Examining stakeholder perspectives and public understanding of the ethical and social issues of cognitive enhancement using methylphenidate

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ABSTRACT

The use of biomedical technology to enhance the capacities of healthy individuals raises ethics questions that touch upon many areas of scholarship. In the field of neuroethics, these questions focus on the enhancement of cognitive function (e.g, attention, alertness, memory, mood), often by means of psychopharmacology ("cognitive enhancement"). Expectations for the widespread prevalence and social benefits of cognitive enhancement persist despite weak scientific support for the efficacy of medications in healthy individuals. The potential impact of cognitive enhancement for individuals, society and professionals is a contentious subject in the academic debate but is not well understood from an experiential point of view. The research and reflections presented in this thesis offer different perspectives on the ethics of cognitive enhancement. The non-medical use of prescription stimulants by healthy university students served as the basis for a qualitative focus group study examining the perspectives of key stakeholders (university students, parents of university students, healthcare providers). Analysis of stakeholder perspectives (1) demonstrated marked ambivalence in reactions toward cognitive enhancement; (2) exhibited tension between the value of personal choice and social pressures; and (3) allowed to clarify the values at the root of different levels of ethical contention. These findings also support the recommendation put forward in this thesis to prevent the diversion of healthcare resources toward enhancement despite professional policies and practices that permit the prescription of medications to healthy individuals. The insights gained through these data and reflections suggest a cautious and complex approach to using psychopharmacology to enhance cognitive performance that is at odds with some of the normative stances in the academic debate. Clearer moral boundaries that reflect the values of both stakeholders and ethicists, answer difficult questions about cognitive enhancement, and guide action might be reached by reinvigorating the deliberative role of bioethics.

RÉSUMÉ

L'utilisation des technologies biomédicales afin d'augmenter les capacités d'individus sains évoque des questions éthiques qui touchent plusieurs disciplines. Dans le contexte de la neuroéthique, ces questions gravitent autour de l'amélioration des fonctions cognitives (attention, vigilance, mémoire, humeur) souvent par le moyen de la psychopharmacologie (« cognitive enhancement »). Malgré le peu de données probantes démontrant l'efficacité des médicaments chez des individus sains, l'anticipation d'une prévalence étendue et des bienfaits sociaux découlant de l'amélioration des performances cognitives se fait sentir. L'impact potentiel de l'amélioration des performances auprès d'individus, la société et des professionnels est un sujet litigieux dans le débat académique mais demeure moins bien compris d'un point de vue expérientiel. Les données et les réflexions présentées dans cette thèse décrivent différentes perspectives sur l'éthique de l'amélioration des performances cognitives à l'aide de la psychopharmacologie. L'utilisation non médicale de stimulants sous ordonnance par des étudiants universitaires sains a servi de point de départ pour une étude qualitative basée sur des discussions de groupe en vue d'examiner les perspectives d'acteurs clés (étudiants universitaires, parents d'étudiants universitaires, professionnels de la santé). Les analyses de ces perspectives ont (1) révélé de l'ambivalence dans les réactions d'acteurs clés envers l'amélioration des performances avec la psychopharmacologie; (2) démontré une tension entre le principe du choix personnel et les pressions sociales; (3) permis de clarifier les valeurs sous-jacentes aux différents niveaux de litige éthique. Ces données appuient aussi la recommandation proposée dans cette thèse, à savoir qu'il faille prévenir la diversion de ressources médicales envers l'amélioration des performances malgré l'existence de pratiques et de politiques professionnels permissives. Ces résultats et ces réflexions donnent lieu à une approche prudente et complexe envers l'utilisation des médicaments pour améliorer les performances cognitives qui s'éloigne de

certaines positions normatives dans le débat académique. Des normes éthiques qui reflètent à la fois les valeurs des acteurs clés et celles des éthiciens pourraient être élucidées en ravivant le rôle délibératif de la bioéthique de façon à répondre à des questions difficiles posées par l'amélioration des performances d'individus sains avec la psychopharmacologie.

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CONTRIBUTION OF AUTHORS

The candidate produced all original material in this thesis (i.e., introduction, chapters 1, 2, 3, 8, connecting texts and conclusion) independently.

The manuscripts in Chapters 4, 5 and 6 were co-authored with Dr. Eric Racine. The data were collected by Cynthia Forlini (planning recruitment strategy, organisation of the focus groups, field notes) and supervised by Dr. Racine (who also moderated the discussions). Forlini led the data analysis (development of coding guide, coding, and analysis of content) in collaboration with Dr. Racine who amended and reviewed these materials. Manuscripts were co-drafted by Forlini and Racine; revisions and reviews were led by Forlini. The funding for this project, which supported data collection and research assistance for transcription was obtained by Dr. Racine.

The manuscript in Chapter 7 was co-authored by Cynthia Forlini, Dr. Serge Gauthier and Dr. Racine. All authors contributed to the outline for the manuscript in Chapter 7. Forlini wrote the first draft of the manuscript, consolidated comments, and revised the manuscript. Dr. Racine added content to drafts and revised the manuscript. Dr. Serge Gauthier revised and commented on the manuscript.

LIST OF ABBREVIATIONS

AAN	American Academy of Neurology
AD	Alzheimer's disease
CE	cognitive enhancement
MPH	methylphenidate
HCP	healthcare provider

INTRODUCTION

In the preface of the 1946 edition of his novel *Brave New World*, Aldous Huxley wrote that, "[t]he theme of *Brave New World* is not the advancement of science as such; it is the advancement of science as it affects human individuals" (Huxley 2010). In this futuristic novel, the population of the World State uses a drug called Soma to produce pleasant feelings. Citizens of the World State are happy, calm, easy-going, and "so conditioned that they practically can't help behaving as they ought to behave" (Huxley 2010). However, the interest in Soma is more for the situations in which it is employed, which range from stimulating social contact to escaping the unpleasantness in day-to-day life, than it is for the physiological and cognitive effects of the drug. Despite its initial apparent benefits for individuals and society, the example of Soma paints a dystopian picture of uses of psychopharmacology where happiness and well-being, human effort, and morality are discounted by the drug (Schermer 2007). What emerges from the novel are interesting relationships between risks/benefits and individual/collective decisions in a context where psychopharmacology is tightly woven into the fabric of society.

This theme of *Brave New World* resonates through the research and reflections presented in the following chapters of this thesis. As neuroscience knowledge translates into healthcare, many current ethical challenges stem from the interpretation of neuroscience research and its predicted potential for clinical and real-world applications (Racine et al. 2007). The approach and methodology of the work I present in this thesis is rooted in the field of neuroethics, "a new field of contemporary bioethics that focuses on the ethics of neuroscience research and related clinical specialities such as neurology, neurosurgery and psychiatry" (Racine 2010). The scope of neuroethics scholarship includes "the analysis of ethical challenges posed by chemical, organic, and electrochemical interventions in the brain" (Wolpe 2004) that are made possible by

neurotechnology. Recently, the non-medical use of prescription medications by healthy individuals to enhance cognitive function (e.g, attention, alertness, memory, mood) and ultimately human performance (often called “cognitive enhancement”) has sparked ethics debates over the evolution of neuroscience outside of a clinical context as well as its impact on society (Caplan and Elliott 2004; Caplan and McHugh 2007).

Public health studies are showing prevalence of cognitive enhancement on university campuses and the neuroethics literature is extensively discussing the ethical, social, legal and scientific issues surrounding cognitive enhancement. The re-purposing of medications for cognitive enhancement poses several challenges on scientific, individual and collective levels. Though cognitive enhancement seems to be increasingly prevalent, the efficacy reported anecdotally by users is not supported by scientific evidence. Still, expectations for enhancement seem to be present in both professional and academic environments. As a result, individuals are called upon to make personal choices of a health and ethical nature. On a collective level, cognitive enhancement can have an impact on expectations and performance standards in competitive environments. Re-purposing of prescription medications also holds implications for healthcare systems in medical practice and management of healthcare resources. A few policies, mainly targeting healthcare professionals, have emerged on how to approach the ethics of cognitive enhancement (British Medical Association 2007; Larriviere et al. 2009; Commission de l'éthique de la science et de la technologie 2009). Involvement of policy makers in addition to scholars in the field of neuroethics and in the ethics debate suggests that cognitive enhancement is a phenomenon not only of academic interest but one of practical importance as well.

A previous discourse analysis[1] examining academic and lay literature has helped to gain a sense of what the main issues in cognitive enhancement may be (Forlini and Racine 2009a). Issues of safety, individual autonomy, fairness, justice, legality and authenticity are currently being debated in academic ethics forums by scholars with supporting and opposing viewpoints on the cognitive enhancement of healthy individuals (President's Council on Bioethics 2003; Chatterjee 2004; Farah et al. 2004; Sandel 2004; Bush 2006; Chatterjee 2006; Greely et al. 2008; Bostrom and Sandberg 2009). Despite reports of increasing prevalence and an active academic ethics debate, ethical perspectives on cognitive enhancement are divergent, loosely informed by empirical data and have yet to closely examine specific points of contention (Forlini et al. 2007; Forlini and Racine 2009a; Racine and Forlini 2010a). Many real-world aspects of this phenomenon remain to be elucidated and considered in concert with scholarly and media discourses in order to foster an informed ethics debate.

The research and reflections I present in this thesis offer different perspectives on the ethical and social issues related to cognitive enhancement. The non-medical use of prescription stimulants by healthy university students seeking to enhance their academic performance is a well-documented example of cognitive enhancement (Arria and Wish 2006; Wilens et al. 2008) and serves as a scaffold for the qualitative research project reported in this thesis. The global objective of this project is to specify the ethical and socially contentious aspects of cognitive enhancement, evaluate and dissect these issues within a comprehensive, perspective-rich context and develop a concerted approach to cognitive enhancement, reflective of a pluralistic society.

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[1] Published as a part of a manuscript based Master's thesis of the candidate: Examining discourses on the ethics and public understanding of cognitive enhancement with methylphenidate. Université de Montréal. 2008.

Three specific aims follow the global objective of this thesis. The first is to identify and analyze ethical and social issues regarding the emerging practice of cognitive enhancement as perceived and experienced by various stakeholders. In this thesis, the term *stakeholders* is intended to denote individuals or groups of individuals that are (or could be) affected by cognitive enhancement in their personal, academic and professional lives. The stakeholder perspectives are gathered by means of focus group discussions where participants are able to elaborate and argue for or against perspectives that arise. These discussions contribute to the second specific aim, which is to assess print media coverage and existing neuroethics literature on cognitive enhancement based on how stakeholders perceive and experience ethical dilemmas related to the non-medical use of prescription medication for enhancement. Empirical findings represent another discourse to consider in conjunction with academic and lay literatures in deliberations about the ethical issues that arise in cognitive enhancement and how they can be approached. Third, these research results and reflections can help recommend avenues for neuroethics scholarship, research dissemination and public communication regarding cognitive enhancement technologies. Notably, the ties between cognitive enhancement and the goals and practice of medicine are in need of clarification. The results and reflections presented in the following chapters hopefully comprise a contribution to a unified and meaningful ethics debate on cognitive enhancement.

