OLDER ADULTS' EXPERIENCES OF POLYPHARMACY AND PERCEPTIONS OF DEPRESCRIBING

NETWORKS, EXPERTS, AND PARADOXES:

OLDER ADULTS' EXPERIENCES OF POLYPHARMACY AND

PERCEPTIONS OF DEPRESCRIBING

By:

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Abstract

As medical researchers test the feasibility of deprescribing programs to reduce medication burden associated with polypharmacy, limited scholarly consideration has been given to the perspectives of the older adults largely targeted by these programs. This dissertation makes central the voices of older adults experiencing polypharmacy and/or deprescribing. Presented as a collection of three articles, this work explores the perspectives of older adults on their use of medication in the context of both polypharmacy and deprescribing. Data were collected using in-depth semi-structured qualitative interviews with older adults concurrently using 5+ prescription medications. The first article draws on Habermas' writing on the contribution of communicative action in negotiating trust within complex social relationships. This analysis highlights the social nature of medication work and challenges to communicative action within personal and professional health systems. The second article applies embodiment theory to understand the way older adults' construct unique forms of expertise regarding their health, resulting from a lifetime of experiences living as and in their bodies. The last article uses social constructionist theories on systems of classification to show the way dichotomies in medical classifications are often paradoxical. This article offers insight into the work older adults do to optimize their use of medicines in the context of these paradoxes. This study, in its entirety, indicates a need for collective efforts to identify and address the problems of polypharmacy while facilitating appropriate polypharmacy for older adults with complex multiple co-morbidities. Doing so encourages a reframing of polypharmacy as a complex phenomenon about which clinical judgments are made through an ongoing collaboration with the patient and family.

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Declaration of Academic Achievement:

I, Alison Ross, am responsible for this thesis in its entirety. I collaborated, however, with Dr. James Gillett and Dr. Mat Savelli to design the interview guide and conduct some of the interviews. The TAPER Team was also responsible for some key aspects of study design. Dr. James Gillet, Dr. Christina Sinding, and Dr. Meridith Griffin, in their capacity as my supervisory committee, also supported the writing process, offering guidance and feedback on multiple drafts of this thesis.

INTRODUCTION

> *"Much scope remains for further inquiries into how lay people understand their bodies in relation to the dominant discourses emerging from such influential institutions as medicine, public health, and the mass media. The relationship between these pre-existing discourses and the meanings developed through individuals' own life experiences of embodiment, illness, and medical care has yet to be fully explored and understood" (Lupton, 2000, p. 61)*

I present this dissertation as a response to this call by Lupton (2000) for examining the relationship between institutional discourses and the lives and bodies that these institutions govern. To answer such a call, this work adopts medicine as a lens through which to study the governance of older adults' lives. In doing so, polypharmacy and deprescribing were selected as biomedical phenomena to which social science perspectives are critical.

Polypharmacy has been defined in many ways (Alpert and Gatlin, 2015; Hajjar, Cafiero, and Hanlon, 2007; Hanlon, Weinberger, Samsa, Schmader, Uttech, Lewis, Cowper, Landsman, Cohen, and Feussner, 1996; Maggiore, Gross, and Hurria 2010; Maher, Hanlon, and Hajjar, 2014; Reason, Terner, McKeag, and Webster, 2012), but is consistently framed as the concurrent use of multiple medications. Deprescribing involves the supervised dose reduction or withdrawal of medications that have been identified as lacking benefit or causing harm (Page, Clifford, Potter, Schwartz, & Etherton-Beer, 2016). These health phenomena demand social science perspectives given the social contexts in which they operate. Expanding analysis beyond bioscientific domains to include critical health studies scholarship centralizes the perspectives and biopsychosocial complexities of the individual experiencing polypharmacy and deprescribing. In collaboration with the participants of this study, this dissertation offers these

perspectives of older adults affected by emerging policies that seek to govern their lives and bodies – in this case, deprescribing programs to reduce medication burden.

The Canadian population is aging and social institutions must respond to meet the unique needs of older adults as they make up an increasing proportion of those in society. In Canada, the number of older adults is projected to grow to somewhere between 9.9 and 10.9 million by 2036 (Statistics Canada, 2018). Over three million of these individuals are predicted to be over the age of 80, and 20,000 are predicted to be Centenarians (Statistics Canada, 2018). Chronic conditions and related poor health are more likely to affect older adults over the age of 65, meaning that health problems increase in prevalence with age (Statistics Canada, 2018). Accordingly, aging is correlated with increasing engagement with the health care sector as a means of managing comorbidities that emerge with age. For these reasons, medicine is a relevant social sphere through which to increase our understanding of the relationship between institutional discourses and the meanings that older adults assign to their experiences of embodiment, illness, and health care.

This introduction provides the context for understanding the entire research project that produces the three scholarly articles featured in this dissertation. In the introduction I discuss polypharmacy and deprescribing as biomedical phenomena and offer social scientific insights into the work of managing medications. I identify gaps in this literature and present the research questions formulated to address these gaps. The methods used for data collection and analysis are outlined followed by an overview of the dissertation

Polypharmacy and deprescribing as biomedical phenomena

The genesis of this research project is the biomedical identification of polypharmacy as problematic. Medical researchers have established the risks of polypharmacy and offer deprescribing as a feasible solution. Importantly, I adopt a critical social science approach to probe further into this problematization and the implications for older adults managing their medications and their health. Prior to peering through this social science lens, it is valuable to first define and expand upon the concepts of polypharmacy and deprescribing as defined in the biomedical literature. Interestingly, this literature offers numerous definitions of polypharmacy. Hajjar, Cafiero, and Hanlon (2007) describe polypharmacy as the unnecessary use of drugs (more medications than clinically indicated) and/or using multiple drugs simultaneously. Hanlon, Weinberger, Samsa, Schmader, Uttech, Lewis, Cowper, Landsman, Cohen, and Feussner (1996) more specifically define polypharmacy as the use of five or more drugs. Maher, Hanlon, and Hajjar (2014) categorize polypharmacy as using more drugs than are medically necessary or using multiple medications. Alpert and Gatlin (2015) offer a broader definition, stating that polypharmacy is when one person uses several different medicines concurrently. Arguably, Maggiore, Gross, and Hurria (2010) provide the most comprehensive characterization of polypharmacy, explaining that it includes "the use of a large number of medications; the use of potentially inappropriate medications, which can increase the risk for adverse drug events; medication underuse despite instructions to the contrary; and medication duplication" (p. 507).

For the purposes of this research, inclusion criteria specified that participants be "polypharmaceuticalized" as defined as the concurrent use of five or more medications. This criterion was set by the larger TAPER Team (Team Approach to Polypharmacy Evaluation and Reduction) prior to the commencement of the qualitative component of the larger study. The

TAPER Team selected this definition for consistency, as this is the most commonly cited definition in the literature (Masnoon, Shakib, Kalisch-Ellett, and Caughey, 2017). This definition has been justified by research finding that five or more medications estimates adverse effects related to medications, such as frailty, disability, mortality, and falls (Gnjidic, Hilmer, Blyth, Naganathan, Waite, Seibel, McLachlan, Cumming, Handelsman, and Le Couteur, 2012).

The risks associated with polypharmacy are well-documented in the biomedical literature, including adverse drug reactions (Palagyi, Keay, Harper, Potter, and Lindley, 2016), financial burden (Reeve and Wiese, 2014), noncompliance, risk of malnourishment, urinary incontinence, inappropriate prescribing, cognitive impairment (Maher, et al., 2014), delirium, falls, decreased physical functioning, increased hospital admissions, and increased risk of mortality (Scott, Anderson, Freeman, and Stowasser, 2014). The Institute for Safe Medication Practices Canada (ISMP, 2018) explains that as the number of medications a patient consumes increases from two to ten, there is an eight-fold increase in that patient's risk of an adverse drug interaction. Importantly, increasing accessibility of over-the-counter medications, vitamins, and other herbal/homeopathic remedies has aggravated the risks of polypharmacy, particularly because consumption of these products is rarely disclosed to physicians (Shrestha, Shrestha, and Khanal, 2019).

Each of these identified risks are amplified for older adults. For example, Hilmer and Gnjidic (2009) draw attention to the problematic use of published evidence-based guidelines for prescribing used by practitioners. Specifically, these guidelines are informed by data from clinical trials that largely exclude the participation of older adults (Hilmer and Gnjidic, 2009). Therefore, the presumption that these prescribing guidelines are safely applicable to the older

population puts older adults at an increased risk for adverse drug events (Hilmer and Gnjidic, 2009).

Further, Reason, Terner, McKeag, Tipper, and Webster (2012) highlight age-related physiological changes that intensify the risks of polypharmacy for seniors. They explain that liver and kidney function decline with age, and therefore older adults are at an increased risk for adverse drug reactions associated with polypharmacy (Reason et al., 2012). Shrestha et al. (2019) contribute to this physiological understanding, noting that aging modifies how the body processes medications, specifically changes to absorption, metabolism, protein binding, distribution, and elimination (Shrestha et al., 2019). These changes may modify the effect of the medication on the target site.

There is also a substantial economic cost of polypharmacy, which is documented by the ISMP (2018). Specifically, inappropriate medication use in Canada has been estimated to cost $419 million in one year (Morgan, Hunt, Rioux, Proulx, Weymann, and Tannenbaum, 2016). Morgan et al. (2016) further estimate $1.4 billion/year is spent to treat the indirect health care costs as a result of this inappropriate prescribing, such as falls, fractures, and hospital admissions.

As a response to these risks of polypharmacy, to the individual older Canadian and to the sustainability of the Canadian health care system, deprescribing programs are being put forward as part of standard medical care of older adults to reduce medication burden. The Canadian Deprescribing Network (CaDeN, 2016) describes deprescribing as the supervised reduction or cessation of medicines that have been identified as harmful or lacking benefit. The advantages to deprescribing generally counter the risks of polypharmacy. For example, advantages include reduced risk of adverse drug reactions, alleviation of financial burden (Reeve and Weise, 2014),

decreased risk of falls, improved physical functioning, declining hospital admissions, and decreased mortality rates (Scott et al., 2014). Deprescribing programs intend to target medications that are either unnecessary, redundant, or harmful, therefore it is important to note that deprescribing plans have been found to improve adherence to necessary and appropriate medications (Reeve and Wiese, 2014). Participation in these plans is additionally associated with an enhancement in patients' overall knowledge of and engagement with their health care (Reeve and Wiese, 2014).

Despite these many advantages to effective deprescribing programs, there are barriers to their successful implementation. Palagyi (2016), for instance, found that patient willingness is an essential ingredient to an effective deprescribing plan. Palagyi (2016) explains that although many patients recognize and accept the burden of the concurrent use of multiple medications, they demonstrate passivity when presented with the opportunity to discontinue medications that have been identified as needless or harmful. Therefore, the inclusion of patient perspectives is essential to the design, implementation, and evaluation of effective deprescribing plans. This assertion is supported by Reeve et al.'s (2013) systematic review which found that barriers to deprescribing plans include patients' beliefs that medication cessation is inappropriate, the absence of clear processes for discontinuation (e.g. inadequate time and support from physicians), fears of discontinuation (typically non-specific), and other negative influences (events/persons that negatively influence the patient's decision to deprescribe). Scott et al. (2014) similarly found that deprescribing programs are ineffective if the risks of polypharmacy are underappreciated by the patient, if there are incentives to overprescribe (the result of an intensification of medical care), if the lists of inappropriate medications eligible for cessation are

inadequate, and if there is a fear of the negative consequences of deprescribing on the part of the patient and/or their physician.

Considerable research focuses on enablers of deprescribing programs, offering recommendations for health care providers seeking to implement programs into standard medical care of older adults. Many of these recommendations call for medicine to align with individual patients' beliefs about medications (Britten, 1994). Family physicians are also vital to effective deprescribing, particularly in long-term care facilities, a setting in which the family doctor often emerges as a trusted figure (Palagyi et al, 2016). Other predictors and enablers of deprescribing include, but are not limited to, a patient-centred approach, open communication between practitioner and patient, training health care teams in deprescribing (Scott et al., 2014), a belief that discontinuation is appropriate, a dislike of medications, positive influences (events/persons that positively influence a person to deprescribe), and the establishment of a clear process for discontinuation, including sufficient time and support from family physicians (Reeve et al., 2013).

It is important to emphasize that the prevalence and severity of polypharmacy intensifies with age. In 2005, the average Canadian filled 14 prescriptions (Statistics Canada, 2015). For adults between ages 60-79, this number rose to 35 prescriptions, and to 74 prescriptions for those 80 years and older (Statistics Canada 2015). The ISMP (2018) further supports this assertion, finding that 25% of adults over age 65 take at least 10 medications, increasing to 40% of adults over age 85. As older adults are more likely to experience polypharmacy and are more vulnerable to its potential harms, the design, testing, and evaluation of potential solutions are critical. Doing so necessitates social science perspectives that centralize the perspectives of older adults.

Polypharmacy and deprescribing as sociological phenomena

> *"Medications themselves are much more than material objects with physiological effects; they are also representations that carry meanings and shape social relations as they evolve in conjunction with individuals and collectivities"* (Cohen, McCubbin Collin, and Pérodeau, 2001, p. 442).

Cohen et al.'s (2001) ground-breaking paper sets the stage for this social scientific analysis of typically medicalized concepts. In this paper, Cohen et al. (2001) offer the fundamental components necessary to position medications as "socially embedded phenomena" (p. 442). Medications exist as a physiological, material reality, yet are also shaped by social, cultural, and economic forces. The complexity of these social spheres - which include diverse actors, systems, and institutions - influence the way medications are understood and used (Cohen et al., 2001). For example, social and technological advances (direct-to-consumer advertising, internet access) now greatly influence who, when, how, and why one might consume medicine. Cohen et al. (2001) challenge researchers to draw connections between social actors and the observed trends in how medications operate and circulate in society. This dissertation follows this call by seeking to understand the experiences and intentions of older adults, as social actors, as we observe this institutionalized reaction to overprescription.

Similarly, Lupton (2000) argues that health, illness, disease, and healthcare are sociocultural products and as such researchers should examine sociocultural representations of these concepts. Specifically, she calls for social scientific inquiry into the relationship between dominant institutional discourses and individual representations and meanings attached to health, illness, and the body. The motivation for the original research presented in this dissertation is best understood as a response to these calls from Cohen et al. (2001) and Lupton (2000).

Conceptualizing medications as sociocultural products (Lupton, 2000) and thus recognizing their susceptibility to social, cultural, and economic forces (Cohen, 2001), it is reasonable to conclude that public perceptions of medications are in a constant state of flux. Consequently, consumption patterns evolve to reflect the ongoing evolution of medicines as sociocultural products. Vuckovic and Nichter (1997) provide a detailed articulation of this transformation, arguing that the pursuit of health has become a moral endeavour, and as a result expectations regarding the scope and potential of health care has risen. Paradoxically, this shift, encouraging a greater dependency on medical authority, is accompanied by growing concern and distrust in doctors and medications (Vuckovic and Nichter, 1997). These doubts question the efficacy, safety, and necessity of medicine (Vuckovic and Nichter, 1997). Although contextualized in late 1990s America, I argue that the overall impression made by Vuckovic and Nichter's (1997) work resonates with a contemporary Canadian phenomenon in which two juxtaposing cultural attitudes have emerged: an impatience with illness and discomfort, creating a "more is better" perception of medications is now accompanied by growing concerns around the hazards and toxicity of medications. As this second trend gains more popularity, medications are no longer perceived as protective solutions, but rather as threats in themselves (Vuckovic and Nichter, 1997).

Williams, Gabe, and Davis (2008) offer a comprehensive history of sociological inquiry into pharmaceuticals which is further helpful in explaining the evolving sociocultural context in which medicines operate. Williams et al. (2008) identify four primary lines of sociological inquiry into pharmaceuticals, including work examining the medicalization and pharmaceuticalization of society which ranges from critiques regarding society's dependency on medicine to more recent and critical claims of disease-mongering (Williams et al., 2008). A

second line of sociological analysis examines the politics of the pharmaceutical industry, with critiques of development, testing, and regulation. These criticisms have justified calls for increased rigor in regulatory practices and procedures (Williams et al., 2008). Next, Williams et al. (2008) consider medicines as consumer products, focusing on both individual consumers and collectivities (self-help groups, patients-advocacy groups). The final line of inquiry into pharmaceuticals identified by Williams et al (2008) is the potential for future innovations in biomedicine which could fundamentally warp biosocial identities. Williams et al (2008) encourage sociologists to engage with these questions regarding the prospects of a biopolitical future.

The significance of Williams' et al. (2008) work to the dissertation presented here is their reminder of the contributions of social scientific inquiry into pharmaceuticals and society. In their words, by "potentially holding those in positions of power to account… and in engaging in informed dialogue and debate with its publics, sociological research on pharmaceuticals admirably demonstrates the continuing importance of the discipline in these developments, discourses and debates" (Williams et al., 2008, p. 821). Thus, as the medical institution encourages older adults to reimagine their relationship with medications and act upon this new reality, informed dialogue and debate must be engaged with those targeted.

Although Vuckovic and Nichter (1997) and Williams et al. (2008) provide succinct and valuable overviews of social scientific inquiry into medications, I will now present a broad review of the literature which positions medications as "socially-embedded phenomena" (Cohen et al., 2001, p. 442). In a review of the literature, four themes emerged: (i) subjective patient experiences, (ii) lay perspectives, (iii) medications as social actors, and (iv) morality and compliance. This review of the literature will also include a brief discussion of medication use in

the context of aging. It is important to note that this is a broad overview and thus each article of this sandwich dissertation will provide a more precise summary of the literature relevant to the specific research question at hand.

Subjective patient experiences.

A substantial amount of scholarly literature diverges from objective biomedical assessments of the polypharmaceuticalized patient and instead centralizes the subjective experiences of persons on many medications concurrently. This work examines the meanings of medications, the influence of medicine on identity construction, and the role of control in medicine consumption.

Meanings of medications. Medications carry complex social meanings far beyond their role in the physiological prevention and/or treatment of medical conditions. These social meanings are sometimes contradictory, as the word "drug" comes from the Greek word *pharmakon*, which can mean remedy, poison, and/or magical charm (Montagne, 1988). Therefore, medications can be perceived as good, evil, and/or mysterious/divine (perspectives that are ever-present in individual and social consciousness). According to Montagne (1988), these drug metaphors hold great influence in establishing cultural attitudes towards drugs and their effects.

One popular drug metaphor is 'drug as doctor' (Britten, 1996) in which a medication is viewed as extension/representation of the physician. In this way, medications are no longer objects, but rather symbolic of medical authority. As a result, Britten (1996) observes that patients who are reluctant to criticize their doctors are similarly unlikely to question their medications. Perhaps then it might also be true that patients who are critical of their doctors are likely to also criticize their medications.

These meanings become more evident when employing a patient-centred perspective (Conrad, 1985). In studying patients' adherence to epilepsy medications, Conrad (1985) found that in the patients' everyday lives, the meanings they attached to their epilepsy medications influenced the self-regulation of their medication routine. Conrad (1985) reframes patients' adjustments to their medication practice as self-regulation, rather than noncompliance. Doing so allows for such modifications to be viewed as a means by which patients exert control over their seizures. Thus, for many with epilepsy, their personalized use of seizure medications, although not necessarily aligned with the prescribed practice, fosters a sense of control over their condition and everyday lives (Conrad, 1985). Shoemaker and De Oliveira (2008) contend that it is through the subjective experience of medication-taking that patients are found to develop and attach personal meaning.

These subjective patient perspectives are found to be culturally variable. Horne, Graupner, Frost, Weinman, Wright, and Hankins (2004) found a pronounced influence of culture on whether or not patients have positive or negative perceptions of medications. Participants of Asian backgrounds were more likely to report negative views of medications than were participants of European backgrounds (Horne et al., 2004). Perhaps extensive social conditioning in favour of the allopathic model in the West has facilitated an affinity to biomedical interventions, such as pharmaceuticals. Knowledge of cultural diversity in medication meaning is important in further understanding diversity in medication usage (Horne et al., 2004).

Despite this cultural subjectivity, Geest and Whyte (1989) were interested in the apparent objectivity of medications, suggesting that medications are so widely appealing because they are concrete and "disengaged from social entanglements" (p. 345). It is the tangibility and objectivity of medications that makes them attractive; they symbolize healing and medical

authority (Geest & Whyte, 1989), an authority that we have been conditioned to trust and admire. This concept is similar to Britten's (1996) work that frames medications as physician representatives.

Identity construction. Adams, Pill, and Jones (1997) give important consideration to the identity work that patients confront when diagnosed with a chronic condition requiring medication. They pay particular attention to the asthma patient's negotiation of social identity given their (chronic) illness-label (Adams et al., 1997). Adams et al. (1997) suggest that an understanding of this identity work is the key to understanding variations in how asthma patients use their medications. It was found that participants with a diagnosis of asthma that had rejected their diagnosis and 'asthmatic' identity rarely took their reliever medication (Adams et al., 1997). In this way, negotiated illness identity acts as a predictor of medication compliance. Therefore, for medical practitioners to understand their patients' willingness or reluctance to deprescribe, an understanding of the patient's perceived illness identity is critical.

Similarly, Malpass, Shaw, Sharp, Walter, Feder, Ridd, and Kessler (2009) write about the processes people medicated for depression move through in an effort to "understand the medicated self" (p. 165). Malpass et al. (2009) theorize that throughout one's 'medication career', many new self-concepts emerge, ultimately the result of a 'meaning-making process'. Fundamentally, a diagnosis of illness, particularly chronic illness, comes with it inherent 'identity work' (Adams et al., 1997). Consideration is given not only to how the individual sees themselves, but how they are seen as part of larger social networks; as 'medicated' people. The material drug itself acts as an ongoing symbol for this new identity, both for the individual and their social network.

Control. The role of control in the subjective experience of medication-taking appears to be paradoxical. Medications can act as both granters and deniers of control – the individual might now be able to control the symptoms of their condition, or the individual might now be drug-dependent. If an individual does not adhere to their medication, Conrad (1985) suggests that this may "actually be a form of asserting control over one's disorder" (p. 29). In Conrad's (1985) study, participants reported that medications controlled their seizures. Participants, however, would self-regulate their medication use in a way that was not in alignment with how the medication was prescribed and intended to be used, which symbolized the reclaiming of control over their condition (Conrad, 1985).

Lay perspectives.

Construction of lay knowledge surrounding the concepts of polypharmacy and deprescribing is a distinct process that diverges from traditional biomedical knowledge sources. This process by which people come to understand medications emerged from the literature as a key theme. Both language and values play a role in constructing lay expertise about polypharmacy and deprescribing. For example, as was the case with subjective meanings attached to medications, the actual language used to describe medications elicits different meanings for lay people (Britten, 1996). Although the terms 'drug' and 'medication' are interchangeable in medical discourse, 'drug' is perceived much more negatively in lay discourse than is 'medication' (Britten, 1996). This suggests that the processes by which lay people assess and construct knowledge about medications/drugs is different than medical experts.

Britten (1996) cites efficacy, comparison with other therapies, and manufacturing as the three criteria that lay people depend upon when assessing a medication. Using these criteria, lay people consider the long-term effectiveness of medications, prefer home/traditional remedies,

and have a distaste for manufactured or 'unnatural' medications (Britten, 1996). By this account, if and how medications are used is dependent not only on medical knowledge, but also on lay logic (Lumme-Sandt, Hervonen, and Jylhä, 2000). This necessitates consideration of alternative sources of logic – beyond biomedical logic – in pursuit of a more comprehensive understanding of the construction of medication knowledge.

