrogate or physician to make decisions on the patient’s behalf. Given these complexities and the emphasis in patient-centred care on involving patients in care, it is especially pertinent to develop an understanding of how patients want to be involved in decision-making processes and their values for care.

The following manuscript addresses early stage PD patient preferences for three important aspects of the decision-making processes: (1) patient preferences for involvement in healthcare decision-making, including preferences for participation and decisional control; (2) patient perspectives on the patient-physician relationship, which is central to decision-making; and (3) patient preferences for communication of information relevant to decision-making. The insight gained from this research can help to inform patient-centred care practices for PD patients.

# What a patient wants: Examining Parkinson’s disease patients’ preferences for involvement in healthcare decision making in a patient-centred care clinic

Natalie Zizzo[1,2], Emily Bell[1,3], Anne-Louise Lafontaine[4], Eric Racine[1,2,3,5]*

1. Neuroethics Research Unit, Institut de recherches cliniques de Montréal
2. Division of Experimental Medicine and Biomedical Ethics Unit, McGill University
3. Department of Neurology and Neurosurgery, McGill University
4. McGill University Health Centre
5. Department of Medicine and Department of Social and Preventive Medicine, Université de Montréal

*** Corresponding author**
Eric Racine, PhD*
Director, Neuroethics Research Unit, Institut de recherches cliniques de Montreal (IRCM)
Associate Research Professor, IRCM
Associate Director, Academic Affairs, IRCM
Dept of Medicine and Department of Social and Preventive Medicine, Université de Montréal
Depts of Neurology and Neurosurgery, Experimental Medicine & Biomedical Ethics
Unit, McGill University Institut de recherches cliniques de Montréal
110 avenue des Pins Ouest
Montréal, QC H2W lR7
Tel: (514) 987-5723
Email: eric.racine@ircm.qc.ca

**Acknowledgements:** Funding for this work was provided by the Canadian Institutes of Health Research (ER (PI) and EB (co-I)) and the Fonds de recherche santé – Québec (career award, ER; master’s scholarship in partnership with Unité SUPPORT du Québec, NZ). We would like to thank the patients who participated in this research, staff at the PD clinic, and members of the Neuroethics Research Unit for feedback on this work.

**Abstract:**

**Objective:** To understand the participation preferences of Parkinson's disease patients from a patient-centred care clinic in healthcare decision-making processes.

**Methods:** Qualitative, semi-structured in-depth interviews with twenty purposefully selected early stage Parkinson's disease patients from a patient-centred care clinic. Interviews examined (1) patient preferences for involvement in healthcare decision-making; (2) patient perspectives on the patient-physician relationship, which is central to decision-making; and (3) patient preferences for communication of information relevant to decision-making. Transcribed interviews were analyzed using thematic qualitative content analysis.

**Results:** Preferences for participation in decision-making varied between individuals, but also within individuals depending on decision type, relational and contextual factors. Patients had consistent preferences for communication of information, but acknowledged limits to what they wanted to know. The importance of communication in the patient-physician relationship was emphasized.

**Conclusion:** Our results highlight the complexities of decision-making processes. Findings suggest that relational autonomy corresponds to how patients envision their participation in decision-making in a patient-centred care clinic.

**Practice implications:** Clinicians may need to assess patient preferences for participation in decision-making on an ongoing basis. Further research is needed to explore strategies to assess patient preferences in the clinical encounter and the field could benefit from further investigations into how preference for participation in decision-making may change over time.

**Keywords:** patient preferences, decision making, Parkinson's disease, patient-centred care, patient-physician relationship, bioethics, relational autonomy

## Introduction

Parkinson's disease (PD) is a chronic neurodegenerative disease, affecting an estimated 7-10 million individuals worldwide [3]. PD provokes progressive impairments in motor movement and can include psychiatric and cognitive co-morbidities in patients as the disease advances. Recently, there has been a call for treatment of PD to be delivered within a patient-centred model of care [2]. Indeed, patient-centred care (PCC) is endorsed by both the Institute of Medicine [4] and the Canadian Medical Association [1], indicating a wider shift towards this model of care in North America. Although there are many definitions of PCC, it has been broadly conceived of as "respectful of and responsive to individual patients' preferences, needs, and values" [4, p. 40], and it aims to have patient values guide clinical decision-making [4]. This model of care has been shown to have instrumental value, with tangible benefits that include better health outcomes [5, 6]. Furthermore, PCC has also been validated from an ethical standpoint (19), and it can be viewed as an extension of the principles of respect for persons and for autonomy.

However, implementing patient-centred care can prove to be challenging, as there is a current lack of understanding on the perspectives, values and preferences of PD patients for care [7-10]. In particular, how patients want to be involved in decision-making processes remains unclear [11-13]. In fact, investigations into the variability of patient preferences for the decision-making process show that physicians misjudge patient desire for involvement in decision making [12]. Accordingly, concerns over a "preference misdiagnosis" have been expressed [11]. This research points to a need to improve understanding of PD patient preferences for involvement in care. While there has been a great deal of quantitative investigations into these preferences, the qualitative literature is far more sparse [14] and they have not been investigated, to our knowledge, in a chronic care neurodegenerative population.

Consequently, we conducted qualitative interviews with PD patients in a PCC clinic to investigate their preferences for involvement in healthcare decision-making processes. We specifically examined (1) patient preferences for involvement in healthcare decision making; (2) patient perspectives on the patient-physician relationship, which is central to decision-making processes; and (3) patient preferences for communication of information relevant to decision making. We draw on the analytic stages of decision-making proposed by Charles et al. [15], including (1) information exchange, (2) deliberation, and (3) decisional control, and consider how patient preferences for involvement may vary with each of these stages. Given the nature of our study, it is likely that our results can provide insight for other chronic illness and neurodegenerative populations.

## Methods

The sample population for this study consisted of early stage Parkinson's disease patients from a PCC movement disorder clinic. Exclusion criteria included if patients were not proficient in English or French, of if they had cognitive deficits, based off of validated cognitive tests on file (Montreal Cognitive Assessment, or MoCA), as this could impact their ability to be involved in decision making. All appropriate candidates, as identified by medical staff at the clinic, were approached for participation. The diversity of participants was maximized by using purposeful sampling (maximum variation sampling) [16]. We sought an even ratio of males and females, and a variety of educational backgrounds. Given the average age of onset of PD, we expected an age range of 50-70 years old. The authors' institutional research ethics boards approved the research protocol, and participants gave their free and informed consent.

We aimed to interview approximately 20 patients, as we expected this was sufficient for theoretical saturation, or the point at which there was no significant new data. This N was supported by a comparable study examining PD patient perspectives which had a sample size of 16 [10], and other studies investigating patient preferences for decision-making which had a sample size of 20 [17, 18]. After 20 interviews, it was apparent that the data was sufficiently dense and represented diverse experiences and perspectives. If there was a partner or another individual who regularly attended clinical appointments with the patient, the patient was invited to include this person in the interview, as this allowed us to acquire ecologically valuable data (i.e., a more natural representation of the decision-making process) [19]. Consequently, in four instances, patients' partners were consented to and present for the interview. The partners contributed significantly in two of these interviews.

Interviews were semi-structured with open-ended questions centred on our research aim to understand patient preferences for involvement in healthcare decision making. We examined: (1) patient preferences for involvement in healthcare decision-making; (2) patient perspectives on the patient-physician relationship; and (3) patient preferences for communication of information. Our questions on participation preferences did not specify the type of healthcare decisions, which allowed patients to interpret the question to the types of decisions most salient in their mind. We also inquired about two hypothetical situations: one in which there is a conflict between patient and physician, and one in which the patient might be excluded from decision making. When patient's partners were present, questions were modified to include their perspectives.

Interviews were conducted face-to-face, and were held at the primary author's research institution or at the specialist clinic, according to the patient's preference. The interviews were conducted in English or French, audio-recorded, and subsequently transcribed *verbatim*. A technical error resulted in failure to record one interview; in this case, detailed notes were taken immediately after the interview and verified by the participant for their accuracy, and then these notes were used for analysis.

We analyzed ("coded") interview transcripts using thematic qualitative content analysis [20]. An initial coding guide was developed after review of transcripts and a team discussion. This coding guide was tested on a diversified sample of interviews (N=5, or 25% of total sample). A review of the results led us to revise the coding guide, re-code the initial sample, and code the remainder of interviews. The coding guide contained definitions and rules for the application of each code to ensure rigor and thoroughness. Upon completion of coding, results were reviewed and some nodes were further analyzed. The primary author conducted the interviews and was the primary coder; the second author systematically reviewed all coding. Disagreements between the coder and the reviewer were discussed to achieve consensus, and the last author arbitrated outstanding disagreements. Coding was supported by the QSR NVivo 9 qualitative analysis software package. The final key themes for coding were: (1) preferred decision-making model (e.g., how should each individual be involved in decision making?); (2) qualities of a good patient-physician relationship (e.g., general features of a good relationship, important qualities of a patient and of a physician, values important to care); (2) PD information preferences (e.g., source of information, desired information during clinical encounter and from other sources, limits to learning information).

Qualitative content is summarized and direct quotes are used to illustrate the perspectives of participants. Some quotes reported in this paper were translated from French to English by the primary author, and verified by another bilingual team member (the last author). Participant's names and identifying details have been removed to protect confidentiality. Patients are identified in text by the letter P followed by a number that was assigned sequentially as potential participants were identified in the clinic. Patient's partners are identified by the same system, followed by the letter "a" (e.g., PXXa), and the letter "I" identifies the interviewer. Minor edits were done to some quotes to enhance their readability.

## **Results:**

### **Participant demographics:**

Twenty PD patient participants were interviewed, 10 males and 10 females, aged 50-77. The mean age of patient participants was 63 (median 64). Fifteen interviews were conducted in English, and five were conducted in French, according to the participant's preference. The average length of time participants were patients in the specialist clinic was three years, with the shortest time of six months and longest time seven years. Two patient participants had a secondary school education, five had professional or college education, four had Bachelor's degrees, seven had Master's degrees, and two had a PhD.

### **Patient preferences for involvement in healthcare decision making:**

#### *Patients prefer shared decision making*

The majority of patients endorsed a model of shared decision making, where at minimum, there was two-way communication of information and of preferences between physician and patient, with deliberation of treatment options. Under this model, the final decision can be taken by the patient or by the physician, as long as this is in line with the patient's preference. Preferences as to who ought to make this final decision varied: 1) between individuals, and 2) between decisions.

#### *Preferences for decisional control vary between individuals*

Between individuals, some patients preferred to make the final decision (patient chooses), some wanted the decision-making process to be evenly shared (shared choice), while others preferred to delegate final decisions to the doctor (patient delegates) (see Table 3-1). Importantly, when patients expressed wanting to delegate the decision to the physician, it was noted that patients would still have to consent to this final decision. Regardless of which of these models patients preferred, all stressed the importance of being informed of treatment options and of being involved in the deliberation of different decisions.

**Table 3-1: Preferences for decisional control varied between individuals***

| Patient delegates | Shared choice | Patient chooses |
|---|---|---|
| **P38:** when we reach a way of treatment I prefer to be mostly doctor directed but with my involvement so I understand, what is this single or multiple treatment…are there several? Which are the benefits? Which are the downsides…and so on and so forth. Pretty much I feel the more interactions you can have the better. You know?<br>**I: Why do you say the doctor should make the final decision?**<br>**P10:** Well, it’s certain that it will be with my consent, but I have so much confidence in the physician. I don’t have the tools to go beyond the information that I have; he has maybe the more broad technical information. Where he goes, in the end, he will always suggest to me one path or another, and if I don’t want it, I think the treatment won't happen. But I have confidence in the medical information, I might not agree with the path because it’s scary, for examples the electrodes in the brain, or the medications, but I will give him the benefit of the | **P14:** I would expect the doctor and I, and my spouse, to be involved as a team<br>**P32:** I think the physician lays out your options and I think that it's up to you both to decide whether this would be best, or better for you, whether it is medication or doing some form of exercise, or climbing mountains or whatever it is. If the options are presented to you then you can both discuss the pros and cons and make a decision, with an informed decision.<br>**P47:** Well I think that it should be done together. The doctor works based off of what he perceives from the patient, and it’s in talking with the patient that he can learn even more. And that’s why, if the patient gives frank and detailed information, well it certainly has to help the guide the doctor to the best solutions for the patient in question. | **P25:** Oh, the patient being involved in decision making, you're involved in everything. It's your life. I mean, it's not up to…I don't think it's up to…well, it's your decision but it should be discussed with your doctor--you and the doctor.<br>**P26:** The ultimate decision should be from the patient.<br>**I: So why do you say that?**<br>**P26:** Because he or she is the one who is suffering. They know what they are going through and they should take a chance on anything they want. It’s not the doctor.<br>**P26a:** Yeah, and I think ultimately it’s, you know, it is the life of the person, you know? It should be…yeah. If the person, the patient has all his mental capacity then I think it should be…as long as it is…yeah…healthy mind.<br>**P45 :** I think that it comes back to the patient in the end. But after a discussion with the doctor that is sufficiently in depth, if you will. I think that the doctor has to be there to guide the patient to make his own decision. […] So I think |

| | | |
|---|---|---|
| doubt to make these types of decisions, and I will accept after information. | | that it's up to the physician to be a bit of a guide, and to try and see when he thinks the patient is headed towards the decision on his own. |

*Note we use a spectrum of shared decision-making, where responses under "shared choice" indicate an even contribution between physician and patient to the healthcare decision, responses under "patient delegates" indicate the patient prefers the physician to make the final decision, and "patient chooses" indicates the patient is more likely to make the final decision. Individuals did not necessarily adhere to one preference for all decisions.

### *Preferences for participation vary between decisions*

Individuals themselves modulated their decision-making preference based on the decision to be made. For example, some patients preferred that decisions about medication (e.g., dosage) be made by the doctor (patient delegates), as they recognized the expertise the physician has in this regard. For other decisions, such as decisions on treatments with potentially severe effects on quality of life, patients wanted to play a bigger role in the decision-making process (patient chooses). This was in recognition that they were the ones who would experience the outcomes of these decisions. The relational context of the decision also affected their decision making preferences (e.g., an established relationship of trust with a physician may be necessary before delegating a decision). See Table 3-2 for examples illustrating that preference for involvement in decision-making are decision-dependent and context and relation-dependent.

**Table 3-2: Examples illustrating that preference for involvement in decision-making are decision-dependent and context- and relation-dependent**

| | |
|---|---|
| **Decision-dependent** | ***Decisions requiring technical knowledge (e.g. medication) are often delegated to the physician:***<br>**P9:** I trust my doctors and I appreciate their treatments, and they are making a lot of decisions. They consult me and they tell me what they are doing. […] I'm not saying "no I want a lower dosage or a higher dosage"… I trust her on that. She's making that kind of decision.<br>**P10:** The final decision on whether or not to increase the medication, it's him [the physician] that makes that decision, that's certain. But I like to know the reasons as to why he's making these decisions.<br>**P16:** (…) for things like doses, I can't regulate that, he has expertise I will never have. […] So, there are certain decisions that he has to take because I |

| | |
|---|---|
| | need it.<br>***Decisions about lifestyle require patient choice:***<br>**P16:** (…) the style of living, the way you need to live your life, that's up to you. You can help me by saying be careful, you know. You may eventually get to the point where you're going to trip and fall, so yeah if you're thinking about changing house, good for you. I think it's a good wise decision but the ultimate decision will be up to me.<br>***Physician has expertise about treatments; patient can decide overall treatment goals:***<br>**P32:** I think…as far as medication treatment, I believe the physician should make the ultimate decisions because he knows more about what effects it has and if it can counter attack whatever is the problem at the moment, but in the long run, we have to decide for ourselves what we're going to do, whether we're going to take that chemotherapy or not…and so on, but as I said before, it has to be an informed decision and listen to what the physician has to tell you…and decide together. |
| **Context- and relation-dependent** | ***Personal and contextual factors impact decisions:***<br>**P24:** How old would I be? What would be my income? Where will I live? All of those are factors that I have that are outside of my [control] but I have to be taking care and into consideration before I make my decision and that's outside the doctor and medical care.<br>***Personal relationships impact decisions:***<br>**P14:** My spouse has a big influence on me. I used to be the one that took charge, and now the roles are reversed now that we are in our 70s and I very much respect her advice.<br>***Trusting relationship with physician is necessary for decision-making:***<br>**P60**: It's their body. It's their life so I think the ultimate decision should be the patient's but taking into account that the doctor has said and bearing in mind whether you trust the doctor or you don't. If you don't trust the doctor you shouldn't be there in the first place. If you do trust the doctor your decision has to be in line with that knowledge…that your doctor would not suggest anything that would be harmful to you. You see? But basically the ultimate decision begins with the patient who has to sign these consent forms, not the doctor. The patient has to realise the doctor has gone to school and has had many more years of practice experience and to trust them. |

### *Navigating decision-making when there is disagreement*

In a hypothetical situation of conflict (e.g., a patient and doctor cannot agree on a treatment) there was large support for the patient to be the final decision-maker. However, this perspective often recognized the knowledge and expertise of the physician, and many patients described how they would prefer to come to an agreement with their physician. In instances where an agreement cannot be met, some described the need to seek second opinions. In a minority of cases, patients were willing to follow the doctor's suggestion, provided they have been sufficiently informed and they trust their physician.

### *Perspectives on patient exclusion from decision making*

Allowing the physician to decide entirely which treatment is appropriate or excluding the patient from healthcare decision-making was viewed as acceptable only when the patient is mentally incapable (i.e., patient lacks capacity). Some patients mentioned lack of education or experience in medical encounters, the severity of disease, or the complexity of treatment as situations that may warrant the physicians taking greater control. However, these situations are hypothetical; they represent what patients think as being acceptable for someone else, and are generally not situations they associate with themselves. Overall, patients generally wanted to be involved in decision making, even if only for information exchange.

## **Patient perspectives on the patient-physician relationship**

The patient-physician relationship is central to medical decision making and is especially important in a neurodegenerative illness such as PD, which requires chronic care. Patients emphasized the importance of this relationship, and they described the need to be treated as a human being rather than as a number. In articulating the values important to their care, patients expressed the need for candor, honesty, understanding and empathy. Values and attributes that were described as being important specifically for the patient-physician relationship included mutual respect, trust, openness, and time for communication. Additionally, the need for the relationship to be non-hierarchical was noted.

### *Desired qualities of a physician*

Patients described a desire for physicians to possess technical skills (e.g., give appropriate information, evaluate how the PD has progressed, be up-to-date), and interpersonal skills (e.g., listen, be empathetic, understanding). Central to both the technical and interpersonal skills was the importance of informed and sensitive communication. Indeed, communication was the chief concern, and other important qualities such as sincerity, caring and empathy were often tied to communication skills.

### *Ideal qualities of a patient*

In identifying qualities that a patient should possess, participants described the responsibilities a patient must take on. This included self-management practices and informing the doctor of new symptoms, preparing questions for the clinical encounter and seeking information from external sources, listening to the medical advice, and complying with the agreed course of action, or informing the physician if they choose to not follow the plan. Additionally, characteristics patients' should possess, such as being open, honest, and proactive, were described. The need for realistic expectations was noted; two participants specifically remarked that doctors are not magicians.

### *The importance of communication in the patient-physician relationship*

Communication was viewed as central to the patient-physician relationship. In line with this, patients recognized that each agent brings different types of knowledge to decision-making processes (see Box 3-1). The physician was viewed as having the technical, specialized knowledge, based on their education and experience. Patients greatly valued this knowledge, recognizing that this set their neurologist apart from other care providers and made them an invaluable part of their care. At the same time, patients viewed themselves as possessing the knowledge of the lived experience of the disease, as well as of their own values and goals for care. Both types of knowledge were recognized as important to communication in the decision-making process and patient-physician relationship.

**Box 3-1: Illustrative examples: each agent brings different types of knowledge to decision-making processes**

***Patient brings experiential knowledge:***
**P16:** I value the doctor's opinion a lot as long as he values my opinion as well, because I'm the one that's living the disease. He might know about it but he doesn't have it. (…) I will always tell you, you don't know what it feels like until you've actually lived it. And [the specialist], there's no way that he can actually honestly and truly deep down inside know how I feel until he's in my shoes and he has Parkinson's. He can know tons of knowledge about it and that's what I respect about him, is his knowledge, but until he can get into my shoes and live with Parkinson's, that's where I come in, to kind of complement his studies.