The literature on cognitive enhancement touches upon many areas of scholarship. In Chapter 1, I review some facts at the foundation of the research and reflections in this thesis including the evidence for safety and efficacy of medications in healthy individuals and data on the prevalence of the non-medical use of prescription stimulants. In Chapter 2, I delve into ethical underpinnings by introducing cognitive enhancement in a neuroethics context that considers standard definitions. Reference has already been made to the diverging perspectives in the ethics debate

around cognitive enhancement, which are explained in this chapter as well. I discuss specific ethical issues in light of these diverging perspectives to illustrate the polarization in normative academic ethics. Finally, in addressing the importance of gathering and including stakeholder perspectives in ethics discussions I open the question of what are the respective roles of normative and empirical ethics in ethical inquiry.

The methodological approaches used to carry out the empirical research described in this thesis are the subject of Chapter 3. I justify the choice of qualitative methodology along with the choice of stakeholder groups recruited for the focus groups. Strategies for recruitment of participants, coding and analysis of data are explained in added detail to the accounts presented in Chapters 4, 5 and 6. The chapter is concluded with a discussion of the limitations of the methodology of this study.

I present the results of the focus-group study with key stakeholders in Chapters 4, 5 and 6. These chapters appear as manuscripts in the form they have been published. Each manuscript represents a segment of the qualitative data collected and an accompanying analysis. The manuscripts are introduced by a text that explains the specific approach to that particular segment, summarizes and contextualizes the results within the broader cognitive enhancement debate. I present these manuscripts in an order that initially captures general reactions of stakeholders and progressively unveils the complex interactions between ethical issues in cognitive enhancement. Chapter 7 is not part of the data set but completes the thesis as a normative response to current guidelines that permit the prescription of medications to healthy individuals for cognitive enhancement.

The first segment of data is presented in Chapter 4. Entitled “Stakeholder perspectives and reactions to ‘academic’ cognitive enhancement: Unsuspected meaning of ambivalence and analogies”, this

article was published in *Public Understanding of Science* in 2012[2]. It focuses on the reactions of stakeholders to the non-medical use of stimulants by university students and the popular analogies employed in ethics and policy discussions. The analysis of these results unveiled ambivalence in stakeholder perspectives with regard to choosing one framework over another.

The second segment of data is presented in Chapter 5. Published in *Neuroethics* in 2009, the manuscript "Autonomy and coercion in academic 'cognitive enhancement' using methylphenidate: Perspectives of key stakeholders" tackles the issue of the autonomy of individuals. In particular, the article addresses whether stakeholders felt that individuals are free to choose to engage or abstain from cognitive enhancement or whether this choice might be the result of coercion. Perspectives of stakeholders converged on the belief that cognitive enhancement was a personal choice motivated by social pressures but diverged on the consequences of that choice and the nature of the pressures.

Chapter 6 presents the third subset of data in an article entitled "Added stakeholders, added value(s) to the cognitive enhancement debate: Are academic discourse and professional policies side-stepping the values of stakeholders?" Published in *AJOB-Primary Research* in 2012, this article offers a novel analysis of stakeholder perspectives of ethical issues by classifying the level of contention and proposing a model of interaction between the ethical issues and stakeholder values that lie at the root of ethical contention. The discussion of this article questions whether academic discourse and professional policies are reflecting stakeholder values such as the ones discussed in the results of Chapter 5.

Based on professional guidelines that ethically and legally permit prescription of medications for cognitive enhancement, the manuscript in Chapter 7 asks, "Should physicians prescribe medications for

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[2] The manuscript was available online as of 5 December 2010 and published in July 2012.

enhancement to the healthy?" The proposed answer is based on considerations of benefit of medications in healthy individuals, the role of stewardship physicians are bound to fulfil and the integrity of the medical profession. The conclusion is that in the Canadian context, physicians should not prescribe medications to healthy individuals for cognitive enhancement since their professional duties trump patient requests. This manuscript is pulished in the *Canadian Medical Association Journal*.

In the general discussion of Chapter 8, I attempt to bind the normative perspectives of Chapters 1, 2 and 7 with the empirical perspectives of Chapters 4, 5 and 6 by suggesting a renewal of the deliberative model of bioethics. In the first section, I review the results presented in this thesis along with the results of other empirical studies on stakeholder perspectives of the ethics of cognitive enhancement. In the second section, I examine the alignment of normative and empirical perspectives in the bioethics debate to highlight some areas where more research and collaboration are needed. The last section, I propose that deliberation can help normative and empirical perspectives move along in concert to work within the ethics debate on cognitive enhancement.

CHAPTER 1: Evidence for safety and efficacy of medications in healthy individuals and data on the prevalence of the non-medical use of prescription stimulants

Cognitive function can be improved in medical and non-medical settings by employing many different strategies (Jones et al. 2005). These strategies include pharmacology (such as prescription medications, over the counter medications and dietary supplements), medical devices and by so-called "brain fitness" software (Merkel et al. 2007; George and Whitehouse 2011; Hamilton et al. 2011). There is also an emerging discussion about cognitive enhancement by means of keeping good lifestyle habits such as adequate sleep and regular physical exercise (Dresler et al. 2013; Lucke and Partridge (forthcoming)). Not all of these instances of enhancement conjure the same ethical debate as the one analyzed in the pages of this thesis. For example, even though there are some adverse effects to caffeine (Moore 2011) little contention exists around its use as an often daily cognitive enhancer as opposed to the use of various types of brain stimulation techniques (Hamilton et al. 2011). Safety, efficacy, invasiveness, prevalence, population (e.g., patient or healthy individual; child or adult), and context (e.g., clinical or competitive environments) are all factors that can change the ethical landscape of using technology for enhancement. The focus, here, is on the specific case of the non-medical use of prescription medications for the cognitive enhancement of healthy individuals. To date "discussion about [pharmacological cognitive enhancements] is fractioned by the different yet overlapping purposes, methods, and circumstances of obtainment" (Morein-Zamir and Sahakian 2011). Yet, it is this fractioned evidence that serves as the basis of assumptions and expectations that cognitive enhancement is valuable (Ferrari et al. 2012). This chapter provides an overview of some of the scientific evidence that the ethics debate on cognitive enhancement draws upon. The first section introduces the neuropharmaceuticals that have garnered a reputation for being cognitive

enhancers in healthy individuals and provides a brief overview of the scientific evidence behind these claims. The second section addresses the subject of prevalence regarding the non-medical use of prescription stimulants by university students seeking to enhance academic performance. Whether evidence shows that healthy individuals are actually benefitting from the effects of prescription medications on their cognition and to what extent this is being done are important considerations for ethical questions about how cognitive enhancement affects individuals and communities, and ultimately whether it can or should be allowed. Ferrari et al. (2012) have even questioned whether the ethics debate on cognitive enhancement can go on if evidence of safety, efficacy and social benefit are scarce.

Prescription medications as cognitive enhancers for healthy individuals

Examples of putative cognitive enhancers often cited in the literature are stimulants (methylphenidate, mixed dextroamphetamine salts, modafinil) to increase attention and vigilance as well as cholinesterase inhibitors (donepezil) and beta-blockers (propranolol) to enhance memory (Mehta et al. 2000; Yesavage et al. 2002; Turner et al. 2003; Glannon 2007). These medications are all currently prescribed for neurological or psychiatric indications. However, the emerging evidence for their use as cognitive enhancers in healthy individuals has not yet demonstrated significant improvements in performance for a majority of individuals.

Methylphenidate

Methylphenidate hydrochloride (Ritalin) is a mild stimulant of the central nervous system acting at the level of on dopaminergic transport in the brain (Cooper et al. 2003). Methylphenidate is one of the most commonly used stimulants in the management of Attention Deficit/Hyperactivity Disorder (AD/HD) for both children and adults (Wolraich et al. 2005) due to its capacity to improve attention and reduce hyperactivity. The condition is

characterized by “a persistent pattern in inattention and/or hyperactivity-impulsivity that is more frequently displayed and more severe than is typically observed in individuals at comparable levels of development” (American Psychiatric Association 2000). In AD/HD patients, dopamine levels are typically low but methylphenidate is able to block the uptake of this neurotransmitter to increase its concentration in the synapses of the limbic system (Moore 2011). It does this by binding to the dopamine transporter but does not act as a substrate. The limbic system is regulated by the higher cortical centers and is responsible for motivation, emotion impulse control and attention (Glannon 2007; Moore 2011). Despite its prevalent use for treatment, methylphenidate is associated with side effects disturbing sleep, appetite and cardiac rhythm (Canadian Pharmacists Association 2008; Godfrey 2009). By virtue of its involvement with dopaminergic neurotransmission, the abuse potential has been likened to that of cocaine (Kollins et al. 2001; Svetlov et al. 2007). As a result, methylphenidate is a Schedule II substance in the United States (Office of Diversion Control Drug and Chemical Evaluation Section 1995) and a Schedule III substance in Canada (Controlled Drugs and Substances Act 1996). These types of substances cannot be possessed by individuals without permission, i.e., a prescription. Treating AD/HD with methylphenidate has evoked difficult dilemmas for parents who appreciate the effects of methylphenidate on the behavior of their child but fear that the medication may affect their child’s development (e.g., slowing growth) (Singh 2005; Hansen and Hansen 2006) and increase demands of parents and educators for performance and behavior in academic settings (Diller 1996).

There are an increasing number of studies using different methods and samples to assess the effects of methylphenidate and other cognitive enhancers on healthy individuals. Reviews of these studies have proposed that the synthesis of available evidence is inconclusive as to whether methylphenidate and d-amphetamine are effective cognitive enhancers of

executive function for healthy individuals (de Jongh et al. 2008; Repantis et al. 2010a; Lynch et al. 2011; Smith and Farah 2011). One review cites that the most prominent enhancement effects of methylphenidate are produced in working memory, the cognitive capacity that stores transitory information (Repantis et al. 2010a). However, improvements in working memory seem to be situation-dependent (i.e., neuropsychological assessments used for the studies) and subject-dependent (Lynch et al. 2011; Smith and Farah 2011). The subject-dependency was demonstrated by a larger improvement in performance of individuals who had a lower performance at baseline (Mehta et al. 2000; de Jongh et al. 2008; Repantis et al. 2010a; Husain and Mehta 2011; Lynch et al. 2011) as well as some genetic factors related to drug response (Husain and Mehta 2011; Smith and Farah 2011). This finding has been interpreted as a potential “species limit” or an “enhancement ceiling” to the improvement of cognition (Farah et al. 2008; Lynch et al. 2011). The variation of improvement in performance is also proposed to be dose-dependent following an inverted U-shaped model where low doses improve performance but high doses impair performance (de Jongh et al. 2008; Repantis et al. 2010a). Another review considers the most prominent effects to be in the consolidation of long-term declarative memory that is responsible for recall and recognition of information after a long delay, an important component for learning (Smith and Farah 2011). Given the interrelatedness of cognitive capacities and “brain networks”, this result inspires concern about cognitive “trade-offs” that might occur if one process is enhanced at the detriment of another (de Jongh et al. 2008; Husain and Mehta 2011). For example, might the enhancement of long-term declarative memory with methylphenidate come at the cost of working memory? Reviews also show that methylphenidate does not enhance cognitive control (attention and impulsivity) in healthy individuals as effectively and universally as has been suggested (Repantis et al. 2010a; Smith and Farah 2011). Repantis et al. propose that despite their

finding of insufficient evidence to support the use of methylphenidate as an enhancer, it is still important to consider “the subjective effects that motivate people to take a certain drug” which might overshadow scientific evidence (Repantis et al. 2010a). Similarly, Smith and Farah (2011) posit that the enthusiasm for the use of stimulants as cognitive enhancers among the public could be the product of a placebo effect. Some research has shown that cognitive abilities can be improved (and worsened) by placebos in response to the expectations for effect (Clifasefi et al. 2007; Van Oorsouw and Merckelbach 2007; Parker et al. 2008). Additionally, enhancement effects may be due to even an alteration in students’ perception of the amount or quality of work accomplished instead of the effects of the medication on cognitive capacities (Smith and Farah 2011).