Medications as social actors.

Much of the social science scholarly literature positions medications at the centre of a complex social web. The medication is not an object that is used by humans, but rather an active social player; it can assert control, it can foster and mediate social relationships, it can represent an illness identity, and/or it can represent humans. Specifically, the 'medication work' that the medicated individual must carry out is supported by their 'social network members' – the people deemed relevant by the individual to their medication work (Cheraghi-Sohi, Jeffries, Stevenson, Ashcroft, Carr, Oliver, and Rogers, 2015). The work, necessitated by the medication, fosters and mediates social relationships between the individual and their social network members, as well as between the social network members (Cheraghi-Sohi et al., 2015).

According to Dew, Chamberlain, Hodgetts, Norris, Radley, and Gabe (2014), the home is the stabilizing centre of this complex social web of medication practice. In this private sphere, various types of medications exist, and competing sources of knowledge are negotiated, with the ultimate goal of shaping medical knowledge to align with the unique household values and practices (Dew et al., 2014). The role of health care practitioners is 'decentralised' to the private sphere – the home – which is at the centre of the social web. (Dew et al., 2014).

Medications have also been presented as active social agents in that they take on the role of physician. For instance, "they bear with them associations to authoritative professionals"

(Geest & Whyte, 1989, p. 345), meaning that they symbolize medical authority. This is similar to the drug as doctor metaphor as presented by Britten (1996) above. In a way, medications act as placeholders for physicians when patients leave medical settings; medications are therefore representative of other social actors.

Morality and compliance.

Crawford (1980) defines the term healthism as a health consciousness movement in which the individual is almost exclusively focused on achieving well-being. Health, from this perspective, although influenced by wider social forces, is deemed the responsibility of the individual (Crawford, 1980). Therefore, "the solution [to health problems] rests within the individual's determination to resist culture, advertising, institutional and environmental constraints, disease agents, or, simply, lazy or poor personal habits" (Crawford, 1980, p. 368). In this way, practices related to health become moralized, and it is this concept of morality that was the final theme to emerge from the social scientific literature on medications.

The moralization of medications operates in two ways. According to the work of Dew et al. (2015), needing to take medications may imply a moral failing, particularly given that illness prevents the individual from fulfilling important social roles, as presented by Talcott Parsons' 1951 functionalist theory of the sick role (Brym and Lie, 2012). This associates illness with social deviance. Non-adherence to medications, however, represents further deviance, as the individual is denying the advisement of medical authority for how to regain social functioning. Dew et al. (2015) summarize this phenomenon in their assertion that "taking substances with active ingredients is saturated with moral concerns relating to issues of responsibility, identity, stigma, agency and power" (p. 272).

This relationship between medications and morality typically operates around questions of compliance. Donovan and Blake (1992) articulate the role of compliance in the moralization of medications, noting that there is an ideology of compliance that positions non-compliance as a behavioural deviance deserving of blame. The biomedical literature on non-compliance tends to imply ignorance and forgetfulness on the part of the patient, which makes the concept of compliance value-laden (Donovan & Blake, 1992).

Fineman (1991) considers the morality of compliance to be socially constructed by health and social system workers. The idea that noncompliance is an act of deviation from the expected patient role (Fineman, 1991) frames the noncompliant patient as deviant and in turn, immoral. Malpass et al. (2009) use the phrase "moral career of medication use" (p. 154) to address the decision-making process that patients move through when contemplating their medication use. Greene (2006), however, takes a different position on morality, focusing more critically on the implications of the overly medicated yet subjectively healthy person. Greene's (2006) analysis found that pharmaceuticals have played a significant historical role in broadening the definitions of certain medical categories. This practice of over-diagnosing and subsequent over-medicating provokes numerous moral debates in the realm of biomedical ethics.

Medication use in the context of aging.

As Ballantyne, Mirza, Austin, Boon, and Fisher (2011) explain, population aging has resulted in an expanding prescription drug market, and thus increased prescribing to older adults. As a result, when compared to previous and less-medication generations, older adults are now facing novel demands in the context of increasing medication reliance (Ballantyne et al., 2011). Accordingly, significant cross-disciplinary research examines the relationship between older adults and medication use (Ballantyne, Clark, Marshman, Victor, and Fisher, 2005, Ballantyne,

Victor, Fisher, and Marshman, 2005, Fisher, Ballantyne, and Hawker, 2012, Gnjidic, Agogo, Ramsey, Moga, and Allore, 2018, Lou, 2019, Lumme-Sandt and Virtanen, 2002). Although diverse, a significant amount of the work investigating older adults and medications emphasizes adherence (Conn, Hafdahl, Cooper, Ruppar, Mehr, and Russell, 2009, El-Saifi, Moyle, Jones, and Tuffaha, 2018, Patton, Hughes, Cadogan, and Ryan, 2017, Schüz, Marx, Wurm, Warner, Ziegelmann, Schwarzer, and Tesch- Römer, 2011, Soones, Lin, Wolf, O'Conor, Martynenko, Wisnivesky, and Federman, 2017, and Unni and Faris, 2011). It is important that research also examines the perspectives of older adults as they navigate the complexities of later life in the context of increased prescribing (for example, Ballantyne et al., 2011), rather than primarily emphasizing the extent to which they adhere or do not adhere. Therefore, I will now present the research questions addressed in this dissertation as a means of centralizing older adults' perspectives on polypharmacy and deprescribing

Research Questions

As evidenced by this literature review, research warns of the harms of polypharmacy and emphasizes the advantages of deprescribing. Social scientists contribute to this topic by centralizing subjective patient experiences, lay perspectives, the role of medications as social actors, and the moralization of medicine consumption. This dissertation is a component of a larger collaborative study with an interdisciplinary team of medical researchers aiming to reduce medication burden for older adults. In this way, deprescribing is adopted as an intervention to address the burden associated with cases of polypharmacy which are causing adverse outcomes for the patient. This distinction between appropriate and inappropriate polypharmacy is important and is taken up in more detail throughout this dissertation. This larger collaborative

study necessitates social scientific inquiry to offer insights from the older adults targeted by these interventions. As such, this study aims to provide these detailed insights and will contribute to the emerging literature on medication reduction by supporting the design, implementation, and evaluation of effective deprescribing programs for medical practice. Based on the existing literature, three important areas for further inquiry were identified:

Social Networks. The role of medications as active social players was a primary finding of the literature review, demonstrating that medications assume social roles beyond their object form. Given that medications are "socially embedded phenomena" (Cohen et al., 2001, p. 441), further research is needed on patients' perceptions of the role their medications assume in their various social networks. Deeper insight into the relationships fostered and mediated by medications will inform the design of effective deprescribing programs. For example, an older adult experiencing social isolation might perceive their pharmacist as a key social support and therefore deeply value the social interactions inherent to that relationship. Information of this nature will provide needed insight into the role medications play in an individual's complex social web, offering valuable knowledge for the construction of safe and effective deprescribing programs. Therefore, the first research question to be answered in this dissertation is:

1. *How do medications mediate different social relationships for older adults, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?*

Knowledge and Expertise. Lumme-Sandt et al. (2000) legitimize alternative sources of logic in the construction of knowledge around medication use, asserting that "not only the biomedical logic, but also other logics are valid in the everyday world where most medical drugs are used" (p. 1843). Lay people assess medications using different criteria than do medical

experts, paying particular concern to efficacy, comparison to other therapies, and how the medication is manufactured (Britten, 1996). The meaning attached to the language of medications also differs between lay and expert circles, with 'drug' carrying a more negative connotation than 'medication' for lay people, whereas these terms are often interchangeable for medical experts (Britten, 1996). For deprescribing programs to be effective, the sources, assessment, and construction of patients' knowledge must be adequately understood. Therefore, the second research question to be answered in this dissertation is:

2. *What forms of knowledge underpin polypharmacy and deprescribing for older adults, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?*

Medication Paradoxes. Numerous paradoxes relating to medications emerge from the scholarly literature, revealing the juxtaposing notions that medications are helpful and/or harmful. Specifically, individuals might feel that they need their medications, while simultaneously expressing concern that their medications may be causing harm. More specifically, the paradox of control is a compelling theme that has emerged from the literature. The relationship between a person and their medications provides space for control to be negotiated; it can be gained and/or lost. The individual may use their medications to exert control over the symptoms of their condition, while also feeling controlled by their dependence on their medication for functioning. Conrad (1985) applied this concept to cases of epilepsy, in which medications were found to give patients a sense of control over their seizures. Patients, however, tended to self-regulate how they took their medications, inserting a level of personal agency into their medication regime (Conrad, 1985). The paradox here is that while medications helped control symptoms, the patient decided when and how the medications were used. The manner by

which medications exert control over the individual body is controlled by the individual. This self-determined prescription management – fundamentally an act of non-adherence – is saturated with moral meaning. Extensive literature has taken up this framing of medication adherence as a moral practice (Bernays, Paparini, Seeley, and Rhodes, 2017, Bishop and Yardley, 2004, Donovan and Blake, 1992, Malpass, et al., 2009, Murdoch, Salter, Cross, Smith, and Poland, 2013, and Werner, Isaksen, and Malterud, 2004). Insights into the various paradoxes that older adults face when confronted with polypharmacy/deprescribing and the narratives they engage to negotiate these contradictions are needed to inform quality deprescribing programs. Therefore, the third research question framing this dissertation is:

3. *How do older adults manage the paradoxes of medications, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?*

Theory

As an interdisciplinary social scientific practice, health studies offer insight into the diverse studies of health and health care. Scholarship of this nature is critical given the social environments in which these systems operate. Rather than simply describing health-related phenomenon or restricting analysis to largely bioscientific domains, critical health studies scholars apply social theory to explain these social phenomena through the identification of key principles. Accordingly, relevant social theories were engaged to serve as conceptual frameworks from which to address the research questions proposed for this dissertation. Each theory is introduced and explained in the relevant article of this sandwich dissertation, therefore only a brief overview of each will be presented in this introduction.

Addressing Research Question 1 – Habermas' work on lifeworld and system.

Critical theorist Jurgen Habermas uses the terms 'lifeworld' and 'the system' to explain the relationship between institutional (political, economic) systems and everyday communication. He argues that in the lifeworld, characterized by communicative acts with family and friends, trust and intimacy are characteristic of relationships. Divergently, in the system, including the market economy, governmental bureaucracy, and legal systems (Gaspar, 1999 and Habermas, 1987), relationships exist as a means to an end. From a medical sociological perspective, doctor-patient relationships operate within the system.

Fundamentally, Habermas problematizes the separation of these social networks and critically observes the colonizing power of the system over the lifeworld (Gaspar, 1999 and Habermas, 1987). This invasion threatens free and open communication acts between humans, which in turn threatens the establishment of mutual understanding between individuals – a prerequisite for the development of trusting and genuine human relationships (Gaspar, 1999 and Habermas, 1987).

Trust is an essential ingredient for relationships to function in both the lifeworld and system. For example, as cited above, the doctor-patient relationship (operating in the system) is contingent upon the patient's trust in the doctor's medical expertise. Thus, although trust operates in both networks, these are distinct forms of trust – coexisting yet independent. From the perspective of Habermas' Theory of Communicative Action, threats to trust must be avoided by creating space for humans to engage in truthful and sincere communication (Gaspar, 1999 and Habermas, 1987). Habermas refers to this space as the 'ideal speech setting' and explains that speech acts in these settings are only possible if participants are empowered and free (Gaspar, 1999 and Habermas, 1987). This type of dialogue is necessary as a means for humans to publicly

debate subjects of social concern (for example, cultural perceptions of medication). Active participation in ideal speech settings will mitigate the system's invading power and intensify the influence of the lifeworld (Gaspar, 1999 and Habermas, 1987).

From this perspective, social institutions have stripped communication of its socially-integrating power (Frank, 2015). According to Habermas, this has created a crisis in the contemporary world in which social institutions are no longer considered legitimate (Frank, 2015). Legitimate institutions are those perceived by the public to be compassionate and acting in the best interest of those that the institution governs (Gaspar, 1999). To construct and conserve legitimacy, people must collaboratively pursue shared understanding – which is to engage in communicative action (Frank, 2015).

It is with this conceptual framework that I undertook both data collection and interpretation in order to answer the first research question of this dissertation: *How do medications mediate different social relationships for older adults, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?* As the institution (in this case, the medical establishment) promotes a modification in older adults' medication use, questions arise regarding the diverse axes of trust across which older adults consider this advice.

Addressing Research Question 2 – Embodied Learning to explain the development of individual expertise.

Embodiment theory explains the accumulation of knowledge by way of bodily experiences. As the body moves through the world, relevant and valid knowledge is constructed, therefore the act of accumulating embodied knowledge is fundamentally a physical act (Griffin, 2017). Of central interest to embodiment theorists are the processes by which embodied

knowledge is acquired when the body assumes two roles: the subject that is acted upon and the agent performing an action (Crossley, 1995, 2004 and Griffin, 2017). This dissertation aims to contribute to this line of inquiry by examining the polypharmaceuticalized body and/or the deprescribing body. In this context, the body is being acted upon by external agents (including medications and health care providers) while concurrently demonstrating agency by adhering to or tapering off of medications (or some other individualized approach to tapering).

Shilling (2016), drawing upon the work of Dewey (2011, 2005 [1916]), is critical of historically inadequate conceptualizations of the role of human cognition in embodiment theory. Shilling (2016) contends that embodied learning is not simply a physical act, but rather the collaboration of physical acts with critical reflexivity. By engaging in this kind of cognitive deliberation, humans are afforded the opportunity to prospectively contemplate possible future actions and consequences without necessarily experimenting with them in the physical present (Shilling, 2016).

Griffin (2017) applies this cognitive element of embodiment theory to health-related behaviours, particularly physical activity and sport, emphasizing the social nature of health behaviours. This dissertation contributes to this work by further applying embodiment theory to medication use, a health-related practice entrenched in the complexities of social life. In doing so, I address the second research question of this dissertation: *What forms of knowledge underpin polypharmacy and deprescribing for older adults, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?*

Embodiment theory is applied as the relevant conceptual framework to explain the construction of knowledge that older adults rely upon when making decisions about their

medication practice – and as it is key to embodiment theory, this form of knowledge is deemed valid and relevant and thus should be understood by health care providers.

Addressing Research Question 3 – Social constructionist theories on systems of classifications to explain medication paradoxes.

Although introductions to the above theories were necessarily brief, this overview of social constructionist theories on systems of classifications is considerably more in-depth. This level of detail is necessary because, for practical reasons relating to length, this overview could not be included in the relevant article of this sandwich dissertation. Nevertheless, an adequate explanation of this conceptual framework in necessary to fully comprehend the approaches used to answer the third research question of this dissertation.

An episteme is "a set of fundamental and taken-for-granted beliefs about what constitutes the world and about how the world works" (Kornprobst, 2005, p. 404). Foucault (1973) wrote about changes to these sets of beliefs, particularly about the construction of systems of classification (Swidler and Arditi, 1994). During the classical age, these epistemes were constructed based on similarity, but changes to epistemes in the age of reason led to classification based on causal association. For Foucault (1977, 1978, 1980), forms of knowledge are concurrently techniques of power (Swidler and Arditi, 1994). The power held by institutions such as mental hospitals allows for the separation of those with mental illness, as psychiatric knowledge is translated into techniques of power by way of diagnosis and treatment (Swidler and Arditi, 1994). Categories of knowledge are enacted by these institutions and dividing practices allow for the segregation of the 'normal' from the 'deviant' (Swidler and Arditi, 1994). It is through these categories of knowledge that subjects are defined and categorized (Swidler and Arditi, 1994).

Durkheim and Mauss (1963) set out to establish the social origin of traditional classifications. The human mind employs the model of society to sort observations into categories; these classifications are not established innately by the brain (Cetina, 1994). Cetina (1994) suggests that the most relevant examples of social classifications are those that are found in highly technical and rationalized social institutions, for example, the medical institution.

Bowker and Star (2000) contribute to this knowledge of institutional systems of classification. To begin, they explain that "to classify is human" (p. 1), and that any system of classification is the result of a dynamic process of compromise. Systems of classification are of particular interest to medical sociologists in that medical classification is the result of complex negotiations infused with questions pertaining to a patient's social value. Bowker and Star (2000) examine how tuberculosis has been described over time and place in order to demonstrate this paradoxical nature of classification systems. I review their publication at some length in order to demonstrate that when health and health care are structured into opposing categories, people must bend their experiences to fit into standardized classification systems. Article three will expand upon this concept, emphasizing that medications themselves are inappropriately dichotomized and thus paradoxical.

Bowker and Star (2000) note that those living with chronic illness, such as those with tuberculosis, "live under a confusing regime of categories and metrics" (p. 26). To live with tuberculosis becomes an intersectional experience as numerous interacting factors, such as patient expectations and the unpredictability of the disease and treatment, are often misaligned (Bowker and Star, 2000). For example, a patient’s hospital release date may become dependent upon a number of seemingly independent (but nonetheless intersectional) factors that may not align, such as a patient’s ability to negotiate with their health care team, that team’s

interpretation of emerging research, and public health demands (Bowker and Star, 2000). This collection of related elements has been termed torque, meaning "a twisting of time lines that pull at each other; and bend or twist both patient biography and the process of metrication" (Bowker and Star, 2000, p. 27). Fundamentally, systems of classification, particularly in the context of medicine, can torque biographies.

Health care systems classify people at various stages of disease, including tuberculosis (Bowker and Star, 2000). Initially, this classification seeks to determine if a patient has tuberculosis or not. Once a diagnosis of tuberculosis is established, the patient is further classified into categories of inactive TB, active TB, or activity undetermined (Bowker and Star, 2000). Classifying then expands, both with tuberculosis and other diseases, to include a dichotomy of spatial elements such as localization in the body, presence in specific populations, and curative interventions, just to name a few. Assigning bodies to categories may be used by practitioners strategically to ensure that the diagnosis will be deemed acceptable by insurance companies (Bowker and Star, 2000), although this is less relevant to the Canadian context. The patient then adopts this label and uses it to self-describe to future practitioners to promote consistency of care (Bowker and Star, 2000). Despite the practical benefits of such classification, challenges emerge when the perpetual state of flux characteristic of both the human body and human history is taken into account.

Despite almost exclusive emphasis on space, both temporal and spatial consideration must be considered together in disease classification (Bowker and Star, 2000). When temporal dimensions are persistently neglected, contradictory disease categories will only emerge as paradoxical when the challenges of time materialize. To return to the case of tuberculosis, a patient begins their treatment program with two states requiring consideration: the state of their

body and the state of their life. The conditions of both these entities have developed across a lifetime and will continue to develop throughout the course of treatment. As the body, the life, and the disease remain in constant motion, committees for disease classification must account for these temporal dimensions. Historical trajectories are imprinted at each unit of analysis, from the patient experience, to the body, to the nature of the disease, to wider population health. It is these trajectories that complicate classification, demonstrating the limitations of an exclusively spatial emphasis (Bowker and Star, 2000).

Historical context is similarly vital to any consideration of disease classification. Bowker and Star (2000) point to the World Health Organization's declaration of the eradication of polio in 1994. A declaration of this nature is arguably one-dimensional in its singular focus on the present-day status of the disease. It does not account for those still living with the ramifications of their polio contracted in the 1940s and 1950s or for the regions of the world still grappling with polio circulation, notably Afghanistan, Nigeria, and Pakistan (Centre for Disease Control and Prevention, 2017). Thus, any observation regarding a disease must be historically contextualized. Deliberation is necessary across multiple dimensions, particularly contemporary theories of disease treatment, which may include antibiotics, quarantine/isolation, fresh air, and so on (Bowker and Star, 2000). Tuberculosis was even thought to have been hereditary during the nineteenth and twentieth centuries (Bowker and Star, 2000). A fundamental shortcoming of disease classification systems is that they do not provide this necessary context and instead tend to indicate only that the patient has lived or died (Bowker and Star, 2000).

This consideration of historical context in disease classification is required to appreciate the ever-changing cultural and symbolic landscape. Paradoxically, tuberculosis was infused with romantic imagery in the nineteenth century. In Sontag's (1977) words, "the recurrent figure of

the tubercular courtesan indicates that TB was also thought to make the sufferer sexy" (p. 25). Once tuberculosis became a mark of distinction and breeding, it had to be considered desirable (Sontag, 1977). Despite the literal agony of tuberculosis symptoms, the "agony became romantic in a stylized account of the disease's preliminary symptoms… and the actual agony was simply suppressed" (Sontag, 1977, p. 29).

A key challenge in classifying any progressive disease is found in the translation of an evolving and unpredictable disease into a "single mark on a sheet of paper" (Bowker and Star, 2000, p. 176). This is further complicated by the chronic malleability of diagnostic categories. Greene (2006) demonstrates this malleability using case studies of hypertension, diabetes, and high cholesterol, finding that in rationalizing prescribing practices, diagnostic thresholds are amended resulting in the reframing of risk factors for disease into diagnosable diseases of their own right (consider the pre-diabetic).

With such shifting categories, it remains unclear when to stop classifying tuberculosis (Bowker and Star, 2000). The committee on the classification of tuberculosis came to accept that any TB category is fleeting and temporary, which speaks to the very nature of classification work (Bowker and Star, 2000). In appreciating the temporal landscape of the illness experience, emphasis shifts from a pinpointed moment in history to include "biography, negotiation, and struggles with a shifting infrastructure of classification and treatment" (Bowker and Star, 2000, p. 177).

Adopting such a perspective complicates the once binary conceptualization of a disease, allowing for the infusion of time, observations, metrics, moralization, and struggle with authority (Bowker and Star, 2000). Historically, committing tuberculosis patients to a TB sanatorium was comparable to an unspecified prison sentence, distorting time and ultimately leading to the

patient's conception of their treatment "largely in terms of putting in time rather than in terms of changes that occur in the lung" (Bowker and Star, 2000, p. 182). In an atmosphere of such uncertainty, a patient may come to know only a life in a sanatorium, predicting considerable anxiety at the prospect of release. Bowker and Star (2000) cite the case of a woman cured of tuberculosis who disrupts her own release by running in the snow, jumping in the lake, and then putting her thermometer in tea to convince her doctors that she has a fever. This distress associated with possible release is understandable, particularly if the patient knows only life in a sanatorium. It is reasonable to wonder if this same legitimate reluctance is found in older adults who have been advised to deprescribe a medication that they have come to know and rely on – physiologically, psychologically, socially, and/or emotionally – for many years.

With medical classification, patients may try to torque their experiences to fit standard classification systems. This becomes a complex process of negotiation in attempting to adapt their body and biography to meet such standards. In accepting that bodies are always in motion, and diseases themselves evolve overtime, we might move to better understand how chronic illness "has a profound temporal effect on the biography of the sufferer" (Bowker and Star, 2000, p. 194).

Bowker and Star (2000) have used tuberculosis to demonstrate the challenges of medical classification systems given changing historical circumstances and the malleability of the body and of disease categories themselves. Their analysis is relevant to the present study because medications have been classified into categories of meaning that are contradictory and paradoxical. Specifically, we are at a moment in time in which two dominant and competing narratives around the use of prescription medications are deemed legitimate. The first account of prescription medications continues to assert their benefit. This extends further to the belief that it

is necessary for older adults to be on (often multiple) prescription medications. This account is present in social institutions and is consequently reflected in the lives of older adults. The other story of prescription medications promotes an opposing message: the population is over-prescribed, and medications are largely damaging. This emerging yet increasingly legitimized understanding of medications is similarly reflected in both social institutions and the lives of older adults. These stories are used as guides to help older adults make decisions for how to best manage their health.