***Physician brings medical knowledge:***
**P24:** Well, basically the doctor has the capacity to evaluate based on the facts, based on the tests, based on everything, her experience and the medication and her training. She can tell me what she thinks is the best and from that time I will talk with her, ask questions, decide about it and together we'll plan for the future. (…) I'll follow her because I trust her. Because I know that she won't propose something for nothing. She'll propose some things because I may need it. With her experience, her know how and her past cases, if it's time for me to take medication. , I will take medication. I won't fight for the pleasure of fighting, but I want to know all of the facts before I change. I've made the decisions.

***Patient brings bodily experience:***
**P25:** Well of course the doctor has more medical experience but the individual is the person having the bodily experience, you know all the problems that come with it, so of course they have to communicate with one another.

***Patient can undertake active information seeking; physician, active listening:***
**P38:** As a patient you should get your hands on as much more specialist information as you can. Try to digest it and write down your questions and refer to ask them, so that's what I did. On the side of the doctor, I prefer the doctor to listen to me and to listen to all the symptoms that I might be able to describe and try to have the diagnosis as early as possible.

## Patient preferences for accessing information relevant to decision-making

### *Utilized sources and types of information patients seek*

Given the importance of information in the decision-making process, we investigated where patients received most of their information relevant to PD. In our study, the most commonly cited sources of information were the Internet (N=16), Parkinson's disease foundations or associations (N=12), and the medical personnel at the specialist clinic, including the neurologist and nurse clinician (N=10). Patients also noted accessing information from books (N=6), personal networks (e.g. family, friends, support groups; N=6), television, radio, or newspaper (N=2), and from other sources such as conferences or specialized rehabilitation centres (N=3). The types of information patients wanted varied with sources (see Table 3-3).

In the medical encounter, patients sometimes expressed a difficulty in knowing which questions to ask. However, they were particularly interested in an assessment of the state of their PD, what to expect in terms of future progression of their illness, and treatment options. From other sources, patients wanted to learn most about PD symptoms, current and upcoming PD research, treatment options, and self-management strategies. This was in line with the primary role patients expected from their physicians, which was to continually assess their condition and correspondingly control their symptoms with medication as needed. They also specifically cited an expectation of physicians to provide them with the information listed in Table 3-3.

**Table 3-3: Various types of information about Parkinson's disease that patients wanted and from which sources**

| Types of info | Sought in clinic | Sought from other sources |
|---|---|---|
| Assessment of PD state | 13 | 0 |
| Progression of PD | 10 | 4 |
| Treatments of PD | 8 | 6 |
| Scientific research related to PD* | 5 | 6 |
| PD symptoms | 4 | 7 |
| Self-management strategies | 4 | 6 |
| Causes of PD | 3 | 1 |
| CAM | 2 | 2 |
| Other | 1 | 0 |

* Reports and opportunities for participation

Different sources of information were viewed as having various advantages and disadvantages. Foundations and medical personnel were viewed positively as reliable sources. Foundations were viewed as a focused source, eliminating the need to hunt for information. Additionally, they often offer e-newsletters that ensure patients receive information regularly. Medical personnel were viewed as an expert and personalized source, but the time between appointments meant that they were not a readily available source of information. The Internet was often used to connect patients to foundations, to confirm information learnt elsewhere, and to investigate information related to PD. However, the unclear reliability of some websites and the uncontrolled nature of the readily available information on the Internet were viewed as disadvantages. In particular, the detailed information on the most advanced stages of the disease was described as upsetting to some patients. As a result, many described limiting what they read online. About half of the patients described different strategies they use to distinguish between the reliability of the sources (e.g., using known sources such as foundation websites, or scientific and medical websites; checking if multiple sites gave the same information; remaining sceptical of unverified sources; limiting their use of the Internet as a resource). At least a quarter of patients did not describe any strategies for reliability; they “just put in Parkinson’s disease” and click on “whatever comes up” (P51).

Some patients complained that some sources (e.g., a video from a foundation depicting various exercises for PD) only represented elderly PD patients. This was viewed negatively as it did not represent their experience, and it could be viewed as problematic in light of the average age of PD patients (early to mid-60s) [21]. The uncertainties of PD, including its cause, an individual’s expected progression, and the lack of objective tests for diagnosis, presented a challenge for some PD patients. Patients struggled with wanting to know this information, despite its unavailability. The extent to which they understood that this information does not exist was unclear.

#### *Limits to learning PD-related information*

Many patients expressed wanting to know as much information about PD as possible. Information about PD, especially about its progression, was viewed as important for the patient to adapt and prepare for the future. Patients acknowledged that the information can be upsetting, but felt that it was important for them to know, and that they should be able to adapt to the news, even if it was difficult. Despite multiple patients’ expressions of wanting to know everything, they also reported a limit either to what they wanted to learn or to what they wanted to focus on (see Box 3-2). In part, this was a practical concern, as many acknowledge the outcomes of the disease are uncertain, and as a result many expressed a “take things as they come” attitude. Little can be done to prevent the various outcomes, and a focus on all the negative outcomes can be emotionally taxing. As such, the desire for information may be geared more towards short-term outcomes rather than long-term outcomes. At the same time, most patients have a general knowledge of the long-term outcomes; this is generally learnt in the first few years after diagnosis, and as they adapt to their diagnosis patients tended to focus on this less. At least one patient did not want to receive any information about PD, due to emotional sensitivity, and preferred that their partner receive the information instead. However, this patient still expressed that they would want information deemed essential by their physician to not be hidden from them.

**Box 3-2: Patient preferences for information**

***Patients express wanting to "know everything":***

**P25:** I need to be told everything that needs to be told, good or bad. […] I think the doctor needs to be totally honest.

**P31:** I would always want to have a chance to know something, even if it was really scary and really painful.

***Patients note limits due to the unknowns of PD:***

**P31:** I don't know that anybody has a crystal ball that can predict how I will turn out. So I just don't want to waste time thinking about… Not that I don't accept it, but how much is it worth devoting time talking about what are the eventual possibilities if they may not happen (…) I think I'm more practical about what is happening, how can that be addressed?

***Adaptation to diagnosis can affect information preferences:***

**P31:** I have a big, busy job. It's more than full time. I have a family that's very active, and I'm very busy with them. […] And I have lots of friends and lots of stuff going on, so I think there is a limit to how much I want to hear and invest in Parkinson's. When I first got the diagnosis, I was reading more, always from good sources. I was thinking about it more. I was writing things down about what I thought, but very naturally, it sort of assumed less of a prominent position. It's like, "Okay, yeah, you got Parkinson's. So what else are you doing?" Whereas, for a little time, it was really everything I was thinking about.

***Emotional sensitivity can preclude desire for information:***

**P44:**I don't want any [information]. I want [my spouse] to get it all. […] Because I'm frightened of what might happen…

## Discussion:

Our results show that there is variation in preferences for participation in healthcare decision making among PD patients, particularly when it comes to choosing who ought to make the final decision. Although most patients seem to describe wanting a kind of shared decision making, especially as this relates to information exchange and deliberation, preferences for decisional control depends on different aspects of the situation in which the decision is being made. Indeed, we found that preferences for participation are dependent on the decision type (e.g., medication versus lifestyle) and on contextual and relational factors (e.g., age, income, need for trust in patient-physician relationship). While prior research has investigated participation preferences and found similar variations [12, 22, 23], our research is the first, to our knowledge, to investigate this qualitatively in a chronic neurodegenerative disease population.

Our findings that most patients want full information about their condition and treatment options are consistent with prior research (e.g., see [24-26]). However, our data demonstrates why, in the context of a chronic neurodegenerative illness, patients might have reasonable limits to the types and amounts of information they want to know or focus on. Such limitations can stem from an acknowledgment of the uncertainty in prognosis of PD, and can develop as a result of adapting to the diagnosis and life with a chronic degenerative illness.

We also explored the importance of the patient-physician relationship and found that patients highly valued this relationship. For an excellent patient-physician relationship, they emphasized the importance of communication, and in particular cited the need for physicians to possess strong interpersonal skills and for patients to take on certain responsibilities in their care. The emphasis on the “human” side of interactions corresponds to the central aim of PCC to treat patients as persons.

Our findings demonstrate how patient perspectives can expand our understanding of decision-making processes, and that a relational model of autonomy can clarify how healthcare providers can better operationalize attention to patient preferences in PCC. We discuss these two issues further below.

### Patient perspectives expand our understanding of healthcare decision making

Patient perspectives give us new insight and understanding to decision-making processes. These processes are not as simple as they have sometimes been conceived; patients’ preferences for involvement are not static; rather, they shift depending on decisions, context, and relationships. This suggests a need to understand decision-making in a more dynamic way. Interestingly, patient preferences for involvement in information exchange and deliberation are more or less consistent, with the variation lying in desire for decisional control. This is noteworthy are there is some debate as to the extent to which each of these stages must be shared in order for the process to be considered shared decision making [27]. If we accept that information and deliberation in shared decision making necessitates involvement of both patient and physician, but that control over the final decision can include the patients delegating the final decision to the physician, then our results align with shared decision making.

Notably, patients in our study specifically described many of the elements of shared decision making identified in a systematic review [28]. They expressed a desire for essential elements such as explanation of the problem, discussion of the pros and cons, and explication of patient values and preferences; ideal elements such as mutual agreement; and general qualities, such as mutual respect, patient participation and partnership. Overall, our study provides empirical support for the relevance of shared decision making to patients in PCC. This is noteworthy considering shared decision making has been referred to as the “pinnacle” of patient-centred care [29].

We also learned importantly that there is an ease with which patients express a preference for information exchange and deliberation that is not mirrored when they are asked about preferences for decisional control. This may be related to the chronic nature of PD, where medically relevant decisions are not as discrete as they may be in more acute illnesses. For the patient with PD, certain decisions necessitate different levels of involvement. Decisions about medication may require patient-provider partnership, as there are many approaches possible based on efficacy and side effect profile; it is not “one size fits all”. Decisions about long-term preparation for the disease and self-management (e.g., lifestyle changes, home adaptation, decisions related to work) are dependent on an uncertain prognosis, and may be viewed as self-directed. Furthermore, progression of the disease can include cognitive deficits and dementia, often requiring the physician or surrogate to assume greater decisional control over time. The fact that PD is a moving target can make decision making even more complex. Articulating preferences about involvement in decision making can be challenging when there are a variety of decision types which might require different levels of involvement.

### Support for relational autonomy in patient-centred care

Patient-centred care, by respecting and responding to the wants, needs and values of patients, seeks to support the patient in decision making and thus needs to adopt a model of autonomy that promotes involvement of the patient but does not leave them without support. PCC, in treating the patient as person, acknowledges that patients are complex, social beings, with interdependencies and interconnections that can influence decision-making, a view that corresponds to “relational” or “contextualized” autonomy [30-32]. This perspective on autonomy contrasts with some narrower understandings that interpret autonomy as conceding to individualistic decision-making without due consideration for the social determinants of choice, or for the commitment to care and beneficence of healthcare providers.

The central tenet of relational autonomy is that “persons are socially embedded and that agents’ identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity” [33, p. 4]. This concept stems chiefly from feminist ethics, but also from pragmatist ethics [34], and recognizes the effects of contextual and relational factors on decision-making. It acknowledges the influence of these various factors, and enables them to be integrated into decision-making processes when appropriate. Indeed, these factors can influence both participation in the decision-making process and the decision itself.

Our findings suggest that relational autonomy corresponds to how patients would envision their participation to decision making in PCC. Patients themselves recognized the impact of contextual and relational factors on their involvement in decision making. They also acknowledged the central role the patient-clinician relationship plays in their care. By adopting relational autonomy in the provision of PCC, clinicians are called on to recognize the different factors that can affect a patient’s desire to be involved in decision-making, and to respond to these factors in such a way that empowers patients in relation to their wants, needs, and values.

### Limitations

There are several limitations to our study. Our sample population was limited to patients who had early stage PD; the effects of advanced stages of PD on decision-making preferences are unclear. Patients came from a large urban area, were serviced by a university level health centre, specialized, PCC clinic, and had a high level of education. This may not be reflective of PD populations as a whole, and preferences of patients in a non-specialized or non-urban clinic, or with lower levels of education may differ. Moreover, this is a cross-sectional study and does not capture how patient’s preferences may change over time.

## **Conclusion:**

Our study on participation preferences of PD patients for decision-making processes in a PCC clinic suggests that patients largely prefer a shared-decision-making approach. Specific adoption of relational autonomy by clinicians complements this approach. In some circumstances (e.g., incapacity, decisions requiring medical expertise), patients are willing to delegate more decision-making control to physicians, but nevertheless want to remain informed. Indeed, communication was considered central to the patient-physician relationship. Patients relied heavily on clinicians to convey information about the state and progression of their condition but also frequently on other sources (e.g., Internet) for other information (e.g., self-management strategies, causes of PD). Many patients would want to know as much as possible on their condition but with some nuances since some would prefer not to know some specific information about potential progression. Our study illustrates that attention must be given to patient perspectives. Improved understanding of individual preferences could enhance respect for persons and autonomy and makes for PCC that is truly respectful of individual patients' wants, needs, and values.

## Practice Implications

By drawing attention to the complexities of participation in decision making and to the role of relational autonomy in PCC practices, we support the need for healthcare providers to elicit the participation preferences of patients on an ongoing basis. Due to the limitations of our study, future investigations could look at how patient preferences change over time and with progression of disease. Investigations into communication strategies to better elicit these preferences in the clinical setting are warranted. Furthermore, it would be of interest to investigate the degree of match between a patient's stated preferred role and their actual role in decision making, providing further insight into decision making processes.

# REFERENCES

1. Canadian Medical Association, *Achieving Patient-Centred Collaborative Care*. 2008.
2. van der Eijk, M., et al., *Moving towards patient-centered healthcare for patients with Parkinson's disease.* Parkinsonism & Related Disorders, 2011. **17**(5): p. 360-364.
3. Parkinson's Disease Foundation. *Statistics on Parkinson's*. 2015 [accessed May 24 2015]; Available from: http://www.pdf.org/en/parkinson_statistics.
4. Institute of Medicine . *Crossing the quality chasm: A new health system for the 21st century*. 2001: National Academies Press.
5. Michie, S., J. Miles, and J. Weinman, *Patient-centredness in chronic illness: what is it and does it matter?* Patient Education and Counseling, 2003. **51**(3): p. 197-206.
6. Stewart, M.A., *Effective physician-patient communication and health outcomes: a review.* Canadian Medical Association Journal, 1995. **152**(9): p. 1423.
7. Abudi, S., et al., *Parkinson's disease symptoms—'patients' perceptions.* Journal of Advanced Nursing, 1997. **25**(1): p. 54-59.
8. Buetow, S., et al., *Perceived unmet needs for health care among Parkinson's Society of New Zealand members with Parkinson's disease.* Parkinsonism & Related Disorders, 2008. **14**(6): p. 495-500.
9. Nisenzon, A.N., et al., *Measurement of patient-centered outcomes in Parkinson's disease: What do patients really want from their treatment?* Parkinsonism & Related Disorders, 2011. **17**(2): p. 89-94.
10. Wressle, E., C. Engstrand, and A.K. Granérus, *Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living.* Australian occupational therapy journal, 2007. **54**(2): p. 131-139.
11. Mulley, A.G., C. Trimble, and G. Elwyn, *Stop the silent misdiagnosis: patients' preferences matter.* BMJ: British Medical Journal, 2012. **345**.
12. Robinson, A. and R. Thomson, *Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools.* Quality in Health Care, 2001. **10**(suppl 1): p. i34-i38.
13. Say, R.E. and R. Thomson, *The importance of patient preferences in treatment decisions—challenges for doctors.* British Medical Journal, 2003. **327**(7414): p. 542.
14. Say, R., M. Murtagh, and R. Thomson, *Patients' preference for involvement in medical decision making: A narrative review.* Patient Education and Counseling, 2006. **60**(2): p. 102-114.
15. Charles, C., A. Gafni, and T. Whelan, *Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model.* Social Science & Medicine, 1999. **49**(5): p. 651-661.
16. Patton, M., *Purposeful sampling*, in *Qualitative Evalutation and Research Methods*. 2004, Sage: London. p. 169-183.
17. Hellström, I. and S. Torres, *A wish to know but not always tell–couples living with dementia talk about disclosure preferences.* Aging & Mental Health, 2013. **17**(2): p. 157-167.
18. Doherty, C. and W. Doherty, *Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences.* Journal of Nursing Management, 2005. **13**(2): p. 119-127.
19. Green, J. and N. Thorogood, *Qualitative methods for health research*. 2013: Sage.

20. Hsieh H-F, S.S., *Three approaches to qualitative content analysis.* Qualitative Health Research, 2005. **15**(9): p. 1277-1288.
21. Samii, A., J.G. Nutt, and B.R. Ransom, *Parkinson's disease.* The Lancet. **363**(9423): p. 1783-1793.
22. Levinson, W., et al., *Not All Patients Want to Participate in Decision Making.* Journal of General Internal Medicine, 2005. **20**(6): p. 531-535.
23. Nilsson, U.G., et al., *The desire for involvement in healthcare, anxiety and coping in patients and their partners after a myocardial infarction.* European Journal of Cardiovascular Nursing, 2013. **12**(5): p. 461-7.
24. Beisecker, A.E. and T.D. Beisecker, *Patient information-seeking behaviors when communicating with doctors.* Medical Care, 1990. **28**(1): p. 19-28.
25. Cassileth, B.R., et al., *Information and participation preferences among cancer patients.* Annals of Internal Medicine, 1980. **92**(6): p. 832-6.
26. Gerteis, M., et al., *Through the patient's eyes: understanding and promoting patient-centered care*. 1993: Jossey-Bass San Francisco.
27. Flynn, K.E., M.A. Smith, and D. Vanness, *A typology of preferences for participation in healthcare decision making.* Social Science & Medicine, 2006. **63**(5): p. 1158-1169.
28. Makoul, G. and M.L. Clayman, *An integrative model of shared decision making in medical encounters.* Patient Education and Counseling, 2006. **60**(3): p. 301-312.
29. Barry, M.J. and S. Edgman-Levitan, *Shared Decision Making — The Pinnacle of Patient-Centered Care.* New England Journal of Medicine, 2012. **366**(9): p. 780-781.
30. Entwistle, V.A. and I.S. Watt, *Treating patients as persons: A capabilities approach to support delivery of person-centered care.* American Journal of Bioethics, 2013. **13**(8): p. 29-39.
31. Ells, C., M.R. Hunt, and J. Chambers-Evans, *Relational autonomy as an essential component of patient-centered care.* International Journal of Feminist Approaches to Bioethics, 2011. **4**(2): p. 79-101.
32. Racine, E., et al., *Broadening the lenses on complementary and alternative medicines in preclinical Alzheimer’s disease: Tensions between autonomy and contextual determinants of choice.* Kennedy Instittue of Ethics Journal, Accepted.
33. Mackenzie, C. and N. Stoljar, *Relational autonomy: Feminist perspectives on automony, agency, and the social self.* 2000.
34. Wolf, S.M., *Shifting paradigms in bioethics and health law: the rise of a new pragmatism.* American Journal of Law and Medicine, 1994. **20**(4): p. 395-415.

# CHAPTER 4: EXPLORING EVERYDAY ETHICS

## Manuscripts 2 & 3

# PART ONE: MANUSCRIPT 2

# CONTEXT OF MANUSCRIPT 2

The investigation in Manuscript 1 (Chapter 3) clearly showed that there are important ethical considerations related to decision making for Parkinson’s disease patients. Having to make decisions about their care is something all Parkinson’s disease patients will face many times throughout their life, and it is something all Parkinson’s disease healthcare providers will be involved in. Consequently, the ethical issues surrounding decision making in Parkinson’s disease may be considered as falling under everyday ethics.