Modafinil

Modafinil (Provigil) is a wakefulness promoting agent that is used to regulate sleep/wake cycles in patients suffering from conditions like narcolepsy, sleep apnea and shift work sleep disorder (Turner et al. 2003). Several theories exist as to its mechanism of action both in terms of neurotransmitters and brain regions. It has been suggested that modafinil acts on histamine, noradrenaline, dopamine and GABA in the hypothalamus, locus coeruleus, forebrain and cerebral cortex, respectively (de Jongh et al. 2008). Modafinil is associated with few side effects and does not produce anxiety or excess locomotor activity (Moore 2011). Its use in healthy individuals is linked to a debate about the medicalization of sleep (Williams et al. 2008). It is reported that 90% of prescriptions for modafinil are off-label, for example, to increase alertness in those looking to remedy jetlag (Vastag 2004). Two reviews have confirmed an increase in wakefulness and attention in healthy individuals with modafinil (de Jongh et al. 2008; Repantis et al. 2010a). However, the strongest effects of modafinil are seen on the executive function of sleep-deprived individuals. Modafinil has appeared to be most effective during sub-

optimal performance caused by either sleep deprivation or ‘lower natural abilities’ (de Jongh et al. 2008).

Donepezil

Donepezil (Aricept) is an acetylcholinesterase inhibitor used in the treatment of mild to moderate Alzheimer’s disease, the most common cause of dementia in the elderly (Cooper et al. 2003). Alzheimer’s disease (AD) is characterized by abnormalities in memory, problem solving, language, calculation, visuospatial perception, judgment and behavior that are caused by neuritic plaques and neurofibrilary tangles in specific cortical regions (Kandel et al. 2000). Acetylcholinesterase inhibitors increase the synaptic concentration of the acetylcholine in the synaptic cleft by preventing the breakdown of the neurotransmitter. In turn, binding of acetylcholine to muscarinic and nicotinic acetylcholine receptors in the cerebral cortex and hippocampal regions is increased, which promotes learning and improves short-term memory (Cooper et al. 2003; de Jongh et al. 2008). Discussion of donepezil’s use as a cognitive enhancer for healthy individuals is contentious given the lack of efficacy and prevalence data (Wade et al. under review). The discussion is due in part to Yesavage et al.’s 2002 study on the retention of flight simulation tasks by pilots who had been given donepezil and placebo controls. The results state that: “flight performance of the pilots in the donepezil group changes little from performance after the initial training to 30-day post-treatment… whereas it declines in pilots in the placebo group” (Yesavage et al. 2002). This conclusion implied that donepezil improved retention of training in healthy individuals. However, subsequent reviews of this and other studies, found that there was insufficient data to support an enhancing effect of donepezil in healthy individuals for memory or any other aspect of cognition (Repantis et al. 2010b).

The evidence for the enhancement effects of these three medications shows they have the potential to enhance certain elements of

cognition but none is a putative universal enhancer. Cognitive enhancements in healthy individuals might not be as specific as presented here but occur by virtue of improvement in arousal (Husain and Mehta 2011). A similar postulate exists regarding evidence showing that caffeine enhances cognition via non-specific arousal (Nehlig 2010). Effect type and size of these medications on the cognitive abilities of healthy individuals are difficult to assess and compare given methodological differences in studies that include population, task and dose (Forlini and Racine 2009a; Repantis et al. 2010b; Husain and Mehta 2011). Furthermore, this evidence represents experimental conditions, which can differ widely from day-to-day activities. As a result, it has been proposed that "there is little reason to think that such drugs will in any sense constitute 'smart pills'—something that will give healthy, alert individuals any intellectual advantages in real world circumstances" (Lynch et al. 2011).

Impact of safety and efficacy research on the ethics debate around cognitive enhancement

The academic ethics debate has cited the scarcity of evidence of safety and efficacy as a major challenge to determining the future directions of cognitive enhancement (Chatterjee 2004; Farah and Wolpe 2004; Hall 2004; Mehlman 2004; Greely et al. 2008). This issue has also emerged as a concern for stakeholders (Bergstrom and Lynoe 2008; Hotze et al. 2011). With small samples and varying methodologies, the results reviewed above do not constitute resounding support for the efficacy of stimulants as cognitive enhancers. Indeed, if cognitive enhancers were not safe or efficacious, their ethical justification would be in peril and the debate could shift toward prevention of a dangerous or ineffective practice.

The ethical debate currently progresses in the midst of disparate evidence and encourages calls for a "programme of research into the use and impacts of cognitive-enhancing drugs by healthy individuals" (Greely et al. 2008) and "growing need for guidance on how to conduct enhancement research in an ethical manner" (Mehlman et al. 2011).

Harris even proposes a moral obligation to participate in research on enhancement as a way of contributing to the public good (Harris 2007). However, there are several challenges associated with carrying out efficacy research (i.e., methodology and funding) at the academic levels (See Appendix A for a more thorough analysis of these challenges). Instead, there are some examples of lay attempts to test and disseminate the effects of medications used as cognitive enhancement via YouTube and blogs (Gwern.net 2012; Anonymous 2011). High priority has been given to collecting information on the safety and efficacy of cognitive enhancers, however, little has been said about more upstream ethical questions in the research on such medications and what ethical justification can be given to endeavour to study the enhancement effects of prescription medication on healthy individuals. Indeed, the prioritization of other issues such as fairness and autonomy with respect to safety and efficacy could change the face of the ethics debate. For example, if academic and professional policies state that cognitive enhancement is cheating then prevention would be needed more than research. These considerations may be important precursors to continuing the debate on the ethics of cognitive enhancement.

Prevalence of the non-medical use of prescription medication by healthy individuals for cognitive enhancement

Perhaps the most compelling example of the non-medical use of psychopharmaceuticals for cognitive enhancement is the use of methylphenidate by healthy students without attention deficit/hyperactivity disorder (AD/HD). Other formulations of AD/HD medications such as d-amphetamine salts are also reportedly used. Recent studies have reported that non-medical use of stimulant medication is especially prevalent on North American university campuses (1996; Graff Low and Gendaszek 2002; Teter et al. 2003; Hall et al. 2005; McCabe et al. 2005; Teter et al. 2005; Arria and Wish 2006; McCabe et al. 2006; Teter et al. 2006; White et al. 2006; Kaloyanides et al. 2007; DeSantis et al. 2008; Dupont et al.

2008; McCabe 2008; Wilens et al. 2008; Weyandt et al. 2009; Teter et al. 2010; Herman et al. 2011; McNiel et al. 2011; Johnston et al. 2012). Non-medical stimulant use has been shown to range from 3% to 35% of university-aged individuals (Wilens et al. 2008; Franke et al. 2011). Some studies have found that high school students also use stimulants non-medically (Poulin 2001; McCabe et al. 2004; Johnston et al. 2012). Students are reportedly obtaining methylphenidate and other stimulants both illicitly (from friends and colleagues, black markets, Internet pharmacies) and licitly (feigning symptoms of AD/HD to obtain prescriptions) to improve attention, concentration and alertness as a way to enhance their academic performance (Barrett et al. 2005; McCabe et al. 2006; Bogle and Smith 2009). Though the academic setting is currently the best documented, some authors have also discussed the promise and peril of cognitive enhancement in the workforce (Chatterjee 2006; Appel 2008; Warren et al. 2009; Sugden et al. 2010; Drabiak-Syed 2011).

The actual prevalence of the non-medical use of prescription stimulants for cognitive enhancement is difficult to establish. International estimates of prevalence in the general population are situated at approximately 20% by two surveys, one conducted by a German health insurer and the other sponsored by the science journal *Nature* (Maher 2008; Leben 2009). Rates for general misuse of prescription stimulants include motives for non-medical use such as recreation and weight loss (Teter et al. 2005; Arria and Wish 2006; Dupont et al. 2008; Rabiner et al. 2009; Franke et al. 2011). A closer look at these studies shows that between 1.3% and 11% of university students in those samples used prescription stimulant medication specifically for cognitive enhancement (e.g., enhance studying, concentration, alertness and intellectual performance) (Racine and Forlini 2010a; Franke et al. 2011). Interestingly, a national American survey on drug misuse found that the prevalence of misuse of stimulants was higher in respondents who had been to college than those who had not (Johnston et al. 2012). This survey suggests that

cognitive enhancement is a potential cause of higher prevalence in college-educated individuals, which is consistent with data showing that stimulants are used to enhance academic performance. Within the college environment, other studies have linked higher prevalence of non-medical stimulant use with risk factors that include: college location, gender, average academic performance, fraternity membership and history of drug use (Teter et al. 2003; Bogle and Smith 2009). Presence of these factors may encourage individuals to use a stimulant non-medically for cognitive enhancement despite poor evidence of efficacy.

The prevalence rates reviewed above have been cited as evidence that the non-medical use of prescription stimulants, and with it cognitive enhancement, is widespread (Greely et al. 2008). As a result, this phenomenon has garnered the title of a “contemporary public health problem” (Arria and DuPont 2010). However, what is considered widespread is itself open to interpretation and met with skepticism in the academic ethics debate about current estimates of prevalence (Hall and Lucke 2010; Lucke et al. 2010; Lucke et al. 2011). In response to this skepticism, it has been argued that even a rate as low as 3% “implies that more than half a million healthy young people are current or recent users in the United States alone” (Farah 2011). Whether cognitive enhancement constitutes a public health problem, in addition to the ethical and social challenges it poses, and how it should be addressed is still a matter of debate (British Medical Association 2007).

Widespread use is significant for the ethics debate on two fronts. First, as Bell et al. explain, “the use of new stimulant drugs often follows a cycle of uncritical enthusiasm that encourages widespread use” (Bell et al. 2012). Individuals seeking cognitive enhancement through the non-medical use of prescription medication are potentially doing so without adequate information about the known harms and benefits. In addition, these individuals are opening themselves up to the adverse effects that can only be identified when use becomes common. Widespread use of

stimulants in an academic setting might also be an indication that education systems are missing opportunities to help students by cultivating certain skills that may achieve the same results as pharmacological cognitive enhancement (George and Whitehouse 2011). Second, widespread prevalence of cognitive enhancement is already forcing ethical reflection on the policy options for regulating the substances and practice (Outram and Racine 2011). However, there are important challenges in producing policy options given the philosophical and operational differences in existing ethical frameworks on cognitive enhancement (reviewed in detail in Chapter 2) (Sarewitz and Karas 2012). A good grasp of prevalence of cognitive enhancement practices has both public health and policy implications.