It is these binary narratives that seek to classify a polypharmaceuticalized person into one of two opposing categories: healthy-sick, moral-immoral, healing-deteriorating. In alignment with Bowker and Star's (2000) position, bodies and diseases change over time and thus these contradictory classification systems lead to the experience of torque in which the individual lives through categories of meaning that are incongruent. Older adults are left to manage their health care within this paradoxical context. Therefore, data collection and analysis were conducted from this conceptual orientation in order to answer the third research question of this dissertation: *How do older adults manage the paradoxes of medications, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?*

Methods

The data collected for the purposes of this dissertation are one component of a larger mixed-methods and interdisciplinary collaboration with the Department of Family Medicine at McMaster University – the TAPER Program (Team Approach to Polypharmacy Evaluation and Reduction). Therefore, to provide the necessary context for a full and adequate explanation of the methods for this dissertation, I will first offer an overview of this larger project.

At its highest level, the TAPER Program is testing a collaborative and structured approach to reducing patient consumption of unnecessary medications. In doing so, the team envisions a health care system in which strategies for reducing the risks associated with polypharmacy are as much a part of preventive care for older adults as other routine medical interventions, such as screenings and vaccinations. To achieve this vision, TAPER engages four design elements: (i) a randomized control trial (RCT); (ii) a systematic review; (iii) the Canadian Longitudinal Study on Aging (CLSA) cross-sectional data analysis; and (iv) a qualitative study for patient perspectives. The present study is the qualitative design element (step iv). As such, this overview of the methods will focus most explicitly on this step but will first briefly outline the other three design elements.

Step 1 – RCT. This multicenter RCT set in routine primary care engages a structured clinical pathway to reduce medication burden. This pathway is collaboratively delivered by pharmacists and physicians, amalgamating evidence, an e-tool (RxISK TAPER Assistant – RxTA) to identify potential medications for discontinuation, and patient perspectives. In doing so, patient data is collected to clarify treatment preferences and priorities. Next, a medication reconciliation is conducted with the pharmacist and family physician to identify appropriate medications for 'pause and monitor' discontinuation. A medication reconciliation is a method of preventing medication errors and adverse drug events by identifying drug discrepancies at transitional points in care (Sholihat, Hanifah, Puspaningtyas, Maharani, and Utami, 2018). These consultations with the pharmacist and physician are supported by RxTA, which is a digital pathway supporting discontinuation by detecting unnecessary or inappropriate medications and providing follow-up monitoring.

Intervention Group: Details. Baseline data collection identifies illness and demographic characteristics, preferences for care, goals for treatment, and perceptions of medical problems. A medication reconciliation is then performed in consultation with the pharmacist to generate the most accurate list of medications. This list is then used to inform a consultation between the participant and family physician to prioritize drugs for discontinuation.

Control Group: Details. Participants in the control group receive usual standard of care.

Inclusion Criteria: Participants must be age 70 or over and experiencing polypharmacy, defined, for the purposes of this RCT, as taking five or more medications. Patients who do not speak English, have cognitive challenges, or anticipated mortality within six months are excluded from participation.

Outcome Measures: outcomes measures are analyzed by interviews (baseline and six-month follow-up) and questionnaires (one week and three month). Patient interviews, prescribing records, and pharmacy dispensing records are used to assess ongoing medication consumption. Health service usage, prescribing, and adverse events are assessed by participant direct report, clinical notes, and pharmacy records. Outcome measures are assessed across two categories: patient quality of life and cost-effectiveness of health services. The primary outcome measure of consideration is the difference in mean number of medications from baseline to six-month follow-up. Secondary outcome measures include: quality of life (assessed via EQ-5D, SF36, Stanford Scale for self-efficacy, PES for patient enablement, and perceived patient-centred care); cognition (assessed via Mini Mental Status Examination); fatigue (assessed via the Avlund Mob-T Scale); nutritional status (assessed via Mini Nutritional Assessment Short-Form); physical functional capacity (assessed via the Manty structured validated interview); pain (assessed via

Brief Pain inventory); falls and adverse events (assessed via patient or clinician report); and healthcare resource utilization data.

Step 2 – Systematic Review. Conducted to synthesize tools for deprescribing in primary care. The systematic review includes data on tool characteristics, country of origin, population of interest, objectives, setting, and relevant outcomes.

Step 3 – CLSA cross-sectional data analysis. To define populations at risk for medication burden associated with polypharmacy, a multivariable analysis on the CSLA cohort dataset assesses predictors of polypharmacy and relationships to functional measures.

Having briefly established the three additional design components of the larger TAPER Project, focus will now shift to the fourth component – a qualitative sub-study. *It is this qualitative sub-study that establishes the parameters of this dissertation.*

Step 4 – Qualitative study. Qualitative data collection began when participants were assigned to an RCT group. A total of 40 participants were enrolled in the RCT, 20 in each group. At time of enrollment, all participants were asked if they could be contacted for an interview. Of the 40 RCT participants, 21 consented to being contacted for an interview. A total of 16 participants consented to and completed the interview (8 participants from each group; 11 female; 8 male). Participants' ages ranged from 73 – 90 (mean age: 81 years). All participants were given a choice of location for their interview, and all chose to be interviewed in their homes. Interviews were conducted between December 2016 and October 2017, and were approximately one hour, on average. Interviews were audio-recorded (with participant consent) and transcribed verbatim.

These in-depth semi-structured interviews involved five sections. Firstly, participants were asked if they had any questions regarding the study and were asked to provide a brief

history of their medication use. Next, participants discussed strategies they use to manage polypharmacy (and deprescribing for those in the treatment group). Through story-telling, participants were next asked to share experiences they had related to their medication use (and potential discontinuation). The fourth line of inquiry involved the elicitation of participants' values and beliefs related to medications. The final section of the interview offered participants the opportunity to add any additional information or stories that they felt were relevant to our shared understanding of their medication use (and potential discontinuation).

Data was analyzed using Dedoose software, which is a web-based application used to organize qualitative data and analyze mix-methods research. In this software, thematic analysis was performed on interview transcripts. This approach was selected as most appropriate for the purposes of this research given its flexibility and range beyond data organization to critical interpretation of that data (Maguire and Delahunt, 2017). Braun and Clarke's (2006) six phase guide to thematic analysis was used to inform this work. Doing so involved becoming familiar with the data by taking notes during/after the interview, transcribing, and reviewing interview transcripts. Codes were then developed and organized into possible themes. The core of each theme was then established to identify how the stories that materialize from each theme could be pieced together to construct a larger narrative that spoke to the spirit of the findings in their entirety. The foundation of this method of analysis outlined by Braun and Clarke (2006) offered the versatility necessary to critically interpret interview transcripts. This method was used in each article of this thesis to identify the relevant themes that were then connected back to the literature via the conceptual framework used to inform the specific research question at hand.

Please note that in the presentation of findings in each of the three articles, participant initials were randomly generated to protect participant anonymity.

Qualitative interviews: Encouraging the patient perspective. Given the interdisciplinary nature of the TAPER Program, qualitative methods were a vital complement to the other methodological approaches of the study. Specifically, in-depth qualitative interviews (rather than clinical interviews with the family doctors) were needed to adequately investigate patient perspectives. Although biomedical practitioners may be interested in their patients' perspectives, clinical interviews seek to mold that perspective into a diagnosable medical category (Britten, 1995). Despite the value in being able to define and thus respond to a patient's health concern, the respondent's narrative is dismantled and restructured to fit into a narrow category so that appropriate treatment measures can be pursued accordingly. The qualitative research methodologies fundamental to critical health studies scholarship, specifically the qualitative research interview, provide a means for ascertaining the patient's "framework of meaning" (Britten, 1995, p. 252).

As I train as a qualitative researcher, it is important that I try to provide this meaning-making space. Doing so better allows for the illness experience to be both articulated and concluded by the participants themselves, rather than reinterpreted and reconstructed to fit narrowly into biomedical categories. This space ensures that the perspectives of patients are centralized, rather than the often-centralized views of clinicians and other stakeholders. For these reasons, the in-depth qualitative interview was selected as the appropriate method for this research.

Outline of Dissertation

Three independent research articles constitute the empirical portion of this dissertation. Each article will address one of the research questions presented in this introduction. For

practical reasons, some information is repeated in these papers as they all draw on the same qualitative dataset. The first of these papers is the most heavily theoretical and draws upon Habermas' work on the lifeworld and system in problematizing the re-characterization of the doctor-patient relationship as a service provider-client relationship, fundamentally commodifying health care, obstructing authentic human connection, and thus threatening communicative action. This article contributes to the social scientific inquiry necessary for the design, implementation, and evaluation of deprescribing programs by highlighting the important role of communicative action in medical interventions.

The second article examines how older adults construct and employ embodied knowledge when making decisions about how to take medications. This research is significant because it reminds medical researchers designing deprescribing programs of the authority and expertise that older adults have over their own bodies – the result of a lifetime of embodied learning.

The third and final article of this dissertation examines the many contradicting narratives that older adults are confronted with regarding their medications. Of particular interest is the processes by which older adults come to negotiate these paradoxes, particularly their use of interpretative repertoires. Interpretative repertoires are tools of communication that are used to convince someone of your perspective of a cultural event (Seymour-Smith, 2017). These repertoires offer insight in how various versions of the world are constructed (Seymour-Smith, 2017) and enable people to justify their behaviours by validating their perspectives (Lumme-Sandt, Hervonen, and Jylhä (2000). Therefore, the identification of these repertoires offers valuable insight into the extensive work that older adults engage in to create a sense of personalization in the highly dichotomized medical institution, ultimately justifying the decisions they have made around medication practice.

A concluding chapter will summarize this research and offer suggestions for future social scientific inquiry into the topics of polypharmacy and deprescribing. In the conclusion I will also discuss limitations, engage in critical reflexive practice regarding my role as a qualitative researcher in training and discuss the interdisciplinary spirit of this research project. Ultimately, the concluding chapter deconstructs the social construction of the problem of polypharmacy and presents a new model, termed the *Polypharmacy Continuum.* This model emphasizes the need to treat problematic polypharmacy while also facilitating appropriate polypharmacy that supports individuals in managing complex and chronic co-morbidities. This is to say that all polypharmacy should be thoughtful and appropriately monitored.

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ARTICLE 1: FORMS OF TRUST AND POLYPHARMACY AMONG OLDER ADULTS

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ABSTRACT:

This article examines how older adults make decisions about their medications through interconnected axes of trust that operate across social networks. Trust is negotiated by older adults enrolled in a deprescribing program called TAPER, which guides them through the process of reducing medications to mitigate the risks associated with polypharmacy. Habermas' work on the significance of communicative action in negotiating trust within complex social relationships informs our analysis, specifically in-depth semi-structured interviews with older adults about their medication use and the role of social networks in managing their health. Participants were age 70+ and experiencing polypharmacy (the concurrent use of five or more prescription medications). Our analysis discusses the social nature of medication practices and the importance of social networks for older adults' decision-making. Their perspective reflects the critique of late modern society put forward by Habermas. Negotiating trust in pharmaceutical decision-making requires navigating tensions across and between system-world social networks (health care professionals) and life-world social networks (family and friends). This study contributes to our knowledge of how distinct forms of trust operate in different social spheres setting the context for the way healthcare decisions are made across social networks. Our analysis reinforces the need for older adults to meaningfully engage in healthcare decision-making such that a convergence between system-world and life-world structures is encouraged. This would improve deprescribing programs' efficacy as older adults optimize their medication use and improve overall quality of life.

Keywords: polypharmacy, deprescribing, older adults, social networks, trust.

"You have to trust whoever is making decisions for you"

Introduction

In 2001, Cohen, McCubbin, Collin, and Pérodeau declared medications to be "socially embedded phenomena" (p. 441) and called for research on the societal significance of medications. Such research grows in importance as polypharmacy becomes ever more central to later-life considerations of well-being. Many qualitative researchers have answered this call by applying a social lens to this largely biomedicalized phenomena (Hawkins, Nickman, and Morse, 2017; Malvini Redden, Tracy, Shafter, 2013; Minet, Lønvig, Henriksen, and Wagner, 2011; Nickman, 2017; Salt and Peden, 2011). This article contributes to this expanding body of qualitative work by examining how older adults make decisions about their medications through diverse axes of trust that operate across social networks.

Our study emerges from the move toward deprescribing guidelines and programs among older adults. Deprescribing involves supervised dose reduction or cessation of medications that are potentially harmful or lack clear benefits (Farrell, Richardson, Raman-Wilms, de Launay, Alsabbagh, and Conklin, 2018). As Murphy, Agostini, Van Ness, Peduzzi, Tinetti, and Allore (2008) explain, health care providers attempt to balance the risks and benefits of multiple medications for their patients. As these risks are particularly burdensome to older adults, scholarly attention must be paid to interventions that diminish the risks of polypharmacy. Deprescribing programs are one such intervention presently being tested. Participation in a deprescribing program is a socially embedded activity involving actors from diverse social networks, including the older adult's family members, friends, physicians, nurses, pharmacists, medications, and those in the pharmaceutical industry. Participating in deprescribing is also situated in social institutions, primarily the healthcare system and the family and kinship

systems. As such, when patients are invited to deprescribe, their subsequent decisions are made at the intersection of these dynamic social networks. The forms of trust that are established through these interdependent social networks are central to informing older adults' decisions regarding how they use their medications.

As people enter into later life, the likelihood they will be involved in the healthcare system increases. As a result, healthcare professionals often become key sources for social interaction. A key component of the ongoing interaction between healthcare professionals and older adults is the use and management of prescribed medications. Literature in this area specifically positions medications as objects at the centre of a complex social web. Cheraghi-Sohi, Jeffries, Stevenson, Ashcroft, Carr, Oliver, and Rogers (2015), for instance, note that the 'medication work' that individuals carry out is supported by social network members (the people considered essential to managing medications). This medication-based work organizes and mediates social relationships among members of different embedded social networks. Medications themselves are then positioned as more than objects consumed by humans. They are social actors with the capacity to organize behavior, foster and mediate social relationships, and even signify and shape the meaning of illness identities.

Medications are also presented as active social agents in that they take on the role of a physician. For instance, "they bear with them associations to authoritative professionals" (Geest and Whyte, 1989, p. 345), meaning that they symbolize medical authority. This is similar to the drug-as-doctor metaphor as presented by Britten (1996), suggesting that medications are commonly seen as an extension of the doctor (Britten, 1996). Therefore, if a patient does not want to criticize their doctor, they are unlikely to criticize their medications. In this way, medications have become a symbol of medical authority

The social networks through which medication work takes place extend beyond medical authority and healthcare settings. As Dew, Chamberlain, Hodgetts, Norris, Radley, and Gabe (2014) point out, the home is in fact the stabilizing center of most medication work. Different medication types exist in this private sphere, as do different sources of knowledge: these compete to align medical knowledge with the household's unique values and practices (Dew et al., 2014). The home, as the centre of the social web, 'decentralises' the role and influence of health practitioners to the private sphere (Dew et al., 2014).

Situating medications as socially-embedded phenomena is particularly relevant to understanding the experiences of polypharmacy among older adults. The definition of polypharmacy is a topic of debate (Alpert and Gatlin, 2015; Hajjar, Cafiero, and Hanlon, 2007; Hanlon, Weinberger, Samsa, Schmader, Uttech, Lewis, Cowper, Landsman, Cohen, and Feussner, 1996; Maggiore, Gross, and Hurria 2010; Maher, Hanlon, and Hajjar, 2014; Reason, Terner, McKeag, and Webster, 2012). Despite this, most competing definitions frame polypharmacy as the simultaneous use of many medications. Regardless of which is used, a key point is the considerable risk associated with polypharmacy, particularly for older adults. These risks include escalating healthcare costs (individually and system-wide), adverse drugs events, negative drug interactions, non-compliance, cognitive impairment, falls, functional decline, malnourishment, and urinary incontinence (Maher, Hanlon, and Hajjar, 2014). According to the Canadian Deprescribing Network (CaDeN, 2016), deprescribing aims to reduce the burdens associated with polypharmacy in order to maintain and/or improve quality of life. This involves a supervised reduction or stoppage of medications deemed to be harmful or lacking benefit (CaDeN, 2016).

In defining deprescribing, as a key means of responding to polypharmacy, CaDeN (2016) notes that it is a collaborative process which engages patients, caregivers, healthcare teams, and policymakers. In this way, deprescribing is a social process and patients' decisions to deprescribe are made with these various networks of support. Therefore, as a way to understand how older adults in Canada make decisions about their medications, it is valuable to understand the diverse sources of trust that operate in these social networks.

Communicative Action and the Formation of Trust in Social Networks

In his theory of communicative action, Jurgen Habermas (1987) problematizes the separation of the life-world and the system-world, arguing that in late modern societies, the former is increasingly colonized by the latter (Gaspar, 1999). The life-world refers to "the realm of everyday communicative life" while the system-world includes "government bureaucracy, legal systems and the market economy" (Gaspar, 1999, 408). The operation of relationships in these two distinct worlds diverge. In the life-world, relationships are meaningful in and of themselves and are based on trust formed through intimacy and interdependency. Family and friends are relationships that exist within the life-world, where relationships are ends in themselves. Conversely, relationships are a means to an end in the system-world, where each interaction serves a unique social purpose. The doctor-patient encounter is an example of a system-world relationship: it is based on trust in the doctor's professional expertise and the physician's status within a formal institutional structure. The formation of trust in each social world is a complex process; each form is distinct yet inter-dependent.

In looking at the relationship between the two systems, Habermas argues that with an increasing reliance on neoliberal market-based logic beginning in the 1980s, the life-world

becomes increasingly colonized by the system-world, which threatens the possibility for human solidarity (Gaspar, 1999 and Habermas, 1987). With this colonization, there are fewer open and free avenues for communication. Instead, interactions become distorted so that all exchanges in social networks begin to reflect a purposeful 'means-to-an-end' logic. This process leads to the ultimate elimination of structures of human communication that the social fabric relies on (Gaspar, 1999 and Habermas, 1987). The deterioration of these communication structures threatens the development of mutual understanding, and consequently, genuine and trusting relationships between individuals (Gaspar, 1999 and Habermas, 1987).

Ideally, the life-world and the system-world would co-exist as they are inter-dependent; each contributes to social benefit and well-being. The system-world would help address the social and material organization while the life-world would enrich the lives of citizens (Gaspar, 1999 and Habermas, 1987). However, given the domination of system rationalization over life-world rationalization, societies are materially wealthy but lack social enrichment and enchantment (Gaspar, 1999 and Habermas, 1987). Gaspar (1999) characterizes such enrichment as "truth, goodness, and beauty" (p. 408). Without this prosperity in the life-world, communication deteriorates and the human qualities characteristic of our everyday relationships, such as trust, begin to be questioned and eroded (Gaspar, 1999 and Habermas, 1987).

The solution is not to destroy the system, as the life-world depends on the accumulating capital in the economic and administrative institutions of the system in order to thrive (Gaspar, 1999 and Habermas, 1987). Habermas (1987) further argues that the solution is not in rational-purposive action, as these actions are aligned with a neoliberal market-oriented logic. This logic makes commodities of all things, including the commodification of human relationships. Human

communication exists only for utilitarian purposes, disrupting the establishment of genuine human connection and intimacy (Gaspar, 1999 and Habermas, 1987).

Given these threats to communicative action and life-world relationships, there is a need to establish an interdependence in human relationships via practical action and critical thought to create space for sincere and open communication (Gaspar, 1999 and Habermas, 1987). This space, referred to as the 'ideal speech setting' is a prerequisite for undistorted communication. 'Ideal speech acts' can only exist in these settings and are populated by empowered and free participants (Gaspar, 1999 and Habermas, 1987). Dialogue in these settings is essential for debating and addressing issues of social concern in public spheres (Gaspar, 1999 and Habermas, 1987). By doing so, the impact of the life-world on the system-world intensifies while the opposite is mitigated (Gaspar, 1999 and Habermas, 1987).

In problematizing neoliberalism, Habermas is concerned with the growing commodification of human relationships. As the system's colonization of the life-world continues to expand, this relationship between patient and doctor is commodified. Consequently, purpose that is given a monetary value must permeate the relationship such that the rapport between a doctor and patient exists only for utilitarian purposes. Accordingly, as the system colonizes the life-world, the healthy body is commodified and as a result, some groups have more opportunity to access this commodity than others via the procurement of goods and services necessary to attain and maintain health. The implication of this commodification is that the doctor-patient relationship is re-characterized as a service provider-client relationship. A relationship of this utilitarian nature interferes with the development of genuine human connection.

In managing the health of their changing bodies, older adults rely on their social networks, both in the system-world and life-world. System-world social networks include doctors, nurses, pharmacists, care workers, and so on. The trust that is developed through these relationships is largely based on medical expertise. Although trust of this nature may appear to be sufficient for older adults to make healthcare decisions, social networks that exist in the life-world are also characterized by a type of trust that is valuable in this decision-making process. Although the basis of this trust is not medical expertise, trusting relationships with family and friends in the life-world are characterized by a high level of intimacy and personal knowledge.

Methods

The purpose of this project was to better understand how older adults make healthcare decisions through axes of trust that operate across the system-world and life-world. This qualitative study was situated within a larger project on deprescribing as a standard preventative care option for older adults. This larger study was a randomized controlled trial (RCT) which operated as a multi-centre project set in routine primary care. Patients of these routine primary care settings were invited to participate in this study by their primary care physicians. Written informed consent was obtained at that time. Once enrolled in the RCT, participants were randomly assigned to the treatment group (deprescribing program) or control group (usual standard of care). At enrollment, participants were asked if they were interested in being interviewed about their experiences with medications. If interested, participants were contacted by a Research Associate to set up a time for interview.

Participants were older adults experiencing polypharmacy, aged 70+, and were patients of the routine primary care centres. Participants who did not speak English were not included in

this study because the scales used in the larger TAPER project are validated in English. Similarly, patients with expected morality within six months were not eligible for participation, as it would be unlikely that they would be available for follow-up for other components of TAPER. Qualitative data collection was conducted at a location of the participants' choosing, which was always in their homes. Of the 40 participants enrolled in the study, 16 consented to and completed the interview; 11 females and 5 males. The mean age of participants was 81 years, ranging from 73 – 90.

When enrolled in the RCT, baseline data was collected to assess illness, demographics, functional/symptom goals, treatment preferences, and perceived medical problems. Based on this baseline information, the pharmacist conducted a medication reconciliation with participants in the intervention group. This list was then used in consultation with the participant and family physician to prioritize medications for possible discontinuation (for participants in the treatment group). Blinding was not feasible or necessary. A total of 40 participants were enrolled in the RCT – 20 in each group. Once the participant was enrolled in the RCT, qualitative data collection for the present study began.

Qualitative data collection continued from December 2016 to October 2017. Of the 16 participants who consented to and completed the interview, eight were from the treatment group and eight were from the control group. In-depth qualitative interviews were conducted with both sets of participants and the average interview was approximately one hour. These interviews were semi-structured and meant to guide, rather than control, the conversation. Interviews evolved in unique ways depending upon how participants responded. This approach ensured the versatility and flexibility of each interview, allowing the participant the space to shape the conversation. Each interview was audio-recorded and transcribed verbatim. Thematic analysis

was conducted on interview transcripts using *Dedoose* software by two coders. This inductive approach was guided by Braun and Clarke's (2006) six-phase method for thematic analysis.