Everyday ethics is a term that has existed in the bioethics literature since at least the 1980s. It is used in a multitude of contexts, but it is rarely defined or explained. Notably, there may be an intuitive notion as to what constitutes ‘everyday ethics’. It was this intuition that initially led us to identify issues related to decision making as falling under the scope of everyday ethics. However, we quickly realized that there is a lack of conceptual clarity about this term. Consequently, we explored the literature to see if there was a consistent description of everyday ethics, and to develop an understanding of how this term has been utilized in bioethics. The following manuscript, entitled “What is everyday ethics? A review and a proposal for an integrative concept” discusses the results of this work. In particular, we examined how everyday ethics has been defined and operationalized in the literature, and identified its key components. We also discussed the importance of everyday ethics, and drew from multiple normative theories to develop an integrative model of everyday ethics. The conceptual clarity that the following manuscript brings can encourage others to more explicitly investigate everyday ethics, which is identified as being under researched in part two of this chapter.

# What is everyday ethics? A review and a proposal for an integrative concept

Natalie Zizzo[1,2], Emily Bell[1,3], Eric Racine[1,2,3,4]*

1. Neuroethics Research Unit, Institut de recherches cliniques de Montréal
2. Division of Experimental Medicine and Biomedical Ethics Unit, McGill University
3. Department of Neurology and Neurosurgery, McGill University
4. Department of Medicine and Department of Social and Preventive Medicine, Université de Montréal

*** Corresponding author**
Eric Racine, PhD*
Director, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM)
Associate Research Professor, IRCM
Associate Director, Academic Affairs, IRCM
Dept of Medicine and Department of Social and Preventive Medicine, Université de Montréal
Depts of Neurology and Neurosurgery, Experimental Medicine & Biomedical Ethics
Unit, McGill University
Institut de recherches cliniques de Montréal
110 avenue des Pins Ouest
Montréal, QC H2W lR7
Tel: (514) 987-5723
Email: eric.racine@ircm.qc.ca

**Acknowledgements:** Funding for this work was provided by the Canadian Institutes of Health Research (ER (PI) and EB (co-I)) and the Fonds de recherche santé – Québec (career award, ER; master’s scholarship in partnership with Unité SUPPORT du Québec, NZ). We would like to thank the patients who participated in this research, staff at the PD clinic, and members of the Neuroethics Research Unit for feedback on this work.

**Abstract:**

Everyday ethics is a term that has been used in clinical and ethics literature for decades to designate normatively important and pervasive issues in health care. However, and in spite of its importance, the term has not been well defined or characterized in the literature. We undertook a literature review to understand how the term has been employed and defined, finding that it is often compared to “dramatic ethics”. We identified the core attributes most commonly associated with everyday ethics. We then propose an integrative model of everyday ethics that builds on the contribution of different ethical theories. This model changes the function of everyday ethics to that of an integrative concept that (1) helps to detect current blind spots in bioethics (i.e., shifts focus from dramatic ethics) and (2) mobilizes moral agents to address these shortcomings of ethical insight. This novel integrative model has theoretical, methodological, practical, and pedagogical implications, which we explore for the first time. Because of the pivotal role that moral experience plays in this integrative model, the model could help to bridge empirical ethics research with more conceptual and normative work.

**Keywords**: Everyday ethics, moral theory, pragmatism, clinical ethics, bioethics, patient-provider relationships

## **Introduction:**

The emergence of bioethics is often tied to various scandals and challenges in biomedicine, including those related to research (e.g., experiments on institutionalized children), and those related to tough dilemmas in clinical practice (e.g., brain death determination and withdrawal of life support). These were, for the most part, issues that had a dramatic public profile. However, it is also true that bioethics was triggered by non-dramatic, everyday ethics issues, such as a culture of growing impersonal care (e.g., large hospitals, specialization of medicine) and the need to recognize and respect individual rights in daily care. As a result of these events, in the past 50 years many changes have been brought to healthcare and biomedicine. At the same time, there is a sense that bioethics has focused on the more dramatic ethical issues, while the issues faced in daily life by healthcare practitioners, patients, and caregivers—"everyday ethics"—are not well considered and reflected in the agenda of bioethics. Indeed, numerous critiques of bioethics stemming from different theoretical perspectives have pointed to bioethics' lack of connection with everyday ethics. Writings from the tradition of clinical ethics [1, 2], feminist ethics [3], pragmatism [4, 5], and narrative ethics [6, 7] have all, in different ways, called for greater attention to everyday ethics, a term that has been in use in bioethics since at least the 1980s. Perhaps most notably, in 1990, Kane and Caplan published a landmark anthology, titled *Everyday ethics: Resolving ethical dilemmas in nursing home life*, that considered ethical dilemmas in nursing home care [8]. Application of the term has since expanded and been applied in a multitude of contexts. Nonetheless, the concept of everyday ethics remains somewhat undefined, is often left unnamed by authors, and is missing integration with other theoretical frameworks.

In this paper, we revisit the concept of everyday ethics. We review the current literature and identify core features and functions of everyday ethics. We then propose an integrative model of everyday ethics, which serves the purpose of drawing attention to a particular set of issues that are understudied in academic research and remain overlooked or unrecognized as ethical issues. We examine how different ethical approaches account for aspects of everyday ethics that, when viewed through an integrated lens, draw the eye to important but underappreciated issues in bioethics. The implications (theoretical, methodological, practical, and pedagogical) of this integrative concept are illustrated and discussed.

## What is Everyday Ethics?

In order to better understand how everyday ethics has been characterized in the academic literature, we performed a search on PubMed (August 13 2014) and MedLine Proquest (September 23 2014) using the terms "everyday ethic*". This search yielded a total of 88 results (excluding duplicates); 27 of these were excluded because they had no abstract and were inaccessible, while 61 results were included and analyzed (two had abstracts but full versions were inaccessible, 59 results were fully accessible). We report the results of this search using the style of a narrative or scoping review [9] to describe the different aspects of everyday ethics and identify core features of everyday ethics.

### Defining everyday ethics

When it comes to describing what is meant by everyday ethics, only a third (33%) of the articles actually gave a description or definition of the term. Nearly half of the articles (41%) used the term only in their title or abstract. This scarcity of definitions seems to indicate that everyday ethics is thought to be an implicitly understood concept. However, when descriptions of everyday ethics were given, they were inconsistent and varied depending on the context. For example, in the nursing literature, many of the definitions were, not surprisingly, focused on the experience of the nurse: "'Everyday ethics' involves those usual encounters that nurses have with patients, their families, and other health providers, (…) [it] centers on who the professional nurse is and how the nurse interacts with and relates to others in the health care environment" [10 p. 60]. Comparatively, other descriptions highlighted everyday ethics as characterized by "multi-perspectiveness" [11]. There was recognition of the importance of different views in identifying and resolving everyday ethical issues [12]. The importance placed on multiple perspectives is perhaps best exemplified by the various studies which investigated not only the views on everyday ethics of healthcare practitioners, including physicians, nurses, and other allied healthcare professionals, but of patients, family members, and caregivers[1].

---

[1] For example, studies by Moon et al. [13], Quarini [14] and McDougall [15] investigated everyday ethics focused on physician perspectives. Seaman and Erlen [16] focused on the nurse perspective. Van der Dam et al. [11] looked at multiple healthcare provider perspectives (from nurse assistant to physician). Smith [17] and Townsend et al. [18] focused on patient perspectives. Powers [19,20] and Hasselkus [21] looked at multiple perspectives, ranging from nurses to social workers, recreational therapists, elder care residents, and relatives. Few articles investigated everyday ethics from the perspective of researchers (e.g., [22. 23]).

Some authors characterized everyday ethics based on its frequency and others emphasized its ordinariness (e.g., “ordinary ethics-related issues commonly faced” [24, p. 45]. The emphasis on the ordinary likely stems from Caplan’s original conception of everyday ethics, wherein he states: “Ethics concerns not only questions of life and death but how one ought to live with and interact with others on a daily basis. The ethics of the ordinary is just as much part of health care ethics as the ethics of the extraordinary” [25, p. 38]. Although some descriptions overlapped, there was no single, consistent definition of everyday ethics (see table 4.1-1). Despite these inconsistencies and variable definitions, everyday ethics seems to be operationalized as a set of ethical issues that occur regularly, arise often in healthcare interactions, and are frequently overlooked.

**Table 4.1-1: Illustrative published descriptions and definitions of everyday ethics**

| |
|---|
| “ethical questions that arise on a day-to-day basis” [11, p. 251] |
| “situations involving values, virtues, obligations, ethical principles (such as respect for persons) or manifestations of these principles (such as truth telling and confidentiality), as well as conflicts between any of these, although conflict [is] not required. In addition, […] matters relating to professionalism and associated responsibilities [are included]” [24, p. 713] |
| “the day-to-day clinical activities that constitute a moral territory lying outside of formal ethics guidelines” [26, p. 188] |
| “the small decisions about the content and order of daily life in nursing homes [25] and other health and social service settings” [27, p. 79] |
| “‘ordinary’ issues of daily living” [20 p. 322] |
| “ethics with a small e, ‘the moral what-to-do questions […] that require […] to evaluate and choose between alternatives’[28] on an everyday basis, while in the field. […] it is not the Ethics with a capital E of Ethics Committees or Ethics Councils.” [23, p. 813] |
| “‘housekeeping issues’, […] the everyday routine issues that constitutes a major part of the health care work performed by nurses and often ignored and invisible in ethical dogma” [29, p. 414] |
| “everyday ethics involves human values and beliefs about how we should live and interact with one another on a daily basis” [19, p. 144] |
| “everyday conflicts that have ethical implications - what we call 'situated ethics'” [30, p. 285] |

### Defining everyday ethics by comparisons

In many of the retrieved articles, everyday ethics was more often described in terms of what it is *not*. For example, everyday ethical issues were often contrasted to ethical issues that are viewed or analyzed as dilemmas [7, 31]. Some authors regarded everyday ethics as overlooked by principle-based or procedural approaches [16], and viewed everyday ethical issues as better analyzed using contextual forms of ethics [7]. Perhaps most commonly, everyday ethics was contrasted to what has been alternately termed “dramatic” [10, p. 60; 14, p. 32], “high-intensity” [13, p. 842], “sensational” [32, p.206], or “tragic” [33, p. 370] ethics. In this paper, we adopt the term dramatic ethics to refer to this type of ethics, although we do not mean to imply any normative judgments in our distinction of these two sets of ethical issues.[2]

Within the retrieved literature, dramatic ethics was often described as rendering everyday ethics invisible [10, 29, 34], causing it to be overlooked [7, 35] and overshadowed [17]. Dramatic ethics is seen as having a higher media and public profile, and correspondingly as retaining the focus of bioethics [10, 17]. However, despite the multiple comparisons of everyday ethics to dramatic ethics, the term dramatic ethics itself was poorly characterized. Our review suggests that dramatic ethics is often associated with acute care, and tends to focus on high technology, often invasive or life-threatening interventions, and research advances. Comparatively, everyday ethics is seen as aligning more closely with regular, practical clinical ethical issues, reflecting “real-life” problems faced by patients or providers. Notably, dramatic ethical issues were perceived as challenging and important, but also as less common and as not reflecting the actual experience of most patients and healthcare providers [17, 36]. In contrast, everyday ethics was described as “subtle and pervasive” [37, p. 20], and was seen as a feature in the experiences of the many [17]. We highlight the differences between everyday and dramatic ethics, derived from the literature and our own reflections, in Table 4.1-2.

---

[2] We also note that we use the terms (1) everyday ethics/dramatic ethics and (2) everyday ethical issues/dramatic ethical issues. The first dichotomy suggests different forms of ethics whereas the second designates a type of ethical issues. We use them somewhat interchangeably since the first set of notions is defined with reference to the second set.

**Table 4.1-2: Commonly described differences between everyday ethical issues and dramatic ethical issues**

| **Dramatic Ethical Issues** | **Everyday Ethical Issues** |
|---|---|
| Focused on “extraordinary” high technology and life-threatening interventions | Focused on daily life, “ordinary” health care and services |
| Often in acute care/high-risk settings | Often in non-acute care/low-risk settings |
| Less common (affects few) | More common (affects many) |
| Salient/high media and public profile | Less salient/low media and public profile |
| Associated with high technology research, innovative care | Associated with everyday healthcare encounters, routine care |
| Perceived higher ethical stakes; high attention in bioethics | Perceived lower ethical stakes; limited attention in bioethics |
| Often described/set up as an ethical dilemma | Often described in non-dilemmatic forms such as angst, moral distress, tensions |
| Of high interest for analyses based on ethical principles (e.g., principlism, casuistry) | Of high interest to contextual forms of ethics (e.g., feminist ethics, pragmatism, and narrative ethics) |

### Common contexts of everyday ethics discussions

Interestingly, everyday ethics seemed to be widely discussed in two contexts: nursing (47% of included sample), and ethics training of healthcare professionals (25%). Meanwhile, a smaller subset (13%) of the literature focused on the experiences of patients and their families, and an even smaller subset (4%) looked at everyday ethical issues for health researchers.

Why has the discussion been highly focused in the nursing context? Some authors have suggested that the focus in nursing may be due to the fact that ethical issues faced by nurses are embedded in everyday clinical practice [38]. Similarly, nursing ethics has more traditionally focused on relational and contextual aspects of care, and may therefore be more attuned to discussing the more basic and prevalent ethical issues that arise in daily provision of care. Notably, everyday ethics was commonly tied to moral distress [31, 38-40], which is a concept that was developed in nursing ethics to refer to when an individual knows the right thing to do, but is impeded from being able to take the right course of action due to institutional constraints [41].

Many authors called for the use of everyday ethical issues in the ethics training of clinicians [15, 24, 33, 42]. The focus on everyday ethics in ethics education may be a result of efforts to utilize the ethical issues that healthcare practitioners are most likely to encounter in provision of care as teaching tools (i.e., those that are frequent and familiar) [33]. In this case, everyday ethics is described as more reflective of the actual provider experience [17] and may help as a bridge between bioethics and clinical practice.

The multiple contexts in which everyday ethics was discussed illuminate an important point: many individual stakeholders are touched by everyday ethics. As a result, a consideration of *whose* everyday experience is examined factors into descriptions of everyday ethics. Everyday ethical issues can involve any of the above parties, but the particular ethical challenge or concern may vary depending on whose perspective is taken. At the same time, it is important to note that different stakeholders may experience the same everyday ethical issues (e.g., issues related to access to care), but in different ways.

### Professionalism, relationships and everyday ethics

Finally, the importance of everyday ethics to professionalism and the common obligations of clinicians to patients were commonly cited in the literature [10, 24, 43, 44]. Everyday ethics was seen as being an integral part of the professional practice, perhaps because it is reflective of the everyday experience of healthcare practitioners. Correspondingly, it was observed that everyday ethics is often captured in a non-experts ethics language, or a folk taxonomy [20]. Indeed, everyday ethics is part of the ordinary experience of individuals, and the issues that they deal with daily are not always classified or described as ethical in nature. However, when the issue is examined more in depth and unpacked, the ethical dimensions can become clearer. Everyday ethical issues may arise from relational or contextual factors intrinsic to everyday encounters (e.g., issues of communication) [18, 24, 29], or as the result of systemic or organizational issues (e.g., challenges in adequate provision of care in light of limited resources) [11].

### Core features of everyday ethics

Upon this review of the literature, we observe that the following attributes have been used to characterize everyday ethical issues:

- First, everyday ethics encompasses real-life issues; everyday ethics is not hypothetical, it includes events that occur often and affect the many.

- Second, everyday ethics is situated in common interactions between people; issues may be especially tied to relational and contextual factors, but also systemic and organizational factors.
- Third, everyday ethics varies depending on the agent or stakeholder, including clinicians (nurses, physicians etc.), patients, and their relatives and caregivers. Notably, while everyday ethics affects more than just clinicians, it is often associated with professionalism.
- Fourth, everyday ethics is often captured in a folk taxonomy, or non-expert ethics language, and the ethical dimension may not always be apparent to stakeholders.

Note that not all of these attributes are necessary for an issue to be considered an everyday ethical issue, but these attributes can enable us to recognize these issues.

## What is the Significance of Everyday Ethics?

Despite the likelihood that patients and healthcare providers encounter everyday ethical issues, these issues are described as under-recognized, under-discussed [24], and as attracting little attention [45].[3] Our own preliminary evidence seems to suggest that, at least in the case of the bioethics literature on Parkinson's disease, everyday ethics is overlooked [47]. Several studies have also reported that even in clinical ethics, there is a tendency to perceive the need for clinical ethics services only in what might be described as dramatic ("crisis") cases [48]. This points to a propensity for bioethics discussions to be held foremost when an issue is striking. A focus on dramatic ethical issues can eclipse pertinent ethics discussions, and high profile type concerns risk becoming the "[lens] through which the topic of ethics in health care is viewed" [19].

This failure to recognize and discuss the importance of everyday ethics may be related to its "ordinariness" [20, 31]. Comparisons of everyday ethics to "tragic" ethical issues [33] perpetuate a problematic idea that everyday ethics cannot have important consequences. Perhaps most notably, everyday ethical issues have been described as having "seemingly small stakes" [25, p. 40]. This may explain why the bioethics literature has had little focus on these issues; they may not be viewed as "exciting". Previous descriptions of them as mundane [17, 25] likely do

---

[3] Determining if this factual claim is true would merit a dedicated investigation (for an example of such epistemological content analysis of "neuroethics" see Racine [46].

not help in illustrating their importance. We contend that everyday ethics only has *perceived* small stakes. Although the consequences of ignoring these issues may not be immediately apparent, they can have significant lasting effects and, in the long-term, may influence how individuals interact with and within the healthcare system. For example, in a qualitative study on the perspectives of young adults with cerebral palsy, we found evidence that the conduct of clinicians in everyday encounters (e.g., belittlement) can have significant impact on future trust in and use of healthcare services [49]. Accordingly, and in spite of its name, the concept should be recognized for its importance and implications. Furthermore, regardless of the size of the stakes of everyday ethics, if these issues occur regularly (i.e., “everyday”), and affect a large number of people then, “the enormity of these ethical problems becomes staggering” [17, p. 34].

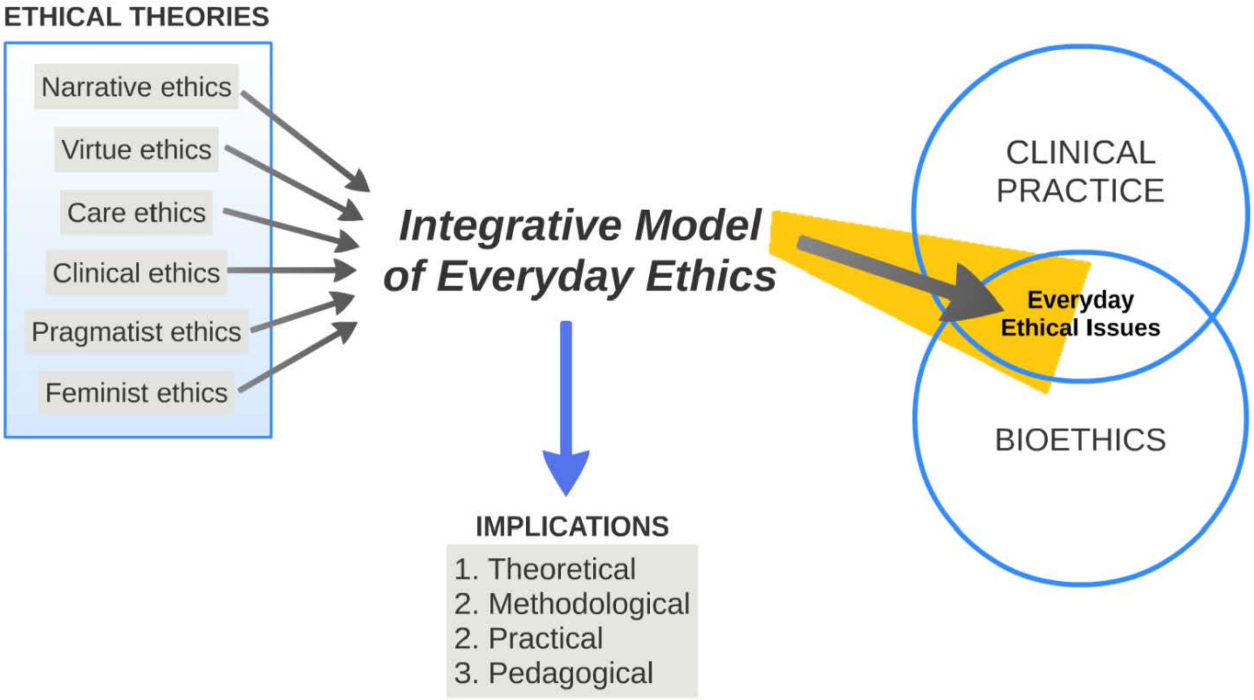
At the same time, since everyday ethical issues occur regularly and are under-discussed, they may be under-recognized in practice. Stakeholders may overlook the ethical dimensions and the moral significance of everyday ethical issues. As a result, these issues may be misclassified as purely logistical or clinical “problems” to be solved [20]. Certainly, an ethical issue may stem from a clinical or logistical problem, but the issue can still have an important ethical dimension. By ignoring the ethical components of these issues, approaches to resolve them may overlook important values, principles, and approaches necessary in the consideration of ethical issues. It is also possible that the failure to recognize some everyday issues as ethical ones may be a result of their description within a folk taxonomy. Indeed, as Callahan (1973) has pointed out, most individuals do not discuss ethical problems using theoretical language. It is the responsibility of the ethicist to move “more deeply into the issues than others do, of giving them a coherence and clarity which they may lack in the formulations of ordinary language, and of bringing to them a nuanced methodology” [50, p. 70]. On this last point, bioethics needs to uphold a commitment to recognizing the ethical dimension of these everyday issues; a more nuanced discussion of how to address these issues must take place.