CHAPTER 2: Literature review

An enhancement *is an intervention- a human action of any kind- that improves some capacity (or characteristic) that normal human beings ordinarily have or, more radically, that produces a new one.*
(Buchanan 2010)

Buchanan's definition of "enhancement" provides a general idea of the subject under study in this thesis. By the definition above, corrective eyewear, immunization, modifications to the human genome and psychopharmacology all fall under the same heading of "enhancement" (Harris 2007). These examples are all biomedical innovations (and interventions) that improve some aspect of the ordinary function of normal human beings. There are, however, three embedded assumptions in this definition that have sown contention by painting all of these examples of human enhancement with the same brush. The first assumption is that said improvements will all be positive, and this, on both individual and collective levels. The second assumption is that what is "normal" is well defined. The third assumption is that being "ordinary" (or "natural") constitutes a moral standard. These assumptions have been troubling ethicists who are trying to determine whether human enhancement is right or wrong, which has resulted in a polarized ethics debate on human enhancement. Specifically in the context of cognitive enhancement, issues related to the mind/body add yet another layer of reflection to the debate on human enhancement within neuroethics. Interventions in the brain, the seat of consciousness and cognition, can have a profound effect on who we are and how we function as a society.

This second chapter aims to provide an overview of ethically contentious aspects in the cognitive enhancement of healthy individuals. This overview begins by drawing from issues in the general debate on human enhancement to introduce two opposing perspectives that have attempted to set moral boundaries. The neuroethics approach to cognitive enhancement is then presented to specify the context of human enhancement. Ethical issues in this debate are examined in this thesis

through the lens of a well-documented example of cognitive enhancement: the non-medical use of prescription stimulants by university students seeking to enhance academic performance. The example of the non-medical use of stimulants helps to highlight challenges in defining cognitive enhancement and the effect of diverging definitions on ethical perspectives. Finally, the chapter will move toward considering the contribution of empirical data from stakeholders and members of the public in ethics debates such as the one around cognitive enhancement.

Culture wars in the debate on the ethics of human enhancement

Whether and in what form enhancement can acceptably progress is an area where some ethicists fundamentally disagree. Two camps have emerged within bioethics with regard to human enhancement (Racine 2010). One approach maintains that "[h]uman history — or at least human progress — is in great part the story of enhancement" (Buchanan 2010) evident by the development of tools, technology and organized societies. Evolution, for its part, might be considered the "original" enhancement by which human capacities and characteristics have been improved. The standpoint labeled as *bioliberal* or *meliorist* argues that enhancement should continue and be pursued because it reduces suffering and improves the quality of human life (Caplan 2003; Savulescu 2006; Harris 2007; Bostrom and Sandberg 2009; Buchanan 2010). At its extreme, the bioliberal perspective incorporates transhumanism, a movement hoping that "by responsible use of science, technology, and other rational means we shall eventually manage to become post-human, beings with vastly greater capacities than present human beings have" (Bostrom 2003). The *bioconservative* or *anti-meliorist* standpoint does not believe that biomedical enhancements make lives better. Bioconservatives fear that enhancement poses a risk to human existence because of the physical and social changes that might be introduced by biomedical interventions (Fukuyama 2002; President's Council on Bioethics 2003; Sandel 2004).

This position strives to preserve the status quo of human nature. Evolution, bioconservatives say, is a process not to be meddled with and that “[i]n enjoying the benefits of biotechnology, we will need to hold fast to an account of the human being, seen not in material or mechanistic or medical terms but in psychic and moral and spiritual ones” (President's Council on Bioethics 2003) . The specific arguments behind bioliberal and bioconservative points of view will be further explored in the following paragraphs. It must be acknowledged at this point that there are many shades of nuanced positions and arguments between those of the bioconservatives and the bioliberals. However, these opposing points of view in the enhancement are compared and contrasted at their extremes to illustrate their association with the broader context of the “culture wars”, which underlies bioethics debates like stem cell research and end-of-life care (Callahan 2005; Racine 2010). The “culture wars” have come to represent “the emergence of radical moral-political divisions in the public domain” (Racine 2010) that are reflective of disagreements between conservative and liberal moral and political positions. Highlighting the fundamental differences between bioconservative and bioliberal approaches to enhancement also illustrates the difficulty in coming to a shared understanding of what is the ethical way to proceed. Some authors have declared a stalemate between bioconservative and bioliberal positions and wonder whether the two positions can ever be reconciled to produce a more productive ethics discussion on enhancement (Roache and Clarke 2009; Banja 2011). The three assumptions in Buchanan’s definition of enhancement that were highlighted earlier provide an interesting framework to compare and contrast bioliberal and bioconservative arguments.

Buchanan defines enhancements as improvements, but even an improvement on one front can bring about harm on another. Parens encapsulates this thought in the title of his essay: “Is better always good?” (Parens 1998). Indeed, the two approaches disagree upon whether the

changes brought on by human enhancement are benefits or harms. These changes would be in relation to the "natural distribution of capabilities and disabilities" (Savulescu 2006) or a "natural lottery". Bioliberals describe a moral obligation to use biomedical innovation to benefit from a society of "healthier, longer-lived, and altogether 'better' individuals," which are able to meet their goals and lead rich lives (Harris 2007). Bioconservatives, describe a moral "repugnance" (Kass 2003) that hinges on the intrinsic value of being human and the inequalities that might be created by human enhancement (Cohen 2006; Roache and Clarke 2009). The conservative position to restrict or ban enhancements is rooted in what Cohen refers to as a *commandment* of equality that does not tolerate the creation of any disadvantages (Cohen 2006). Enhancement would be unjust if the biomedical technologies were inaccessible for reasons of cost or regulation (President's Council on Bioethics 2003). From this perspective, enhancements are regarded as personal goods that can be bought or accessed, in addition to natural endowments, to gain a positional advantage over individuals who do not have access. Conversely, if enhancements were readily available, positional advantages would be harder to obtain in a population where many or most people were enhanced. The nature of competition and what constitutes a "*humanl*y superior performance" would have to be redefined (President's Council on Bioethics 2003). This prediction, however, uses "availability heuristic" to estimate the likelihood that enhancements will create injustice (Roache and Clarke 2009). Roache and Clarke explain that in using a heuristic model (morality based on experience) a dystopian view of widespread enhancements akin to *Brave New World* would be most probable. The "Equality or Nothing View" is criticized by the liberals for being zero-sum where it is assumed that one individual's gain is another's loss (Buchanan 2009). In relation to the natural lottery, liberals believe that "the more enhancement, the less bad luck and the more products of good fortune there are available for redistribution" (Harris 2007). Equality of opportunity

would be promoted through individuals who are building upon their endowments and contributing to society (Savulescu 2006). There is also potential for inequalities to be leveled off once enhancements are made more widely available (Chan and Harris 2006; Savulescu 2006). In this positive-sum scenario, even if the biomedical enhancements are not available to everyone, society reaps the benefits of even some individuals being enhanced. As long as an ethically principled approach to the distribution of biomedical enhancements exists, the bioliberal stance does not regard inequalities in access as inherently unjust or as an imperative to put a ban on enhancements (Harris 2007; Buchanan 2010). On the issue of justice, bioconservatives emphasize the harms that could be done to individuals whereas bioliberals concentrate on the net benefits to society.

Definitions of enhancement require a baseline from which an "improvement" is evaluated. Buchanan's definition refers to what "*normal* human beings *ordinarily* have" (emphasis added). This definition establishes a baseline by linking that which is *normal* to those characteristics that usually occur (i.e., what is natural). The challenge for the ethics debate around enhancement is in determining exactly what is meant by normal and natural and whether the established baseline actually matters in determining whether human enhancement is right or wrong (Siipi 2012). For instance, normal can be a statistical characteristic. It has been argued, however, that not all characteristics that make us statistically normal are desirable (e.g., dental cavities) (Siipi 2012). Normal can also be defined as a non-pathological medical state based on "normal functioning" (Sabin and Daniels 1994). From one point of view, normal can be the ideal between treatment and enhancement. Treatment restores function that was lost while enhancement surpasses this level of function (Juengst 1998). However, functional normalcy can also be considered as a medically ideal point of reference as opposed to a baseline. From this different point of view, the concept of enhancement would be moot

because no improvements can be made to an ideal state (Siipi 2012). Normal and natural can refer to suitability or belonging to something or someone. Suitability is the rationale behind Daniels' concept of "species-typical functioning" which builds on the statistical definition. In this sense, "functional abilities are traits that exist in populations because they have contributed to the reproduction and survival of organisms that possessed them" (Resnik 2006). Sabin and Daniels have used normal and species-type function to define medical necessity to propose models for equitable distribution of resources within a population (Sabin and Daniels 1994; Daniels 2000). It has been argued that the goal of attaining and maintaining a species-normal function is not ethically justified in every context and is thus, not a valuable measure for defining treatment or enhancement across the board (Silvers 1998). Silvers (1998) gives the example of correcting for albinism to prevent stigma. Finally, normal can simply refer to familiarity with a certain characteristic consisting mostly of "resistance toward odd and unknown" (Siipi 2012). Siipi (2012) argues that, though intuitive, familiarity is of moral relevance because it implies a certain amount of experience that can ease risk assessment of enhancement. Familiarity can be interpreted as one of the underpinnings of bioconservative hesitation to redefine standards of human performance. The objections to each definition of *normal* complicate the choice of just one as a morally relevant guide of the ethics debate around enhancement.

Despite the difficulties in defining normalcy, the bioconservative perspective on enhancement relies heavily on the concept and its relationship to what is considered natural. The approach draws from a philosophical definition of nature that refers to "that which is independent of significant human influence or control, in effect, that which is given or that which is independent of human choice" (Lustig 2009). From a conservative perspective, normalcy and naturalness go hand-in-hand as the results of human evolution and the natural lottery (President's Council on Bioethics 2003). According to Sandel's "giftedness" perspective, the

characteristics we are handed in the natural lottery are gifts that should be cherished and preserved (Sandel 2004). These gifts make us who we are. Biomedical enhancements that meddle in the natural lottery, "represent a kind of hyperagency— a Promethean aspiration to remake nature … to serve our purposes and satisfy our desires" (Sandel 2004). Sandel considers this hyperagency, a "drive to mastery"[3] and a quest for perfection spurred by dissatisfaction with the status quo (Sandel 2004). Our proper role as humans, according to the bioconservative perspective, is one of stewardship of nature and not mastery of it (Lustig 2009).

The bioliberals have two objections to using *normal* as a qualitative, and *nature* as a moral, measure for enhancement. Evolution, they say, is not the "master engineer" bioconservatives consider it to be (Harris 2007; Buchanan 2008). Instead, it is a flawed process that has produced even undesirable outcomes such as disease, thus, "evolution isn't about what's good; if it's about anything, it's about reproductive fitness" (Buchanan 2008). Indeed, enhancement is seen as "a more fruitful, advantageous evolution than the haphazard 'opportunistic' ways of nature, which only aim to maximize reproductive success, rather than quality of life" (Scripko 2010). The reverence of what is *natural* and the need to preserve status quo is also criticized by the bioliberals on the basis that enhancement can be consistent with preserving certain characteristics if it is considered that, "[w]e may need to improve some particular capacity in order to preserve what we value" (Buchanan 2010). The other objection is that normal is determined not only by biology but also by valuations of health and disease. From a bioliberal perspective, biomedical interventions minimize harm, whether they are used for treatment or enhancement. As Harris states, "[n]ormalcy plays no part in the definition of harm and therefore no part in the way the distinction between therapy and enhancement is drawn" (Harris 2007). Though used as a general benchmark in

[3] Others have renamed the drive to mastery as "playing God" (Buchanan 2010).

enhancement definitions, reference to that which is normal or natural is a major source of divergence in the ethical arguments of bioconservatives and bioliberals against and for enhancement.