Findings

The older adults interviewed for this project demonstrated the very social nature of their medication work. The findings illustrate the way life-world forms of trust are being colonized and eroded by the increasing predominance and reliance on a system-world orientation to medication decision-making among older adults. Further to this, the findings also illustrate resistance to this colonization that is anchored in forms of trust unique to life-world social relationships. Interpretation of these findings reflects the convergent relationship of the life-world and system-world. This process of colonization, resistance, and convergence gives insight into the medication work that older adults engage in when managing polypharmacy and the possibility of deprescribing.

Colonizing the Lifeworld

Participants interviewed in this study consistently articulated the colonization of their life-world relationships (for example, with family and friends) by their system-world relationships (for example, with doctors and pharmacists). This was evidenced by a reliance upon the system for expert advice regarding health management coupled with the avoidance/dismissal of lay advice from life-world relationships. The expansion of medical authority in the governance of bodies has encouraged this avoidance and dismissal of life-world experience in favour of medical expertise, perhaps simply for peace of mind in medical decisions. One participant, I.P., spoke to this need for peace of mind when she said, "You have to trust whoever is making decisions for you." The decisions that I.P. is referring to are those

made by the system. Here, I.P. has revealed the necessity of trust in the system, and therefore an unquestioned trust in medical authority. Several other participants emphasized this need for trust in the (medical) system. For example, when asked about her feelings towards her medications, W.T. explained, "I don't think I've ever said no to any med." As was the case with I.P. above, W.T. demonstrated implicit confidence in decisions made by medical authorities over her body. If a doctor recommends a medication, W.T. sees no need to question or refuse that advice. Accordingly, as the life-world is bracketed by the system, the people who exist in these worlds are encouraged to place trust in medical expertise alone.

L.C. similarly revealed an inherent faith in his healthcare team as a social network: "Well, I take my medication because my doctor told me to take it… they know more than I do, so I would obey them and take the medication." Importantly, L.C. has added an element of assumed expertise; he has articulated that his trust in medical authority assumes his doctor knows more than he does. X.M. echoes this expectation: "I'll just wait and see what [my doctor] says and go with it, whatever she says because I'm assuming that she knows what she's talking about. That's all I can do." This sentiment, expressed in many of the interviews, is significant because it reveals that many older adults deem trust in the system as necessary, and assume the system holds the most relevant and legitimate knowledge. Ultimately, decisions about one's body are easier to make if one has implicit trust in an authority deemed more knowledgeable. In the words of L.C., "If they keep me healthy, I'll just listen to my doctor and keep on taking them."

As a result of this confidence in medical authority, advice provided by relationships operating in the life-world is avoided and dismissed. In some cases, participants reported avoiding discussions relating to their health and medications with friends and families assuming these people would not be interested. For example, W.T. explained, "if I was to talk about my

meds to an 80 year-old that I see somewhere, I would think that is making me self-centered talking about me and my life." Here, W.T has revealed that she protects her life-world relationship from talk of medicine in order to be perceived as well-mannered. To share her health issues with life-world friends would be egocentric and perhaps boring. These types of discussions are reserved for system relationships with doctors and other healthcare professionals – experts who are trained and compensated to engage in these interactions.

H.S. describes similar feelings, stating that he and his friends "…don't sit around and say 'how are you doing wish such and such a drug.' I don't do that with anybody but my doctor." In addition to not wanting to be perceived as boring or self-centered, a second inference is that life-world relationships are not characterized by the necessary expertise required for engagement in such discussions. In L.C.'s words, "I don't talk about it because they don't know. Most people won't know, because they are like me, you know, so I don't talk to them about it. No, I only talk to my druggist or my doctor." For L.C., neither he nor his friends/family are considered knowledgeable enough to discuss medicine. X.M. reinforces L.C.'s feelings, explaining, "I would only go to the pharmacist or the original doctor. I wouldn't ask a friend or anything what she thinks." Perhaps it is common sense that older adults do not view their life-world relationships as sources of trusted medical knowledge, but what is particularly compelling about this finding is that older adults do not appear to confide in their life-world relationships about their hopes, fears, desires, concerns, frustrations, and/or successes that are related to their medications. Rather, the majority of talk regarding medication is relegated to the system-world.

As established in these participants' accounts, communicative action, as Habermas defines it, does not (or cannot) exist in the current legitimacy crisis. Communicative action is constituted by open and respectful communication between people in the ongoing hunt for

common understanding. As participants explained, they take their medication because their physicians told them to, and they do not question it; it is evident that communicative action does not thrive in the system as it currently exists. Patients are not encouraged to engage in discussions about their prescription medications in order to attain a shared understanding of their health-management plans. This system relationship therefore does not facilitate the formation of ideal speech settings.

This observed colonization of the life-world by the system is facilitated through human relationships. The system is supported by relationships operating according to specific modes of communication. Medicine as a social institution (system relationships) infiltrates life-world relationships by limiting the extent to which life-world relationships discuss health and the body and influence decision-making. This intrusion shifts the predominant form of trust away from life-world relationships and privileges system-world understanding and expertise.

This is not to say that life-world relationships cannot consist of communication about health and medicine. Analysis of these qualitative interviews reveal that the system has particularly influenced spousal relationships (an example of a life-world relationship) in that medication work constitutes a significant, and occasionally dominant, aspect of marriages between older adults. Most commonly, participants reported that quite often the female partner was responsible for the medication work for both partners (note: all married participants were in heterosexual relationships.) For example, M.S. reported that her husband is not aware of her medications, but that she is aware of his and even keeps a book on his health information. Two married participants, P.N. and P.S., were interviewed together and reflected this same observation. According to P.N. (wife): “I know what he’s on and what he should be taking. I don’t know if he’s so sure about me.” And P.S. (husband) confirms this: “No, I’m not sure about

you at all." In this way, the system's colonization of these life-world relationships has been facilitated by people's trust in medical authority, which has embedded itself into the fabric of the marital relationship. Couples are not discussing the advantages and disadvantages of their medications, debating the merit of medical opinion, or asking one another for advice. Rather, these life-world relationships are reinforcing the system-world's embedded authority. The system exerts dominance in these life-world relationships, particularly through this gendered division of medication labour.

Older Adults' Resistance

Further analysis of these in-depth interviews found that older adults do resist the erosion of the life-world in their medication work and decision-making. They often spoke of working to establish and sustain life-world forms of trust within their system-world relationships. In the words of X.M., "I have my faith in the medication, the doctors. [I] just do." Reinforcement of this trust functions to ensure older adults that following doctors' orders is in their best interest. Interestingly, older adults invest in their relationship with medications a life-world orientation, even if it is to validate and justify their reliance on the medical system.

One of the ways older adults are working to bring the life-world into the system-world is via the development of deep, trusting, and personal relationships with their healthcare providers. It is not enough that a doctor is a highly-trained medical expert; older adults are seeking a highly-trained medical expert with whom they have a meaningful and personal relationship. The establishment of life-world relationships in the system signals a response to the loss of communicative action and a disjuncture between the life-world and system-world. In interviews, older adults expressed a desire to bring life-world social relationships into the medical system. For instance, I.P. summarizes this kind of work in making decisions about medications:

> I know the people who were recommending different meds and so on at the hospital. I didn't know those people, didn't know their background. They didn't know me. Whereas my cardiologist, I've had her for a number of years. She knows my background. She knows what's happened to me, so I trust her more than some stranger.

Here, I.P. does not question the expertise of the people at the hospital recommending different medications. Rather, she is emphasizing that their medical expertise alone is not enough for her to adopt their advice. I.P. is comforted by a personal and long-term relationship with someone who holds relevant medical knowledge, assuring her that the advice given to her is informed by a deep knowledge of her unique history. This account by I.P. illustrates how older adults are trying to create a reliable situation in which two forms of trust converge: a system-world trust based on medical expertise and a life-world trust formed out of their personal relationship with their healthcare provider, not as a medical expert but as another caring person in their life.

Another way in which older adults seek to link the life-world and system is by welcoming into their medication work healthcare professionals from their life-world social networks. Older adults report dismissing and avoiding conversations about their medications with family and friends. The exception is family and friends who are doctors and nurses themselves, or family and friends who similarly defer to medical expertise for much of their decision-making. For example, although L.O.'s sons are not medical professionals, they are also managing hypertension with medications. According to him, "When I talk to my sons out in BC on the phone, it's more about their medications… because they too are dealing with high blood pressure, they'll say, 'Dad, what's the medication you're on?" In such cases, the instructions older adults receive from the system permeate life-world relationships with others who have received similar instructions.

In cases where a life-world relationship is with a person who also happens to be a medical professional – which is very common – the emphasis of the relationship shifts to

healthcare. For example, I.P. described her relationship with a friend from her orchestra: "Well Marg, who play in the orchestra with me… she's nurse background. And I know she aches and pains and arthritis too, just like we commiserate." For I.P., this relationship provides the combination of a medical expert and a friend with shared aches and pains. These types of life-world interactions indicate older adults' efforts to integrate personal and trusting relationships into the larger system relationships that seek governance over their bodies and health. This effort may be more pronounced in older adults with higher healthcare needs and lives more heavily governed by social institutions, such as medicine.

X.M. speaks to this phenomenon in her account of seeking medical advice from a life-world relationship with someone who works in the system:

> I'd maybe ask my daughter if it had anything to do with her line of work, the one in Montreal. You know, in fact I did ask her once about something I was taking, and she said it should be okay for you. She said we get people for dialysis that are a lot worse off. Oh I know, I had a urine test for creatine and they said it was elevated a little bit. And they were stopping – I was taking three methotrexate a week and they put it down to two, and then I was a little bit achy so I asked her. I said, 'should I go back on it?' She said, 'no, just go with what the doctor says'.

As demonstrated in this account, the system and life-world are not divergent entities. All people operate in both the life-world and system-world as either professionals or lay people. Life-world relationships are fostered in the system by older adults and system relationships are fostered in the life-world.

Discussion

The system's infiltration of the life-world is facilitated by human relationships. In order for the system to gain dominance, it relies upon the life-world. Older adults demonstrate this reliance in numerous ways, such as avoiding medical conversations with lay people and privileging medical conversation with 'expert' friends and family; an overlap of the life-world

and system-world that signals their interdependence. This study found that older adults are hard at work to promote this interdependence. The promotion of this integration, Habermas argues, might lead to the creation of ideal speech settings, which are necessary for ideal speech acts (Habermas, 1987 and Gaspar, 1999). In Gaspar's (1999) words, the absence of these settings may be due to, "constraints that prohibit the actors from speaking up freely, [the actors] do not share the same presuppositions and assumptions, and there is a lack of consensus on the values that help to define the collective goals" (p. 410). These are the prerequisites for communicative action. Older adults' efforts to form life-world-type relationships with the system's actors (for example, doctors, nurses, and pharmacists) demonstrates their efforts to create these preconditions.

These efforts to establish interdependence between the life-world and system are supported by Ballantyne, Mirza, Austin, Boon, and Fisher (2011) in their work describing older adults as active agents in the management of their medications. Ballantyne et al. (2011) find that older adults' "health-related dispositions and actions are informed, but not defined, by biomedical culture" (p. 181). Rather, participants demonstrated efforts to create a hybrid patient culture in which their life experiences are blended with conventional and alternative approaches to health (Ballantyne et al., 2011). These efforts establish older adults' resistance to system colonization by way of merging the considerations of both worlds.

The system in disguise: patient-centred care

Patient-centred care has gained popularity in many health systems (Canadian Medical Association [CMA], 2010). The key components of this model involve the partnering of health care providers with patients and families in the provision of care that is individualized and best for the patient (CMA, 2010). According to Kolind (2017), a patient-centred approach involves

identifying and emphasizing the outcomes the patient desires and the ongoing and active engagement in discussions regarding treatment goals. An admirable aim, it is nonetheless important to consider the ways in which this approach, promoted within the system, has donned a life-world mask.

Patient-centred care appears, at first glance, to be part of the life-world. It is, however, designed by, advocated for, and administered within the system. The system driven practice of patient-centredness is therefore tested when the patient/family introduces something from the lifeworld that is not system oriented. For patient-centred care to be truly patient-centred, the desires of the patient (and family) must be prioritized above those of the system. This is especially true for patients who are invited to deprescribe in response to their polypharmacy. Despite biomedical support for deprescribing, a patient-centred approach should involve the collaboration of the life-world and system – the patient (and family) and healthcare team – in this decision-making process. To holistically support older adults in a 'patient-centred' manner, medical practitioners ought to be cognizant of the different axes of trust through which older adults make decisions about medications, specifically deprescribing. Medical practitioners should be aware of and receptive to the ways in which older adults promote this collaboration of the life-world and system-world. Doing so will hopefully create opportunities for forms of true and authentic communication that are not distorted.

These findings are consistent with Barry, Stevenson, Britten, Barber, and Bradley's (2001) work which draws upon doctor and patient interviews to demonstrate that patients receive better care when doctors are sensitized to patients' lifeworld concerns. Barry et al. (2001) note that structural reform is necessary to offer an appropriate environment for doctors to engage in this type of lifeworld-sensitized care. Doing so will involve doctors reframing their

understanding of quality care from technological considerations towards "their patients feeling understood, listened to and treated like whole and unique human beings (Barry et al., 2001, p. 504).

Restoring communicative action

Older adults are managing decisions about their health across the axes of trust in two interdependent social networks – the system and life-world. This conceptual framework allows us to map deprescribing decisions that older adults make along these different lines of trust. Habermas views communicative action as communication between people to address differences and arrive at a shared understanding (Frank, 2015). Frank (2015) observes its breakdown in the medical system, where life-world communicative action has been excluded by the system's communication. For healthcare providers implementing deprescribing programs, there must be a willingness to restore communicative action in medicine: this means medical professionals should spend time with patients/families in pursuit of a common understanding of what is best for the patient (Frank, 2015). According to Frank (2015), this ongoing process provides opportunity for society to reinforce value-commitments and increase trust and legitimacy among social institutions.

The findings of this study offer important contributions to our knowledge of how distinct forms of trust operate in different social spheres and influence healthcare decisions. Practically, this study reinforces the call for active patient engagement in decisions relating to their bodies and their health. In the 1989 study by Brody, Miller, Lerman, Smith, and Caputo, patient attitudes towards illness and recovery were correlated with their perceived involvement in their healthcare decisions. Patients who felt they were actively involved in their healthcare had less discomfort, fewer illness-related concerns, greater feelings of control over their illness, increased

satisfaction with their physicians, greater symptom alleviation, and an improvement in their medical conditions (Brody et al., 1989). These findings are well supported in the literature. For example, Greene and Hibbard (2012) highlight the untapped potential of patient engagement (or activation) in improving health outcomes and call for interventions to support this engagement. Accordingly, more patient and family involvement in healthcare decisions – which is to say, greater validation of the life-world within the system – improves patient outcomes.

To conclude, the commodification of human relationships (such as the doctor-patient relationship) by way of the system's colonization of the life-world, holds important, contemporary implications for practitioners implementing deprescribing programs. The re-characterization of the doctor-patient relationship as a service provider-client relationship obstructs the establishment of authentic human connection. If the commodification of healthcare is to continue, and thus the commodification of the healthy body, we will witness further threats to communicative action. For deprescribing programs to optimize medication use and improve older adults' overall quality of life, communicative action in the medical system needs to be established and maintained.

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ARTICLE 2: "AT 80 I KNOW MYSELF": EMBODIED LEARNING AND OLDER ADULTS' EXPERIENCES OF POLYPHARMACY AND PERCEPTIONS OF DEPRESCRIBING

ABSTRACT:

In response to the risks of polypharmacy for older adults, there is an increasing call for the development and implementation of deprescribing programs. This article examines the forms of expertise that inform older adults' decisions about how to use medications given concerns over polypharmacy and a clinical focus on deprescribing. In-depth interviews with older adults found that diverse sources of knowledge underpin decisions regarding polypharmacy and deprescribing. Findings indicate that this knowledge is formed through a life time of embodied learning – the production of relevant knowledge through lived experiences of the body. By way of this embodied learning, older adults possess individualized knowledge bases that inform health and health care decisions, especially regarding the use of medications. If deprescribing programs are to be embedded into standard preventive medical care of older adults, then it is valuable for health care providers to be aware of and take seriously the contribution of embodied knowledge.

Key words:
Polypharmacy, deprescribing, older adults, embodied learning, embodied knowledge.

"You have the feelings of your body. I'm a firm believer that your body tells you a lot of things. So you just have to be aware"

Introduction and Background

A growing body of literature centralizes polypharmacy and deprescribing as key determinants of well-being in later life (Barnett, Oboh, & Smith, 2016; Canadian Deprescribing Network, 2017; Garfinkel, Ilhan, & Bahat, 2015; Reeve, Shakib, Hendrix, Roberts, & Wiese, 2014; Scott, Anderson, Freeman, & Stowasser, 2014). In response to the risks of polypharmacy for older adults, there is an increasing call for the development and implementation of deprescribing programs. Drawing on data from in-depth interviews, this article examines the forms of expertise that inform older adults' decisions about how to use medications given concerns over polypharmacy and a clinical focus on deprescribing.

Despite variations in the definition of polypharmacy (Alpert, & Gatlin, 2015; Fried & Mecca, 2019, George & Verghese, 2017,Hajjar, Cafiero, & Hanlon, 2007; Hanlon, Weinberger, Samsa, Schmader, Uttech, Lewis, & Feussner, 1996; Maher, Hanlon, & Hajjar, 2014; Maggiore, Gross, & Hurria, 2010, Morin, Johnell, Laroche, Fastbom, and Wastesson, 2018), the key component common among them is the concurrent and ongoing use of usually five or more medications. Using this broad definition, polypharmacy is a very common phenomenon among Canadian seniors (Reason, Terner, McKeag, & Webster, 2012). According to Statistics Canada (2015), pharmacists dispensed 14 prescriptions to the average Canadian in 2005. This number rose to 35 prescriptions for adults ages 60-79, and to 74 prescriptions for adults over the age of 80 (Statistics Canada, 2015). In 2014, the Canadian Institute for Health Information (CIHI) reported that of seniors over age 65, 25% take at least 10 medications. This increases to 40% for

Canadians over age 85 (CIHI, 2014). Both Statistics Canada and CIHI have identified an important trend: concurrent use of multiple medications (or polypharmacy) intensifies with age.

This intensification may be burdensome to the well-being of many older adults given the numerous risks found to be associated with polypharmacy. Medications are intended to treat, manage, or cure disease. In the case of polypharmacy, however, the "'cure' may have become the 'disease'" (Page, Clifford, Potter, Schwartz, & Etherton-Beer, 2016, p. 584). Morin, Johnell, Laroche, Fastbom, and Wastesson (2018) indicate that negative outcomes associated with polypharmacy are the result of drug-disease interactions and adverse drug effects. According to Molokhia and Majeed (2017), the severity of these adverse drug reactions can lead to hospital admissions and potentially death. In fact, Ammerman, Simpkins, Warman, and Downs (2019) note that these adverse drug reactions account for one of the five greatest threats to older adults' health. Polypharmacy has also been found to interfere with adherence to necessary and appropriate medications, which Kaufman (2016) explains leads to missed opportunities for improvements to health and wasted medications. These risks may be particularly troublesome for older adults with multiple chronic conditions as this population is often excluded from or underrepresented in drug trials (Ouellet, Ouellet, and Tinetti, 2018).

In addition to such significant adverse effects to the quality of life of older adults in Canada, polypharmacy has also been found to hold notable economic implications (Morgan, Hunt, Rioux, Proulx, Weymann, and Tannenbaum, 2016). The use of inappropriate medications has been estimated to cost Canada $419 million annually; this number grows to $1.4 billion annually when costs for treating the adverse effects of polypharmacy are included (Morgan et al., 2016). Therefore, from both gerontological and economic perspectives, solutions to the apparent

problem of polypharmacy are needed. Accordingly, deprescribing programs are being tested and widely applied as a possible solution to the iatrogenic effects of polypharmacy.

With the intent to improve health outcomes and overall quality of life, deprescribing is a process of identifying medications that are no longer beneficial or that are perhaps causing harm, and the subsequent reduction or withdrawal of those medications, under the supervision of a healthcare professional (Page et al., 2016). Krishnaswami, Steinman, Goyal, Zullo, Anderson, Birtcher, Goodlin, Maurer, Alexander, Rich, Tjia (2019) argue that good prescribing practice includes deprescribing as a fundamental element. The benefits of deprescribing directly reflect the burden of over-prescription and include alleviated financial burden (Reeve & Weise, 2014), reduced risk of falls, fewer hospital admissions, improved mortality rates (Scott, Anderson, Freeman, & Stowasser, 2014), reduced risk of adverse drug reactions (Reeve & Wiese, 2014), improved adherence to appropriate medications, and enhanced patient knowledge and engagement (Reeve & Wiese, 2014).

Given this shift toward deprescribing in clinical practice as a part of routine medical care of older adults, the Department of Family Medicine at McMaster University has designed and adopted the TAPER Project (Team Approach to Polypharmacy Evaluation and Reduction) which is a standardized pathway designed to reduce medication burden. In pursuit of this goal, the TAPER project must identify barriers to effective and appropriate deprescribing and determine gaps in knowledge. One of the key gaps in knowledge is the establishment of diverse patient perspectives on polypharmacy and deprescribing, particularly the knowledge and expertise that they bring to their medication practice. Using an embodied learning conceptual framework, this article explores this embodied expertise of older adults through an analysis of in-depth qualitative interviews with older adults age 70+ experiencing polypharmacy.

Embodied Learning: Physical Experience and Cognition

Embodiment and experiences of the body are central to the dynamic and multifaceted way humans learn. Embodied learning refers to the construction of valid and relevant knowledge accumulated by living in and through our bodies (Gustafson, 1998). In this process, the body operates as both possession and identity: "we both have bodies and… are bodies" (Blaxter, 2010, p. 48, citing Turner, 1994). As the body moves through the world, this embodied knowledge base expands, meaning that this knowledge is accumulated by doing over time (Griffin, 2017).

Citing Crossley (1995, 2004), Griffin (2017) states that one, key objective of an embodied learning perspective is to explain how knowledge is acquired in contexts wherein the body is both the subject that is being acted upon and the agent that is doing the acting. One such context is the polypharmaceuticalised body, which includes but is not limited to the subcategory of the deprescribing polypharmaceuticalised body. In this instance, the body is the subject being acted upon by both medications and health care professionals, while the body is also potentially the agent that is actively adhering to or tapering off of medications. Across one's lifetime, this co-existence of agency and subjectivity mutually reinforce each other in the development of habits and practices (Griffin, 2017).

Another advantage of an embodied learning perspective is a consideration of cognition. Shilling (2016) uses the early pragmatist writings of Dewey to argue that the role of thought is inadequately taken up in embodiment theory. Building on this point, embodied learning is conceptualized as happening from physical experiences in combination with reflexivity and cognitive awareness. Shilling (2016) emphasizes that knowledge flows through the body's pre-reflective sensory routes and that learning is facilitated by cognitive deliberation. This cognitive

deliberation is fundamental to the collection and diffusion of institutionalized cultural practices (Shilling, 2016), including the ways in which we use medications.

The scope of human cognition and thought allows "people to experiment reflexively with alternatives without exploring them physically, it helps individuals scrutinize their own desires and habits" (Schilling, 2016, p. 1209). Medication practices are in an ongoing process of such exploration and scrutiny, particularly when the individual is encouraged/instructed by their health care team to modify their medication practices via deprescribing. In deciding if they are willing and/or able to deprescribe, the individual employs systematic and symbolic thought to assess the feasibility and desirability of such a task. Such an observation aligns with Archer (2012), arguing that this capacity for reflection permits the individual to strike a balance between bodily impulses and competing demands. Although symbolic thought serves a critical purpose, its lack of connection with the material world increases the risk for error and "consequent disappointments and practical failures" (Shilling, 2016, p. 1209). For this reason, knowledge acquisition demands both physical experience and cognition. As such, embodied learning relies upon the body's experiences as it moves through the world in combination with that same body's capacity for critical thought.