Good bioethics needs to address all relevant ethical issues, not just those that dominate journals and headlines [51]. In the next section we discuss an integrative model of everyday ethics that can enhance the function of this concept.

## Proposal: An Integrative Model of Everyday Ethics

Based on the importance of everyday ethics and our review of the relevant literature, we propose that everyday ethics, from a functional (pragmatist) perspective [52], should be utilized as an integrative concept that (1) helps to detect current blind spots in bioethics (i.e., shifts focus from dramatic ethics) and (2) mobilizes moral agents to address these shortcomings of ethical insight. This integrative model draws from multiple ethical theories and has important methodological, practical, and pedagogical implications (see Figure 4.1-1).

**Figure 4.1-1: The Integrative Model of Everyday Ethics**



Diverse ethical theories contribute to an integrative model of everyday ethics. The integrative model can shed light on everyday ethical issues in clinical practice and in bioethics. This model has theoretical, methodological, practical, and pedagogical implications.

### What is an Integrated Everyday Ethics?

We propose that the concept of everyday ethics can be enriched with open-ended descriptions that tap into the resources of diverse normative theories. As part of this proposal, various ethical theories can be used as “lenses”, an approach originally suggested by the feminist scholar Sherwin [53], through which we see everyday ethics. Thus far, many different ethical theories have endeavored to attend to clinical and daily ethical issues; they have explored issues related to everyday ethics, but have not always identified them as such. The proposed integrative model brings together the contributions that these different ethical approaches make to a concept of everyday ethics (see Table 4.1-3). For example, narrative ethics has stressed the importance of listening to the patient and understanding how personal histories and different aspects of the clinical encounter, which may seem minor, can have major impact within the broader perspective of the person [6]. Indeed, there have been specific writings exploring the role of narrative in everyday ethical expertise and socially embedded caring practices [7]. We can also draw from pragmatism, which has stressed historically, and in its contemporary rendition in bioethics, the importance of understanding daily and ordinary challenges in ethics, as well as the importance of context in shaping our understanding of moral agents [4, 5, 46]. A role for clinical ethics is evident; it was actually first described by Jonsen et al. as a field "both about the ethical features that are present in every clinical encounter and about the ethical problems that occasionally arise in those encounters" [54, p. 1]. For virtue ethics, according to Levine:

> Ethical behavior is not the display of one's moral rectitude in times of crises. It is the day-by-day expression of one's commitment to other persons and the ways in which human beings relate to one another in their daily interactions. [55, p. 734]

Even the *Principles of Biomedical Ethics*, despite often being considered inadequate for the analysis of everyday ethical issues [16, 18, 56] may illuminate everyday ethics. Within principlism there is an acknowledged role for common morality as a starting point for ethics. As a method, it does not preclude the analysis and consideration of everyday ethical issues [57]. By superimposing different theoretical lenses, an integrative approach supports the richness of the concept of everyday ethics and strengthens its potential to de-bias bioethics. And since all lenses carry blind spots, only a comprehensive model can help introduce checks and balances for different perspectives.

Table 4.1-3, below, schematically displays the idea that different ethical theories can serve as lenses through which we can view the different attributes of everyday ethics. The inclusion of the spheres of (1) self; (2) proximate other; and (3) distal other helps capture the notion that everyday ethics is multi-perspectival and that it should be considered and operationalized as such. We consider each ethical approach's theoretical contribution to the integrative model, its practical contribution to both bioethics and clinical practice, and its operational contribution to the clinical encounter.

**Table 4.1-3: Integrative model of everyday ethics and its applications**[4]

| | **Spheres** | | |
|---|---|---|---|
| | **Self** | **Proximate other** | **Distal other** |
| **Contribution of various ethical theories** | **Narrative Ethics**<br>**Theoretical:** Everyday ethical issues are often captured in a personal or folk taxonomy/non-expert ethics language which merits full attention. Narrative ethics brings attention to non-expert formulation of ethical challenges and a comprehensive outlook on the person.<br>**Practical:** Avoid using prematurely expert concepts in ethics to capture patient's perspectives.<br>**Operational:** Questions to keep in mind: How did the patient talk about her situation? Is my understanding of ethics overly constrained by assumptions? What is the history behind this problem? Are there ethical issues embedded in narratives we fail to recognize? | **Care Ethics:**<br>**Theoretical:** Everyday ethical issues may arise as a result of relational and contextual factors. Care ethics brings attention to these factors, as well as our obligations to particular others in relationships. Emphasizes the caring aspects of relationships.<br>**Practical:** Avoid making no room or time to integrate the relational dimension of care.<br>**Operational:** Questions to keep in mind: Does the patient feel comfortable with me? Is the patient censoring his own views? | **Pragmatist Ethics:**<br>**Theoretical:** Everyday ethics is embedded in contexts and the importance of context has been vastly neglected in philosophical ethics. Bioethics tends to abstract unduly and "essentialize" everyday ethical issues. Pragmatist ethics brings attention to the need to focus on "real life" issues, the impact of different (clinical and societal) contexts and how they are conducive or not to the ability and comfort of patients to voice everyday ethical concerns.<br>**Practical:** Avoid an individualistic and abstract understanding of moral agency that impedes the ability to understand the broader context underlying everyday experience.<br>**Operational:** Questions to keep in mind: Is this patient's experience of the situation shaped by his socio-economic status? Is my own social position |

---

[4] In this table, we are only illustrating examples of contributions of different theoretical perspectives. We are not claiming that any of the cited approaches have relevance to only one sphere (self, proximate other, distal other) or that we have in anyway described their full or most important contributions.

| | | | |
|---|---|---|---|
| | | | impeding my ability to relate and understand the everyday experience of this patient? |
| | **Virtue Ethics:**<br>**Theoretical:** Brings attention to the fact that an excellent (virtuous) clinician must have sound judgment on where the best interests of the patients are, based on a generous understanding of and significant engagement with the patient's values.<br>**Practical:** Avoid lack of recognition that the ability to express everyday ethical concerns is contingent on good listening skills on the receiving end.<br>**Operational:** Questions to keep in mind: Are my interpersonal skills as a clinician allowing sufficiently developed to allow patients to express themselves and feel comfortable with me? | **Clinical Ethics:**<br>**Theoretical:** Brings attention to the fact that every clinical act involves values and that ethics is an integral part of healthcare encounters.<br>**Practical:** Avoid viewing ethics as something extrinsic to clinical practice, thereby evacuating ethics from everyday practice.<br>**Operational:** Questions to keep in mind: Is ethics part of my analysis of clinical situations I encounter? Does my view of their decisions provide a generous understanding of values in clinical practice? | **Feminist Ethics:**<br>**Theoretical:** Everyday ethical issues can be shaped by asymmetrical relationships based on gender, race, professional hierarchies, and other socially constructed categories. Related biases and influences need to be taken into consideration.<br>**Practical:** Avoid gender biases and propagation of relational asymmetries that disempower individuals and their ability to speak for themselves.<br>**Operational:** Questions to keep in mind: Am I treating like cases alike? Are individuals with different social and cultural backgrounds equally able to express themselves? |

## The Implications of an Integrative Everyday Ethics

This proposal for an integrative model has several theoretical, methodological, practical, and pedagogical implications:

### *Theoretical Implications*

From a conceptual standpoint, this integrative model moves us away from defining precisely the boundaries of the concept of everyday ethics, which, after some initial clarification and identification of common characteristics (e.g., Table 4.1-2), is bound to be superfluous. Indeed, a proposal for a precise definition of the domain and application of the concept would risk introducing unwelcomed positional biases. Such a definition would need to reflect the stakeholder's own everyday experience, which by definition is rooted in a first-person perspective. It also raises fundamental questions about *whose* everyday ethics is at stake, in *which situation* is the patient or other moral agent involved, and what is one's *everyday.* A rigidly defined concept can only have a limited degree of precision. Furthermore, if the concept is ossified in a precise definition, there is a risk that the normative functions of the concept (i.e., its role as a bioethics blind spot detector) will be forgotten and that everyday ethics will be reduced to a descriptive concept. Such an outcome would then defeat its purpose to enhance the moral lens. Any definition or specification of everyday ethics should remain open to enrichment to prevent the possibility that it becomes self-limiting.

### *Methodological Implications*

From a methodological standpoint, the integrative model of everyday ethics points to a need for bioethics to empirically investigate stakeholder perspectives and experiences (descriptive methodological contribution), and to attend to everyday ethical issues which may not be obvious or salient (normative methodological contribution). In terms of the descriptive methodological contribution of everyday ethics, there has been qualitative research exploring everyday ethical issues in clinical practice (e.g., [13, 17,18, 20, 21, 24]), and other research investigating some of the concept's descriptive components. An integrative model supports such research on the experience and perspectives of stakeholders and calls for multiple empirical research approaches (including qualitative and quantitative, observatory and participatory approaches) to understanding everyday ethics. That being said, based on its function, everyday ethics may be more legitimate as an initial focus of empirical research rather than an overall concept that should be applied to deductively interpret these experiences and perspectives. It is possible that research on the common experience of ethically problematic situations could help generate an ethical taxonomy that better reflects everyday moral experience.

Perhaps more novel is the normative methodological contribution of everyday ethics, which supports an understanding and application of moral theories that aligns with pragmatism and feminism. Within this understanding, moral theories can be described as "hypotheses" to be tested in real-world settings, as well as lenses or perspectives that define both the nature of a problematic situation as well as a path to their resolution [52, 53, 58]. The integrative model operationalizes this view, which broadens the outlook on the nature of everyday ethics and mobilizes resources from different perspectives to address concerns related to the neglect of everyday ethical issues. In drawing attention to ethical issues that have been ignored, the model points to a need to foster more comprehensive analyses of the kinds of ethical issues that exist, and the active listening and engagement needed to capture them.

### *Practical Implications*

The integrative model of everyday ethics not only serves to draw attention to the methodological changes that bioethics can implement, but to the practical changes that can be implemented clinically. The model highlights various important practical contributions from different ethical theories (Table 4.1-3), such as the need for narratives, attention to relational and contextual factors, and the recognition of the ethics inherent in every clinical encounter. These contributions could lead to practical changes that can be implemented clinically, with the goal of enhancing care and addressing everyday ethical issues.

Changes can include recognition of the influence of contextual and relational factors on behavior and care (e.g., racial, age or gender-based attitudes and discrimination), with greater self-reflection and awareness of biases. The integrative model promotes a clinical practice model with more room for patient perspectives and calls for dedicated training on skills for active listening. It also recognizes the need to tackle systemic biases and impediments that exist for certain groups of patients. Indeed, improving ethical climate and culture requires a focus on “the everyday circumstances and situations in which issues or problems are defined to have ethical content, and how the organization resolves or manages them” [27, p. 78].

These practical implications are only a few examples of what everyday ethics might contribute to care; further consideration may illuminate other important changes to undertake at both the individual and organizational levels. By integrating the practical contributions from multiple ethical theories, the integrative model of everyday ethics can be utilized to support change in clinical practice.

### *Pedagogical Implications*

Finally, the integrative model of everyday ethics underscores the importance of teaching about everyday moral experience in the healthcare sciences. Moral theories have been taught with the assumption that they teach moral reasoning and provide ways of resolving ethical dilemmas. This understanding of ethics education set the stage for teaching ethics in a way where ‘ethical questions’ can find ‘answers’. Writings on everyday ethics as well as many other movements in medical pedagogy (e.g., [33, 59]), have criticized this narrow focus of ethics education and called for a wider array of teaching methods (role playing, patient presentations, films and commentaries; see for example [60]), that more fully convey the experiential and personal aspects of ethical situations. In this scheme, the clinician or stakeholder is mobilized to act as a moral agent who must find a ‘response’, and not simply an answer, to the problematic situation. This type of scheme is supported in the everyday ethics literature itself [42, 61, 62].

By bringing attention back to the ethics inherent to the everyday clinical encounter, the integrative concept of everyday ethics provides support for a more comprehensive way of teaching ethics. The integrative model of everyday ethics lends support to the need to train clinicians in ethics in ways that are more in line with their practice (i.e., with the everyday ethical issues they are likely to encounter). It becomes a tool for clinicians to scrutinize their position as moral agents.

## **Limitations**

This paper reports a first review of the literature on everyday ethics and attempts to define its core features. It also proposes a way forward to mobilize the resources of different moral theories to help operationalize everyday ethics. We acknowledge that, having provided a rather ambitious overview and model, the detailed implications of the integrative model would benefit from individual dedicated attention. The aim of our general view is to explain the connections that could be drawn from a better understanding (generated by research) of everyday ethics to the improvement of clinical practices and educational practices. By doing so, the model of integrative ethics generates possible pathways to bridge research (empirical or theoretical) and practice informed by ethical theory. In this sense, moral experience is at the core of the model as both a starting and ending point, and ethics is construed as a disciplined undertaking to help prevent and resolve ethically problematic situations.

We also note that our discussion of everyday ethics has been largely limited to the clinical context; this is a direct result of the existent everyday ethics literature, which is also focused in this domain. Few articles explored everyday ethics for researchers [22, 23]. We acknowledge that everyday ethics may have its own considerations for research ethics, which is beyond the scope of this paper but which certainly merits investigation.

## **Conclusion:**

The concept of everyday ethics has been described and justified from several theoretical bioethics lenses. It has often been pitted against “dramatic ethics”. Our review shows divergence in the descriptions and definitions of everyday ethics but also the richness of theoretical perspectives on the concept. We propose that a broader theoretical perspective can lead to the view of everyday ethics as an integrative concept whose paramount functional roles are to identify blind spots created by dramatic ethics and to redirect attention to everyday ethical issues. Within this account, different theoretical lenses can be mobilized in the service of de-biasing bioethics and enriching the implications of the concept in research, practice, and education.

# REFERENCES

1. Siegler, M., E.D. Pellegrino, and P.A. Singer, *Clinical medical ethics.* 1990.
2. Singer, P.A., E.D. Pellegrino, and M. Siegler, *Clinical ethics revisited.* BMC Medical Ethics, 2001. **2**: p. E1.
3. DeRenzo, E.G. and M. Strauss. *A feminist model for clinical ethics consultation: increasing attention to context and narrative*. HEC Forum, 1997. **9**(3): p. 212-227.
4. Wolf, S.M., *Shifting paradigms in bioethics and health law: the rise of a new pragmatism.* American Journal of Law and Medicine, 1994. **20**: p. 295-415.
5. Moreno, J.D., *Bioethics is a naturalism.* Pragmatic Bioethics, 1999. **2**: p. 3-16.
6. Brody, H. and M. Clark, *Narrative ethics: A narrative.* Hastings Center Report, 2014. **44**(s1): p. S7-S11.
7. Benner, P., *The role of experience, narrative, and community in skilled ethical comportment.* Advances in Nursing Science, 1991. **14**(2): p. 1-21.
8. Kane, R.A. and A.L. Caplan, *Everyday ethics: Resolving dilemmas in nursing home life*. 1990: Springer New York.
9. Arksey, H. and L. O'Malley, *Scoping studies: towards a methodological framework.* International Journal of Social Research Methodology, 2005. **8**(1): p. 19-32.
10. Erlen, J.A., *Everyday ethics.* Orthopaedic Nursing, 1997. **16**(4): p. 60-63.
11. Van der Dam, S., et al., *"Here's my dilemma". Moral case deliberation as a platform for discussing everyday ethics in elderly care.* Health Care Analysis, 2012. **20**(3): p. 250-267.
12. Boyd, K., *Medical ethics: Principles, persons, and perspectives: from controversy to conversation.* Journal of Medical Ethics, 2005. **31**(8): p. 481-486.
13. Moon, M., et al., *Everyday ethics issues in the outpatient clinical practice of pediatric residents.* Archives of Pediatrics & Adolescent Medicine, 2009. **163**(9): p. 838-843.
14. Quarini, C.J., *A day in the life of a junior doctor: everyday ethical encounters.* Postgraduate Medical Journal, 2010(86): p. 632-635.
15. McDougall, R. and D.K. Sokol, *The ethical junior: a typology of ethical problems faced by house officers.* Journal of the Royal Society of Medicine, 2008. **101**(2): p. 67-70.
16. Seaman, J.B. and J.A. Erlen, *"Everyday ethics" in the care of hospitalized older adults.* Orthopaedic Nursing, 2013. **32**(5): p. 286-9.
17. Smith, K.V., *Ethical issues related to health care: the older adult's perspective.* Journal of Gerontological Nursing, 2005. **31**(2): p. 32-39.
18. Townsend, A., et al., *Everyday ethics and help-seeking in early rheumatoid arthritis.* Chronic Illness, 2010. **6**(3): p. 171-182.
19. Powers, B.A., *Everyday ethics of dementia care in nursing homes: A definition and taxonomy.* American Journal of Alzheimer's Disease and Other Dementias, 2000. **15**(3): p. 143-151.
20. Powers, B.A., *Ethnographic analysis of everyday ethics in the care of nursing home residents with dementia: A taxonomy.* Nursing Research, 2001. **50**(6): p. 332-339.
21. Hasselkus, B.R., *Everyday ethics in dementia day care: Narratives of crossing the line.* The Gerontologist, 1997. **37**(5): p. 640-649.
22. Kingori, P., *Experiencing everyday ethics in context: Frontline data collectors perspectives and practices of bioethics.* Social Science and Medicine, 2013. **98**: p. 361-370.