Nature is evoked in a second sense, alongside that of giftedness, in the ethics debate on human enhancement. In the drive for mastery there are opportunity costs. One that is of particular concern for bioconservatives is that if we try to improve any part of human function we will alter or inadvertently destroy the positive aspects of *human nature* (Fukuyama 2002; Habermas 2003; President's Council on Bioethics 2003). As Fukuyama explains, “biotechnology will cause us in some way to lose our humanity— that is, some essential quality that has always underpinned our sense of who we are and where we are going” (Fukuyama 2002). This postulate has also been called the “Extreme Connectedness Assumption” (Buchanan 2010). In order to assess whether enhancements will affect it, human nature must be defined. What, then, makes us human? Fukuyama refers to a “Factor X” that:

> cannot be reduced to the possession of moral choice, or reason, or language, or sociability, or sentience or emotions, or consciousness, or any other quality that has been put forth as ground for human dignity. It is all these factors coming together in a human whole that make up Factor X (Fukuyama 2002).

Kass proposes that biomedical enhancements run the “danger of violating or deforming the nature of human agency and the dignity of the naturally human way of activity” (President's Council on Bioethics 2003). The dignity Kass speaks of is found in the discipline and effort required to attain excellence that promotes human flourishing and establishes identity (Kass 2003). However, human activity and its contribution to an individual’s flourishing are separated under biomedical intervention that serves as a “short cut” because less effort or discipline might be required to complete

these activities. As a result, Kass argues that "'personal achievements' impersonally achieved [with the help of enhancements] are not truly the achievements of persons" (Kass 2003). Furthermore, as humans we are not only our achievements, but engaged in a process of "a life-long being-at-work exercising one's human powers well" and one achievement impersonally gained could put this process in peril (Kass 2003). There is, however, an underlying assumption that every type of human activity is laden with virtues, conferred through suffering and effort that will enrich human nature (Schermer 2007). This conservative perspective is criticised on the basis of its essentialist and stereotypical perception of human nature being composed of a specific set of traits (Buchanan 2009; Banja 2011). Contrasting definitions do not give as much weight to the relationship between human nature and effort nor do they consider human nature to be gifted. Savulescu's definition, coming from a bioliberal perspective, states concisely that what makes us human is our ability to use our rationality for self-improvement (Savulescu 2006). Bostrom would add that humans are "not solely a function of our DNA but also of technological and social contact. Human nature in this broader sense is dynamic, partially human-made, and improvable" (Bostrom 2005). However, there is also an essentialist critique of the liberal definition of human nature as well because "[t]he rational animal is here interpreted as an *essentially* self-enhancing animal" (Hauskeller 2011). As a result, those not endeavouring to improve their situation could oppose the liberal definition of human nature. Just as with normalcy, definitions of human nature vary within the ethics debate on human enhancement but all seem to rely on a prescribed set of traits.

Human nature plays a prominent role in the enhancement debate yet it is not clear whether biomedical enhancements alter it and whether any such alteration carries moral weight. From a bioconservative perspective, biomedical enhancements stifle human flourishing by discounting hard work and suffering (Kass 2003). In addition, the traits

targeted by enhancements define our identities and are considered gifts for which we are grateful and should not expect to choose (Sandel 2004). In relation to the giftedness framework, Kamm argues that altering or choosing human traits is inappropriate, not because it changes who we are, but that due to a "lack of imagination" everyone might choose the same type of enhancement creating less diverse societies (Kamm 2005). These arguments about human nature have served as reasons for a moral objection to enhancements. However, proponents of human enhancement contend that:

> [c]onservatives who oppose the use of biological, internal technological, and other private enhancements are guilty of a crude form of social determinism, predicting some adverse social consequence of allowing enhancement when it is within our power to prevent these adverse social consequences and reduce inequality. (Savulescu 2006)

By this token, bioliberals believe the moral impetus for human enhancement is that it would actually promote human flourishing and equality. These reasons seem to constitute more concrete moral arguments than the intuitions and repugnance[4] that underlie conservative positions (Chan and Harris 2006; Roache and Clarke 2009). There have been attempts to bridge the perceptions of humans as receivers of gifts versus designers of traits. Individuals can be "co-creators" of their identities (Lustig 2009). Parens suggests a complimentary framework to Sandel's gratitude for gifts in the form of "creativity" (Parens 2006). He explains that:

> it is not only our responsibility to be grateful, to remember that we are not the creators of the whole. It is also our responsibility to be creative, to use our creativity

[4] Several authors admit that these terms are "hard to translate into sound moral arguments" (Kass 2003) because "our moral vocabulary is ill equipped" (Sandel 2004) to deal with the unease of using biomedical enhancements.

> to mend and transform ourselves and the world (Parens 2006).

The creativity framework acknowledges the gifts or traits humans may receive but does not carry a moral imperative to keep them pristine. Thus, human nature and what is included and excluded from it does not contribute to determining whether human enhancement is ethical. Indeed, some authors have gone further in circumventing alterations of human nature as arguments in the enhancement debate because, "[a]n enhancement is an improvement of some particular capacity, but not necessarily something that makes us better off *overall* … That's why it is better to talk about enhancing capacities rather than enhancing people" (Buchanan 2010). Enhancing capacities can take on a different significance depending on the task at hand (Schermer 2007). There are some instances where enhancements can be detrimental to the effort and hard work required to reach a goal (e.g., athletic training). Rather than asking whether a capacity is a part of human nature, some authors have urged that the enhancement debate is more fruitfully pursued through consideration of whether we have good reason to enhance the capacities that allow humans to attain the type of goals we value (Bostrom 2005; Schermer 2007; Buchanan 2009). There have been strong arguments for and against using alterations to human nature in the debate on the ethics of human enhancement but none of these arguments has been able to settle whether enhancements change who we are or whether it even matters from an ethical perspective.

Fleshing out three assumptions embedded in Buchanan's definition of enhancement has illustrated some of the issues that define the ethics debate on human enhancement. It has also shown how these issues have created another battle in the culture wars by polarizing academic ethics perspectives. On the one hand, bioconservatives argue for the prevention of enhancements to avoid altering human experience. On the other hand, bioliberals argue for the promotion of enhancements in order to improve

human experience. As the ethics debate progresses so does the science generating the technologies that make human enhancements possible. In the context of this thesis, the enhancement technologies being discussed are first and foremost *health* technologies that are subsequently repurposed (Parens 1998; Buchanan 2010). Just as the enhancement technologies are couched in the medical context; the same can be said of the ethics debate. It has even been suggested that "saying no to biomedical enhancement isn't really an option— unless we want to stop medical progress" (Buchanan 2010). For now enhancement is inextricably linked to a medical context though this might not always be the case. Enhancements may be developed in their own right. Many authors are predicting the inevitability of enhancements and calling for ethics debates that address ethically sound approaches to enhancements as opposed to debating whether they are ethically acceptable in principle (Baylis and Robert 2004; Chatterjee 2004; Farah et al. 2004; Rose 2005; Synofzik 2009; Buchanan 2010). In whichever direction the debate develops, what is needed is a way to mediate the culture wars to foster more decisive ethical action that strikes a balance to benefit individuals and societies.

A neuroethics approach to cognitive enhancement

The above comparison and contrast of bioconservative and bioliberal approaches to human enhancement did not differentiate between the types of interventions (means) used to enhance capacities or the ends for which this might be done. Considering these two elements can change the ethical landscape of a phenomenon such as human enhancement (President's Council on Bioethics 2003; Harris 2007). For example, genetic enhancements evoke the issue of designer parenting (i.e., selection of sex or prevention of genetic mutations) in a way that neurotechnological enhancements do not because these interventions are not involved in conception (Bostrom 2003; Sandel 2004). Similarly, issues of authenticity, identity and knowing one's "true self" vary according to whether affective

or cognitive processes in the brain are being enhanced as compared to what gene is enhanced. The definition of enhancement presented above paints many interventions with the same brush, but examining the ethical issues of all types of enhancements through the same lens may lead to generalizations that overlook the particular benefits and risks of means and ends within different contexts. Indeed, Levy argues that in comparing new technologies used for enhancement with "traditional" means of enhancement that "they can all be misused … and none is intrinsically good or bad" (Levy 2007). He explains that the priority for ethicists is to "assess them one by one, in the context in which they are used and examining the details of their application, before we accept or reject them" (Levy 2007). The scope of this thesis is limited to examining the ethics of using neurotechnology for enhancement and more specifically, neuropharmacology. This area of investigation falls within the purview of the field of neuroethics, which is the lens that will be used to examine the non-medical use of prescription stimulants for cognitive enhancement of healthy individuals.

Neuroethics is a field within contemporary bioethics that is dedicated to examining ethical issues arising from advances in neuroscience as they relate to research and its translation into related clinical specialties (neurology, neurosurgery, psychiatry) and into the public domain (Racine and Illes 2008; Racine 2010). The specific aims are manifold and have practical underpinnings that can impact the care of patients as well as philosophical underpinnings that impact interdisciplinary understanding of the neurosciences (Racine 2008a). The range of neuroethical issues has garnered pluralism in definitions of the field (Racine 2010) with different perspectives driven by knowledge (Roskies 2002), technology (Wolpe 2004) and healthcare (Racine and Illes 2008). Of particular interest for this thesis is the technology-driven perspective that examines the uses of neuroimaging, neurostimulation and

neuropharmacology, to name a few. In his definition, Wolpe (2004) considers that:

> [n]euroethics is a content field, defined by the technologies it examines rather than any particular philosophical approach. The field's distinctiveness derives from novel questions posed by applying advanced technology to the brain, the seat of personal identity and executive function in the human organism.

Some authors have questioned whether it makes any sense at all to "reinvent the bioethics wheel" with a new specialty like neuroethics (Parens and Johnston 2007). Roskies retorts that the issues are novel and distinct from those in other areas of bioethics because of "the intimate connection between our brains and our selves" (Roskies 2002). There is some precedent to the issues in neuroethics, especially given recent advances in the field of genetics. These precedents are acknowledged and drawn from to guide the ethical use of neurotechnology (Farah 2005). Moreover, progress in neuroethics can provide feedback by "reflecting on the new neurosciences gives us the opportunity to reassess older ways of altering minds" (Levy 2007). As a part of bioethics, the scholarship in neuroethics provides a unique venue in which to explore the connections between neurotechnology, neurobiology, and human experience.