Griffin (2017) observes this embodied learning in the context of engagement in health behaviours, particularly physical activity and sport. Griffin (2017) emphasizes that health behaviours operate within specific social contexts and as such are social practices themselves. Accordingly, the decision to participate in a certain health behaviour is a deeply complex process situated in social life, characterized by "people's everyday lives and their routines and habits, alongside insecurities, pressures, concerns and fixations" (Griffin, 2017, p. 556). The same can be said for the way older adults make decisions relating to how they use their medications. These

decisions are not characterized by the simplistic and binary choice 'to take or not to take' but are rather permeated by the complexities of social life.

To adequately address how older adults make decisions about their medications, it is not enough to only consider embodied learning in the development of knowledge that informs these decisions. It is equally necessary to adopt a lifecourse perspective as the physical experiences and cognitive reflection informing embodied knowledge and ultimately decisions regarding medications has been gathered across the lifecourse. This is of particular importance for the sample used in the present study (age 70+). It is in combination of many forms of expertise and knowledge through which older adults make medication decisions. A lifetime of embodied learning equips older adults with an individualized knowledge base that should be recognized as a source of valuable information used to inform decisions around medication practice. If tapering programs are to be embedded into standard preventative medical care of older adults, then understanding, recognition, and validation of the embodied knowledge that underpins older adults' decisions regarding their medications are critical.

Methods

This study constitutes the qualitative element of a larger mixed-methods project, TAPER (Team Approach to Polypharmacy Evaluation and Reduction). Conducted in the Department of Family Medicine at McMaster University, the ultimate the goal of the TAPER Project is to reduce medication burden for older adults. In pursuit of this goal, this larger interdisciplinary team of researchers aims to implement deprescribing programs into standard medical care of older adults. In its entirety, this mixed-methods study includes four design elements: cross-sectional cohort data from the Canadian Longitudinal Study of Aging, a systematic review, a

randomized control trial for deprescribing, and a qualitative study for patient perspectives (which is the present study).

Before this qualitative element of the project could begin, three key steps of the TAPER Project had to first be completed. Firstly, baseline data was collected for demographic information, illness assessment, functional goals, symptoms goals, treatment preferences, and perceived medical problems. Next, the pharmacist performed a medication reconciliation, which involves the creation and maintenance of an accurate medication list, including information related to medication name, dose, frequency, and route of administration (Al-Hashar, Al-Zakwani, Eriksson & Al Za'abi, 2017). The list produced from this medication reconciliation was then used to inform a consultation between the participant and their family physician to identify possible and appropriate medications to deprescribe. If medications were identified for possible discontinuation, participants in the treatment group were invited to deprescribe. A total of 4o participants were enrolled; 20 in the treatment group and 20 in the control group. Regardless of group assignment, all participants were asked if they could be contacted for an interview.

Following RCT assignments, the qualitative methods that constitute the present study began. Of the 40 participants enrolled in the study, 21 consented to being contacted for an interview. All 21 of these participants were contacted by phone, of which 16 consented to and completed the interview. Eight participants from each group were interviewed. The overarching goals of the interviews were to identify patient perspectives on medication use and/or deprescribing and to investigate the lifetime construction of knowledge which inform these perspectives.

The average interview length was approximately one hour. Each interview was audio-recorded and transcribed verbatim. Participants were asked where they would like the interview to take place, and all respondents asked to be interviewed in their homes. Interviews were conducted between December 2016 and October 2017. A semi-structured interview guide was used to help steer, rather than control, the conversations. The interviews expanded beyond the guide in diverse ways, depending on how participants shaped the conversation. Kallio, Pietilä, Johnson, and Kangasniemi (2016) note that it is this versatility and flexibility of the semi-structured interview that makes it one of the most popular methods of data collection for qualitative research in the context of health care. This method allows participants the space for unique verbal expressions guided by questions based on previous knowledge and research into the topic area of interest (Kallio et al., 2016). Therefore, the semi-structured interview guide evolved from interview to interview, allowing for impromptu follow-up questions dependent upon the participants' responses. These follow-up questions were focused upon specific experiences related to medication use, and probes were used to unpack participants' values and beliefs about their medications.

To be eligible for this study, participants had to be over the age of 70 and experiencing polypharmacy (defined for these purposes as the concurrent use of five or more prescription medications). Patients who did not speak English, had cognitive challenges, and/or had anticipated morbidity within six months were not eligible for this study. Interviews were conducted with 16 older adults ranging in age from 73-90 (mean age: 81 years). All participants resided in southern Ontario, Canada. Eleven respondents identified as female and five respondents identified as male. All participants were recruited from a primary care setting. This research was approved by the Hamilton Integrated Research Ethics Board (HiREB), Project

#0665. The participants' initials used in the upcoming presentation of results were randomly generated to protect participant anonymity. All participants provided written consent.

Thematic analysis of interview transcripts was informed by Braun and Clarke's (2006) six phase method. Thematic analysis is a flexible method of qualitative data analysis and allows the analyst to move beyond basic data organization and description toward critical interpretation and analysis (Maguire and Delahunt, 2017). There were two coders and the analysis used qualitative software to assist with the process. Qualitative data was analyzed for apparent themes and patterns (Maguire and Delahunt, 2017). The first step of this method involved the coders familiarizing themselves with the data. This was accomplished by recording hand-written notes immediately after the interview, interview transcription, and reading through the transcripts several time to record initial observations. In step two, codes were developed and excerpts from the interview transcripts were recorded under these codes (Braun and Clarke, 2006). In the next step, the codes identified in step two were organized and reorganized into possible themes. Next, Braun and Clarke (2006) advise analysts to look for themes that should be removed (not enough support from data) or collapsed together (two themes overlapping). During this process, themes that could be broken into two separate themes were also identified. Next, the fundamental spirit of each theme was identified, allowing for the stories of each to fit together to construct the 'big picture story' of the larger research project. The final stage of Braun and Clarke's (2006) six phase method involves the presentation of this 'big picture story' in the form of a written report.

Braun and Clarke's (2006) method for thematic analysis allowed for the identification of relevant themes that were then linked back to the literature using the conceptual framework of embodied learning: agency and subjectivity, reflexivity and cognitive deliberation, capacity for symbolic thought, and lifecourse expertise. These smaller stories fit together to explain how

older adults develop authority over their own bodies and health. This authority is helpful in understanding older adults' perspectives on polypharmacy and deprescribing.

Findings

Forms of Embodied Knowledge

To act independently, autonomously, and of free will is to have agency. Many of the older adults interviewed for this study demonstrated such self-determination in the establishment and maintenance of their medication routines. Respondents commonly reported that they blend expert medical advice with other sources of knowledge to make independent judgements about the best course of action for themselves as individuals. Such acts of agency were demonstrated by participants' *active engagement* in the management of their health care. By actively engaging in this complicated work, older adults accumulate active embodied knowledge on which to base their decisions about how to use medicines.

Active embodied knowledge: Participants expressed numerous and diverse processes through which they actively engage in the management of their medications. In addition to many external agents (most notably health care professionals), the intellectual self, dwelling within the body, also acts on the body. For many respondents, this intellectual self maintains active engagement in their medication routines – accepting, modifying, or rejecting the prescribed direction of health care professionals. This critical cognitive participation takes on many forms. In some cases, participants reported an ongoing self-surveillance, as was the case for I.P, who articulated her reliance on the messages that she receives directly from her body: "I think probably I'll be watching how my body reacts". Information obtained via this surveillance is then used to justify the maintenance, termination, or modification of the medication use. Engagement of this nature was revealed in the words of L.C:

> Well that's what they told me to do, but I don't think there's any rule. I think I can break the rule, I never asked them, but that's the way I like to do it. And it seems to be working because my count seems to be lowering.

This is demonstrated active intellectual engagement with the body; the data collected by way of this engagement facilitates the development of embodied expertise, consequently informing how the individual will use their medications moving forward.

Active engagement with health and medications was not only found to be important in helping older adults to make decisions about their medications – it also proved to serve an important function in the preservation of self-esteem. Participants demonstrated a preferred autonomy derived from having the physical and cognitive capacities necessary to manage their own medication routines. In L.C.'s words, "I am in control and I know what I am doing". One way that older adults reported maintaining this level of engagement (and in turn, autonomy) was through the performance of their own independent research. In conjunction with formalized medical advice, this independent research is used to more fully complete the knowledge base that older adults' access to support their health-related decisions. As H.D. explained, "the first thing I would do if… somebody put me on a new drug is go on the computer and find out what I could about it".

Having accessed diverse knowledge sources, many participants of this study reported using this information to generate and articulate personal theories to explain health and illness. These theories are used to make predictions, as was the case for H.D: "my theory is that all the things you've had in the past recur when you're old, ten times worse sort of thing". These theories were also found to offer analysis of the health care industry, as articulated by P.S: "I'm quite sure every medication out there in the world has comparable manufacturers doing it, maybe giving it a different name". P.S. also offered theories which infused a hierarchical value into

medications: “my blood pressure medication [is the most important], I need that now”. Others, including I.P., offered hypotheses: “I am getting older, and I wondered if maybe because your body slows down and so on and so forth, that maybe I don’t need such a big dosage of them. So I wondered about checking the dosages”.

Lastly, some respondents constructed theories in order to offer diagnostic insight, including W.T., who stated: “I don’t think I’m depressed with a capital D, I think all of us could be depressed at times”. Here, older adults are establishing their personal agency by actively engaging in the management of their health care, as evidenced by the proposal of these broad and unique personal theories which predict, analyze, assess, hypothesize, and diagnose. These theories are illustrations of the embodied knowledge that older adults deem legitimate and relevant when making decisions about their medications.

Several of the older adults interviewed for this study were health care experts, not only as the result of their personal experiences, but of their professional specialities. Most commonly, nursing was the disciplinary background responsible for such professional expertise. K.G. holds a PhD in physiology (“Because I’m a physiologist, I know my body”). This form of expert embodied knowledge and hands-on experience required for such careers involves an active engagement by the participant into the field of medication practice. Such engagement positions the participant not as the body being acted upon, but rather as the body doing the acting, perhaps on other bodies, specifically in medication administration. Beyond the practical experience of administering medications, these occupations demand an expertise in the biochemistry of medications. These competencies are evidenced in many participants’ superior comprehension of how the medications are acting on their bodies (for instance, adverse side effects, symptom management, improved longevity) and how the medications are interacting with each other.

Participants with these professional backgrounds also demonstrated expertise in the operational aspects of the health care system, as evidenced by K.G., the physiologist, when she explained her familiarity with health care settings: "I also know the system! I've been and worked within the hospital system for a very long while". These expert participants also articulated a deep understanding of their medical histories, as was the case for X.T., an 85-year-old retired nurse. X.T. explained the influence of her nursing education on her understanding of her body when she said, "the first thing you learn as a nurse is to be objective and to be observant. And as I was saying, I've been observant about my own body and how it works since I was young". It is through these lifecourse careers which necessitated medication expertise that some older adults actively engaged in their medication practice. In such cases, this active engagement – or agency – is both physical and intellectual. For these participants, the knowledge that informs their decisions about medications in strengthened by specialized expertise accumulated throughout their professional lives.

Through active engagement (including independent research and the proposal of personal theories) and professional experiences, older adults act as agents of their own lives. This agency is key to the construction of embodied knowledge, which older adults rely upon in the establishment of habitual medication routines. If health care providers intend to guide patients through deprescribing programs, appreciation of this lifecourse of agency-informed expertise is critical.

Passive embodied knowledge: The older adults in this study consistently reported the nature of embodied learning by way of the effect medical interventions had on their bodies. H.D. described her understanding of her body by observing and articulating its reaction to Tylenol: "All drugs have a big effect on me. And if I take one Tylenol and I sit down… I just fall asleep

like that". This surveillance of one's own bodily responses to medical intervention enables older adults to advocate for themselves with medical professionals. This was the case for X.T.; her body was telling her that one of her medications was not working for her, and she had to work to have this knowledge validated: "I kept saying, this isn't working for me. So finally somebody heard me and put me on something else and I like that". By way of embodied knowledge, X.T. detected that a particular medication was inappropriate for her, and she had to work to have this knowledge legitimized.

In addition to this type of advocacy, participants reported using embodied knowledge to promote their own quality of life by balancing medical advice regarding their particular diagnoses with a personal desire for indulgence. An awareness and ultimately an expertise of one's diagnosis, coupled with an awareness of how one's body responds to specific lifestyle behaviours allows older adults to promote quality rather than only quantity of life. This process is expressed in a rather detailed but revealing passage from W.T:

> Because I think a diabetic knows their body, knows what they're eating. If I go to the Keg for dinner, if I'm going to have a nice big steak and a roast potato with, I don't like sour cream, but with butter. And I'm going to have salt, and I'm going have things and a couple of drinks, a glass of wine and a dessert and that, why not? You know, that happens twice a year. Then I know that I can maybe take two more units because I'm going, and I take my sugar the next day and of course it's up. And I treat myself with ice cream in the summer once a week. Ice cream seems to be the worst for diabetics, over chocolate bars or anything. Certainly for me. So when I have ice cream, it's usually a Sunday. When you're alone, it's challenging to make your own meals, to eat nutritiously and properly. Anyway, it's a nano, but I'm not that bad a diabetic. Then I don't adjust it or anything because that's me knowing I'm taking something that's on a list to be careful about. And for a day or two, my sugar and glucose will be elevated. It takes that long to get the ice cream out of the system. Interesting. So that, I will adjust and know what to do with it and everything falls back into place when I'm okay. That same would be if I go for a brunch, birthday brunch and I'll have waffles and maple sugar. Yeah, I mean, we're going to live or might as well be dead and that might be once or twice a year too.

Another participant, M.N., was similarly alert to the influence that occasional changes to dining habits have on her body:

> Sometimes it depends on what we eat too. You know, we had a dinner to go to, the rehearsal dinner to go to. Well the rehearsal was so late, we were in the restaurant at 9 o'clock getting dinner. So I ate things I shouldn't have eaten. So the next morning I took my blood and underneath it, I wrote 'was at rehearsal dinner' [to remember] why it went up that high.

X.T. provided a similar report, stating:

> I just had it this morning, I had a half an apple for breakfast and a bowl of bran flakes and that shot my blood sugar up. And I could always feel it because I get visual problems. So I took a cinnamon and I'm back down again"

In some cases, it is not only dietary considerations, but other environmental triggers that respondents have, over time, learned to associate with unique physiological outcomes. In recognizing these particular associations, older adults have accumulated the knowledge necessary to know what is 'normal' for their own bodies, and what is 'abnormal' and thus cause for concern. L.J. demonstrated this type of knowledge as she explained the relationship she has discovered between weather conditions, her activity levels, and her blood pressure:

> I'd even try checking [my blood pressure] on a hot day when I'd come home hauling groceries and I'm hot. Yeah, my heart rate will be a bit higher, my blood pressure would be higher. Sit down for 15 to 20 minutes and its back down.

Here, L.J.'s body is the subject being acted upon by external forces. As these external forces take action on the body, L.J. learns more about her body. I.P. summarizes this learning in promoting the importance of remaining attuned to the messages that her body sends, explaining that "you have the feelings of your body. I'm a firm believer that your body tells you a lot of things. So you just have to be aware".

In these respondents' experiences (representative of many other participant reports), a lifetime of embodied learning has equipped them with the knowledge necessary to make decisions regarding their bodies. For older adults, decades of observing their physical reactions to various medicines and other dietary behaviours locates them as experts of their own bodies. Health care teams must recognize this knowledge if deprescribing programs are to become standard medical care for older adults.

Although this evidence for embodied learning positions the body as subject being acted upon by medical intervention and lifestyle behaviours, embodiment theory has inadequately addressed the role of thought (Shilling, 2016). In these physical experiences alone, learning is not achieved. It is these physical experiences in combination with cognitive awareness through which learning is facilitated (Dewey, 2011, Schilling 2016).

Reflexivity and expertise

Evidence of reflexivity and cognitive deliberation is reflected in the above discussion of agency. Specifically, participants' professional expertise (as nurses and academics) and active engagement in their health care plans (via the performance of independent research and the development of personal theories) demonstrates the multifaceted ways in which older adults cognitively deliberate upon their medication use. According to Dewey (2011) and Shilling (2016), this is a necessary ingredient in embodied learning.

Many of the participants report that they are motivated to know all that they can about the medications that they are prescribed. X.M. expressed, "I'm happy to learn anything at all about medications and what I'm taking and if they're the right thing or not". Here, X.M. is inclined to acquire the necessary information, reflect on that information, and then draw her own conclusions regarding the appropriateness of the prescribed medication. In the same way, L.C.

would “just like to know the ins and outs”. Neither X.M. nor L.C are passive recipients of medicines. Rather, they are reflexive and engaged in cognitive deliberation to evaluate the suitability of their medicines. This evaluation demonstrates the influence of embodied expertise on the choices participants make concerning their medications.

By evaluating the suitability of one’s medications, some older adults are empowered to resist any actions taken upon their bodies that they deem unnecessary or harmful. For example, L.G. reported that following her own personal research, she had determined that a medication was unsafe. She was therefore qualified to express her resistance to that medication: “I knew what the drug was and the problems they’re having with it. I would have refused it”. For some, this work is informed by their professional expertise, as was the case for K.G., holding a PhD in physiology. K.G. is able to assess the suitability of a medication by engaging in intellectual deliberation underpinned by her academic qualifications: “Because I’m a physiologist, I know my body and I know what’s necessary”. K.G. even reported that she often refers back to her textbooks to evaluate her treatments. X.T., a retired nurse articulated this relationship when she explained: “I didn’t really feel the medication I was on was appropriate to me – I’m a nurse by training”. This ongoing reflexivity is evidence of the intellectual engagement necessary for the facilitation of embodied learning, the production of expertise, and the subsequent decisions made about how to use medications.

Reflexivity and cognitive deliberation are not exclusively used to evaluate whether or not one should take a prescribed medication. These intellectual practices are also engaged to determine how and when a prescribed medication should be taken. For example, O.F. demonstrated extensive critical thought regarding her insulin dosage:

> The insulin that I take, I’ve reduced the amount based on what the readings are. I do my blood every morning. I think the order was for 40 mg of Lantus at nighttime – insulin and

> I reduced it to 24 units because that keeps the blood in normal range. When I shared that with the family practice, that was ok because I was making a judgment call based on fact.

After deliberating over her situation, O.F. made a judgment call about her medication dosage. She did not passively accept the higher dosage, but rather considered other factors and came to an alternate conclusion. L.C. also made a judgement call regarding his medication dosage, despite his doctor's reassurance that the prescribed dosage was safe:

> I figured that they interact with each other so just like grapefruit juice interferes with Lipitor, you never know with all those other drugs. Doctors said it's ok, but they could be wrong, you never know. It might interfere with me and I might be allergic to it and things like that so I like to spread it out and it's been working ok with me.

Here, L.C. was concerned that taking certain medications too close together might result in adverse drug interactions. Despite his doctor's opinion, L.C. remained apprehensive and modified his medication routine based on his own evaluation of the situation.

As evidenced in each of these respondent's reports, knowledge accumulation is the result of physical experiences of the body coupled with critical reflection upon those experiences. The ways in which older adults engage with their medications are underpinned by this embodied expertise. Analysis will now unpack the additional role of symbolic thought in the ongoing accumulation of this knowledge.

Symbolic thought and decision-making

Older adults are now being encouraged to deprescribe, despite a history of socially ingrained age-related norms that equate the aged body with the polypharmaceuticalised body. As demonstrated by W.T., "you've probably heard from all the seniors, you've probably heard them talking about Lasix… most seniors who have any bone loss do that, it's called Prolia. And just about every senior takes Prolia every six months". From W.T.'s perspective, all older adults are

taking the same medications; to be medicated is very much the norm. This perspective holds implications for deprescribing, as older adults may be hesitant to reduce their medications if they hold the belief that polypharmacy is an age-related expectation.

As cultural attitudes toward medications evolve in alignment with a biomedical awareness of the risks of polypharmacy and the benefits of deprescribing, older adults must engage in symbolic thought in order to make decisions relating to their medication practice. This type of thought operates around the search for answers to the following questions: What are the benefits and risks? What information do I require to make this decision?

What are the benefits and risks?

For many of the respondents, it is necessary to weigh the potential future benefits and risks of taking a medication as prescribed. For example, L.C. described how he decided to spread out the dosage of a certain medication, for fear that it might cause adverse reactions: "It might interfere with me and I might be allergic to it and things like that so I like to spread it out and it's been working okay with me". Here, L.C. has contemplated possible future outcomes, drawn conclusions, and used this expertise to justify a modification to his present behaviour.

What information do I require to make this decision?

In order to make a decision about future behaviour, older adults were found to deeply consider the various forms of information required to take action. For M.K., pain level was a clear indicator for whether or not a medication is necessary: "if I was in pain two or three times a day, or constant, I'd just go back on it". Accordingly, participants were found to most heavily rely on the messages they receive from their body to determine whether or not they should take a certain medication. I.P. summarizes this phenomenon: "I just make my own decisions, sort of check, listen to both sides, and then sort of think about how [my] body reacts… I think that's my

decision, right? I think probably I'll be watching how my body reacts". Therefore, many older adults rely upon their bodies' signals to help them decide if/how to take a medication.

In addition to information received from the body, older adults accessed further information to complete their medication knowledge base. For some, the internet was an easily accessible source of information, as was the case for L.O:

> Say we were put onto a new medication or dosage increased or we're having some, like for instance the swelling or something like that, we'd go onto the internet and check and see if it's some of the medication that's a side effect for.

The pharmacist and family physician were also considered reliable sources of information. Notably, some respondents reported that they would 'shop around' for the response that they were most comfortable with. W.T. explained that she would assess the information provided by a professional, and if necessary seek out further and possibly alternative professional advice: "I might go ask the pharmacist first because it's close and if I don't like his answer or if he's iffy, I'll go to my doctor". For these respondents, in order to make decisions about how they will engage with medications in the future, they must consider and evaluate the various sources of information necessary to support that decision-making process.

As older adults are placed on deprescribing plans, engagement in these hypothetical exercises becomes increasingly necessary. Although strongly supported by the biomedical evidence, deprescribing programs compel older adults to reconceptualize their relationship to medications and to reassess their medication knowledge. It is largely this embodied knowledge that predicts their relationship to and use of medications, therefore it is the capacity for symbolic thought that creates space for this reconceptualization to occur.

Accumulating expertise across the lifecourse

As participants reflected upon their lives, various themes were identified that represent their long-term relationships with their bodies, health, and medicine. Participants' long-term experiences in and relationships with their bodies have resulted in unique personal medical histories of which they are the experts. In the words of O.F., "I've been a diabetic for 19 years, so I'm pretty used to it". For O.F., nearly two decades of living in a diabetic body has familiarized her with the ways in which her condition acts on her body and the many factors (for example, diet and insulin) that influence her condition. Supported by this longitudinally-informed knowledge, O.F. has become an expert of her own body and relies upon this expertise to make health-related decisions.

Conversely, X.T. relied upon her knowledge of her personal medical history to advocate for herself and identify a diagnostic error:

> I was diagnosed at that time as Type II Diabetic and I felt terrible. I never honestly believed that I had diabetes, and I know that that could be part of denial, but in my case I don't think it was because I've been hypoglycemic since I was a child.