23. Lichtner, V., *The everyday ethics of field work research with vulnerable patients.* Studies in Health Technology and Informatics, 2013. **205**: p. 813-817.
24. Carrese, J.A., et al., *Everyday ethics in internal medicine resident clinic: an opportunity to teach.* Medical Education, 2011. **45**(7): p. 712-721.
25. Caplan, A.L., *The Morality of the Mundane: Ethical Issues Arising in the Daily Lives of Nursing Home Residents*, in *Everyday ethics: Resolving dilemmas in nursing home life*, R.A. Kane and A.L. Caplan, Editors. 1990, Springer: New York.
26. Loblay, V. *Everyday ethics: Ultrasound and sex-determination in Australia*. Indian Journal of Medical Ethics, 2007. **6**(4): p. 188-193.
27. Messikomer, C.M. and C.C. Cirka, *Managing everyday ethics in assisted living: A research-based case analysis for the classroom.* Gerontology and Geriatrics Education, 2008. **28**(4): p. 71-93.
28. Nuffield Council on Bioethics, *Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age*. 2010, Nuffield Council on Bioethics: London.
29. Öresland, S., et al., *Home-based nursing: An endless journey.* Nursing Ethics, 2011. **18**(3): p. 408-417.
30. Balka, E. and M. Tolar, *Everyday ethical dilemmas arising with electronic record use in primary care.* Studies in Health Technology and Informatics, 2010. **169**: p. 285-289.
31. Austin, W., *The ethics of everyday practice: Healthcare environments as moral communities.* Advances in Nursing Science, 2007. **30**(1): p. 81-88.
32. Scheilling, S. and E. Drury, *Everyday ethics and nurse/midwifery education.* Nurse education today, 1994. **14**(3): p. 203-208.
33. Opel, D.J. and M.E. Olson, *Ethics for the Pediatrician Bioethics Education and Resources.* Pediatrics in Review, 2012. **33**(8): p. 370-373.
34. Frith, L., A. Jacoby, and M. Gabbay, *Ethical boundary - work in the infertility clinic.* Sociology of Health and Illness, 2011. **33**(4): p. 570-585.
35. Scott, S.L., P. Marck, and S. Barton, *Exploring ethics in practice: creating moral community in healthcare one place at a time.* Nursing Leadership, 2011. **24**(4): p. 78-87.
36. O'Mathuna, D.P., *The place of dignity in everyday ethics.* Journal of Christian Nursing, 2011. **28**(1): p. 12-20.
37. Healy, T.C., *The complexity of everyday ethics in home health care: An analysis of social workers' decisions regarding frail elders' autonomy.* Social Work in Health Care, 1998. **27**(4): p. 19-37.
38. Hamric, A.B., *Moral distress in everyday ethics.* Nursing Outlook, 2000. **48**(5): p. 199-201.
39. Sporrong, S.K., A.T. Höglund, and B. Arnetz, *Measuring moral distress in pharmacy and clinical practice.* Nursing Ethics, 2006. **13**(4): p. 416-427.
40. Scarborough, T., *Moral distress in everyday ethics.* Nursing outlook, 2001. **49**(6): p. 288.
41. Jameton, A., *Nursing practice: The ethical issues*. 1984: Prentice Hall.
42. Fox, E., R.M. Arnold, and B. Brody, *Medical ethics education: Past, present, and future.* Academic Medicine, 1995. **70**(9): p. 761-768.
43. Taylor, H.A., et al., *Teaching ethics to paediatrics residents: the centrality of the therapeutic alliance.* Medical Education, 2009. **43**(10): p. 952-959.
44. Horowitz, B.P., *Ethical decision-making challenges in clinical practice.* Occupational Therapy in Health Care, 2003. **16**(4): p. 1-14.

45. Ulrich, C.M., et al., *Everyday ethics: ethical issues and stress in nursing practice.* Journal of Advanced Nursing, 2010. **66**(11): p. 2510-2519.
46. Racine, E., *Pragmatic neuroethics: Improving treatment and understanding of the mind-brain*. 2010: The MIT Press.
47. Zizzo, N., Bell, E., and Racine, E. , *Exploring everyday ethics and its applications in Parkinson's disease (selected abstracts from the 2014 International Neuroethics Society Annual Meeting).* American Journal of Bioethics Neuroscience, In Press. **6**(4).
48. Racine, E., *HEC member perspectives on the case analysis process: a qualitative multi-site study*. HEC Forum, 2007. **19**(3): p. 185-206.
49. Larivière-Bastien, D., et al., *Perspectives of adolescents and young adults with cerebral palsy on the ethical and social challenges encountered in healthcare services.* Narrative Inquiry in Bioethics, 2011. **1**(1): p. 43-54.
50. Callahan, D., *Bioethics as a discipline.* Hastings Center Studies, 1973: p. 66-73.
51. Bowman, D., *What is it to do good medical ethics? Minding the gap(s).* Journal of Medical Ethics, 2015. **41**(1): p. 60-63.
52. Dewey, J., *Human nature and conduct: An introduction to social psychology*. 1922, New York: Holt.
53. Sherwin, S., *Foundations, frameworks, lenses: The role of theories in bioethics.* Bioethics, 1999. **13**(3- 4): p. 198-205.
54. Albert R. Jonsen, M.S., and Winslade W. J., *Clinical Ethics: A Practical Appraoch to Ethical Decisions in Clinical Medicine*. 4 ed. 1998, USA: McGraw Hill.
55. Greipp, M.E., *Greipp's model of ethical decision making.* Journal of Advanced Nursing, 1992. **17**(6): p. 734-738.
56. Torres, J.M. and R.G. De Vries, *Birthing ethics: What mothers, families, childbirth educators, nurses, and physicians should know about the ethics of childbirth.* The Journal of Perinatal Education, 2009. **18**(1): p. 12-24.
57. Beauchamp, T.L. and J.F. Childress, *Principles of biomedical ethics*. 2001: Oxford University Press.
58. Mahowald, M.B., *So many ways to think. An overview of approaches to ethical issues in geriatrics.* Clinics in Geriatric Medicine, 1994. **10**(3): p. 403-418.
59. Siegler, M., *Lessons from 30 years of teaching clinical ethics.* Virtual Mentor, 2001. **3**(10).
60. Macer, D.R., *Moral games for teaching bioethics*. 2008, Bangkok: UNESCO.
61. Robichaux, C., *Developing ethical skills: From sensitivity to action.* Critical Care Nurse, 2012. **32**(2): p. 65-72.
62. Doane, G.H., *In the spirit of creativity: The learning and teaching of ethics in nursing.* Journal of Advanced Nursing, 2002. **39**(6): p. 521-528.

# PART TWO: MANUSCRIPT 3

# CONTEXT OF MANUSCRIPT 3

The investigation in part one of this chapter (Manuscript 2) defined and highlighted the importance of everyday ethics. This work found that everyday ethics is often compared to dramatic ethics, and that it is often described as overshadowed by discussions of dramatic ethical issues. Indeed, there are concerns that everyday ethics is under discussed in bioethics.

Parkinson's disease patients, as recipients of chronic care, regularly interact in the healthcare system and are thus likely to encounter everyday ethical issues. In Chapter 3, we identified salient ethical concerns surrounding the 'everyday' process of decision making. However, literature on decision-making processes for PD patients is sparse (identified in Chapter 1), providing little ethical guidance or reflection. We wondered if this might be the case for all bioethics literature relevant to PD. Consequently, we investigated this hypothesis by performing a scoping review of the PD bioethics literature.

In the following manuscript, entitled "What do we talk about in bioethics? A characterization of the Parkinson's disease literature and an examination of everyday ethics", we aimed to see if the types of issues most PD patients are likely to face, or everyday ethics, was being discussed. Specifically, we evaluated the context within which bioethics discussions related to Parkinson's disease were occurring. This research gives us insight into where scholarly bioethics, at least in discussions relevant to Parkinson's disease, seems to place its focus, and enables us to identify potential gaps in discussions.

# What do we talk about in bioethics? A characterization of the Parkinson's disease literature and an examination of everyday ethics

Natalie Zizzo[1,2], Emily Bell[1,3], Eric Racine[1,2,3,4]*

1. Neuroethics Research Unit, Institut de recherches cliniques de Montréal
2. Division of Experimental Medicine and Biomedical Ethics Unit, McGill University
3. Department of Neurology and Neurosurgery, McGill University
4. Department of Medicine and Department of Social and Preventive Medicine, Université de Montréal

*** Corresponding author**
Eric Racine, PhD*
Director, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM)
Associate Research Professor, IRCM
Associate Director, Academic Affairs, IRCM
Dept of Medicine and Department of Social and Preventive Medicine, Université de Montréal
Depts of Neurology and Neurosurgery, Experimental Medicine & Biomedical Ethics Unit, McGill University
Institut de recherches cliniques de Montréal
110 avenue des Pins Ouest
Montréal, QC H2W lR7
Tel: (514) 987-5723
Email: eric.racine@ircm.qc.ca

**Acknowledgements:** Funding for this work was provided by the Canadian Institutes of Health Research (ER (PI) and EB (co-I)) and the Fonds de recherche santé – Québec (career award, ER; master's scholarship in partnership with Unité SUPPORT du Québec, NZ). We would like to thank the patients who participated in this research, staff at the PD clinic, and members of the Neuroethics Research Unit for feedback on this work.

## Abstract:

Everyday ethics refers to those issues that arise regularly within healthcare and research and that have an important moral dimension that sometimes goes unrecognized. These issues are often contrasted to dramatic ethics issues; such issues have seemingly higher stakes, and often arise in acute care situations or are associated with high technology, invasive or life-threatening interventions, and research advances. Claims have been made that scholarly bioethics tends to focus on dramatic ethics at the cost of discussing everyday ethics. However, empirical evidence showing this has been lacking. To test this claim, we characterized the context and content of bioethics discussions occurring in the Parkinson's disease literature. Parkinson's disease is a common neurodegenerative disease and associated ethical issues have been widely discussed in bioethics. We conducted a broad literature search using the keywords "Parkinson's disease" AND ("ethics" OR "bioethics"), and classified results inductively based on the context in which the bioethics discussion was occurring. We found that, at least in the case of the Parkinson's disease bioethics literature, there is indeed an increased focus on dramatic ethics. Discussions of ethical issues within the general research and healthcare ethics contexts made up a minority of the ethics issues discussed, while dramatic issues, such as those related to deep brain stimulation and neuronal cell transplantations, dominated bioethics discussions. Given the potential utility of everyday ethics in improving healthcare and research, this mismatch in focus ought to be addressed. There is a clear need for further understanding and discussion of everyday ethical issues in scholarly bioethics.

**Keywords**: bioethics, everyday ethics, dramatic ethics, Parkinson's disease

## Introduction:

Parkinson’s disease (PD) is a common neurodegenerative disease that affects an estimated 7 to 10 million individuals worldwide [1]. It can include progressive motor impairments as well as cognitive and psychiatric comorbidities [2]. Given that PD requires chronic care, patients must regularly access the healthcare system and, as a result, they are likely to encounter everyday ethical issues. Everyday ethical issues are considered to be those issues that arise regularly within the healthcare system and that have an important ethical dimension, but they often go unrecognized. They are sometimes characterized as encompassing “real-life issues”, as being situated in common interactions between individuals, and as being captured in a folk taxonomy [3]. The importance and pervasiveness of everyday ethics as well as the need for greater attention to this set of issues within bioethics has been highlighted within different theoretical frameworks such as feminist ethics, pragmatist ethics, and narrative ethics [3].

Everyday ethics is sometimes discussed in contrast to dramatic ethics. Dramatic ethical issues are often seen as having higher media and public profiles; consequently, they retain the focus of bioethics [4, 5], casting a shadow on everyday ethics. In the context of Parkinson’s disease, we might expect everyday ethical issues to arise in the diagnostic process, in the communication of prognosis and progression of disease, or in decision-making processes. These sets of issues can be quite different from the dramatic ethics issues discussed in the PD literature, such as those related to high risk treatments (e.g., deep brain stimulation (DBS)), and novel interventions under research (e.g., neuronal stem cell transplantation, gene therapy). Given the likelihood that PD patients and healthcare providers may encounter everyday ethics issues, we aimed to characterize the current PD literature within bioethics, to understand where the ethics focus has been, and to review if everyday ethical issues are being discussed.

## Methods:

We conducted a broad literature review on PubMed using the search terms “Parkinson’s disease” AND (“ethics” OR “bioethics”) (N=333). Exclusion factors were: low relevance to ethics and/or PD (N=135), non-academic sources (N=8), no abstract with an article in a language other than English (N=13), no abstract and inability to access the full article (N=28), and duplicates (N=3). Abstracts of included results (N=146) were analyzed and classified based on the context in which they discussed ethics. These contexts were derived inductively based on a pilot sample (N=50), refined based on team consensus, and then applied systematically to the remainder of the sample. If in this process new contexts were identified, the whole sample was revisited and classified accordingly. Articles with no abstracts were analyzed based on the first 1-3 paragraphs. Topics that were discussed in each context were also identified. The first author did the primary analysis (classification), and the last author systematically reviewed this. Articles falling within the “general healthcare” context, which was considered most directly connected to everyday ethics, were fully read to further identify in detail the types of ethical issues discussed.

## Results:

Fourteen different contexts were identified and used for categorization of abstracts (see Figure 4.2-1). The major contexts in which ethical issues related to PD were discussed included DBS (N=26), foetal tissue transplantation (N=21), stem cells (N=19), sham surgery (N=19), general research (N=17), neural transplantation (N=17), and general healthcare (N=13). Ethical discussions reflected the technology of the time. That is, technology like DBS was a large focus of the ethics literature in the 2000s, which coincides with the time that DBS was approved for the treatment of PD [6]; similarly, neural and fetal tissue transplantation was largely discussed in the 1990s, when this intervention was being actively investigated.

Specific ethical issues examined in the literature were grounded in the context of discussion (e.g., literature on DBS raised philosophical issues associated with identity, whereas literature on foetal tissue transplantation provoked discussion about the moral status of the foetus). A minority of articles (9%) discussed ethics within the general healthcare context, which was the most important context for discussion of everyday ethical issues. Furthermore, within the general healthcare context, a variety of topics related to ethics were captured. Specific examples of the issues discussed within each major context are presented in Table 4.2-1.

**Figure 4.2-1: Contexts of discussion in Parkinson's disease bioethics literature**

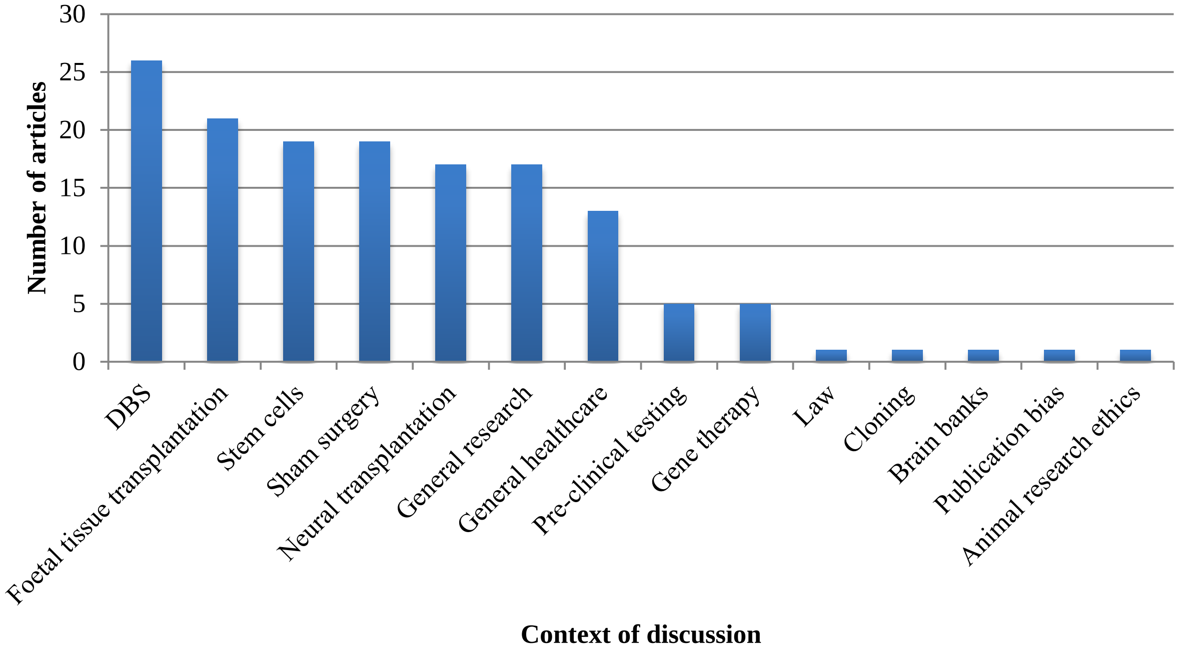


**Table 4.2-1: Ethics issues discussed within the major contexts of Parkinson's disease in the bioethics literature**

| Context | Topics |
|---|---|
| **DBS** | • Clinical ethics (e.g. consent, decision-making, autonomy)<br>• Research ethics (e.g. subject selection, subject vulnerability, consent, risks/benefits)<br>• Philosophical (e.g. effects on personal identity, authenticity)<br>• Resource allocation<br>• Evaluation of results<br>• Psychosocial effects |
| **Foetal tissue transplantation** | • Moral status of foetus<br>• Ethical inter-relation of foetal use and abortion<br>• Consent to use of foetal tissue<br>• Efficacy |
| **Stem cells** | • Source of cells<br>• Research ethics (e.g. clinical trial design, external review, risks/benefits, translational research)<br>• Ethical acceptability |
| **Sham surgery** | • Research ethics (e.g. informed consent, risks/benefits, criteria for controls)<br>• Subject perspectives (e.g. expectations, willingness to participate, acceptability) |
| **Neural transplantation** | • Research ethics (e.g. informed consent, risks/benefits, trial design)<br>• Use of foetal tissue<br>• Philosophical (e.g. personhood, effects on personal identity) |
| **General research** | • Use of placebo<br>• Use of animals<br>• Informed consent |
| **General healthcare** | • Use of placebo<br>• Diagnosis<br>• Clinical ethics (e.g. late stage care, palliative care, refusal of care)<br>• Decision-making process and capacity<br>• Non-medical approaches and relational aspects of care<br>• Pain and non-motor symptoms<br>• Quality of life<br>• Predictive testing |

## Discussion:

The concept of everyday ethics has not been explicitly discussed in the Parkinson's disease bioethics literature. The limited ethics discussions occurring within the general healthcare context and the widespread focus on issues related to DBS, stem cells, sham surgery and neural tissue transplantations indicate that most ethics discussions within the PD context are focused on dramatic ethical issues. Discussion within the general healthcare context, where we might expect to see most discussion of clinical everyday ethics issues, was sparse, making up only 9% of the overall sample. Furthermore, within the healthcare context, a wide range of topics was discussed. This indicates that there might be many everyday ethics issues that could be further explored.

Everyday ethical issues may also arise in research; we would expect discussion of these issues to occur within the general research context, which made up 12% of our sample. However, the more dramatic research ethics issues associated with sham surgery eclipsed these general research context issues. Thus, in both research and clinical ethics, dramatic ethics retains the focus of bioethics scholarly work.

Everyday ethical issues are clearly being under-explored, and we must ask why this is the case. One hypothesis is that bioethics scholarship could generally be oriented toward issues associated with more controversial technologies [7]. Another explanation could be that there is a demand placed on bioethics to be innovative and to address ‘novel’ issues, to the detriment of common, everyday issues despite their practical relevance [8]. Irrespective of the potential causes of the focus on dramatic issues, this disparity takes on an important moral dimension if we consider that investigations of everyday ethical issues could give us telling insight into healthcare systems and lead us to identify areas in need of improvement for the best ethical care and research. Furthermore, everyday ethics can have important methodological and educational implications for healthcare providers and researchers [3]. From an educational standpoint, there is a need to further explore everyday ethical issues specific to PD, as utilizing everyday ethics in teaching bioethics is a pragmatic orientation which can prepare healthcare practitioners to address the issues they are most likely to encounter in practice. From a broader methodological perspective, there is a need for bioethics to empirically investigate stakeholder perspectives and experiences, and to attend to everyday ethical issues that may not be obvious or salient.

Indeed, there have been some empirical investigations into stakeholder perspectives that aimed to uncover everyday ethical issues. These investigations are particularly prevalent in the nursing and ethics education literature [3]. We may be able to draw on this literature to inform future investigations. For example, an examination of everyday ethical issues in a group of rheumatoid arthritis patients [9] could give us insight into the types of issues that PD populations face, given that both require chronic care from a specialist and typically affect older adults. This research identified everyday ethical issues related to autonomous decision-making and procedural justice. These issues were complicated by factors such as inadequate knowledge about symptoms, difficulties accessing specialists and unsatisfactory patient-practitioner interactions. We propose that further investigations into potential everyday ethical issues in PD could reveal specific concerns related to autonomy, capacity, decision-making and communication of information, and broader issues related to health system organization and health services delivery. These issues are relevant for the provision of ethical care to PD patients and for the responsible conduct of research.