A neuroethics definition of cognitive enhancement

Formally, cognitive enhancement has been defined as "amplification or extension of core capacities of the mind through improvement or augmentation of internal or external information processing systems" (Sandberg and Bostrom 2006). Collectively, these processing systems are known as "cognition" which is a "combination of skills, including attention, learning, memory, language, praxis (skilled motor behaviors), and so-called executive functions, such as decision making, goal setting, planning, and judgment" (Whitehouse et al. 1997). Thus, in its most basic sense, cognitive enhancement simply signifies the improvement of

cognitive function. However, the significance of improving cognitive function differs if cognition is discussed as separate or integrated systems and skills. Whitehouse et al. (1997) distinguish between interventions that target a particular system (e.g., memory) and those that might enhance cognition more generally. Wisdom, morality and emotion are attributed to cognition more generally and, if enhanced, would have a bigger impact than memory enhancement that allows an individual to memorize facts more readily (Whitehouse et al. 1997; Glannon 2008).

Cognitive enhancement can be perceived in two distinct ways. On the one hand, a drug such as donepezil can be referred to as a "cognitive enhancer" to describe its therapeutic effects on memory in AD patients (Whitehouse et al. 1997). The expression "cognitive enhancement" is also used in discussions of treatment of mental illnesses such as schizophrenia (Mohamed and Sahakian 2011). On the other hand, cognitive enhancement also refers to "the use of drugs and other interventions to modify brain processes with the aim of enhancing memory, mood, and attention in people who are not impaired by illness or disorder" (Hall 2004). It is this latter use of the term cognitive enhancement that raises the issues that dominates the neuroethics literature. In order to use terminology consistent with the neuroethics debate, as opposed to the other paradigms explained below, the term "cognitive enhancement" will be used in this thesis.

There are examples of cognitive enhancement that have not been as objectionable to the same extent as the non-medical use of prescription stimulants and other psychopharmacology. Buchanan argues that "[t]he great nonbiomedical enhancements— institutions, literacy, numeracy, science— have made us who we are" and are not met with the same hand-wringing as biomedical enhancements (Buchanan 2010). Others have argued that, cognitive enhancements "should be viewed in the same general category as education, good health habits, and information technology- ways that our uniquely innovative species tries to improve

itself" (Greely et al. 2008). What, then, makes using a medication or device any different from these other things humans do?

Diverging definitional approaches

Semantic pluralism surrounds the non-medical use of prescription medication for cognitive enhancement. The neuroethics literature has coined several terms to refer to cognitive enhancement such as "neurocognitive enhancement" (Farah et al. 2004), "neuroenhancement" (Hall 2004), "cosmetic psychopharmacology" (Kramer 1997), "cosmetic neurology" (Chatterjee 2004; Chatterjee 2006; Chatterjee 2007). Due to the nature of prescription drugs, in the public health literature, terms like "illicit use of prescription medication" (McCabe et al. 2006), "prescription abuse" (McCarthy 2007) and "non-medical use of prescriptions" (McCabe et al. 2005) are often used. The medical literature has also used the terms "lifestyle use" of prescription drugs (Flower 2004) or "elective psychopharmacology" (Mohamed and Sahakian 2011). In reporting on cognitive enhancement, the print media has developed popular vocabulary reflected by phrases like "better living through chemistry" (Zernike 2005) and a "new kind of drug abuse" (Laurance 2003). With so many terms, difficulty arises in navigating each of their theoretical assumptions for efficacy, benefit, proper use of medication and freedom to exercise individual autonomy as well as their ethical implications (Forlini and Racine 2009a; Racine and Forlini 2010a; Outram 2012).

Distinguishing between treatment and enhancement

The dichotomy between treatment and enhancement exacerbates confusion about the appropriate terms to use in reference to the non-medical use of prescription medication for performance enhancement. Often, the terms "treatment" and "enhancement" are used in opposition and in an exclusionary manner such that a so-called enhancement is "designed to produce improvements in human form or function that do not

respond to legitimate medical needs" (Juengst 1998). Consequently, this approach ousts improvements in the healthy from the boundaries of healthcare evoking the question of what can be considered a "normal" level of function and what type of impairments qualify for "medical necessity" (Sabin and Daniels 1994; Daniels 2000). Others have argued that enhancement might well fit within the goals of medicine because "[w]hat we currently consider enhancement may in fact promote heath" and wellbeing (Scripko 2010). Another troublesome aspect of the term "enhancement" is its embedded assumption and equation with benefit (Racine and Forlini 2009; Schermer et al. 2009). As explained above, it is not obvious why surpassing a "normal" or natural state is positive or beneficial. Surpassing this state may not actually reveal any advantages at all given that "[we understand very little about the design constraints that were being satisfied in the process of creating a human brain" (Farah 2002). Nonetheless, Parens has argued that regardless of what term is used, some ambiguities and assumptions would still exist (Parens 1998).

Lifestyle use of prescription medication

Terms such as "elective psychopharmacology" have begun to blur the lines between what are considered medical and non-medical interventions to cognition (Mohamed and Sahakian 2011). Parallels have been drawn between cognitive enhancement and cosmetic surgery, a procedure that, for some, can be used for treatment and, for others, for the fulfillment of a non-medical wish (Chatterjee 2007). These types of interventions have been grouped under the heading of "wish-fulfilling medicine" (Buyx 2008; Asscher et al. 2012). There are two significant worries about the emergence of lifestyle uses of prescription medications. The first is that lifestyle drugs, especially for the treatment of so-called lifestyle illnesses (e.g., obesity and illnesses resulting from smoking), "remove responsibility or control from the individual or society" (Gilbert et al. 2000). From this perspective, the use of lifestyle drugs can be a detriment to strategies

promoting different aspects of public health because lifestyle choices would not pose the health hazard they once did.

The second worry is for the process of “medicalization” (Conrad 1999; Mbongue et al. 2005) that would turn “natural expressions of human behavior into a ‘disease’ that requires- or would benefit from- drug treatment” (Flower 2004). At one extreme, medicalization has been associated with “disease mongering” (Moynihan et al. 2002) or a “diagnostic bracket creep” (Kramer 1997), a way to grow drug markets to sell and deliver treatments by the creation of new medical conditions. Thus, certain levels of cognitive performance that have, until now, not been part of a diagnosis, could become the target of treatment with medications based on redefined definitions of normal human function, and with it, dysfunction. On the contrary, some also believe that medicalization has improved health over the years (Farah et al. 2004). For example, the development of oral contraceptives, drugs that do not cure but prevent, has positively impacted family planning. However, Sadler and colleagues argue that medicalization “may represent a broad range of human interests and values, as well as serve one or more social purposes or functions” (Sadler et al. 2009). Because of these interests and values, the normative valence of medicalization is not universal, but rather case-dependent and can be elucidated by philosophical analysis to find common ground between frequently opposed political groups or normative stances. Yet, the potential medicalization of cognitive performance may not be as deliberate as is thought. The reliance upon pharmacology may be a response to current limitations in resources in medical practice where “[i]t takes thirty seconds to write a prescription for Valium but thirty minutes to explain why a patient shouldn’t have it” (Tone 2009). The framework of lifestyle uses and non-medical wishes imply a certain level of individual autonomy in setting goals for how one wants to look and feel while promoting the use of substances as normal levels of performance are redefined.

Prescription abuse

Prevalence studies on the non-medical use of prescription stimulants have portrayed it as prescription drug abuse (Forlini and Racine 2009a). Methylphenidate, in particular, has some of the highest rates of non-medical use among prescription medications (Levine 2007). In recent years, Canada has ranked fourth internationally for use of sedative-hypnotics and was among the top fifteen countries for the use of prescription stimulants (Haydon et al. 2005; Canadian Centre on Substance Abuse 2007). With so many prescriptions for stimulants circulating, it has been suggested that high rates of non-medical use are due to the availability of diverted prescriptions (Schepis et al. 2008). Chapter 1 listed the known risks of prescription stimulants that have sparked a discussion about whether non-medical uses, and cognitive enhancement with them, are a public health problem. Indeed, the non-medical use of stimulants has resulted in an increase in emergency room visits from side effects of the drugs caused by dosing errors and negligence of contraindications (Bogle and Smith 2009). However, in contrast to what some call a *public health* problem, others describe a potential *medical* problem whereby individuals are self-medicating with stimulants to alleviate the symptoms of undiagnosed AD/HD (Rabiner et al. 2009; Peterkin et al. 2011; Outram 2012). The prescription abuse approach to enhancement puts emphasis on the availability of medications- whether too much or not enough- bringing scrutiny onto the medical profession that is officially responsible for the distribution of prescription medications.

The medical ethics of cognitive enhancement

One of the most contentious points in the cognitive enhancement debate, only beginning to be addressed, is the role of healthcare professionals (Bush 2006; Schermer et al. 2009; Synofzik 2009; Singh and Kelleher 2010). Though the treatment/enhancement distinction may exclude

prescribing medications for cognitive enhancement from the duties of a physician, they are currently described the “gatekeepers” of these substances (Chatterjee 2004). As a result, there have been calls for guidance for medical professions to inform how they might approach cognitive enhancement (Outram and Racine 2011). Contemporary guidance imposes no ethical restriction or obligation to prescribe medications for enhancement purposes though this guidance may change as new research on stakeholder perspectives and perhaps the safety and efficacy of medications themselves emerges (British Medical Association 2007; Larriviere et al. 2009).

Guidance from the Ethics, Law and Humanities Committee of the American Academy of Neurology (AAN), a leading neurological society, has stated that prescribing medications for cognitive enhancement is “1) not ethically obligatory, 2) not ethically prohibited and therefore, 3) ethically permissible” (Larriviere et al. 2009). Additionally, the AAN specified that refusing to “prescribe medications for neuroenhancement is ethically and legally permissible” (Larriviere et al. 2009). Thus, according to the AAN guidance, physicians can, but are not obliged to, grant requests for cognitive enhancement. This guidance has been criticized for its permissive approach despite a lack of efficacy evidence (Boot et al. 2012) and its lack of attention to the broader social context that may encourage patient requests for cognitive enhancement (Racine and Forlini 2010a).

The different definitional approaches discussed above can affect the responsibility of healthcare providers each in their own right. For instance, if the non-medical use of prescription medications were deemed outside the realm of medicine, could individuals be missing out on the valuable oversight of medical professionals given the harms associated with the medications being used? Considering this type of cognitive enhancement as treatment raises the deep ethical concerns for doctors’ “playing God” (Hotze et al. 2011), which connects to Sandel’s giftedness

objection of human enhancement. In contrast, physicians might be criticised for promoting the misuse of medications if they prescribed them to patients for enhancement purposes. Some have warned about physicians becoming “lifestyle consultants” (Chatterjee 2007) through their prescription pads. However, just because physicians “play a de facto role” in gate keeping the technologies used for enhancement does not mean that this is the role they should be playing (Asscher et al. 2012). Indeed, some authors have argued that it is not appropriate for the medical profession to be correcting social injustices by helping individuals meet academic or professional expectations for performance with medications (Dees 2004). Nor is it the place of the medical profession alone to curb the non-medical use of prescription medication for enhancement purposes (Rosenfield et al. 2011). Nonetheless, the role physicians play, is in part dependent upon the definition of cognitive enhancement and respective ethical framework is adopted. Physicians might be in a position to promote cognitive enhancement through a lifestyle framework or serve in the prevention efforts against prescription abuse.