Knowing that she had been hypoglycemic since childhood, X.T. could not accept a diagnosis that did not fit with her personal expertise. H.D. similarly had experiences with medical error, creating a general distrust of health care providers: "I've never ever thought that the doctor knew best… I've had some very unfortunate episodes in my life with the medical profession. Partly through, well ignorance, they just didn't know". For H.D., some medical errors were inevitable and perhaps justifiable simply because the research and technology that we rely upon today was not historically available. These experiences, however, have coloured her relationship with the health care system, have been influential in the production of her embodied knowledge base, and thus are predictive of how she engages with medicine.

Having observed these advancements in research and technology, older adults have witnessed the evolution of the health care system. H.D. laughed as she shared her perspectives on how the delivery of health care has transformed:

> But now the fashion is the sooner they get it fixed, the better, you know? Fashions over the years have changed enormously… I'll refer to something and these young [doctors] will say, 'what's that?!' Or somebody said, 'why didn't they give you an MRI or something?' And I'll say, 'well they didn't have any!'

Here, H.D. is positioned as expert, sharing with her health care providers why her medical care has unfolded in a certain way. For health care providers who have not personally witnessed these historical transformations in health care, the answers to what are seemingly simple questions to older patients may not be so obvious.

Having accumulated many decades of experiences, older adults have developed a rich understanding of their personal medical histories and a nuanced awareness of both the flaws and improvements of the medical system. It is these lifecourse experiences that position older adults as experts of their own bodies and that ultimately predict how they engage with medicines. As X.T. summarizes, "you pick things up as you go along".

Discussion

The findings of this study are largely consistent with the literature on embodiment and embodied learning. Data analysis revealed that in collaboration with traditional medical advice, older adults rely upon a diverse number of sources, accumulated across their lifetime, to help them make decisions about their medications. The body itself was found to be a fundamental source of this learning.

As detailed by Griffin (2017), the human body simultaneously engages in two social practices in the ongoing development of embodied knowledge and habits. The first of these social practices is *agency*, in which the body engages in a certain action. In this particular case, the action of relevance is medication practice. The second of these social practices in the expansion of embodied knowledge is *subjectivity*. When the human body is positioned as subject, it is being acted upon by external agents. As it relates to medication practice (and particularly deprescribing), these external agents might include family physicians, specialists, pharmacists, other allied health professionals, family, friends, and even the medications itself. The simple physical experience of living in a body that is being acted upon by external forces creates opportunity for knowledge acquisition regarding how the body, as the passive subject, reacts to such forces. Fundamentally, as medications and health care teams take action on the body, the inhabitant of that body learns. In turn, that learning is predictive of medication-related decisions.

Habits are developed as the result of this ongoing and synchronized nature of agency and subjectivity (Griffin, 2017). Accordingly, older adults' habitual medication routines and overall relationships with their medications are the result of a lifetime of experiences as both agent and subject, which is consistent with the findings of this study. These experiences are fundamental to the formation of embodied knowledge, which was found to be a predictive factor in how older adults make decisions about their medications.

As our bodies (as subjects) physically experience the role of medications, our minds (as agents) must critically reflect on that role in order for embodied learning to occur. Cognitive deliberation is essential to the understanding and transmission of cultural norms (Shilling, 2016), including norms related to health practices. According to Shilling (2016), information passes

through the pre-reflective sensory routes of the body, but learning is only achieved when one cognitively deliberates on that information. This learning was found to facilitate the construction of embodied knowledge which subsequently was found to influence medication-related decisions.

Symbolic thought involves the virtual maneuvering of symbols that represent the world around us (Dewey, 201; Shilling, 2016), allowing humans to consider challenges and propose feasible solutions. Doing so provides humans the opportunity to generate these solutions without tangible and instantaneous sensory knowledge. To be constrained to perceptions of only the present would be limiting to human thought – symbolic thought therefore provides humans the means needed to predict, consider, and solve future problems. This skill is especially important given the ever-changing social institutions in which our lives operate (Shilling, 2016). In order for humans to thrive in such evolving social contexts, we must engage in this cognitive practice. The health care system is an example of one such evolving institution. With changing cultural attitudes and emerging research, our relationships with medications are in a state of flux. Specifically, despite popularized images of the polypharmaceuticalized older adult, older adults are now being encouraged to deprescribe. The participants of this study demonstrated engagement in symbolic thought as a means of navigating this changing cultural landscape.

This discussion of participant engagement is consistent with not only embodiment literature, but also literature that specifically examines how people use medications in the context of aging. For example, Ballantyne, Mirza, Austin, Boon, and Fisher (2011) explain that older adults demonstrate a sense of personal responsibility over their own health. Attaining and maintaining health is the result of one's own initiatives and actions (Ballantyne et al., 2011), including physical/social activities, diet, and the critical evaluation of medical advice (Ballantyne

et al., 2011). In this way, rather than positioning older adults as passive recipients of conventional medical intervention, they should be more accurately understood as active players in the ongoing management of their health and well-being in later life.

This discussion of embodied learning would be exceptionally limited if it were not to explicitly adopt a lifecourse perspective. A cross-sectional snapshot of older adults' embodied knowledge would be an inadequate representation of the many years of lived experience that older adults rely upon when deciding how to engage with their medications. Given that medical practitioners aim to integrate deprescribing programs into standard medical care of older adults, the many years of lived experience of these patients must be considered. The findings of this study demonstrate that older adults possess a lifetime of experience related to their personal medical histories, experiences with medical errors, and observed evolution of the health care system. These themes represent older adults' long-term relationships with their bodies, health, and medicine.

Limitations

The cross-sectional nature of this study places limits on its implications. Given that participants were interviewed only once, the findings do not offer adequate insight into how embodied knowledge is developed over time. Future longitudinal approaches would be valuable in offering this perspective. Further to temporal considerations, this work does not address the gendered patterns of medication management. Although gendered differences are beyond the scope of the present research, it is noteworthy that the majority of participants identified as female. Future studies might consider gendered differences in the accumulation and application of embodied knowledge, although significant differences were not identified in the data of this study.

Importantly, the researchers conducting the qualitative component of the larger TAPER Project did not have access to other information that should be deemed relevant for future research. This information includes level of education, employment history, socioeconomic status, race and ethnicity, living arrangements (alone/shared), number of medications, and type of medications (prescribed, over-the-counter, herbal, etc.). Much of this information should be deemed meaningful as some (race/ethnicity, education, socioeconomic status) represent different forms of capital which inform biographical experience and thus different forms of expertise. Bourdieu (1985) identified four types of capital, including social, economic, cultural, and symbolic – which together determine one's social life trajectories. Based on this identification, Coleman (1988) emphasized how individuals use concrete resources that have been actualized from social capital. This access to concrete resources for use by individuals – which ultimately informs biography and narrative – is relevant to the findings presented in this article as participants' educational and professional backgrounds are reasonable predictors of their capacity to engage in reflexivity and cognitive deliberation. Simply, some older adults are better positioned to engage intellectually to facilitate embodied learning, produce expertise, and subsequently make decisions about how to use their medications. Accordingly, future research should investigate how various marginalized communities construct the knowledge necessary to inform decisions around medication management.

Conclusion

Embodied learning, bolstered by the scope of human cognition, "helps individuals scrutinize their own desires and habits" (Schilling, 2016, p. 1209). Such personal analysis is evident in older adults' medication practices and intensifies when their health care providers

encourage a modification of this practice. Encouraging modification forces older adults to evaluate not only if the modification is feasible, but also if it is in alignment with their personal expertise. In doing so, a lifetime of embodied learning, including systematic and symbolic thought, allows the older adult to negotiate the relationship between their bodily impulses and other competing demands. In the context of deprescribing, this negotiation might include balancing one's instinct to medicate despite medical advice to the contrary.

Using in-depth semi-structure qualitative interviews, this randomized control trial set in routine primary care allowed for the examination of older adults' relationships with their health care routines, specifically medication practice. Through the lens of embodied learning, this examination demonstrated the ways in which older adults rely upon their personally curated expertise to inform their decisions regarding medication use when confronted with the task of deprescribing. Particularly, older adults are engaging in the processes of agency and subjectivity, reflexivity and cognitive deliberation, and symbolic thought. These are social processes that occur cross the lifecourse and are critical in the generation of knowledge and expertise, ultimately informing how older adults make decisions about their medications.

The problematizing of polypharmacy in the biomedical literature (Garfinkel, Ilhan, & Bahat, 2015; Reason et al., 2012; Scott et al., 2014) has motivated health care providers to advocate for programs of deprescribing to be integrated into the standard care of older adults (Scott et al., 2014). The design of these deprescribing programs necessitates a profound understanding of and appreciation for the knowledge that older adults hold over their own bodies. As health care practitioners aim to promote quality of life in older adults by addressing the risks of polypharmacy, thoughtful and critical reflection on this expertise will increase the value of such programs whilst protecting patient dignity and autonomy.

As Griffin (2017) observes, health behaviours are social processes as they operate within specific social contexts. As such, human engagement with health behaviours is infused with the very complexities of social life, including our "personal insecurities, pressures, concerns, and fixations" (Griffin, 2017, p. 556). Therefore, designers of deprescribing programs are tasked with understanding the social networks within which deprescribing exists. Future research should examine the role of medications as dynamic social agents acting in these complicated social networks. Social science perspectives such as these are essential in addressing the risks of polypharmacy and ultimately in optimizing the ways in which medications are used to promote quality of life for older adults.

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ARTICLE 3: CONFRONTING MEDICINE'S DICHOTOMIES: OLDER ADULTS' USE OF INTERPRETATIVE REPERTOIRES IN NEGOTIATING THE PARADOXES OF POLYPHARMACY AND DEPRESCRIBING

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ABSTRACT:

To address the risks associated with polypharmacy, healthcare providers are investigating the feasibility of deprescribing programs as part of routine medical care to reduce medication burden to older adults. As older adults are enrolled in these programs, they are confronted with two dominant and legitimate accounts of medications, labeled the medication paradox: *medications keep you healthy but they might be making you sick*. We investigated how the medication paradox operates in the lives of older adults. In-depth qualitative interviews were conducted and analyzed with older adults aged 70+ to identify the various paradoxes that seniors live through regarding their medications and the narratives that they engage to negotiate these contradictions. Older adults were found to have established interpretative repertoires to make sense of the incongruent narratives of the medication paradox. In this article, we demonstrate older adults' efforts to carve out their unique place in the dichotomized institution of medicine.

Key words: Polypharmacy, deprescribing, paradox, interpretative repertoire, older adults

"We need the pharmaceuticals… but we don't need all the pharmaceuticals"

Introduction

Considerable qualitative research has examined the complicated work of medication management (Hawkins, Nickman, & Morse, 2017; Malvini Redden, Tracy, Shafter, 2013; Minet, Lønvig, Henriksen, & Wagner, 2011; Nickman, 2017; Salt & Peden, 2011). Few studies, however, have centralized the voices and perspectives of older adults in their efforts to manage their medications given the many paradoxes that they encounter. This work is necessitated by the problematizing of polypharmacy and the promises of deprescribing in the biomedical literature (Barnett, Oboh, & Smith, 2016; Canadian Deprescribing Network, 2017; Garfinkel, Ilhan, & Bahat, 2015; Reeve, Shakib, Hendrix, Roberts, & Wiese, 2014; Scott, Anderson, Freeman, & Stowasser, 2014). This literature has identified that overprescribing older adults is as an issue, and consequently recommends a shift towards deprescribing. This article therefore presents older adults' experiences and identifies contradictions emerging at this unique moment in history when medications are paradoxically conceived as being both a prerequisite and detriment to good health.

The important work of Cohen, McCubbin, Collin, and Pérodeau (2001) marks a shift in how scholars think about medications. This shift is notable because it demonstrates the ways in which medications are socially entrenched actors. Cohen et al. (2001) call for systemic thinking regarding medications and note the challenging task of drawing connections between society's consumption/evaluation of medications and the motives of the numerous actors involved. Engagement in this systemic thought allows for us to "reach more profound understandings by situating [our] results within the broader social, cultural, economic, and technological transformations and contradictions at work" (Cohen et al., 2001, p. 459). The present study

answers this call by situating older adults' management of polypharmacy and deprescribing in the context of the concurrent and paradoxical narratives of diverse social actors.

We are at a point in history in which we, as consumers of health care, must confront the paradoxical nature of medications themselves. The medication paradox can be stated simply as *you need your medications to be healthy but your medications might be making you sick*. Therefore, when patients make decisions around if and how to use medications, they must do so in the context of these equally dominant and legitimate accounts of medications.

Older adults are particularly vulnerable to the complexities of this paradox given the likelihood of increasing engagement with the health care system as we age. In 2016 the Canadian Institute for Health Information (CIHI) found that 1.6 million Canadian seniors, which translates to 1 in 4 Canadians over age 65, have prescriptions for medications from 10 or more different drug classes (CIHI, 2018). The number of prescriptions was also found to increase with age (CIHI, 2018). Statistics Canada (2015) similarly found that use of medications among Canadian seniors is very common. In fact, a nation-wide population-based study found that all seniors living in long-term care facilities (LTCF) and over 75% of seniors living at home had used a medication in the preceding two days (Statistics Canada, 2015). This same study also found that 53% of seniors in LTCF and 13% of seniors in the community (which translates to over half a million Canadian seniors) reported the simultaneous use of 5+ medications (Statistics Canada, 2015). Given this overwhelming presence of medications in the lives of older adults, Canadian seniors are regularly confronted with the challenges of the medication paradox. This article investigates how the medication paradox operates in the lives of older adults in Canada. In-depth qualitative interviews were conducted and analyzed with older adults aged 70+ to identify the

various paradoxes that seniors live through regarding their medications and the narratives that they engage to negotiate these contradictions.

Polypharmacy and Deprescribing

This work holds great contemporary significance in light of the problematizing of polypharmacy and the promises of deprescribing. Polypharmacy has been defined in numerous ways. Although this is not an exhaustive list, some of these definitions include: the use/administration of more medications than are clinically indicated (Hajjar, Cafiero, and Hanlon, 2007), the use of five or more medications (Hanlon, Weinberger, Samsa, Schmader, Uttech, Lewis, Cowper, Landsman, Cohen, and Feussner, 1996; Reasons, Terner, McKeag, and Webster, 2012), using multiple drugs or more drugs than are considered medically necessary (Maher, Hanlon, and Hajjar, 2014), and using several different medications simultaneously (Alpert and Gatlin, 2015). Perhaps the most wide-ranging definition comes from Maggiore, Gross, and Hurria (2010), who define polypharmacy as "the use of a large number of medications, the use of potentially inappropriate medications, which can increase the risk for adverse drug events; medication underuse despite instructions to the contrary; and medication duplication" (p. 507). These definitions of polypharmacy all seem to converge on the point that polypharmacy is characterized by the concurrent use of multiple medications.

The risks of polypharmacy have been well-documented in the biomedical literature. These risks are diverse and include, but are not limited to, adverse drug events (Barnett, Oboh, and Smith, 2016, Reason et al., 2012), escalating health care costs (Barnett, Oboh, and Smith, 2016), declines in physical functioning (Scott, Anderson, Freeman, and Stowasser, 2014), and increased rates of hospitalization (Barnett, Oboh, and Smith, 2016, Garfinkel, Ilhan, and Bahat, 2015). To mitigate these many documented risks, health care providers are testing the feasibility

of deprescribing programs. Deprescribing has gained increasingly popularity as the solution to polypharmacy, even leading to the establishment of the Canadian Deprescribing Network (CaDeN). CaDeN defines deprescribing as a process of decreasing or discontinuing medications that are either ineffective or harmful (CaDeN, 2017). CaDeN has further documented the importance of deprescribing for seniors experiencing polypharmacy given the bodily changes that accompany the aging process. These age-related changes to the body include: muscle and fat loss causing the medications to stay in the body longer, increasing sensitivity of the brain to medications, decreasing efficiency of the liver and kidneys, and water loss in the body leading to increased concentrations of the medications (CaDeN, 2017). Other benefits to deprescribing include resolving adverse drug interactions, improved patient outcomes, improved adherence to necessary medications, and reduced financial costs (Reeve, Shakib, Hendrix, Roberts, and Wiese, 2014).

McMaster TAPER Project

As health care providers produce, consume, replicate, and disseminate this research regarding polypharmacy and deprescribing, they are reasonably encouraged to incorporate deprescribing programs into their clinical practice. It is this incorporation of deprescribing programs that sets the stage for the present study. The Department of Family Medicine at McMaster University has developed and implemented the "TAPER" Project ("Team Approach to Polypharmacy Evaluation and Reduction"). The vision of TAPER is to design a systematic pathway for reducing the burden of polypharmacy that is part of routine primary care prevention for older adults. To do so, TAPER is tasked with identifying both gaps in knowledge and barriers to design.

Arguably one of the most important gaps in knowledge is the patients' perspectives on their relationships with medications and their perceptions of deprescribing. Informed by in-depth qualitative interviews with patients of McMaster Family Practice, this article seeks to fill that gap. The design and analysis of these interviews were conducted with specific interest in the participants' perceptions of the various paradoxes that they are forced to negotiate when a medication is prescribed or deprescribed. Despite their differences, each of these health-related paradoxes are similar in that they offer conflicting yet seemingly true propositions – "my medications are good for me… my medications are bad for me", "my health care provider is trustworthy… I cannot trust my health care provider", "adhering to my medications makes me a good patient… needing medications make me a bad patient", "using multiple medications is normal at my age… using multiple medications is dangerous at my age", "my medications prevent me from getting sick… my medications help me because I am sick". The operation of these paradoxes in both public and private spaces requires older adults to resolve the various paradoxes and justify defense of these resolutions. The specific aim of this article is therefore to identify these paradoxes and describe the work that older adults do to bring them to resolution.

To proceed, this article will define and provide an overview of interpretative repertoires which older adults engage to negotiate the many medication paradoxes that they encounter. Having established the conceptual orientation for this project, I will then shift attention to the methods used for data collection. Drawing on medication paradoxes, analysis will investigate how older adults navigate a complex and often contradictory medical landscape. This article will conclude with a discussion of the need for health care providers to be attuned to these types of challenges faced by older adults as they are presented with simultaneously legitimate and contradictory narratives regarding their medication practice. It is in these conditions that older

adults experience polypharmacy and deprescribing. Therefore, an understanding of these conditions is a prerequisite to health care providers' and patients' collaborative efforts to reduce the burden of polypharmacy.

Interpretative Repertoires

Interpretative repertoires are "culturally variable ways of discussing and evaluating certain actions or events that constitute a cultural commonplace" (Charlebois, 2015, p. 1). Seymour-Smith (2017) explains interpretative repertoires as familiar routines of argument and description found in the ways we communicate. As an analytic concept, they are valuable in that they provide insight into the construction of our various versions of the world (Seymour-Smith, 2017). In the context of conversational interaction, interpretative repertoires can be adopted to persuade someone of your perspective regarding a particular cultural event. Lumme-Sandt, Hervonen, and Jylhä (2000) use interpretative repertoires to refer to a "relatively coherent system of meanings" (p. 1845) and note that they enable people to validate their specific versions of events thus justifying their behaviour in the face of criticism (Burr, 1995; Lumme-Sandt et al., 2000). Therefore, in the lives of older adults, interpretative repertoires are used to speak to medications in a way that upholds their chosen side of the medication paradox. For example, "I believe medications are good for me because…" or "I believe medications are bad for me because…"

We are at a unique moment in history in which two dominant and competing narratives around the use of prescription medications are deemed legitimate. The first account of prescription medications continues to assert their benefit. This extends further to the belief that it is necessary for older adults to be on (often multiple) prescription medications. This account is

present in social intuitions and is consequently reflected in the lives of older adults. The other story of prescription medications promotes an opposing message: the population is over-prescribed and medications are largely damaging. This emerging yet increasingly legitimized understanding of medications is similarly reflected in both social institutions and the lives of older adults. These stories are used as guides to help older adults make decisions for how to best manage their health.

It is these binary narrative that seek to classify a polypharmaceuticalized person into one of two opposing categories: healthy-sick, moral-immoral, healing-deteriorating. In alignment with Bowker and Star's (2000) position, bodies and diseases change over time and thus these contradictory classification systems lead to the experience of torque in which the individual lives through categories of meaning that are incongruent. Older adults are left to manage their health within this paradoxical context.

Data collection and analysis were conducted from this orientation. The research design and thematic analysis used in this study investigates the interpretative repertoires that older adults engage with as a means of normalizing their relationship with medications in the context of numerous paradoxes. It is only through this type of reasoning that older adults can make decisions about how to use their medications specifically and how to manage their health and wellbeing more generally. These paradoxes are the result of the institutional systems of classifications that categorize polypharmaceuticalized bodies into incongruent categories. As health care providers aim to reduce the burden of polypharmacy on these bodies, they should be mindful of these conditions that older adults encounter when advised to deprescribe.

Methods

The present study is one component of a larger interdisciplinary mixed-methods research project with the overall goal of reducing the burden of polypharmacy as part of routine medical care for older adults. To do so, qualitative methods were necessary to provide insight into patients' perspectives on polypharmacy and deprescribing. The present study is the qualitative element of the larger study.

It is important to begin this explanation of the methods used by first providing an overview of the larger interdisciplinary study, as it is this larger project that sets the stage for this qualitative study. This larger study was a randomized controlled trial (RCT) for deprescribing (blinding participants was neither feasible nor necessary). Participants were recruited from McMaster Family Practice – a routine primary care setting – and provided written consent. All participants had to be age 70+ and experiencing polypharmacy (defined as using 5+ medications concurrently). Participants were excluded for language and cognitive challenges, and/or if mortality was anticipated within 6 months.

Baseline data was collected, including demographic information, illness assessment, functional goals, symptom goals, treatment preferences, and perceived medical problems. At this time, all participants were asked if they may be contacted for an interview to discuss their perspectives on medication use and/or deprescribing. Next, the pharmacist performed a medication reconciliation. A medication reconciliation involves the creation and maintenance of an accurate medication list, including information related to medication name, dose, frequency, and route of administration (Al-Hashar, Al-Zakwani, Eriksson, and Al Za'abi, 2017). The list produced was then use to inform consultation between the participant and family physician. Participants in the intervention group were invited to deprescribe if medications were identified

as appropriate and feasible for deprescription. In total, 40 participants were enrolled in the study. Both the control and treatment groups consisted of 20 participants.

Following the establishment of these plans for deprescribing, qualitative methods began. Participants who had consented to being contacted for an interview (regardless of group assignment) were called. When called for an interview, participants were asked where they would like the interview to take place. All participants wished to be interviewed in their homes. In total, 16 participants agreed to participate in the interview; 8 participants from the deprescribing group and 8 participants from the control group. In-depth qualitative interviews were completed with these 16 adults ranging in age from 73-90. The mean age was 81 years. All participants were patients of McMaster Family Practice; 11 identified as female and 5 identified as male. Data were collected from December 2016 to October 2017. Interviews ranged in length from 30 minutes to 82 minutes.