We note that, because the moral dimension of everyday ethics issues may not always be recognized, there may be other literatures that capture everyday ethics issues without naming them as such. Moreover, classifying the PD bioethics literature according to context may not be wholly telling of the types of issues that are being discussed. This leads to a potential limit where everyday ethics issues might be discussed within a seemingly dramatic context. However, whether or not an everyday ethics issue can exist within a dramatic context is unclear. For example, although it could be argued that some issues aligned with the notion of everyday ethics (e.g., quality of life) are discussed in dramatic contexts (e.g., DBS) the fact that a minority of patients will be exposed to these dramatic contexts (a minority of PD patients will undergo DBS, and many more patients will live for longer periods of time without the device) challenges the idea that these issues should be conceived of as *everyday* issues. We have attempted to reconcile the boundaries and uses of this concept in another place [3].

## Conclusion:

Claims have been made that bioethics tends to focus on dramatic ethics to the detriment of everyday ethics. Our research indicates that, at least in the case of the bioethics literature relevant to Parkinson’s disease, there is indeed such a discrepancy in focus. Identifying the most salient challenges that PD patients face may necessitate empirical evidence gathered from PD patients themselves. There is a clear need for further understanding and discussion of everyday ethical issues in scholarly bioethics.

# REFERENCES

1. Parkinson's Disease Foundation. *Statistics on Parkinson's*. 2015 [accessed 5 May 24 2015]; Available from: http://www.pdf.org/en/parkinson_statistics.
2. Parkinson Society Canada. *Parkinson's Disease: Social and Economic Impact*. 2003 [accessed 26 June 2015]; Available from: http://www.parkinson.ca/atf/cf/%7B9ebd08a9-7886-4b2d-a1c4-a131e7096bf8%7D/PARKINSONSDISEASE_EN.PDF.
3. Zizzo, N.B., Emily; Racine, Eric, *What is everyday ethics? A review and proposal for an integrative model.* Theoretical Medicine and Bioethics, Under Review.
4. Erlen, J.A., *Everyday Ethics.* Orthopaedic Nursing, 1997. **16**(4): p. 60-63.
5. Smith, K.V., *Ethical issues related to health care: the older adult's perspective.* Journal of gerontological nursing, 2005. **31**(2): p. 32-39.
6. University of Wisconsin Hospitals and Clinics Authority. *Deep Brain Stimulation (DBS) Frequently Asked Questions*. 2014 [accessed 26 June 2015]; Available from: http://www.uwhealth.org/neurosurgery/deep-brain-stimulation-dbs-frequently-asked-questions/12764.
7. Evans, J.H., *Playing god?: Human genetic engineering and the rationalization of public bioethical debate*, 2002. Chicago: University of Chicago Press.
8. Racine, E., *Pragmatic neuroethics: improving treatment and understanding of the mind-brain*, 2010. Massachusetst: MIT Press.
9. Townsend, A., et al., *Everyday ethics and help-seeking in early rheumatoid arthritis.* Chronic illness, 2010. **6**(3): p. 171-182.

# CHAPTER 5: DISCUSSION AND CONCLUSION

## Discussion:

In this thesis, three interconnected topics have been discussed: patient-centred care, patient preferences, and everyday ethics. In Chapter 1, the concept of patient-centred care was explored. Review of the literature on patient-centred care revealed the importance of patient preferences, and in particular highlighted an important gap in understanding Parkinson's disease (PD) patient preferences. In Chapter 2, our epistemology and methodologies were described. In Chapter 3, we aimed to fill the knowledge gap identified in Chapter 1 by investigating PD patients' preferences for involvement in decision-making. In Chapter 4, we explored the concept of everyday ethics, drawing from the available literature and normative theories to strengthen the concept in an integrative model. We also characterized the current PD bioethics literature, examining the extent to which everyday ethics is discussed.

In this discussion, three main inferences based on the above research will be explored. First, I demonstrate that investigations into patient preferences can give us insight into patient-centred care theory and can improve patient-centred practices. Second, I show that investigating patient preferences can reveal everyday ethical issues. Finally, I explore the connections between everyday ethics and patient-centred care, and I demonstrate that they are related concepts that can inform each other.

### Investigating patient preferences gives us insight into patient-centred care theory and improves patient-centred practices

Patient-centred care emphasizes treating patients as persons, taking into account their context, as well as their needs, values, and preferences. Patient-centred care also engages patients in healthcare decisions and management of care. Given the central role of patient preferences and perspectives to patient-centred care, there is a need to understand patient preferences for care.

In this thesis, the focus has been on patient preferences for involvement in decision making. Research in various populations has shown patients' preferences for decision making vary and can be context dependent [8, 9]. Patients generally want to be involved to some extent, and especially desire to be informed of their illness and treatment options [8, 9]. However, there is a particular knowledge gap surrounding the preferences of PD patients for involvement in decision making. This gap in understanding PD patient preferences requires attention, especially in light of calls for a patient-centred approach to PD treatment [5].

To address this knowledge gap, we undertook qualitative research investigating PD patient preferences for decision making (reported in Chapter 3). Our findings were congruent with the existing literature pointing to variability in preferences. In particular, we found that patient preferences for decision-making varied between individuals, with the decision to be made, and based on relational and contextual factors. In general, delegating decisions to the physician required an established relationship of trust. Most patients expressed a desire for information, stating that they would want to learn something relevant to their condition, even if it was bad news, recognizing that it was “their life”, thus their information to learn. However, patients acknowledged that limits to their desire for PD information do exist. These limits were placed on information about the later stages of the disease; for example, once a general understanding of the possible progression of PD was gained, patients did not necessarily view it as useful to learn in detail about all the possible outcomes or to focus on what might happen. These limits stemmed from an acknowledgment of the practical limits of being able to predict the future of their PD, and from an adaptation to life with Parkinson’s, where information about possible far-off outcomes is not necessarily conducive to current decision making. As a result, many patients adopted a “take things as they come” attitude. Finally, patients detailed the importance of the patient-physician relationship, and they saw communication as key to this relationship. They detailed interpersonal qualities that the physician should embody, and responsibilities that the patient should take on. They recognized the central roles the therapeutic relationship and communication play in decision-making processes. These findings, in addition to enhancing our understanding of decision-making processes for PD patients, can give us gives us key insight into patient-centred care theory and practice.

### *Investigations into patient preferences provide insight into patient-centred care theory*

Since the theoretical literature calls for shared decision making and relational autonomy in patient-centred care [6, 7], we can investigate patient preferences to see if they are aligned with these models of decision making and autonomy.

Our evidence suggests that patients support a broad model of shared decision making. Although patients may not have knowledge of the theoretical underpinnings of shared decision making, they unknowingly described many of its elements [85]. They expressed a desire for elements that have been previously identified as essential [85], such as explanation of the problem, discussion of the pros and cons, and discussion of patient values and preferences; ideal elements such as mutual agreement; and general qualities of shared decision making, such as mutual respect, patient participation, and partnership.  Furthermore, although patients did not necessarily need or want to retain decisional control, all wanted to be involved in the first two analytical stages of decision making [41], including information exchange and deliberation, which are crucial to shared decision making. Consequently, the broader model of shared decision making (discussed in Chapter 1) is in line with how patients view themselves as participating in their care.

Our findings also suggest that relational autonomy corresponds to how patients envision their participation in decision-making. Patients described the effects that contextual and relational factors can have on their preferences for involvement in decision-making, and they acknowledged the central role the therapeutic relationship plays in their care. As a result, patients themselves support a relational autonomy approach in patient-centred care.

Overall, our investigation illustrates how patient perspectives can inform patient-centred care, as our empirical evidence confirms previously proposed theory. This is in line with the tenets of pragmatism, our theoretical underpinning for this research. Pragmatism holds that ethical norms can be informed not only from reason, but also from observation and experience [74]. And indeed, here we see that empirical investigations into patient preferences reveal the appropriateness of shared decision making and relational autonomy for patient-centred care theory.

### *Investigations into patient preferences provide guidance for patient-centred practice*

The implications of investigations into patient preferences are not limited to informing theory. Investigating patient perspectives and preferences can provide insight into how best to provide patient-centred care, making for patient-centred care that truly embodies respect for persons. Our research into Parkinson's disease patient preferences suggests that, for effective patient-centred care, physicians need to assess patient preferences on an ongoing basis, and tools to facilitate patient engagement in decision making need to be developed.

The evidence presented in Chapter 3 demonstrates that patient preferences for involvement in decision-making varied between individuals and between decisions and situations. This suggests that, in order to capture fluctuation in preferences, physicians need to assess patient preferences on an ongoing, decisional basis. This could be similar to recommended practices for evaluating decisional capacity [86]. Decisional capacity is assumed in all patients, but when physicians engage patients in decision-making, they continually assess patients' understanding and appreciation of the treatment options and their possible outcomes. This helps to promote respect for persons as it ensures that patients are truly informed and involved in the decision-making process. In a similar way, physicians might assume patients want to be involved in decision making, but when they interact with patients in this process they should continually assess the individual patient's interest in receiving information and their preferences for decisional control. This ongoing assessment is in line with recommendations from previous research on cancer patient preferences for involvement in decision making [49], indicating that this technique may need to be adopted more broadly. An ongoing, decision-based assessment of patient preferences for involvement in decision making tailors the decision-making process to the individual patient, which consequently promotes patient-centred care and enhances respect for persons.

Furthermore, our findings suggest that tools to facilitate patient engagement in decision making need to be developed. We found that patients had difficulty understanding how to participate in decision-making processes, with multiple patients describing not knowing what questions to ask in the medical encounter. At the same time, patients expressed a need to take on responsibilities in their care. These findings, along with prior evidence indicating that patients face challenges being involved in decision making [67], point to a need to develop tools that will help patients engage in decision-making processes. Such tools could include information sheets which answer some frequently asked questions about their condition. Decision-making aids that provide ideas on the types of questions patients might want to ask their physician, as well as detail what types of information patients ought to communicate to their physician, would be advantageous. These types of tools would help patients be involved in their care and decision-making processes, and are in line with our findings on PD patients' perceived needs and perspectives on their own role in the patient-physician relationship. Taking such steps towards increasing patient involvement in care is thus respectful of patient preferences and helps to promote respect for persons. This approach to patients recognizes the individuality of each person, and facilitates engagement, thus promoting patient-centred care.

Overall, our research into Parkinson's disease patient preferences suggests a need for practical changes in PD care. Moreover, this research has implications for the improvement of patient-centred care in other populations; it illustrates how investigating patient perspectives and preferences can provide insight into the provision and practice of patient-centred care.

## Investigating patient preferences can provide insight into everyday ethics

Research into patient preferences is not limited to informing patient-centred care, but it can also inform the concept of everyday ethics. In part one of Chapter 4, we explored this concept in more detail. We saw that everyday ethics encompasses real-life issues and includes events that occur regularly, affecting many individuals. We found that everyday ethics is situated in common interactions between people, that it may be especially tied to relational and contextual factors, and that it is often captured in a folk taxonomy (i.e., non-ethics expert language). Furthermore, we noted that particular issues in everyday ethics can vary depending on the agent or stakeholder. The significance of everyday ethics was explored, and we found that its associated set of issues have only *perceived* small stakes; in reality unacknowledged everyday ethical issues can have profound effects. We also noted that everyday ethics tends to be under-discussed, and overshadowed by dramatic ethics. Evidence presented in part two of Chapter 4 corroborated this claim; we saw that the majority of discussions in the Parkinson's disease bioethics literature focused on dramatic ethics, and that only a small portion of the literature examined what could be considered everyday ethics. Notably, within the discussions relevant to everyday ethics, a multitude of topics were touched upon, indicating that there may be a wealth of untapped issues to explore and discuss. We suggested that investigating stakeholder perspectives could help to reveal relevant everyday ethical issues, and indeed, in our investigation into Parkinson's disease patient perspectives, we uncovered such pertinent issues.

Our investigation revealed important ethical concerns surrounding decision-making processes. In particular, patients detailed instances where their physician did not respond adequately to their needs, resulting in patients feeling as though there was a lack of respect for them as persons. Patients described experiences where their concerns were brushed off, they were not given sufficient information to understand their condition, or their appointments were too short to meet their needs; these experiences left patients feeling uncared for, and were out of step with patient preferences and expectations for involvement in care. These types of experiences are real-life issues, situated within common interactions between people, and they have an important ethics component; in sum, these issues are everyday ethical issues, as we have seen them described in Chapter 4.

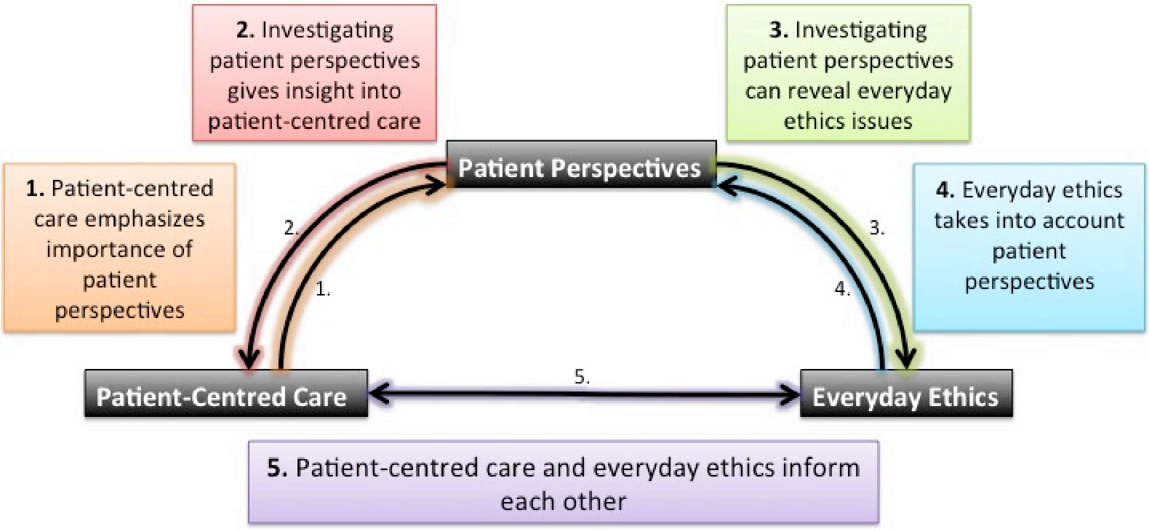
In order to address these ethics concerns, greater attention should be paid to patient preferences and needs. If practitioners understood the significance of certain symptoms to some patients, they might not brush off these concerns; if they better understood patient's preferences for information, they could empower patients in their care; and if they were attentive to what patients felt they needed, patients may not perceive appointments as being too short. Hence, attending to patient preferences can provide a means to address everyday ethics concerns.

Other investigations into patient perspectives have revealed similar everyday ethical issues [87]; this further strengthens the suggestion that patient perspectives can provide insight into everyday ethics. Furthermore, attending to these ethical aspects of care, especially patients' preferences and values, is in line with the goals of patient-centred care. This suggests that everyday ethics and patient-centred care may be aligned.

### Everyday ethics and patient-centred care are interconnected

Thus far, everyday ethics and patient-centred care have been considered separately. However, these concepts are interconnected (see Figure 5-1). Both of these concepts are concerned with the patient experience and stress a need to focus on their perspectives and values. Both embody the principle of respect for persons and enhance ethical care. Moreover, the implications of the integrative model of everyday ethics, discussed in Chapter 4, have clear methodological and practical overlap with patient-centred care. Finally, effective patient-centred care requires an attention to everyday ethics, while attending to everyday ethics can help to inform patient-centred care.

**Figure 5-1: Everyday ethics and patient-centred care are interconnected**



*Overlap between the implications of everyday ethics and patient-centred care practice*

In developing the integrative model of everyday ethics (Chapter 4), we highlighted the fact that many ethical theories have attempted to draw attention to everyday ethics, although they did not necessarily name them as such. By drawing from these diverse normative theories, we enriched the concept of everyday ethics, pointed to ways in which everyday ethics can be operationalized in research and practice, and identified a normative imperative to study these issues. This integrative model has important theoretical, methodological, practical, and pedagogical implications. Many of these implications are directly in line with patient-centred care.

Among the methodological implications of an integrative model of everyday ethics, we saw the need for bioethics to empirically investigate stakeholder perspectives and experiences. Moreover, in this discussion, we have seen that investigating patient preferences can reveal everyday ethical issues as well as inform patient-centred care practice and theory. Thus, patient perspectives can inform both patient-centred care and everyday ethics; both concepts stress the importance of attending to patient perspectives, and can be strengthened by methodologies that recognize these perspectives. These two concepts are thus connected via the utility of patient perspectives.

The integrative model of everyday ethics also has practical implications, including the need to recognise the influence of contextual and relational factors on behaviour and care. An integrated model of everyday ethics promotes clinical practice that leaves room for patient perspectives. This is directly in line with a patient-centred approach to care where patients are treated as persons, their perspectives matter, and they are considered within their unique life experiences, context, and relationships. Furthermore, the pedagogical implications for healthcare practitioners that follow from an integrated everyday ethics are likely to overlap with the training practices for patient-centred care. For example, the integrative model calls for dedicated training on active listening, and training on active listening is among the teaching techniques used to impart patient-centred skills to healthcare practitioners [19]. Thus, there is clear overlap between the implications for an everyday ethics in practice and the practice of patient-centred care.

### *Everyday ethics and patient-centred care can inform each other*

Effective patient-centred care requires attention to everyday ethics. Patient-centred care, with its whole-person orientation, recognizes that each clinical encounter includes not only patients and healthcare providers, but also individuals who have dignity and require respect as persons situated in a particular context, with distinct relationships and histories. Patient-centred care's recognition of patients (and practitioners) as persons necessitates recognition of the moral aspects of each clinical encounter, and thus calls attention to everyday ethics.

Furthermore, studying everyday ethics can inform patient-centred care. As described in Chapter 4, studying everyday ethics requires investigating stakeholder perspectives; this can enhance understanding of the commonplace ethical issues patients and providers face. This knowledge, in turn, can facilitate the delivery of patient-centred care by highlighting the preferences, needs, and values of stakeholders. Additionally, patient-centred care in practice, by attending to stakeholder perspectives, can help to address or prevent everyday ethical issues. Thus, an effective patient-centred practice can facilitate addressing everyday ethical issues.

Moreover, research on or within the patient-centred paradigm may be ideal for informing everyday ethics. Patient-centred care and everyday ethics have conceptual and practical overlap, and both can benefit from certain methodological approaches, especially investigations of patient perspectives. A patient-centred paradigm for clinical care and clinical research could serve as an ideal platform from which to both identify and address issues in everyday ethics. The broad support for patient-centred care could then serve as a springboard from which to re-focus some of the attention in bioethics towards everyday ethics, which is currently under recognized and under discussed.

### *Everyday ethics, patient-centred care, and Parkinson's disease*

In this thesis, we have seen that many ethical issues in patient-centred care are in fact everyday ethical issues. In particular, we saw that Parkinson's disease patients in a patient-centred care clinic can face everyday ethical issues. Recognizing the link between the two concepts can strengthen the need to study everyday ethics, as well as improve the provision of patient-centred care. This is important in light of the calls for patient-centred care for PD patients [5] and the apparent under-discussion of everyday ethics in the Parkinson's disease bioethics literature.

Parkinson's disease is a chronic, unpredictable, neurodegenerative condition, which necessitates integrated and attentive care. PD patients would benefit from recognition of their daily experiences, which could be ideally addressed through a patient-centred paradigm for both healthcare and ethics.

## **Recommendations:**

In this chapter, I have shown the important role of investigating patient preferences, as this type of research provides insight into patient-centred care and reveals everyday ethical issues. This thesis has considered the context of Parkinson's disease patient-centred care, and demonstrated the utility of investigating patient preferences within this context. Our investigation supports the adoption of shared decision making and relational autonomy in patient-centred care. Practical recommendations for patient-centred care include the need to elicit patient preferences for involvement in decision-making on an ongoing, decisional basis. Tools to enable patient participation in decision-making, which highlight disease-centric information and important questions for the patient, should be developed. Such recommendations, when implemented, can improve patient-centred care.