Ethical, legal and social issues surrounding cognitive enhancement

Debate on the ethical, social and legal issues related to cognitive enhancement has been firmly grounded in academia and has yielded highly polarized viewpoints ranging from “cognitive liberty” (Sententia 2004) to “pharmacological Calvinism” (Kramer 1997) mirroring the debate over human enhancement in general (President's Council on Bioethics 2003; Caplan and Elliott 2004; Parens 2006; Caplan and McHugh 2007). Many of the arguments in the debate on general human enhancement are argued similarly in the context of cognitive enhancement. Below is a brief overview of the issues that will be addressed in more detail within Chapters 4, 5, 6, and 7. These issues are introduced according to how they are considered ethically problematic on individual or social levels. On an individual level, cognitive enhancement raises questions about

authenticity, identity and personhood as well as autonomy of the individual, freedom of choice and coercion. On a social level, the concerns are for justice and fairness in the use of cognitive enhancement in competitive environments.

Authenticity, identity and personhood as a result of cognitive enhancement

What is referred to as "authenticity" in the ethics debate on cognitive enhancement is typically the issue of whether enhancing any part of an individual's cognition through changes in neurochemistry might also alter characteristics fundamental to their identity (Parens 2005; Bolt 2007; Riis et al. 2008; Bublitz and Merkel 2009). Distinctions have been made in the ways authenticity is understood: (1) authenticity is based on what is valuable to an individual ("wholeheartedness"); (2) authenticity is based on honesty and autonomy in choices one makes (existentialist account); and (3) authenticity is based on a "true self" that is composed of gifts to a certain extent (Erler 2011). Arguments against cognitive enhancement on the grounds of authenticity are related to the discussion of human dignity reminiscent of bioconservative stances. In essence, these opponents of enhancement believe that "biotechnological enhancement fundamentally alters the essence of what it means to be an individual" (Bush 2006). However, Levy argues that "[t]o be authentic is to find one's way in life and one's values *within*; it is to make one's entire life an expression of who one truly is" (Levy 2007). This view is consistent with wholeheartedness as long as an individual identifies with the trait(s) transformed through cognitive enhancement (DeGrazia 2000). After all, traits (i.e., the components of cognition) are not static and can change over time as a result of experience and learning.

Cognitive enhancement can be a way to pursue a desired trait and ultimately self-actualize whether it is through changing one's disposition or reaching a certain performance level (Kramer 1997). In contrast, cognitive enhancements are also considered shortcuts in changing a trait (Schermer

2007). However, some have argued that the trait remains authentic and the means appropriate as long as the choice is motivated by self-creation, based on the individual's values and self-conception, and does not distort one's view of the world (DeGrazia 2000; Dees 2007). Self-creation and self-fulfillment are lauded by the existentialist account of autonomy but criticized by bioconservatives and other authors that believe that cognitive enhancement for this end *does* change an individual. Elliott, for one, explains that self-fulfillment is a moral ideal rife with conceptions of what constitutes a "good life" (Elliott 1998). Thus, cognitive enhancements are a cure for "existential illnesses" caused by not identifying with one's traits. However, whether one's "true" self refers to what is gifted or the product of enhancement and to what extent a pharmacological cognitive enhancement severs how one feels about one's life has yet to be elucidated (Bolt 2007).

Autonomy of the individual, freedom of choice and coercion in cognitive enhancement

Considering the current practice of cognitive enhancement, individuals are left up to their own devices to procure cognitive enhancers. However, whether an individual's motivation for obtaining medication for enhancement is autonomous or the result of coercion from social pressure to perform (e.g., academic, professional, military) is currently under debate (Hall 2004; Mehlman 2004; Lev 2009). Proponents of cognitive enhancement maintain that using pharmacology to improve cognitive performance is part of a voluntary self-improvement (Caplan 2003). Likewise, the concept of cognitive liberty reflects "every person's fundamental right to think independently, to use the full spectrum of his or her mind, and to have autonomy over his or her brain chemistry" (Sententia 2004). Though the act to enhance might be voluntary, it is unclear whether "neuroenhancements may modify a person's motives or general disposition to undertake certain actions" (Bublitz and Merkel 2009). However, as with authenticity, as long as the enhancement is

voluntary and the individual identifies with the change, the action can be considered autonomous (Bublitz and Merkel 2009).

The concern of opponents of cognitive enhancement is for the ability of individuals to make free and informed choices. Explicit coercion on the part of employers, for example, has been discussed (Appel 2008) but there is also concern about more subtle pressures and influences on decision-making. Some argue that "there exist a myriad of influences on the formation of pro-attitudes that bypass rational control, depend on natural contingencies and are not self-arranged" (e.g., attributes of the natural lottery) (Bublitz and Merkel 2009). Thus, no choice is ever completely free from any influence. In addition, a truly autonomous choice is an informed choice about effects and risks (Whitehouse et al. 1997; Mehlman 2004) which is currently not entirely possible given limited data. Another type of pro-enhancement influence may exist alongside social and professional pressures. Chneiweiss asks whether it is:

> possible to hypothesize that we can become addicted to personal technologies because our brain anthropomorphizes these objects using the same networks as it does for emotion. And so the question arises: Are we still able to decide how we use it? (Chneiweiss 2011)

This question implies a type of modern slavery that arises not from other people or environments but on human dependency upon technology. Though it is beyond the scope of this thesis to answer Chneiweiss' question, reflection on how humans decide to use technology is relevant to cognitive enhancement when considering comparisons of neuropharmacology to informatics and calculators (Greely et al. 2008).

Cognitive enhancement in competition

A chief concern for both academics and stakeholders is equal distribution of neurotechnology with enhancement effects (Whitehouse et al. 1997;

Mehlman 2004; Bergstrom and Lynoe 2008; Banjo et al. 2010; Hotze et al. 2011). The arguments in favor and against equal distribution of medications for cognitive enhancement are similar to those in the general enhancement debate. However, the competitive aspects of cognitive enhancement merit additional attention because of the environments where the practice is seen to be prevalent. The treatment/enhancement distinction carries with it the implicit assumption that the primary beneficiary of cognitive enhancement is the individual. This assumption is consistent with the zero-sum model explained in the first section of this chapter, which is at the root of the perception that cognitive enhancement confers an unfair advantage. As a result, cognitive enhancement has been labeled “cheating” because the medications are expected to provide a shortcut in the work it takes to achieve a goal (Butcher 2003; Chatterjee 2004; Hall 2004; Schermer 2007). Zero-sum has evoked analogies of cognitive enhancement with sports competitions where there is a fixed number of winners and losers, and performance enhancement is “against the rules” (Savulescu 2006; Schermer 2008).

There may be some cases in which academic and professional regulations prohibit cognitive enhancement but many of the competitive situations discussed in the literature are not zero-sum. In *non*-zero-sum situations, “each advance by a participant contributes to the success of the group, so that participants have an interest in each others’ success” (Goodman 2010). In this more collaborative approach, reflective of the academic situations described by students, enhancement of one individual does not preclude another’s (perhaps unenhanced) performance. This view is more consistent with the benefits of cognitive enhancement for the common good (Vedder and Klaming 2010). Non-zero-sum situations demonstrate that not all uses of cognitive enhancement constitute cheating and are not ideally regulated by a sports-type ban (Goodman 2010). Additionally, other uses of cognitive enhancement such as the example of memory enhancement to improve eyewitness testimony

presented by Vedder and Klaming (2010) can contribute to the common good[5]. The benefit to the common good is an important consideration for judging the fairness of cognitive enhancement in competitive situations and especially highlights the incongruence of analogies to sports doping that are prevalent in ethics discourses.

Broader implications of cognitive enhancement

In addition to these specific ethical issues, cognitive enhancement may bring about broader social implications as explained by Whitehouse et al.'s hypothesis that "we cannot change ourselves without disturbing that larger web of identities" so that "personality changes are by necessity a community event and should be undertaken as such" (Whitehouse et al. 1997). The question is whether the cognitive enhancement of healthy individuals using prescription medication can occur in a way that does not encroach on the liberty of individuals in a democratic society while benefiting the common good (Hall 2004; Vedder and Klaming 2010). But for all of the ethical debate and hand-wringing, Persson and Savulescu (2008) posit that the human race is not morally capable of using cognitive enhancement responsibly. Their solution is that "moral enhancement should accompany cognitive enhancement, since the latter is a means that could be put to both good and bad uses" (Persson and Savulescu 2008). Whether moral enhancement will promote more thoughtful uses of cognitive enhancement technologies is a valuable question to pursue but our current understanding of the "neuroscience of ethics" does not permit moral enhancement as such[6]. In the meantime, research efforts still need to be directed toward further understanding and deliberating on the ethics

[5] Glannon rightly acknowledges that there are potential "trivial" uses of cognitive enhancement that do not contribute to the common good but would not constitute a competitive good (e.g., memorize phone numbers or sports statistics) (Glannon 2008).
[6] The hormone oxytocin ("love hormone") is being discussed as moral enhancer that promotes trust and bonding in relationships (Savulescu and Sandberg 2008).

of current non-medical use of prescription medications by healthy individuals for cognitive enhancement.

Gathering and including stakeholder perspectives in the ethics debate on cognitive enhancement

Cognitive enhancement has spurred heated discussions about ethical and social issues among academics in various fields as well as in the popular media (Forlini and Racine 2009a; Talbot 2009; Partridge et al. 2011; Schwarz 2012). Discussions on the ethics of cognitive enhancement have evoked the perception of (1) the strong need for professional guidance, (2) the urgent need for social discussion, (3) estimates of high prevalence and widespread demand for enhancers (Outram and Racine 2011). Based on these motivators, the AAN, British Medical Association and a Canadian government committee (Commission de l'éthique de la science et de la technologie) have developed discussion papers and guidelines on how to approach the practical aspects of cognitive enhancement in an ethical manner based on assumptions that cognitive enhancement is a well-established and understood phenomenon (British Medical Association 2007; Larriviere et al. 2009; Commission de l'éthique de la science et de la technologie 2009; Outram and Racine 2011). However, results from previous and ongoing studies have highlighted significant differences within academic ethics debates as well as between the academic and broader stakeholder perspectives (Sabini and Monterosso 2005; Bergstrom and Lynoe 2008; Riis et al. 2008; Forlini and Racine 2009a; Forlini and Racine 2009b; Banjo et al. 2010; Forlini and Racine 2011a; Dodge et al. 2012; Forlini and Racine 2012a). These differences range from diverging definitional approaches and perceptions of prevalence to polarized stances on ethical, legal and social issues. There is, thus, a need to identify and explore these differences in order to foster a more comprehensive debate on the ethics of cognitive enhancement. Stakeholders can be an important source of evidence to be used in determining what these broader social implications are and how they are

related to the ethical issues identified in the academic ethics literature. Indeed, stakeholder and public engagement is promoted in the field of neuroethics to increase understanding of and dialogue about the applications of neurotechnology (Illes et al. 2005; Racine et al. 2005; Illes et al. 2010; Racine 2010). One area in which stakeholder perspectives would be especially important for cognitive enhancement is in determining what the potential and appropriate policy approaches are. Nadler and Reiner propose that an empirical approach is necessary to resolve the regulatory question of how to deal with cognitive enhancement by "[d]iscerning whether people, by and large, tend to approach this issue as cool-headed technocrats or principle-driven moralists" (Nadler and Reiner 2011). The findings of studies examining stakeholder perspectives will be compared and contrasted with each of the segments of results presented in this thesis.