The interviews were in-depth and semi-structured. The interview guide included 5 sections. Section 1 involved clarifying any questions that the participants had about the study and asking about their history of medication use. Section 2 facilitated a discussion around the approaches that participants use in managing their polypharmacy and potential deprescribing. Through story-telling, section 3 involved identifying specific experiences that participants had involving their polypharmacy and potential deprescribing. Section 4 aimed to elicit participants' values and beliefs about their medications. Lastly, section 5 provided space for participants to add any information that they felt was relevant and to ask any questions about the study. This interview structure was consistently used across all interviews to ensure trustworthiness and credibility of the data. All interviews were audio recorded and transcribed verbatim. Thematic analysis involved the use of inductive measures to identify emerging theoretical insights from the

data. Facilitated by Dedoose software, thematic analysis was conducted on interview transcripts by two coders. Materials were coded in three stage. First, coding involved a line by line analysis of the transcripts to identify and label phenomenon. Relationships were then drawn between these identified phenomena. The final stage of analysis involved the identification of central phenomena to which all other coded categories were related. Fundamentally, the focus of this analysis was to identify incongruent systems of classifications that torque the biographies of older adults, and to highlight the various ways in which older adults employ interpretative repertoires in order to resolve the many resulting medication paradoxes. This research was approved by the Hamilton Integrated Research Ethics Board (HiREB), Project #665.

Results

Data analysis revealed that older adults are confronted with numerous emerging contradictory narratives (paradoxes) that must be negotiated in order for health-related decisions to be made. Before presenting in-depth analysis of this finding, it is important first to acknowledge my position as researcher and the paradoxes that are inherent to the research process. Social science research itself is a paradoxical endeavor as it is a social process with the clear objective of deepening our understanding of social processes. In conducting each interview, it was necessary for me, as the interviewer, to be aware of the social nature of the qualitative interview itself. These interviews were social engagements about the complexities of participants' social engagements with the health care system. In fact, many participants initially believed that I was a health care provider visiting their home to help them with their medications. For example, I was frequently asked if I was a medical student, pharmacist, or nurse. As a result, the interviews often began with an explanation of my role as a social science student and

qualitative researcher interested in how they perceive their medications, rather than a health care provider seeking to influence their perceptions of their medications. As such, each interview began with a collaborative process between myself and the participant to negotiate the first identified paradox: "I work with members of your health care team who advise you to use your medications in a certain way, but I am not here to promote that advice". This collaborative negotiation typically occurred before audio recording began, as it was important to establish this level of trust and understanding before seeking informed consent to record the interviews.

Having established the irony of the paradoxical social endeavor of uncovering social paradoxes, analysis will now shift to the medication paradoxes confronted by older adults experiencing polypharmacy uncovered in these interviews and their efforts to bring them to resolution. Doing so addresses the specific aims of this research. Regardless of the nature of the identified paradox, older adults were found to have established interpretative repertoires to make sense of these incongruent narratives. Analysis will continue by presenting each interpretative repertoire that participants employed to resolve the medication paradoxes.

Interpretative Repertoire 1: A personalized medication routine is needed to promote well-being in later life.

The older adults interviewed in this study reported that they receive competing narratives regarding how medications affect their bodies, health, quality of life, and longevity. One of the stories that is often told is that "medications keep you healthy". This story suggests that it is through medications that aging is optimized. In framing medications this way, they are seen as a possible means of mitigating the common fears associated with aging, including a lack of independence, immobility, and deterioration in cognitive function.

In some cases, respondents explained that their medications – or perhaps one or two of their medications in particular – are serving a very important and identifiable function. This specified functioning proved important in older adults' understandings of how medications act on their bodies and the resulting implications for overall quality of life. For example, one respondent explained that by taking Prolia, a drug to treat osteoporosis, she may be preventing a future fracture:

> Taking [Prolia], I'm hopeful my bones will stay as strong as they can for quality of life. If I fall, break my hip, well that's how the ball bounces. But I try very hard and hope that won't happen and maybe having taken Prolia, which improves bone growth, you know, will make the fracture not as bad.

This respondent has identified a specific body system (the skeletal system) that a specific medication (Prolia) is improving. She has further identified the manner by which this specified targeting might lead to positive outcomes in her overall quality of life. In striking a balance between being optimistic and realistic, this person acknowledges that even if the medication cannot be guaranteed to prevent a future fracture, at the very least it may make the inevitable fracture less severe.

This type of explanation was very common from participants, many even noting the immediate positive effects of medications on their bodies. In describing his medication for hypertension, one participant reported that "if I don't take it, my blood pressure goes up". It is this identification of the immediate positive effects of taking a medication (my blood pressure stabilizes) or the immediate negative effects of not taking a medication (my blood pressure goes up), that contributes to the construction of the interpretative repertoire regarding the benefits of medications for older adults.

Beyond noting the influence of medications on specific body systems, many respondents spoke to the more general ways in which medications improve their lives, often asserting their

lifesaving benefits. In one participant's words, "God help if I was in the States. I would be dead because I couldn't afford them at all". In this example, access to medications is of such importance because it is the medications that are keeping her alive. This participant explained further that it is not simply enough to stay alive, but that her life must not be burdensome to others: "If I were to stop all [the medications], I'd be a vegetable or dead. I don't want to be a burden to my family, I want to live as long as I have quality of life". This sentiment was expressed by almost all participants, emphasizing the positive roles that medications play in their lives, not only in promoting life, but in promoting a life deemed worth living.

For others, the role of medications was not so gravely related to life and death, but the smaller benefits still warranted their use. For example, one respondent explained her realistic expectations regarding her medications, laughing as she noted that, "I know you're not going to get the fountain of youth, just less aches and pains". In this way, medications are not deemed powerful enough to reverse aging, but were justifiable if they alleviate the physical discomforts characteristic of the aging body.

Health care providers were found to be the key actors in the construction of this narrative of the benefits of medications for seniors' health. For example, one participant stated: "I asked [my doctor] why don't you take me off my cholesterol pill and they tell me your cholesterol is good because you're taking it". In such cases, the person questioned the benefit of their medication, and the benefit was reinforced by the physician and consequently internalized by the patient. For other participants, it is not necessary to question the health care provider, because the prescription itself represents reason enough to believe in the beneficial power of medications: "I just take them because they were prescribed, I want to stay well, and I just do it. I don't even

question it". This demonstrates the power of physician as prescriber in the construction of interpretative repertoires.

Opposing this narrative promoting the benefits of medications is an equally dominant yet contradictory story of medications as destructive. In this story, respondents express concerns that medications (or perhaps, too many medications) might be harming the body and mind, and ultimately impacting quality of life and longevity. When framed this way, medications arguably are associated with more risks than benefits. Participants consistently reported that these medication-related harms are of particular concern for older adults given the likelihood that they are on multiple medications. For example, in most interviews, participants described their medications as beneficial to their lives on a personal level, but would frequently point to the overmedication of older adults more generally and the negative consequences of this overmedication:

> You read and hear things and so on, and we have a pharmacist friend who, you know, often told us about all these old people in hospital that are overmedicated and they're sick and so on. And then once they get them off some of those meds, they go home and they're a lot better".

In this quotation, the participant suggested that overmedication can be harmful and deprescribing is a means of mitigating these harms. Accounts such as these demonstrate that respondents are aware of the risks of polypharmacy in a general sense, but these stories were consistently told secondhand and were rarely the direct personal experiences of the interviewees themselves. These secondhand stories were a common theme that was thread throughout the interviews and were sometimes informed by the participants' own sense of the available research. For example:

> I keep hearing about seniors and I know of a lot of seniors who take so many drugs and that they're finding in studies, some of them are on drugs they shouldn't be on anymore or drugs are counteracting other drugs".

Here, the participant indicated an awareness of the opposing narrative, but this awareness was not personalized. Rather, the risks of overmedication were positioned as the experience of other seniors who are inappropriately medicated. None of the interviewees reported that they believed they were currently exposed to the risks of overmedication. Rather they recognized the risks of overmedication, but their personal use of medications was classified as appropriate.

In many cases it was found that participants became aware of the risks associated with certain medications from their doctors. As one respondent recounted:

> One of the concerns that the medical people had was when you are on high blood pressure medication for a long time, you have to watch the kidney. So, [my doctor] was trying to get me off some of the medication. There's something she's watching in my kidney.

This story is representative of many other participants' experiences. The common occurrence was that they did not mind taking their medication, but when their doctor explained any risks associated with the medication and recommended deprescribing, they were "happy to do it".

An additional source of the "medications are destructive" narrative was found to be the older adults' social circles. It was commonly reported that many members of their peer groups frequently discuss the risks of medications and in some cases, take pride in taking few to no medications. As one participant shared: "This one friend mentioned, he's kind of proud that he doesn't take any… it seems to him to be important. I mean, some people are like that but if something can help, why not?" This participant has touched on a theme that was found to ring true for many of the older adults interviewed for this study: some people say that medications are bad, but they help me, therefore in the context of my life, medications are good.

The existence of side effects promotes this paradox, as what was meant to be helpful (medications) may result in harm (side effects). It is this iatrogenic nature of medications that frames this first paradox. Therefore, older adults were found to negotiate the medication paradox

that medications promote health and cause illness by employing the following interpretative repertoire: *A personalized medication routine is needed to promote well-being in later life.*

Interpretative Repertoire 2: The harms associated with medications are externalized to other older adults.

The cultural image of the overmedicated older adult is familiar. Underpinning this image is extensive biomedical research indicating the risks of polypharmacy to which the senior population is uniquely vulnerable (Alpert & Gatlin, 2015; Hajjar et al., 2007; Hanlon et al., 1996; Maggiore & Gross, 2010; Maher et al., 2014; Scott et al., 2014). In the context of this cultural commonplace emerges a medication paradox that confronts older adults with contradictory and competing accounts of polypharmacy: it is acceptable for older adults to be on many medications, but being on many medications is unacceptable because it threatens seniors' health. When an older adult is placed on a deprescribing program, they encounter both narratives and must make sense of their incongruent elements.

Evidence of the normalizing of the 'medicated older adult' emerged in many of the interviews. Much of this evidence has been presented above in accounts of participants' general awareness of the risks of overmedication to seniors' health (therefore it will not be repeated here). This awareness, however, was often followed up with the normalizing of the image of the medicated senior. For example, several respondents speculated about the likelihood that the other seniors in this study were also taking the same medications. In one respondent's words, "most seniors who have any bone loss do that, it's called Prolia. And just about every seniors takes Prolia every six months". This statement suggests she is aware of the common age-related changes to the body (i.e. bone loss) and is further familiar with the commonly prescribed

treatment regime (i.e. Prolia). Another participant shared a similar sentiment in stating, "at our age, arthritis is a part of your life", noting the seeming inevitability of certain health conditions associated with age. Another respondent further supported this point of view in her prediction that the other participants in the study are reporting the same experiences: "You've probably heard from all the seniors, you've probably heard them all talking about Lasix". As a result of this shared understanding of what happens at "our age", participants were found to point to their age as the reason they take medication, rather than the action that the medication takes on their body. As such, polypharmacy was found to be widely accepted as safe by the older adults interviewed in this study, not because of the effect medications have on the body, but more specifically the effect medications have on the aging body.

This comparison to other aging bodies was also employed as a means for older adults to practice gratitude. For example, when asked why she takes her medications, this participant responded:

> It's just, getting older is very challenging. You're just going to meet it the best you can at this stage, and I feel I'm very lucky. Some people have cancer and are in terrible predicaments or other diseases, and I feel so sorry for them. And I think, you know, [I should] shut up about [my] problems, because [I'm] so much better off and I know that I am.

Here, the participant uses medications as a way of meeting the challenges of aging. As was true for many of the participants interviewed, she does not give much worry to her use of medications, sharing the sentiment that "other seniors have it worse". By speculating that other people are worse off, older adults attempt to free themselves of concern regarding the risks of polypharmacy.

In resolving this paradox of polypharmacy as acceptable and unacceptable, older adults were found to employ the following interpretative repertoire*: The harms associated with*

medications are externalized to other older adults. Adopting this perspective allows for older adults to acknowledge age-related decline, use medications to manage that decline, and practice gratitude for their health in comparison to others. In the words of one respondent: "I am 87 years old, so it's only natural that certain things in my body are going to deteriorate and on the whole I've been enjoying good health".

Interpretative Repertoire 3: Age-related illnesses are common and therefore seniors need medications to promote health and maintain quality of life.

A third medication paradox characterizes the ambiguous role that medications were found to play in the lives of the older adults of this study: are medications used as preventative medicine or as a means of chronic disease management? As such, older adults may take medications to prevent disease, to slow the progression of disease, and/or to manage the symptoms of disease. In this way, medications can be both a sign of health and/or a sign of illness. In essence, older adults encounter the following conflict: I am healthy because I take medications, or, I am not healthy therefore I need medications.

In support of the belief that medications promote health, this participant explained why she takes her medications:

> Well, simply because I want to live a good life and I feel as though they are helping. And there are days where I don't have a lot of energy, but I know that I'd probably have less if I didn't have the medication, the heart medication that I take.

Here, the participant has asserted the role of medications in supporting quality of life, in a similar spirit to that of another respondent: "I'm hoping that with this puffer… it's a chance to get back on my feet and get down for choir after Christmas". Representative of many other respondents,

both of these accounts reveal that engaging with medications allows for fulfillment and joy, not simply the management of disease.

Others, however, noted the need for medications in controlling disease progression and symptom management. Framed in this way, an older adult has already been classified as "ill" or as having some physiological dysfunction. One participant explained that he uses medications for this reason, stating that, "hopefully it will make me better, or fix the problem, or control the problem". Here, there is no indication of the pursuit of well-being, but rather a desire to fix or control a problem.

What makes this paradoxical is that medications may be playing out both roles – health promoter and disease preventer – thus the individual might be classified by themselves or others as healthy, sick, or both. One participant summarized this embodied contradiction when he said:

> I don't think medicine – I don't think it controls my body. I think it just keeps me healthy and keeps my blood healthy I guess, by taking medicine to control my diabetes and so on. So as far as muscles and things like that, it doesn't affect me.

For this participant, medications keep him healthy by controlling his diabetes. Such an observation reveals that we can have both health and disease concurrently. For the polypharmaceuticalized older adult, this is a key paradox – needing medications means I am "old" and "sick", but it is medications that keep me well. As evidenced above, in negotiating this paradox, the following interpretative repertoire is adopted: *Age-related illnesses are common and therefore seniors need medications to promote health and maintain quality of life.*

Limitations

It is important to note that this work is limited by its cross-sectional nature. The participants of this study were interviewed at one point in time and asked to retroactively reflect

on their relationship with medications. Future longitudinal approaches would add substantial insight into how older adults negotiate medication paradoxes by providing participants the space to share how their attitudes towards medications evolve or remain stable over time.

Discussion and Conclusion

Despite logical reasoning and a seemingly true premise, a paradox is self-contradicting. Carl Jung believed that it is through our paradoxical nature that we may realize the richness of life, thus making the paradox one of our top valued spiritual possessions (Jung, 1951). These paradoxes operate in all realms of human life, contributing to the fullness of each realm, and the realm of medicine is no exception. Through uncovering these medication paradoxes, this qualitative research has demonstrated the problematic presence of dichotomies in medicine. As evidenced in the findings of this study, medications themselves are inappropriately dichotomized as causing health/illness, as being acceptable/unacceptable, or as symbols of health/illness. Structuring health and health care into opposing categories of this nature leads to the torqued biographies of older adults in which they bend their experiences to fit into standard systems of classification. As an analytic concept, interpretative repertoires have offered valuable insight into how diverse accounts of medications (as social actors and cultural symbols) have been produced. Accordingly, the interpretative repertoires found to be used by the older adults of this study allow for more complete understandings of how older adults negotiate the inadequate dichotomies of medicine. These three interpretative repertoires are summarized as:

1. *A personalized medication routine is needed to promote well-being in later life;*
2. *The harms associated with medications are externalized to other older adults;*

3. *Age-related illnesses are common and therefore seniors need medications to promote health and maintain quality of life.*

Each of these statements demonstrate the work done by older adults to carve out their unique place in the dichotomized institution of medicine.

Greene (2006) offers significant insight into this classification system in medicine and the resulting implications on the lives of consumers of health care. He notes that medical categories and definitions of disease are not stable and objective, but are more accurately the result of a complex interplay of clinical trials, marketing strategies, epidemiology, bureaucracy, and technology. Greene (2006) provides three case studies – hypertension, diabetes, and high cholesterol – as evidence for the malleability of disease categories in the interest of pharmaceutical intervention. Notably, a threshold for diagnosis can be adjusted to justify prescription, thus risk factors for disease become reframed as diseases of their own right. Simply, the pharmaceutical market expanded its reach to incorporate subjectively healthy people. The development of a new drug indicates the development of a new disease category; what was once a pre-pathological state becomes the pathological state (for example, the 'pre-diabetic').

Bowker and Star (2000) also cite incentives for assigning bodies to categories, including the need for health care providers to ascribe illness labels that will be deemed appropriate by insurance companies and the subsequent self-identification with this label by patients. Despite such pragmatic motivators, the ongoing flux of the human body and human history make these efforts futile. Assigning bodies to categories is ineffective, as neither bodies nor disease categories are fixed. It is in this ever-changing landscape that older adults construct and inevitably re-construct images of themselves as healthy, unhealthy, or in some other uniquely ambiguous space in between.

This qualitative work was particularly important in labeling these dichotomies and identifying how older adults operate outside of categories in a highly categorized system. Britten (1995) notes that clinical interviews seek to mold patient perspectives into diagnosable medical categories. Despite the value in being able to define and subsequently respond to a patient's health concern, the respondent's narrative is dismantled and restructured to fit into a narrow category so that appropriate treatment measures can be pursued accordingly. Therefore, qualitative research methods, such as those used in this research, are fundamental in providing a means for ascertaining the patient's "framework of meaning" (Britten, 1995, p. 252).

A promising conclusion of this research is the alignment between the participants' frameworks of meaning and the concept of medication optimization promoted by polypharmacy and deprescribing researchers. In reference to the National Institute for Health Care Excellence's definition, The King's Fund (2013) defines medication optimization as a person-centred and individualized approach to using medications that necessitates patient engagement, evidence-informed decision making, professional collaboration, and effective patient engagement (Duerden, Avery, & Payne, 2013). This conceptualization offers an opportunity to optimize the influence of medications for the individual user, rather than categorizing polypharmacy as inherently good/bad, helpful/harmful. By reframing polypharmacy in this way, health care providers and policy makers can more effectively advocate for the well-being of older adults in Canada. Accordingly, emerging policies that govern the lives of Canadian seniors should support optimal health care utilization, which may include appropriate and optimal use of five or more medications concurrently.

Important qualitative work has examined how people undertake the complex work of medication management (Hawkins et al., 2017; Malvini Redden et al., 2013; Minet et al., 2011;

Nickman, 2017; Salt & Peden, 2011). It is now important to examine and amplify the voices and perspectives of older adults as they try to manage polypharmacy and deprescribing. This article offers important contributions to this growing body of qualitative work as it specifically investigates the paradoxes that must be managed throughout the polypharmacy and deprescribing experiences. This work suggests that the institution of medicine is arguably a few steps behind its patients in recent shifts toward medication optimization: the interpretative repertoires identified in this research demonstrate that patients have long been doing the work of optimizing medications in their own lives. The institution is just starting to follow suit.

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CONCLUSION

This concluding chapter summarizes the key findings of this dissertation, identifies the implications of these findings, offers proposals for potential and relevant research endeavors, discusses limitations, reflects on my experiences as a social science researcher-in-training, highlights the interdisciplinary spirit that characterizes this work, and concludes with a summary of the primary contribution of this thesis in its entirety.

Key findings and their implications

As the Canadian population ages, pharmaceutical markets have expanded to increase prescribing of older adults (Ballantyne, Mirza, Austin, Boon, Fisher, 2011). As a result, older adults are now tasked with navigating the complexities of later life in the context of this pharmaceuticalization (Ballantyne et al., 2011). It is in this context that significant literature takes up the relationship between older adults and medication adherence (Conn, Hafdahl, Cooper, Ruppar, Mehr, and Russell, 2009, El-Saifi, Moyle, Jones, and Tuffaha, 2018, Patton, Hughes, Cadogan, and Ryan, 2017, Schüz, Marx, Wurm, Warner, Ziegelmann, Schwarzer, and Tesch- Römer, 2011, Soones, Lin, Wolf, O'Conor, Martynenko, Wisnivesky, and Federman, 2017, and Unni and Faris, 2011). In the context of polypharmacy and deprescribing, emphasis should shift to prioritize patient perspectives in this complicated work of medication management in later life. Therefore, the overall objective of this project is to identify and emphasize patient perspectives in the conceptualization, development and implementation of deprescribing programs. These deprescribing programs are a seeming inevitability, and thus work of this nature is needed to ensure that they are informed by those most influenced by their implementation. To begin, I will summarize the findings and key contributions to the literature of

each individual article of this sandwich thesis, followed by a reflection upon the thesis in its entirety.

The first article of this dissertation applied Habermas' work on the lifeworld and system to explain how older adults make decisions about their health and medications in the context of competing sources of trust. Doing so underscored the very social nature of medication work. This work aligned with Habermas' observation of the system's colonization of the lifeworld, finding that medical authority permeates personal relationships. Importantly, however, the findings of this article contribute an element labeled 'older adults' resistance'. Namely, older adults were found to challenge this colonization by constructing lifeworld-type relationships in the system's space. Doing so signals older adults' efforts to restore legitimacy in the system – a necessity for compassionate care.

Considering polypharmacy and deprescribing from Habermas' perspective offered important contributions to dialogues regarding well-being in later life. For example, health care providers are reminded of the power of lifeworld relationships and their influence on how older adults make decisions about how to use medications. Further, the need to restore communicative action in the medical establishment is emphasized, characterized by a collaborative pursuit of shared understanding. Lastly, it is important to consider this research in the context of scholarly literature which has observed a correlation between patient-perception of involvement in their health care and patient outcomes (Brody et al., 1989). If there is to be greater validation of lifeworld relationships within the system (meaning more patient/family involvement in health care decisions), it is reasonable to predict improved patient outcomes. Fundamentally, this work calls for a restoration of authentic human connection in the medical establishment by way of the formation and maintenance of what Habermas terms communicative action.

The second article of this dissertation sought to explain older adults' lifetime acquisition of knowledge related to health and the body that predicts their eagerness, reluctance, or refusal to modify their medication routine given current medical advice. Using embodiment theory as a conceptual framework, this article emphasized the role of human cognitive deliberation on physical interactions with the world as a means to facilitate learning about health and the body. Embodied learning was found to promote the construction of expertise which ultimately informs medication-related decisions. This embodied knowledge base is constructed across the lifecourse and engages systematic and symbolic thought, providing older adults the opportunity to consider medical advice that may be contrary to their personal instincts.

The clinical applications of this article are significant, specifically offering insight into the sources of knowledge that older adults rely upon when making health-related decisions. As such, as deprescribing programs are implemented into standard medical care of older adults, validation of the diverse forms of knowledge underpinning perceptions of medications is necessary for these programs to offer value and promote patient autonomy.

Lastly, the third article of this dissertation offers an analysis of the contemporary medication paradox in which consumers of health care are confronted with inconsistent narratives regarding the health promoting and health destructing nature of medications. These inconsistencies are especially relevant to the lives of older adults as the risk of polypharmacy increases with age. Three interpretative repertoires were identified that older adults use to confront the paradoxical nature of medications: (1) a personalized medication routine is needed to promote well-being in later life, (2) the harms associated with medications are externalized to other older adults, and (3) age-related illnesses are common and therefore seniors need medications to promote health and maintain quality of life.

The identification of these interpretative repertoires contributes to emerging understandings of how diverse accounts of medications have been produced. This work is valuable as it offers a more complete understanding of how older adults confront the inadequate dichotomies of medicine – dichotomies which are often paradoxical. Labelling these dichotomies allowed for an analysis of how older adults operate outside of categories in the highly categorized medical system. In this way, article three has identified the optimizing work that older adults have long applied to their own health and bodies – a project which medical institutions have only recently considered and termed 'medication optimization'.