Recognizing the relationship between patient-centred care and everyday ethics is paramount, and supports the need to investigate the latter. This thesis calls for greater attention to everyday ethics, and recommends that research on patient perspectives, particularly in a patient-centred paradigm, be conducted so as to address these issues. Furthermore, greater attention to everyday ethics is necessary as this can improve patient-centred care.

## Conclusion:

This thesis covered a number of topics, including patient-centred care, patient perspectives and everyday ethics. These topics are united in that they focus on the patient experience, and all aim to improve care by addressing ethical issues relevant to the patient. Everyday ethics and patient-centred care can inform each other, and both call for a focus on patient perspectives. Future research into either domain should consider the sphere of the other, and how they may complement one another.

Although bioethics has tended to focus on more ‘dramatic’ ethical issues, there is clearly a wealth of issues to be investigated in everyday clinical practice. Stakeholder perspectives can illuminate these issues, and a specific focus on patient perspectives can help to inform both everyday ethics and patient-centred care. This thesis has specifically investigated patient-centred care and everyday ethics as it pertains to Parkinson’s disease. We have investigated PD patient preferences for involvement in care, giving us insight into how to improve patient-centred care for this population, and illuminating some everyday ethical issues. We have sought to gain conceptual clarity on everyday ethics, and proposed an integrative model of this concept that draws on multiple normative theories. The implications of this integrative model have clear overlap with patient-centred care. Both everyday ethics and patient-centred care are important in healthcare and bioethics as they promote respect for persons, and recognize the importance of context and relationships. In addition, both draw attention to those issues that are under discussed in bioethics. Indeed, we have found that, at least in the PD bioethics literature, ethical issues that are most likely to affect the average PD patient are under discussed. Further reviews of the bioethics literature could be of use to identify other blind spots in bioethics research.

Overall, this thesis pushes for a re-focus in bioethics towards everyday ethics, illuminating issues that are likely to arise in the provision of care and affect a greater number of patients. Investigations into patient perspectives, especially in a patient-centred paradigm, would deepen the scope of bioethics and can lead to improved provision of ethical care.

# REFERENCES

1. Erlen, J.A., *Everyday Ethics.* Orthopaedic Nursing, 1997. **16**(4): p. 60-63.
2. Smith, K.V., *Ethical issues related to health care: the older adult's perspective.* Journal of Gerontological Nursing, 2005. **31**(2): p. 32-39.
3. Scott, S.L., P. Marck, and S. Barton, *Exploring ethics in practice: creating moral community in healthcare one place at a time.* Nursing leadership, 2011. **24**(4): p. 78-87.
4. Benner, P., *The role of experience, narrative, and community in skilled ethical comportment.* Advances in Nursing Science, 1991. **14**(2): p. 1-21.
5. van der Eijk, M., et al., *Moving towards patient-centered healthcare for patients with Parkinson's disease.* Parkinsonism & Related Disorders, 2011. **17**(5): p. 360-364.
6. Barry, M.J. and S. Edgman-Levitan, *Shared decision making — The pinnacle of patient-centered care.* New England Journal of Medicine, 2012. **366**(9): p. 780-781.
7. Ells, C., M.R. Hunt, and J. Chambers-Evans, *Relational autonomy as an essential component of patient-centered care.* International Journal of Feminist Approaches to Bioethics, 2011. **4**(2): p. 79-101.
8. Say, R., M. Murtagh, and R. Thomson, *Patients' preference for involvement in medical decision making: A narrative review.* Patient Education and Counseling, 2006. **60**(2): p. 102-114.
9. Robinson, A. and R. Thomson, *Variability in patient preferences for participating in medical decision making: Implication for the use of decision support tools.* Quality in Health Care, 2001. **10**(suppl 1): p. i34-i38.
10. Parkinson Society Canada. *Parkinson's disease: Social and cconomic impact*. 2003 [accessed 26 June 2015]; Available from: http://www.parkinson.ca/atf/cf/%7B9ebd08a9-7886-4b2d-a1c4-a131e7096bf8%7D/PARKINSONSDISEASE_EN.PDF.
11. Parkinson's Disease Foundation. *Statistics on Parkinson's*. 2014 Sept 30 2014]; Available from: http://www.pdf.org/en/parkinson_statistics.
12. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*. 2001: National Academies Press.
13. Abudi, S., et al., *Parkinson's disease symptoms—'patients' perceptions.* Journal of Advanced Nursing, 1997. **25**(1): p. 54-59.
14. Buetow, S., et al., *Perceived unmet needs for health care among Parkinson's Society of New Zealand members with Parkinson's disease.* Parkinsonism & Related Disorders, 2008. **14**(6): p. 495-500.
15. Nisenzon, A.N., et al., *Measurement of patient-centered outcomes in Parkinson's disease: What do patients really want from their treatment?* Parkinsonism & Related Disorders, 2011. **17**(2): p. 89-94.
16. Wressle, E., C. Engstrand, and A.K. Granérus, *Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living.* Australian Occupational Therapy Journal, 2007. **54**(2): p. 131-139.
17. Mulley, A.G., C. Trimble, and G. Elwyn, *Stop the silent misdiagnosis: patients' preferences matter.* British Medical Journal, 2012. **345**.
18. Say, R.E. and R. Thomson, *The importance of patient preferences in treatment decisions—challenges for doctors.* British Medical Journal, 2003. **327**(7414): p. 542.
19. Dwamena, F., et al., *Interventions for providers to promote a patient - centred approach in clinical consultations.* The Cochrane Library, 2012.

20. Balint, E., *The possibilities of patient-centered medicine.* Journal of the Royal College of General Practitioners, 1969. **17**(82): p. 269-276.
21. McWhinney, I., *'An acquaintance with particulars...'.* Family Medicine, 1989. **21**(4): p. 296.
22. Gerteis, M., et al., *Through the patient's eyes: understanding and promoting patient-centered care*. 1993: Jossey-Bass San Francisco.
23. Stewart, M., *Patient-centered medicine: Transforming the clinical method*. 2003: Radcliffe Pub.
24. Entwistle, V.A. and I.S. Watt, *Treating patients as persons: A capabilities approach to support delivery of person-centered care.* American Journal of Bioethics, 2013. **13**(8): p. 29-39.
25. Mead, N. and P. Bower, *Patient-centredness: A conceptual framework and review of the empirical literature.* Social Science & Medicine, 2000. **51**(7): p. 1087-1110.
26. Canadian Medical Association, *Achieving Patient-Centred Collaborative Care.* 2008.
27. World Health Organization, *The world health report 2000 - Health systems: Improving performance.* 2000, Geneva: World Health Organization.
28. Stewart, M., et al., *Evidence on patient-doctor communication.* Cancer Prevention & Control, 1999. **3**(1): p. 25-30.
29. Stewart, M., et al., *Improving communication between doctors and breast cancer patients.* Annals of Family Medicine, 2007. **5**(5): p. 387-394.
30. Golin, C.E., M.R. DiMatteo, and L. Gelberg, *The role of patient participation in the doctor visit: Implications for adherence to diabetes care.* Diabetes Care, 1996. **19**(10): p. 1153-1164.
31. Epstein, R.M., et al., *Patient-centered communication and diagnostic testing.* Annals of Family Medicine, 2005. **3**(5): p. 415-421.
32. Stewart, M., *Towards a global definition of patient centred care: The patient should be the judge of patient centred care.* British Medical Journal, 2001. **322**(7284): p. 444.
33. Duggan, P.S., et al., *The moral nature of patient-centeredness: Is it "just the right thing to do"?* Patient Education and Counseling, 2006. **62**(2): p. 271-276.
34. Friedman, M., *What are friends for?: Feminist perspectives on personal relationships and moral theory*. 1993.
35. Noddings, N., *Caring: A relational approach to ethics and moral education*. 2013: University of California Press.
36. Oakley, J., *A virtue ethics approach*. 1998: Wiley Online Library.
37. Epstein, R. and R.L. Street, *Patient-centered communication in cancer care: promoting healing and reducing suffering*. 2007: National Cancer Institute, National Institutes of Health.
38. Ontario Medical Association, *Patient-centred care*, in *Ontario Medical Review*. 2010. p. 34-49.
39. Beauchamp, T.L. and J.F. Childress, *Principles of biomedical ethics*. 2001: Oxford University Press.
40. Callahan, D., *Can the moral commons survive autonomy?* The Hastings Center Report, 1996. **26**(6): p. 41.
41. Charles, C., A. Gafni, and T. Whelan, *Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model.* Social Science & Medicine, 1999. **49**(5): p. 651-661.

42. Makoul, G. and M.L. Clayman, *An integrative model of shared decision making in medical encounters.* Patient Education and Counseling, 2006. **60**(3): p. 301-12.
43. Emanuel, E.J. and L.L. Emanuel, *Four models of the physician-patient relationship.* Journal of the American Medical Association, 1992. **267**(16): p. 2221-2226.
44. Charles, C., A. Gafni, and T. Whelan, *Shared decision-making in the medical encounter: What does it mean?(or it takes at least two to tango).* Social Science & Medicine, 1997. **44**(5): p. 681-692.
45. President's Commission for the Study of Ethical Problems in Medicine, Biomedical, and Behavioral Research (US). *Making Health Care Decisions*. Vol. 1. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982.
46. Flynn, K.E., M.A. Smith, and D. Vanness, *A typology of preferences for participation in healthcare decision making.* Social Science & Medicine, 2006. **63**(5): p. 1158-1169.
47. Whitney, S.N., A.L. McGuire, and L.B. McCullough, *A typology of shared decision making, informed consent, and simple consent.* Annals of Internal Medicine, 2004. **140**(1): p. 54-9.
48. Street, R.L., G. Elwyn, and R.M. Epstein, *Patient preferences and healthcare outcomes: an ecological perspective.* Expert Review of Pharmacoeconomics and Outcomes Research, 2012. **12**(2): p. 167-180.
49. Tariman, J., et al., *Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review.* Annals of Oncology, 2010. **21**(6): p. 1145-1151.
50. Levinson, W., et al., *Not all patients want to participate in decision making.* Journal of General Internal Medicine, 2005. **20**(6): p. 531-535.
51. Ende, J. and M.A. Moskowitz, *Measuring patients' desire for autonomy.* Journal of General Internal Medicine, 1989. **4**(1): p. 23-30.
52. Gaston, C.M. and G. Mitchell, *Information giving and decision-making in patients with advanced cancer: a systematic review.* Social Science & Medicine, 2005. **61**(10): p. 2252-2264.
53. Arora, N.K., J.Z. Ayanian, and E. Guadagnoli, *Examining the relationship of patients' attitudes and beliefs with their self-reported level of participation in medical decision-making.* Medical Care, 2005. **43**(9): p. 865-872.
54. Nease Jr, R.F., *Patient desire for information and decision making in health care decisions.* Journal of General Internal Medicine, 1995. **10**(11): p. 593-600.
55. Nilsson, U.G., et al., *The desire for involvement in healthcare, anxiety and coping in patients and their partners after a myocardial infarction.* European Journal of Cardiovascular Nursing, 2013. **12**(5): p. 461-7.
56. Cassileth, B.R., et al., *Information and participation preferences among cancer patients.* Annals of Internal Medicine, 1980. **92**(6): p. 832-6.
57. Beisecker, A.E. and T.D. Beisecker, *Patient information-seeking behaviors when communicating with doctors.* Medical Care, 1990. **28**(1): p. 19-28.
58. Doherty, C. and W. Doherty, *Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences.* Journal of Nursing Management, 2005. **13**(2): p. 119-127.
59. Chewning, B., et al., *Patient preferences for shared decisions: a systematic review.* Patient Education and Counseling, 2012. **86**(1): p. 9-18.

60. Thorne, S.E. and B.L. Paterson, *Health care professional support for self-care management in chronic illness: insights from diabetes research.* Patient Education and Counseling, 2001. **42**(1): p. 81-90.
61. Kenny, P., et al., *Participation in treatment decision-making by women with early stage breast cancer.* Health Expectations, 1999. **2**(3): p. 159-168.
62. Sainio, C., S. Lauri, and E. Eriksson, *Cancer patients' views and experiences of participation in care and decision making.* Nursing Ethics, 2001. **8**(2): p. 97-113.
63. Krupat, E., et al., *The practice orientations of physicians and patients: the effect of doctor–patient congruence on satisfaction.* Patient Education and Counseling, 2000. **39**(1): p. 49-59.
64. Swenson, S.L., et al., *Patient - centered communication.* Journal of General Internal Medicine, 2004. **19**(11): p. 1069-1079.
65. Ruiz-Moral, R., et al., *Physician–patient communication: A study on the observed behaviours of specialty physicians and the ways their patients perceive them.* Patient Education and Counseling, 2006. **64**(1): p. 242-248.
66. Deber, R.B., *Physicians in health care management: 8. The patient-physician partnership: decision making, problem solving and the desire to participate.* Canadian Medical Association Journal, 1994. **151**(4): p. 423.
67. Paterson, B., *Myth of empowerment in chronic illness.* Journal of Advanced Nursing, 2001. **34**(5): p. 574-581.
68. Deber, R.B., *Physicians in health care management: 7. The patient-physician partnership: changing roles and the desire for information.* Canadian Medical Association Journal, 1994. **151**(2): p. 171.
69. Rodriguez-Osorio, C.A. and G. Dominguez-Cherit, *Medical decision making: paternalism versus patient-centered (autonomous) care.* Current Opinion in Critical Care, 2008. **14**(6): p. 708-713.
70. Kiesler, D.J. and S.M. Auerbach, *Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions.* Patient Education and Counseling, 2006. **61**(3): p. 319-341.
71. Grosset, K.A. and D.G. Grosset, *Patient - perceived involvement and satisfaction in Parkinson's disease: Effect on therapy decisions and quality of life.* Movement Disorders, 2005. **20**(5): p. 616-619.
72. Martin, R.C., et al., *Medical decision - making capacity in cognitively impaired Parkinson's disease patients without dementia.* Movement Disorders, 2008. **23**(13): p. 1867-1874.
73. Moreno, J.D., *Bioethics is a naturalism.* Pragmatic Bioethics, 1999. **2**: p. 3-16.
74. Racine, E., *Pragmatic neuroethics: Improving treatment and understanding of the mind-brain*. 2010: The MIT Press.
75. Goldkuhl, G., *Meanings of pragmatism: Ways to conduct information systems research.* Action in Language, Organisations and Information Systems, 2004.
76. Hunt, M.R., *Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work.* Qualitative Health Research, 2009. **19**(9): p. 1284-1292.
77. Thorne, S., S.R. Kirkham, and K. O’Flynn-Magee, *The analytic challenge in interpretive description.* International Journal of Qualitative Methods, 2008. **3**(1): p. 1-11.

78. Patton, M., *Purposeful sampling*, in *Qualitative Evalutation and Research Methods*. 2004, Sage: London. p. 169-183.
79. Hellström, I. and S. Torres, *A wish to know but not always tell–couples living with dementia talk about disclosure preferences.* Aging & Mental Health, 2013. **17**(2): p. 157-167.
80. Stiggelbout, A.M., et al., *Ideals of patient autonomy in clinical decision making: a study on the development of a scale to assess patients' and physicians' views.* Journal of Medical Ethics, 2004. **30**(3): p. 268-274.
81. Hsieh H-F, S.S., *Three approaches to qualitative content analysis.* Qualitative Health Research, 2005. **15**(9): p. 1277-1288.
82. Mays, N., E. Roberts, and J. Popay, *Synthesising research evidence.* In N. Fulop, et al. (Eds). *Methods for studying the organisation and delivery of health services.* 2001, Routledge: London. p. 188-220.
83. Sherwin, S., *Foundations, frameworks, lenses: The role of theories in bioethics.* Bioethics, 1999. **13**(3- 4): p. 198-205.
84. Arksey, H. and L. O'Malley, *Scoping studies: Towards a methodological framework.* International Journal of Social Research Methodology, 2005. **8**(1): p. 19-32.
85. Makoul, G. and M.L. Clayman, *An integrative model of shared decision making in medical encounters.* Patient Education and Counseling, 2006. **60**(3): p. 301-312.
86. Etchells, E., et al., *Bioethics for clinicians: 3. Capacity.* Canadian Medical Association Journal, 1996. **155**: p. 657-664.
87. Larivière-Bastien, D., et al., *Perspectives of adolescents and young adults with cerebral palsy on the ethical and social challenges encountered in healthcare services.* Narrative Inquiry in Bioethics, 2011. **1**(1): p. 43-54.

# APPENDICES

# APPENDIX 2-1: Manuscript 1 Consent Form

IRCM
Institut de recherches cliniques de Montréal

neuro

## INFORMATION AND CONSENT FORM - INTERVEIW

**TITLE:** Investigating preferences for decision making and expectations about care in Parkinson's patients

**PRINCIPAL INVESTIGATOR:** Eric Racine, PhD, Director, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM), 110 avenue des Pins Ouest, Montréal QC H2W 1R7, Tel.: 514 987-5723, email: eric.racine@ircm.qc.ca.

**CO-INVESTIGATORS AND COLLABORATORS:** Emily Bell, PhD, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM); Anne-Louise Lafontaine, MD, Director of Neurology, Montreal Neurological Institute; Natalie Zizzo, BSc, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM)

**FUNDING:** Canadian Institutes of Health Research (CIHR).

**DESCRIPTION:** You are invited to participate in a research study exploring Parkinson's disease patient preferences for involvement in decision making and communication of information as well as expectations for care programs and patient-centered care. We hope that your participation in this study will allow us to identify key issues, and suggest means of improving care programs and other current practices based on the experiences and perspectives of Parkinson's disease patients.

**STUDY PROCEDURES:** This portion of the study consists of one 35-40 minute semi-structured audio-taped interview with a member of the research team. If you choose to participate, the interview will explore your experience with the healthcare system and obtaining a Parkinson's diagnosis, your perspectives on the decision making process, preferences for communication of information, and expectations for care programs.

**RISKS:** There are no known risks associated with participation in this study other than the unlikely event of a breach of confidentiality and the potential for the interview to raise your anxiety.

**BENEFITS:** There are no known benefits to you associated with participation in this study but results of the study will be used to inform better practices of care and other patient-centered models of care for Parkinson's disease.

**CONFIDENTIALITY:** The interview will be audio-recorded and transcribed *verbatim*. Your identity will be kept as confidential as possible as required by law. Your identity and the information you provide will

Page **1** of **4**
Version 4, March 19 2014

remain entirely confidential through an alphanumeric coding system that we have developed and that will be available only to the investigators. Information about the coding system will be kept in a secure location and access limited to research study personnel. Your individual privacy will be maintained in all published and written data resulting from the study. Only the investigators and their research personnel will have access to the study data. The original data will be kept in a locked filing cabinet and documents will be coded before analysis. Data analysis will be performed on a password-protected computer.

The data collected will only be used to respond to the objectives of this study, which are described in the consent form. All research data will be kept for 7 years and destroyed after completion of study. Dr. Eric Racine will be responsible for supervising the destruction of data from the study, including digital deletion of your audio recordings and shredding of your file.

Your individual privacy will be maintained in all published and written data resulting from the study. The results of this study could be published in specialized publications or be the subject of scientific discussions but we will not identify you. Moreover, if results stemming from your participation are reported, they will be reported in a way that others will not be able to identify you (i.e., using an alphanumeric code and not your name).