Future research

An important theme emerged in many interviews but was not fully addressed in the articles of this dissertation. I would like to take the opportunity afforded by this conclusion to address this theme and offer suggestions for future research that unpacks its meaning. It was found that the majority of respondents did not see polypharmacy as a problem in need of a solution, but rather an inevitability of age to be accepted. A caveat to this finding is that participants acknowledged the risks of overprescribing for other older adults (taken up in article three), but their individual experience with polypharmacy was optimized in their own lives. W.T. summarizes this finding in a comparison of her age-related challenges to the presumably greater challenges of other older adults:

> …my glaucoma, and I'm diabetic, and I have high blood pressure, and obviously overweight… It's just getting older is very challenging. You're just going to meet it the best you can at this stage. And I feel I'm very lucky, some people have cancer and are in terrible predicaments or other diseases, and I feel so sorry for them. And I think, yes…, you know, [I should] shut up about [my] problems, because [I'm] so much better off and I know that I am.

According to W.T., she is meeting the challenges of age the best she can – and in the context of our conversation, one way she meets these challenges is by taking her medications. Further, for W.T., her medication routine should not be considered burdensome as she is grateful that she does not have the health challenges facing other older adults. W.T. later referred to these age-related difficulties in her explanation of her medication use, acknowledging my younger age, saying, "you're so young dear, and when you get old, there's just so many challenges". Once again, in the context of our conversation, a primary way to confront these challenges is by optimizing her use of medications.

L.O also offered a concise summary of this theme when he stated: "I am 87 years old so it's only natural that certain things in my body are going to deteriorate and on the whole, I've been enjoying good health". Here, L.O speaks to the spirit of the conversations I had with many participants of this study – an acceptance of age-related physical decline, an appreciation that it could be worse, and an acknowledgment of the role medications play in striking this balance.

This important finding could be interpreted as older adults' awareness of the distinction between appropriate and problematic polypharmacy. In a 2013 report from the King's Fund, Duerden, Avery, and Payne (2013) acknowledge that for some patients, polypharmacy might be beneficial. Poorly managed polypharmacy, however, can be damaging (Duerden et al., 2013). As such, 'appropriate polypharmacy' refers to an individual with complex and/or multiple conditions for which the prescription of medications has been conducted in accordance with best evidence in a way that optimizes their use. On the other hand, 'problematic polypharmacy' is defined as the inappropriate prescription of multiple medications or cases in which a medication does not realize its intended effect.

In the context of this dissertation, older adults seemingly categorized themselves as 'appropriately polypharmaceuticalized' while simultaneously recognizing the 'problematic polypharmacy' experienced by many of their peers. I found this particularly interesting because the inclusion criteria of this study dictated that all participants be "polypharmaceuticalized" as defined as the concurrent use of five or more medications. Criteria did not, however, specify whether this polypharmacy be appropriate or problematic. As a result, at least from the perspective of most participants, this was a study of *appropriately polypharmaceuticalized* older adults.

This leads to three important areas for future research:

How do health care providers and patients define appropriate/problematic polypharmacy, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?

Unpacking the similarities and differences between expert and lay conceptualizations of appropriate and problematic polypharmacy is a worthwhile activity, contributing much needed insight into why older adults may choose to engage in (fully or partially) or opt of a deprescribing program. Further, answers to this question offer more general insight into incongruent narratives that filter through the medical establishment and lay communities.

How do appropriately and problematically polypharmaceuticalized older adults view their medications, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?

This dissertation was not an analysis of older adults experiencing polypharmacy, but more accurately an analysis of older adults who understand their polypharmacy to be appropriate. Therefore, further studies are needed to understand the perspectives of older adults who

understand their polypharmacy to be problematic. It is reasonable to hypothesize that older adults concerned about their polypharmacy will offer different perspectives on medications and will be more willing to participate in deprescribing programs. This research would hold great clinical implications as health care providers would have a more nuanced understanding of why patients differ in their willingness to deprescribe.

> *If older adults view (appropriate) polypharmacy as an age-related norm, how do younger people experiencing polypharmacy view medications, and what are the implications of this for designing and implementing an effective deprescribing program for medical practice?*

Many of the conversations I had with participants of this study centralized around our difference in age. Very commonly, I was told that I would be less likely to have questions about medications when I am older and understand the associated "aches and pains" for which medications help manage. Accordingly, a compelling line of research would replicate the present study with participants of different ages who are polypharmaceuticalized (appropriately or problematically) for reasons unrelated to advanced age. This information would contribute generally to the field of aging studies by highlighting similarities and/or differences in how people relate to health and medications at different life stages. If age is not a justification for one's polypharmacy, how does one interpret their medications, and importantly, oneself in relationship to their medications?

This dissertation is unique in that it exclusively centralizes the perspectives of older adults experiencing polypharmacy. The value of additional research of the nature outlined above is that it more specifically unpacks patient perspectives when experiencing appropriate or problematic polypharmacy – a key distinction. No value statement can conclusively be made

about polypharmacy in and of itself. Rather, the phenomenon becomes pathologized or rationalized according to patients' and health care providers' evaluation of its appropriateness or inappropriateness. An important conclusion of the present study is that we are wrong if we problematize polypharmacy without consideration. Polypharmacy is certainly problematic if it is unquestioned. Polypharmacy itself, however, should remain a neutral concept to which value can only be applied following careful and collaborative evaluation of each patient's unique case.

Limitations

The findings of this thesis are hindered by a few important limitations. These limitations can be well addressed by future research that builds upon the work presented here. Specifically, the cross-sectional nature of this study does little to illuminate the lifetime of experiences necessary to construct networks, expertise, and repertoires that inform health decisions and medication management. Longitudinal approaches would be well suited to address this shortcoming and map patterns of both stability and change that operate across the lifecourse, influencing how older adults come to experience polypharmacy and/or deprescribing.

Furthermore, it is reasonable to question the wide applicability of these findings given the participant population. The collaborators of this study note that as McMaster Family Practice operates within an academic network, the patient population includes many retired academics and other educated professionals. As a result, the insights that participants offered in these interviews are arguably insights of those with the necessary capital to acquire and utilize certain social resources. Admittedly, I did not have access to the socioeconomic, educational, or employment history of the participants in my capacity as the qualitative research associate. This information emerged, however, during the interview process. As many participants discussed

their academic careers at McMaster University, it became evident that the population being studied was not diversified enough to offer the perspectives of older adults from other, specifically marginalized, backgrounds. Therefore, it would be worthwhile to replicate this study in other communities, in hopes of offering a more intersectional interpretation of older adults' experiences with polypharmacy and/or deprescribing.

A final limitation of this study is the overrepresentation of female participants. As eleven respondents identified as female, and only five as male, there are certainly gendered implications of this work. Although beyond the scope of the research questions addressed in this dissertation, it is necessary for future research to further underscore how the gendering of the lives and bodies of older adults determines their relationship with health and medicine – specifically examining how gender informs their experiences with polypharmacy and/or deprescribing.

Reflexivity

"A scientific practice that fails to question itself does not, properly speaking, know what it does"

(Bourdieu, 1992, p. 236).

To preserve its integrity, I will now proceed to question this scientific practice and reflect upon my role as a researcher-in-training in the construction, execution, and interpretation of this work. This act of reflexivity is particularly important to social science research given its paradoxical nature – it is a social process that pursues in-depth comprehension of social processes. It is therefore necessary to remain aware that the interpretative qualitative research process that facilitates these understandings of social processes is itself characterized by relationships of the same nature. In the words of Bourdieu (1992) "the sociology of the sociologist… is a necessit[y], not luxur[y]" (p. 253-254).

It is in this spirit that I reflect upon the very social nature of this dissertation. The participants of this study can be more accurately understood as collaborators, inviting me into their homes, offering me tea, sharing family photo albums, taking me on garden tours, sewing room tours, and tours of their art collections – all while offering their valuable insight into health and the body. As I participated in these social engagements, I remained acutely aware of Bourdieu's characterization of such relationships, particularly their asymmetry (Bourdieu, 1996). In my role as interviewer, I held a disproportionate amount of power in this social activity. In my power, I had crafted a research program and predetermined the nature of the conversation that was to be had. In the words of Bourdieu (1996), I had "start[ed] the game and set up its rules" (p. 19). Given the inevitability of this power imbalance between interviewer and interviewee, the interviewer must engage in reflexivity in order to mitigate the dangers associated with this misdistribution of power (Bourdieu, 1996). Doing so involves an acute and ongoing awareness of the social location of both researcher and participant. This awareness must be practiced through an intersectional lens, ensuring non-additive interpretations of mutually-constituting social identities (Bowleg, 2008; Christensen and Jensen, 2012).

To mitigate the inevitable power imbalance of these qualitative research interviews, I was tasked with cultivating an acute awareness of the control I had over the nature of the conversation in the context of a significant age disparity. Learning to mitigate the effects of this asymmetry of power was an ongoing process that involved much trial and error. For example, during the first few interviews, I tried very hard to keep on the topics of health, the body, and medications, trying to re-route the conversation if I thought necessary. As a result, those interviews were short and offered less depth. Following transcription and active reflection, I came to believe that by tightening my grip on the flow of the interview, I was interfering with the

participant's unique construction of meaning. As a corrective strategy, I began scheduling more time between interviews so that my time with the participants was not rushed. I was then able to be more fully present in my visits to the participants' homes, able and enthusiastically willing to participate in the social engagements that were kindly extended to me, including many cups of tea, home tours, and sharing of photographs. Full participation of this nature helped to diminish the risk of objectifying the participant – turning them into an object to be studied.

Bourdieu (1996) speaks to this risk of objectification, stating that "when the sociologist is perceived as socially superior, [this] often adds itself to the very general, if not universal, fear of being made into an object" (p. 22). The potential for such a problematic perception was ever-present throughout the data collection process given the significant difference in age between myself and the participants. I was in my late twenties at the time of data collection and all participants were age seventy and above. It was therefore imperative that I remained keenly attuned to the social and cultural privileges afforded me based on my youth and the age-based assumptions and subsequent marginalization faced by the participants of this study. For example, it was important that I avoided age-based stereotyping (assuming the participants has limited mobility, auditory impairment, etc.) while still remaining open and respectful toward possible age-related circumstances (accommodating for limited mobility, auditory impairment, etc) if necessary.

Upon reflection, the age difference between myself as interviewer and the participants as interviewees afforded a key advantage – the dynamic of the typical interview could be characterized as grandchild/grandparent. Participants seemed genuinely excited for my visit, warmly welcoming me into their homes, often taking opportunities to guide me by offering wisdom and advice. Our age difference set the stage for participants to respond to questions

about health and medications with, “well dear, when you’re older you will understand…” Accordingly, our age difference allowed for participants’ insights to be framed as the sharing of wisdom.

Many participants of this study were offering wisdom not just based on lived experience, but also based on professional expertise. A number of participants were retired nurses, one held a PhD in physiology, others were academics of various disciplinary backgrounds, and many were informal caregivers. Therefore, the assumption that I was the expert interviewer and they were the lay participants would have been misleading and destructive to the interview process. Bourdieu’s (1996) warning of participant objectification by way of the perceived social superiority of the sociologist is of key relevance here. These interviews necessitated a reframing of this problematic dynamic by raising the participants above the researcher and celebrating their expertise.

Further to assuming the lay status of the participant, a second assumption to be confronted and dismantled was that of polypharmacy as pathological. Admittedly anecdotal, it is interesting to note that when people hear that I am studying polypharmacy, the typical response is “yes, what a terrible problem”. This almost exclusive and automatic reaction coupled with biomedicine’s problematizing of polypharmacy led to my mistaken expectation that participants would feel the same way. At an early meeting with my supervisory committee, they observed that I was uncritically aligned with biomedicine’s assumption and had inadequately taken up the social science perspective. I accepted this feedback and reframed my research proposal through a more social lens. Looking back now, although I had adjusted my work on paper, I had not truly reframed the issue in my mind until I met with participants and heard their insights in their own words. After only a few interviews, I quickly learned that many older adults do not see their

polypharmacy as problematic – very few ever even used the word polypharmacy. Upon this realization, I was reminded of Bourdieu's (1992) observation of social problems, stating that:

> In all these cases [of social problems] we will discover that the problem that ordinary positivism (which is the first inclination of every researcher) takes for granted has been *socially produced,* in and by a *collective work of construction of social reality,* and it took meeting and committees, associations and leagues, caucuses and movements, demonstrations and petition drives, demands and deliberations, votes and stands, projects, programs, and resolutions to cause what was and could have remained a *private* particular, singular problem to turn into a *social problem,* a public issue that can be publicly addressed… or even an official problem that becomes the object of official decisions and policies, of laws and decrees (p. 239).

In this spirit, it is necessary to confront the social construction of the problem of polypharmacy. Collective social works have established polypharmacy as a social problem to be addressed by social policies that govern the lives and bodies of older adults. Had this "collective work of construction of social reality" (Bourdieu, 1992, p. 239) not been conducted, polypharmacy would have remained a private, singular problem. This is not to say that the collective social efforts to identify and mitigate the risks of polypharmacy are unfounded, but rather to say that an individual's polypharmaceuticalized status is not a problem unless is causes a problem for that person's functioning and quality of life. The collective effort would be well spent identifying and confronting the polypharmacy that "hurts" and facilitating unique brands of polypharmacy that help.

Researchers at Oxford University are addressing this issue of individualized experiences of polypharmacy. I had the privilege of meeting with these researchers during the fourth year of my PhD studies to hear about their work on the TAILOR Realist Review. This project asks "how, for whom, and in what contexts safe and effective individual tailoring of clinical decisions related to medication use work to produce desired outcomes". Accordingly, rather than deprescribing (reducing the number or dosage of medications), medications are *tailored* to that individual. This

tailoring *may* involve reduction in number and dosage, but may also involve increases, swapping one medication for another, or no change at all.

Reframing the biomedical problem of polypharmacy as a neutral phenomenon to which value can only be applied following analysis of each individual's unique case demands a profound cognitive shift. To do so, cross-disciplinary contributions are needed to offer a more fully dimensional view of diverse experiences with medications. I will therefore proceed by highlighting the interdisciplinary spirit necessary and characteristic of the TAPER project and this dissertation.

Interdisciplinary spirit

Scholars proclaim the necessity of interdisciplinary collaboration in the pursuit of solutions to the complex emerging challenges of the contemporary world (Bronstein, 2003; Brown, Deletic, Wong, 2015; de Bruin and Morgan, 2019; Iglič, Doreian, Kronegger, and Ferligoj, 2017; Mariano, 1989; Rhoten and Parker, 2004; Weinstein, 1999). Bronstein (2003) defines interdisciplinary collaboration as "an effective interpersonal process that facilitates the achievement of goals that cannot be reached when individual professionals act on their own" (p. 299). Given the social and scientific complexity of many issues under study, interdisciplinarity is not simply a philosophical belief but rather a scholarly necessity (Rhoten and Parker, 2004). As Rhoten and Parker (2004) explain, these lines of inquiry cannot easily be categorized into traditional disciplinary frameworks but rather demand effective interpersonal collaboration across frameworks. In 1989, Mariano observed the increasing complexity of modern health issues and interventions and the subsequent expansion of specialization and fragmentation in medicine. As a result, Mariano (1989) predicted an associated demand for researchers to collaborate. Thirty years later, polypharmacy has emerged as one of these modern health issues

requiring interdisciplinary collaboration. Therefore, I would like to take this opportunity to reflect upon the interdisciplinary spirit of the TAPER project.

TAPER – or Team Approach to Polypharmacy Evaluation and Reduction – envisions a medical system that integrates explicit interventions to reduce treatment burden into routine preventive care of older adults. The "team approach" is of primary importance, as this vision cannot be realized by a single person working within the framework of a single specialty or discipline. Rather, the TAPER team adopted polypharmacy as a lens through which researchers from multiple perspectives could view and investigate how this system would function, how it would address supposed risks of polypharmacy, and what effect it would have on the Canadian population. The multiple perspectives included those of physicians, pharmacists, health economists, sociologists, and other social scientists. As Weinstein (1999) explains, creative problem solving necessitates professional collaboration – a creative solution to treatment burden is not simply treatment reduction. By working together, the TAPER team constructs a more holistic picture of the issue and does not simply reduce medications. Rather, as its name suggests, TAPER takes a collaborative approach to evaluating one's polypharmacy and reducing burdens *if necessary.*

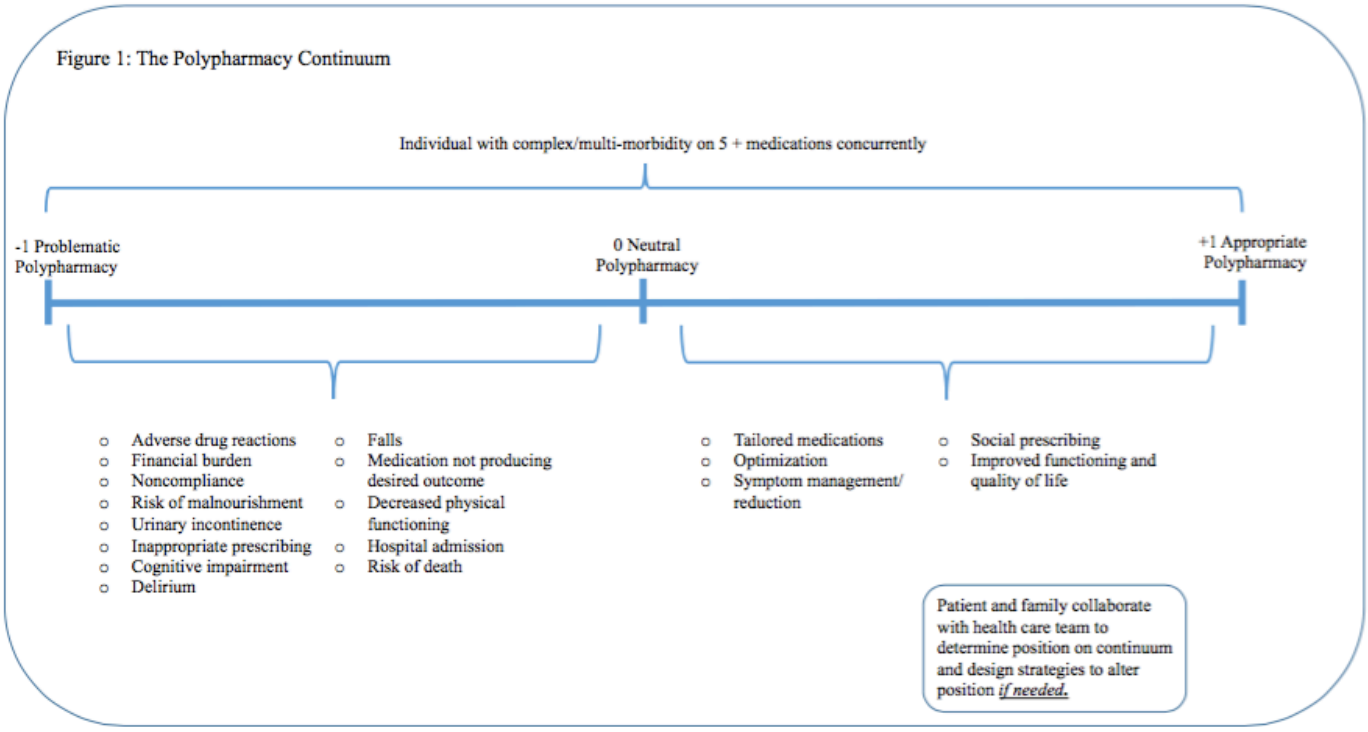
As I prepare this thesis for submission in partial fulfilment of the requirements for the Degree Doctor of Philosophy, I find myself appreciating how very fitting my role in TAPER was for a Doctorate in Health Studies. Critical health studies is an interdisciplinary endeavor contributing substantially to policies that target the health and bodies of various communities. In doing so, critical health studies scholars offer perspectives from many disciplinary frameworks, including sociology, political science, cultural studies, critical theory, environmental studies, economics, anthropology, gender studies, gerontology, history, geography and so on. Demand

for these insights is justified by the social nature of medical experiences – these experiences are not played out in biomedical vacuums but are rather saturated in social meaning. Critical health studies constructs a fully dimensional landscape from which to view these experiences and, as in the case of polypharmacy and deprescribing, centralizes the perspectives of those targeted by emerging policies. As a member of the TAPER team, I was offered the crucial interdisciplinary training fitting to fulfil the requirements for a Doctorate Degree in the interdisciplinary field of health studies.

The Polypharmacy Continuum

To conclude, I present a model to summarize the overarching implication of this dissertation: The Polypharmacy Continuum (see figure 1). This model suggests an alternative way to consider polypharmacy. Rather than assuming pathology, this model presents a value neutral alternative of the experience of being on five or more medications concurrently to manage complex and/or multiple conditions. In *ongoing* collaboration with one's health care team, patients, families, and clinicians track the fluidity of the polypharmaceuticalized experience. For simplicity, the left end of the continuum reflects problematic polypharmacy and is characterized by the presence of one or more of the harms associated with polypharmacy. A patient's position on the scale moves closer to -1 given the number and severity of these harms as assessed in collaboration with their health care team. The opposite end of the continuum reflects appropriate polypharmacy at +1, in which an individual's concurrent use of multiple medications contributes to improved functioning and quality of life. These improvements are achieved by way of tailoring medications to the individual's unique needs, optimizing their use to reduce/manage symptoms, and/or engaging in 'social prescribing'. Social prescribing is an

approach designed in response to substantial evidence documenting the influence of the social determinants of health (Alderwick, Gottlieb, Fichtenberg, and Adler, 2018). To better address



these determinants, social prescribing connects patients with non-medical services in their community to improve overall health and well-being. In this way, physicians can attend to the social needs of a patient in a clinical setting (Alderwick, et al., 2018). In the centre of the Polypharmacy Continuum is "0- Neutral Polypharmacy". In this position, neither advantages or disadvantages of the polypharmaceuticalized state can be identified. In this position, the patient, family, and health care team develop strategies to move closer to a +1 position. For some patients in the $\leq$0 position deprescribing may be necessary and appropriate. Of critical importance to this continuum is the patients' involvement in assessing their position on the scale and validation of their willingness, reluctance, or refusal to adopt strategies that might change their position.

Through the application of social theory to the apparent problem of polypharmacy and solution of deprescribing, this thesis informs the design of deprescribing programs by offering patient perspectives. By examining the social networks in which medications operate, the construction and application of embodied knowledge informing health-related decisions, and the paradoxes patients must navigate, this research endeavor fundamentally reshaped my understanding of the topic I set out to study at the beginning of my doctoral work. When I began this research training program, I was of the belief that I would come out the other side with a profoundly deep understanding of a health problem. Years later, I have negotiated a new meaning of the word "research" for myself. The etymology of the verb "research" specifies that it is derived from the Middle and Old French word *recercher,* meaning to seek out, search closely. This is what I understood research to be prior to this work. Now, I see research as an even more simplified act – re-search, to me, means, "look again". In the social world we are exposed to diverse phenomenon to which we have instinctive reactions heavily informed by politics, economics, media, and other powerful institutional forces. Social scientific *re-search* compels us to *look again* – to question and scrutinize the phenomenon we are accustomed to, to peer through different lenses, and ultimately challenge the habitual reactions to which we have been conditioned. In this way, I no longer see polypharmacy as the health problem I am studying, but rather an experience that, when we *look again*, holds different meaning for different people. This is the true value of my doctoral studies.

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