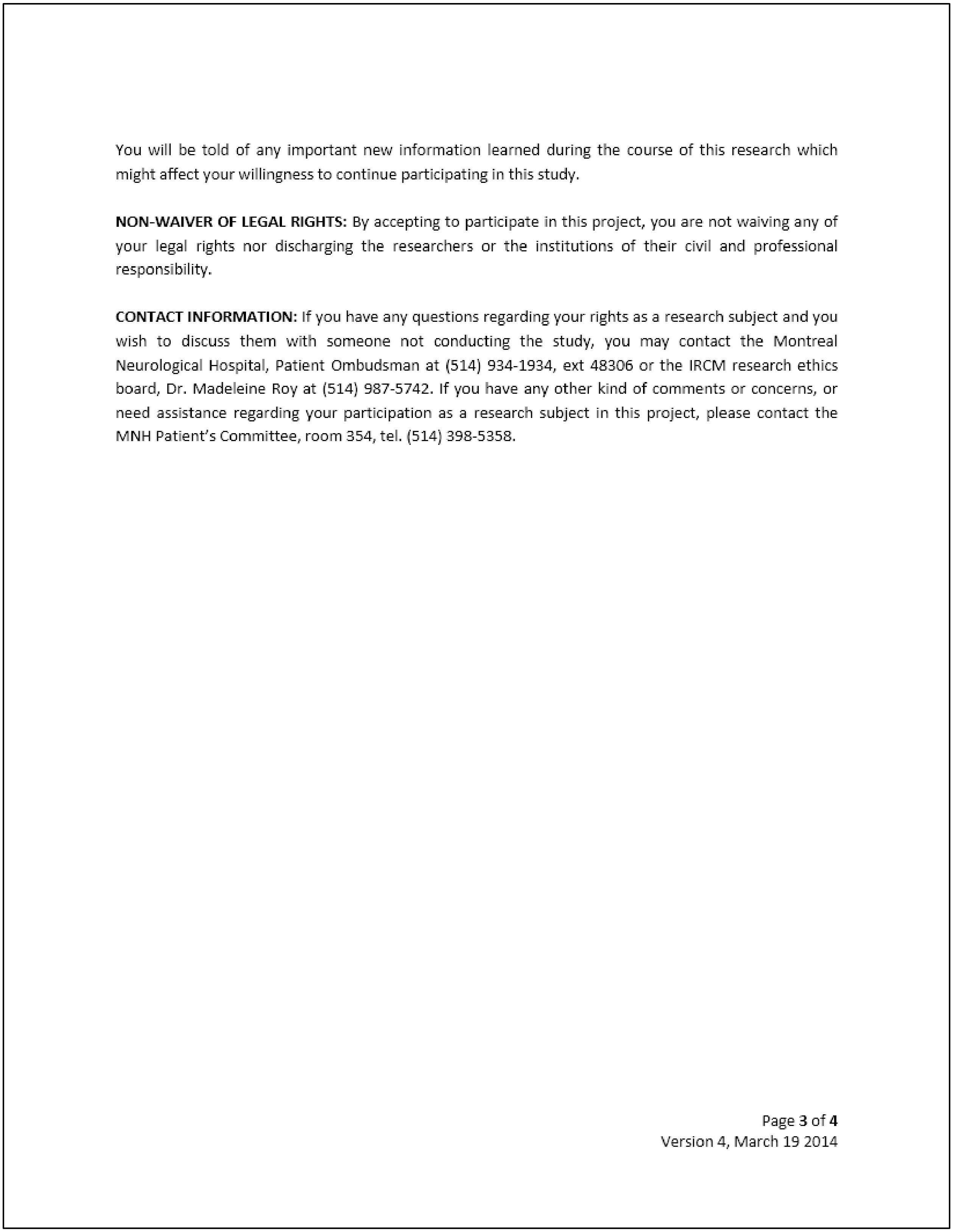
For quality assurance your research file may be reviewed by the quality assurance officer of the institutions, ethics committees, or funding agencies involved. All third parties from these organizations will be bound by strict confidentiality policies.

You have the right to review your research folder to verify the data collected and to correct them as needed and this as long as the responsible or the PI of the project or the institution of the study possess this information. However, in order to preserve the scientific integrity of the project, you may only have access to certain information once your participation has been terminated.

**COMPENSATION:** In recognition of your participation we will compensate you $100 for travel and transportation costs, as well as lost time.

**VOLUNTARY PARTICIPATION:** If you have read this form and decide to participate in this project, please understand that your participation is voluntary. You have the right to refuse to answer particular questions. If you first agree to participate and then change your mind, you are free to withdraw your consent and discontinue your participation at any time. Your refusal to participate or withdrawal from the study will not affect your relationship with your physician. Please inform the principal investigator if you wish to withdraw from the study. If you choose to withdraw from the study we will destroy all the results which concern you, except those which are already analyzed in order to preserve the integrity of the study.

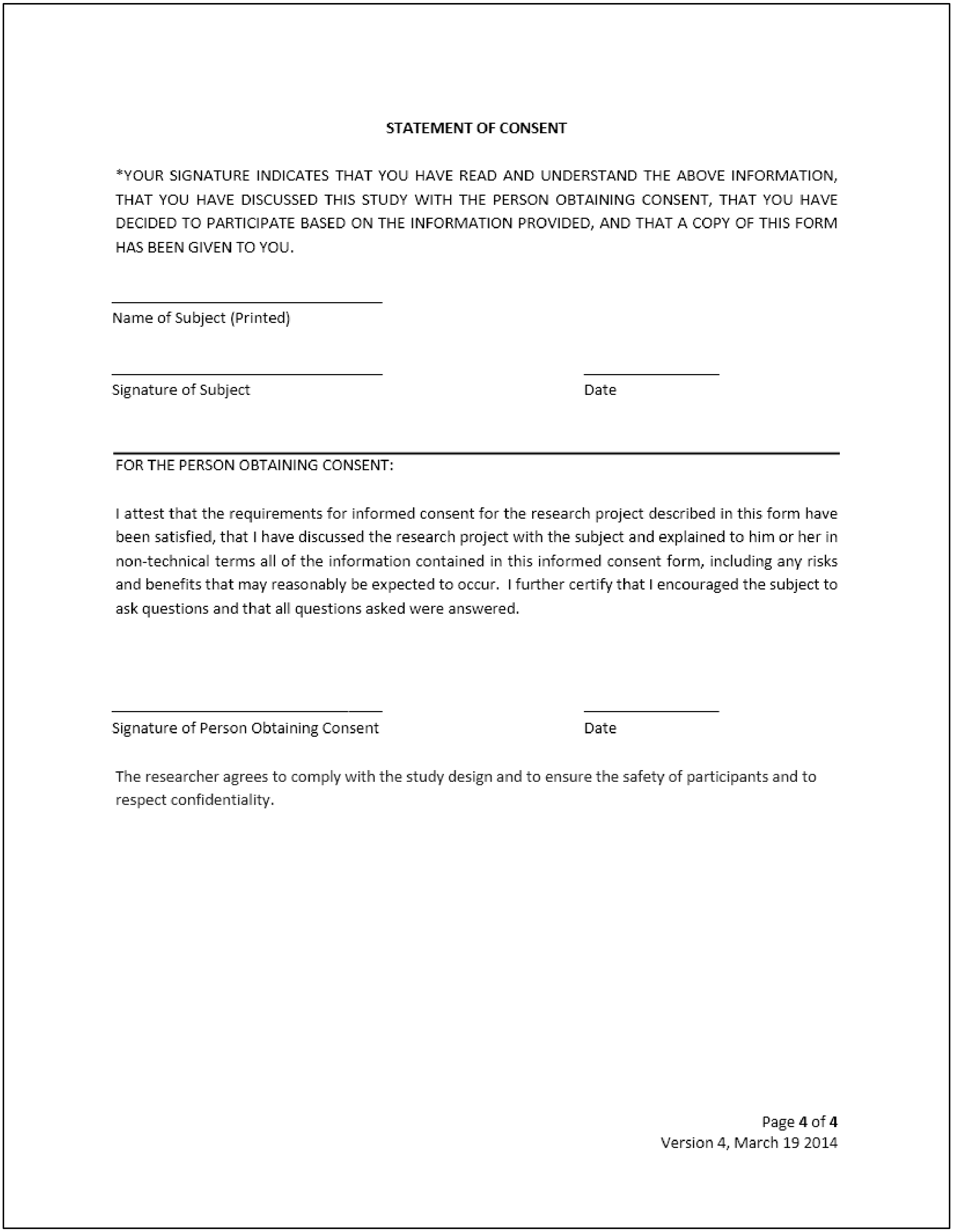
You should not feel obligated to agree to participate. Your questions should be answered clearly and to your satisfaction.



You will be told of any important new information learned during the course of this research which might affect your willingness to continue participating in this study.

**NON-WAIVER OF LEGAL RIGHTS:** By accepting to participate in this project, you are not waiving any of your legal rights nor discharging the researchers or the institutions of their civil and professional responsibility.

**CONTACT INFORMATION:** If you have any questions regarding your rights as a research subject and you wish to discuss them with someone not conducting the study, you may contact the Montreal Neurological Hospital, Patient Ombudsman at (514) 934-1934, ext 48306 or the IRCM research ethics board, Dr. Madeleine Roy at (514) 987-5742. If you have any other kind of comments or concerns, or need assistance regarding your participation as a research subject in this project, please contact the MNH Patient's Committee, room 354, tel. (514) 398-5358.



**STATEMENT OF CONSENT**

*YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PERSON OBTAINING CONSENT, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

Name of Subject (Printed)

Signature of Subject Date

FOR THE PERSON OBTAINING CONSENT:

I attest that the requirements for informed consent for the research project described in this form have been satisfied, that I have discussed the research project with the subject and explained to him or her in non-technical terms all of the information contained in this informed consent form, including any risks and benefits that may reasonably be expected to occur. I further certify that I encouraged the subject to ask questions and that all questions asked were answered.

Signature of Person Obtaining Consent Date

The researcher agrees to comply with the study design and to ensure the safety of participants and to respect confidentiality.

Page **4** of **4**
Version 4, March 19 2014

## APPENDIX 2-2: Manuscript 1 Interview Grid

**PART ONE: Understanding the patient experience and the types of information patients want to receive about PD and when**

- Can you describe the process that you went through from first feeling like you needed medical attention to arriving to see a specialist at the movement disorder clinic?
    - What were you thinking about when you were waiting to see the specialist?
    - What was your experience of receiving the diagnosis?
    - How did you want the diagnosis to be communicated to you?
    - What information specifically were you most eager to learn at the time of diagnosis?
    - Who first consulted with you when you were seen at the Movement Disorder Clinic (i.e., nurse, specialist themselves)?
        - if you met with and talked with a nurse clinician (Lucie or Jen), what information did they provide that helped you deal with/prepare for receiving this diagnosis? Did the assistance of the nurse clinician better prepare you for your diagnosis and the treatment and care you received afterwards (prepare you with what to expect but also with the practical achievement of care)?
    - Were you satisfied this first consultation, were your questions answered, did you feel prepared to go forward and understand the plan for your care?
- Where do you get most of your information on PD? Sources?
- What are the types of information you are seeking most when you visit your doctor or medical clinic? (e.g. about your medication, side effects, alternative treatments as treatment options, complex treatment options, home care, about ability to drive a car, about where to receive reliable information about PD, about possible PT, OT, psychosocial specialized care) Who do you prefer communicate this information?
- Do you want to know about the near future course of your Parkinson's as well as the potential long term effects of the disorder and medications as early as possible?
- Are there limits to the amount of information you feel you want, or can retain and make use of at a single visit? *Are there some types of information that you want your doctor to avoid telling you? If so, why?*
- If you didn't want to know some information, should your doctor keep this information to themself? Would you still want your doctor to disclose this information to a family member or caregiver? * Can you give an example?

**PART TWO: Understanding patient preferences on involvement in decision making and autonomy in the medical encounter.**

- How would you describe an excellent patient-physician relationship for you? How would each person, the patient and physician be involved in making decisions?

  - What does the physician bring to the relationship? What attitudes and values are important?
  - What does the patient bring? What attitudes and values are important?
- Do you think that your actions in medical consultations are consistent with what you describe? *Why or why not? Barriers? Does your physician participate in a way coherent with this ideal?*
- If you and your doctor cannot agree on which treatment is best, who do you believe should make the ultimate decision? (Doctor knows best or Patient should decide?) *
  - E.g. if your doctor advocates for one type of treatment, but you are hesitant to comply, what would you do?
- Is there ever a situation where you feel that letting your doctor decide entirely what treatment is best for you is appropriate? *
  - E.g. if you are overwhelmed by the treatment options and are completely indecisive, how would you want your doctor to proceed?
- Is there ever a situation where you feel that patients should not to be involved in the decision about treatment?*
- Is there anything you do, or would like to do, to manage your Parkinson's that might depart from advice given in medical encounters? Would you feel open to discussing these situations with healthcare professionals?

**PART THREE: Understanding expectations about a patient-centred care program for Parkinson disease**

- In this program you meet with nurses, what is the role you expect them to play? What values and attitudes would you like them to display?
- What has nurse involvement contributed to your care? What have they added? (Probes: Have they contributed to your knowledge and understanding of Parkinson's? Have they helped you to deal with issues specific to your Parkinson's or your experience with Parkinson's?)
- What is the role that you want, or see your specialist doctor playing?
- What about your primary health care provider (GP)?
- What about other members of the interdisciplinary healthcare team (speech therapists, physios etc.)? What role do they play in your care? Is this consistent with your expectations?
- Who do you value most in the provision of your care? What sets them apart from other care providers?
- What is the importance of values to your care? What types of values are most important to you?
- Do you feel as though there are any gaps in your key supports, healthcare personnel, places, or things that would make your experience and care of your PD easier? If yes, can you describe what would improve it?

- Would you have any recommendations for this new program?
    - Recommendations on how to improve patient engagement? (patient-centred)
    - Recommendations to improve relationship with providers? (HCP-centred)
    - Recommendations to make the program better? (Program/institution centred)

# APPENDIX 2-3: Manuscript 1 Coding Guide

Note: data from the nodes marked with an asterix (*) and their associated sub nodes were used for the manuscript entitled "What a patient wants: A look at Parkinson's disease patients' preferences for involvement in healthcare decision making in a patient-centred care clinic"

| **Node** | **Sub-node** | **Sub-sub node** | **Sub-sub-sub-node** |
|---|---|---|---|
| Narrative of diagnosis and access to movement disorder clinic | | | |
| Experience of diagnosis | Experience before diagnosis | | |
| | Desired information at time of diagnosis | | |
| | Communication of diagnosis | | |
| | Reactions to diagnosis | | |
| Learning PD related information* | Sources of PD information | Types of sources | Foundations/societies |
| | | | Internet |
| | | | Books |
| | | | Television, radio, newspaper |
| | | | Personal connections |
| | | | Medical Personnel |
| | | | Other |
| | | Do they check reliability of sources | Yes (+ how) |
| | | | No |
| | | Advantages of certain types of info/sources | |
| | | Disadvantages of certain types of info/sources | |
| | Desired information during clinical encounter | PD symptoms | |
| | | Progression of PD | |
| | | PD research | |
| | | Causes of PD | |
| | | Treatment of PD | |
| | | CAM, remission of PD | |
| | | Self- | |

| | | | |
|---|---|---|---|
| | | management strategies | |
| | | Assessment of PD | |
| | | Other | |
| | Desired information from other sources | PD symptoms | |
| | | Progression of PD | |
| | | PD research | |
| | | Causes of PD | |
| | | Treatment of PD | |
| | | CAM, remission of PD | |
| | | Self-management strategies | |
| | Limits to learning about PD | Yes limits | Emotionally-based reasons |
| | | | Rationally-based reasons |
| | | No Limits | Reasons why information shouldn’t be held back |
| How would you describe an excellent patient-physician relationship for you? Qualities of a good/excellent dr-patient relationship* | Important qualities of a physician | Technical Skills | |
| | | Interpersonal skills | |
| | Important qualities of a patient | Responsibilities | |
| | | Characteristics | |
| | General attributes of a good Dr-patient relationship | | |
| | Things that facilitate patient involvement | | |
| | Barriers to patient involvement in care | | |
| | Openness in medical encounters | | |
| How would each person, the patient and the physician, be involved in making decisions?* | Shared decision making | | |
| | Patient priority | | |
| | Physician priority | | |
| If you and your doctor cannot agree on which treatment is best, who do you | Patient | | |
| | Physician | | |
| | Other | | |

| | | | |
|---|---|---|---|
| believe should make the ultimate decision?* | | | |
| Is there ever a situation where you feel that letting your doctor decide entirely what treatment is best for you is appropriate?* | | | |
| Is there ever a situation where you feel that patients should not be involved in the decision about treatment?* | Impermissible except if incapacity | | |
| | Permissible for a reason other than incapacity | | |
| | Always impermissible | | |
| Nurse Involvement | Expected role of nurses | | |
| | Values and attitudes of nurses | | |
| | Perceived contribution of nurse care | | |
| Expected role of neurologist* | | | |
| Expected role of GP | | | |
| Interdisciplinary health team involvement | Expected role of interdisciplinary health team | | |
| | Value and attitudes | | |
| | Perceived contribution to care | | |
| Perceived most important individual to care | Qualities/experience that sets them apart | | |
| Values important to care* | | | |
| Gaps in care or support | Yes | | |
| | No | | |
| Recommendations for the movement disorder clinic | | | |

| | | | |
|---|---|---|---|
| Negative experience related to Parkinson’s | | | |
| Positive experiences related to Parkinson’s | | | |

# APPENDIX 2-4: Manuscript 3 Reasons for Exclusion

Excluded results (N=187):

| **Reason for exclusion** | **N** |
|---|---|
| Lack of focus on ethics | 36 |
| Lack of focus on PD | 66 |
| Not relevant to ethics AND PD | 21 |
| Research trial with ethics approval | 7 |
| Methodological paper | 2 |
| Basic research | 1 |
| Duplicate | 3 |
| Researcher profile | 1 |
| No abstract and unable to access article | 28 |
| Non-academic media (e.g. Time Magazine, NY Times, Newsweek, Life) | 8 |
| No abstract and article in language other than English | 13 |
| Erratum | 1 |

# APPENDIX 2-5: Manuscript 3 Coding Guide

Each article was coded for the context in which it discussed bioethics. Main topics of discussion for each context were noted.

| **Context** | **Main topics of discussion** |
|---|---|
| Deep Brain Stimulation | o Philosophical problems (e.g. authenticity)<br>o Quality of life<br>o Harm to others<br>o Psychosocial effects<br>o Early and pediatric applications<br>o Research ethics<br>o Clinical ethics<br>o Legal questions<br>o General ethics<br>o Unintended consequences<br>o Cognitive capacity |
| Fetal tissue transplantation | o Burden on investigators<br>o Implications for patients<br>o Guidelines on the retrieval and use of fetal tissue<br>o Moral status of fetus<br>o Paternal consent to fetal use<br>o Ethical inter-relation of fetal use and abortion<br>o Funding policies<br>o Consent to use of fetal tissue<br>o Efficacy<br>o Ethical guidelines |
| Stem cells | o Research ethics issues<br>o Issues of justice<br>o Ethical acceptability<br>o General ethics<br>o Stakeholder understanding<br>o Fetal stem cells |
| Sham surgery | o Subject expectations/perspectives<br>o Research ethics<br>o Risks |
| Neural transplantation | o Informed consent<br>o Therapeutic misconception<br>o Risk/benefits<br>o Ethics of study design<br>o Use of tissue from fetal tissue<br>o Use of neural tissue<br>o Graft recipient well-being<br>o Personal identity<br>o Personality |

| | |
|---|---|
| | o Alternatives sources of tissue<br>o Personhood<br>o Use of embryonal CNS tissue<br>o Psychological risks<br>o Efficacy |
| General Research | o Use of animals<br>o Risk analysis<br>o External ethics review<br>o Subject perspectives/expectations<br>o Informed consent<br>o Use of placebo<br>o Validity<br>o Biases<br>o Clinical research |
| Healthcare | o Decision-making capacity<br>o Quality of life<br>o Advanced care planning<br>o Non-medical approaches<br>o Pain and non-motor symptoms<br>o Ethical aspects of predictive testing<br>o Diagnosis<br>o Palliative care<br>o Late stage care<br>o Refusal of care<br>o Decision-making process |
| Genetic/Pre-clinical testing | o Ethics of patents/ commercialization<br>o Development and implementation of genetic susceptibility tests in research, clinical and consumer settings<br>o Data banks |
| Gene transfer/therapy | o Research ethics<br>o Safety<br>o Efficacy<br>o Informed Consent<br>o Allocation of resources |
| Law | o Forensic evaluation |
| Cloning | |
| Brain banks | o Donor program<br>o Handling and management of organs<br>o Research ethics |
| Publication bias | |
| Animal research ethics | |