CHAPTER 3: Methodological approaches

Chapters 4, 5 and 6 report the results of a qualitative study examining stakeholder perspectives on the ethical and social issues related to the non-medical use of methylphenidate for academic performance enhancement by healthy university students. In this chapter, the methodological approach to the data collection is explained. First, the relation of empirical research to normative stances in bioethics is explored. Second, the contribution of a qualitative methodology, specifically, to empirical ethics is discussed. The remainder of this chapter is devoted to describing the specific methods used to gather and analyze stakeholder perspectives.

Using empirical approaches to inform normative reasoning

The word ethics is typically used in reference to "the systematic and rigorous examination of moral norms" (Amundsen 2001). Moral norms can be used differentiate between right and wrong behaviors. In bioethics, these right and wrong behaviors concern advances in biomedical science and how they affect the way we conduct research, practice medicine and live together in society. Ultimately, ethics is a prescriptive and action-oriented field of study seeking to respond to the question of: "what should I do?" (Durand 1999). How this question is best answered and what information must, should, or could be considered to guide the choices is in itself an area of methodological debate.

The work in this thesis draws upon two sources of wisdom that are present in the ethics debate around cognitive enhancement. Principles and theories about what is good can be used in moral reasoning to guide action (normative ethics). In an interdisciplinary field such as bioethics, moral principles have historical, religious, professional, and social roots (Amundsen 2001). Though several normative principles are common to many bioethics debates (e.g., autonomy and justice) the approach taken

toward these principles in determining right and wrong courses of action can radically change human experience (Parker 2009). For example, models of the physician-patient relationship based on varying levels of patient autonomy and physician paternalism affect medical decision-making. The debate between the bioconservative and bioliberal position in cognitive enhancement is a good example of the way different approaches to principles yield different outcomes for action. However, several authors have argued that it is "not only sufficient for an ethicist to discuss the moral rightness or wrongness of a certain practice on a theoretical level, but also to think about the conditions under which a norm can be effective in society" (Birnbacher 1999) (de Vries and Gordijn 2009; Salloch et al. 2012). The concern here is for successful implementation of the fruits of moral reasoning. Indeed, this is the type of criticism of mainstream bioethics that spurred what has been called the "empirical turn" (Borry et al. 2005). This second source of wisdom (empirical ethics) describes how bioethics can use "real facts in normative reasoning, becoming an empirical discipline through a shift to the social and neurosciences, and conducting empirical research to inform normative reasoning" (Hurst 2010). The results presented in Chapters 4, 5 and 6 are part of an empirical ethics approach to cognitive enhancement that has aimed to consider and discuss normative frameworks in light of data.

Meta-ethical challenges in reconciling normative and empirical ethics to bring about the right choices have caused the two approaches to be somewhat isolated one from another. These challenges result in trying to equate normative statements about what "ought" to be done and empirical observation about what "is" done or in deriving one from the other. De Vries and Gordijn (2009) describe three specific challenges that have plagued relations between normative and empirical ethics. The first is the "is-ought problem", originally proposed by Hume, which describes "the fallacy of drawing an ought-conclusion from a set of is-premises" (de Vries and Gordijn 2009). The second is the "naturalistic fallacy" introduced

by G.E. Moore that states it is impossible to define the predicate good much less with any data. The third challenge is a combination of meta-ethical views named the “fact-value distinction” maintaining that scientific facts are value-free. However, the goal of empirical ethics is to “defend or criticize concrete moral principles or practices” rather than making claims about moral concepts in general (de Vries and Gordijn 2009). From this perspective, the way in which empirical ethics creates a forum to question and reassess the principles and practices involved in contentious issues matters more than whether the results of empirical studies are able to definitely solve meta-ethical issues (Molewijk and Widdershoven 2012; Schicktanz et al. 2012).

By assimilating facts into normative reasoning, proponents of empirical ethics argue that an empirical approach better equips bioethicists to “grapple first hand with value conflicts in real life situations” (Shelton 2008). Real life situations often present situations beyond what can be created in a normative setting that present limitations in human agency (Potter 1971; Hurst 2010). The first-hand account of value conflicts can help reshape our understanding of theoretical structures and their relation to practice so that the principles being discussed are relevant to the decisions people are making (Shelton 2008; Leget et al. 2009; Frith 2012; Salloch et al. 2012). Studies in empirical ethics can also identify “the areas where normative analysis is most needed, acting as a guide to bioethicists who may be inclined to focus on more esoteric problems and ethical puzzles that are interesting to them” (Leget et al. 2009). In reshaping and focusing normative reflection, empirical ethics can help bioethicists “move from moral vision and ethical analysis to ethically justifiable behavior” (Solomon 2005) in a way that is mindful of limitations in decision-making and has the potential to be a viable guide for action in an ethical dilemma (Schicktanz et al. 2012).

A qualitative methodological approach to study stakeholder perspectives on cognitive enhancement

There are several methods, mainly from the disciplines of sociology and anthropology, that empirical ethics draws upon to collect data. Two of these empirical approaches, quantitative and qualitative, will be compared in this section to explain the choice of method for this study. The normative ethics literature on cognitive enhancement provides ample discussion over what the important issues *might* be in determining right and wrong actions regarding cognitive enhancement. However, this literature cannot describe compliance of stakeholders with the moral norms prescribed or test whether policies are followed or have been effective (Sugarman and Sulmasy 2001). The empirical data collected for this thesis aims to identify and analyze ethical, social, medical and scientific issues regarding the emerging practice of cognitive enhancement as perceived and experienced by various stakeholders. The data collected on stakeholder perspectives can shed light not only on the actual practices of stakeholders but also on their understanding of normative principles as discussed in the literature. Empirical data helps ethics reach its goal of guiding action by increasing relevance to social and cultural context, which can affect whether ethical principles can be followed in practice.

Identifying issues in an ethical dilemma can be achieved using quantitative or qualitative methods. These two methodological approaches differ in the type of information obtained and the conclusions that can be gleaned. Quantitative methods can help to observe interactions by recording and quantifying particular behaviors and beliefs in populations of interest (Sugarman and Sulmasy 2001). Quantitative studies often use surveys to gather data because they are simple, easy to administrate, pose limited risks to participants and are adaptable to many types of phenomena (Pearlman and Starks 2001; Gauthier 2006). Surveys can assess current practices or use vignettes to inspire an ethical reflection and reaction from participants. One major advantage is the potential to

question large samples that can be used to test hypotheses and observe generalizable associations by means of statistical analysis. Quantitative surveys have had a role in identifying cognitive enhancement as a motive for non-medical stimulant use and in providing an indication of the prevalence of the practice (Graff Low and Gendaszek 2002; Hall et al. 2005; Teter et al. 2005; Teter et al. 2006; White et al. 2006; Franke et al. 2011). They have also proven useful in measuring willingness to consume and prescribe medications and other substances for enhancement purposes (Bergstrom and Lynoe 2008; Banjo et al. 2010; Hotze et al. 2011) and conditions for acceptability regarding authenticity and fairness (Sabini and Monterosso 2005; Riis et al. 2008). A disadvantage of quantitative surveys is the limited description of attitudes that can come from yes/no or multiple choice answers to survey questions. Another disadvantage is that the approach is limited to the questions the investigator chooses to include and there is not always room for spontaneous comments from the participants. Quantitative methodology can observe and record practices, but are limited in their ability to engage participants for a richer understanding of ethical dilemmas.

Qualitative methods, in particular, allow researchers to inquire “into the meaning individuals or groups ascribe to a social or human problem” (Creswell 2007) and understand what experiences, beliefs or attitudes are associated with the phenomena being studied (Hull et al. 2001). Data collection is open-ended and flexible such that researchers can adapt it to assumptions, biases, participant reactions and novel perspectives that arise during the collection process. Qualitative methods such as surveys, interviews and focus groups employ questions that are “discovery oriented, descriptive and exploratory” to yield rich data that takes context into consideration for a holistic approach to issues under study (Hull et al. 2001). Two interview studies with university students have contributed to the landscape of the cognitive enhancement debate. One examined general attitudes of students regarding issues such as cheating and peer

pressure (Bell et al. 2012). The other provided depth in comparisons of the use of medications with the use of caffeine for cognitive enhancement (Franke et al. 2012a). The depth of qualitative data and its relevance to specific populations limit the generalizability of findings but can generate large amounts of data for analysis (Hull et al. 2001; Simon and Mosavel 2008). This type of data collection is influenced by biases and subjectivity of investigators because they are immersed in the analysis of data more so than during quantitative inquiry. However, precautions can be taken to increase the reliability of qualitative data by using peer review or checking back with participants to verify the researcher's interpretation of data (Hull et al. 2001). From the point of view of scope and depth, quantitative and qualitative methods are complimentary approaches to characterizing the ethical landscape of a phenomenon. At present, the ethics debate around cognitive enhancement largely academic and the practice is poorly understood from an experiential point of view. Therefore, qualitative research methodology was chosen to gather information about stakeholder perceptions and experience regarding cognitive enhancement. The results of this study are reported in Chapters 4, 5 and 6.

Methods used to examine stakeholder perspectives

The "focus group" discussion is the qualitative tool used in this thesis to gather stakeholder perspectives on the use of methylphenidate by North American university students to enhance academic performance. A focus group discussion is typically a sample of five to ten participants and a moderator that guides the discussion (Morgan and Krueger 1998). The moderator asks questions based on the phenomenon of interest to stimulate discussion around the topic under study. Participants generally address their responses to the group so that other discussants have the opportunity to respond and react. The moderator can ask follow-up questions to more closely explore a specific area of interest or

spontaneous ideas that arise during the discussion. Such group interviews allow for rich and detailed responses where participants can react in real time to debates evoked during the discussion and perhaps to novel points of view from other participants (Morgan and Krueger 1998; Hull et al. 2001). These kinds of discussions have been used in bioethics to "shed light on the diversity of views, opinions and experiences of individuals and groups" on different types of issues (Simon and Mosavel 2008) and to understand why they hold specific views on certain issues (Hull et al. 2001). To date, focus groups have not been used to examine stakeholder perspectives on cognitive enhancement. A focus group discussion was the most appropriate tool to use in this qualitative study, which aimed to discover the perspectives of three stakeholder groups. By grouping stakeholders, participants were able to work through and elaborate upon their respective points of contention on the ethics of cognitive enhancement. Because of their focus on the individual, a survey or interview study could not have fostered the ethical deliberation being sought.

Participants

Participants consisted of three groups: university students twenty-five years old and younger, parents of university students, and healthcare providers (HCP). The prevalence of the non-medical use of methylphenidate in university student populations has been widely studied and provided a concrete and well-documented example of cognitive enhancement for further discussion (Teter et al. 2003; Barrett et al. 2005; Arria and Wish 2006; Teter et al. 2006; Wilens et al. 2008). The age limit on university students (25 years old and under) reflects data showing that the practice exists mainly among undergraduate students in this age range (Babcock and Byrne 2000; White et al. 2006). For the purposes of this qualitative project it was important to recruit a student (undergraduate and graduate) sample that was familiar with the context and motives

described in prevalence studies on the non-medical use of stimulants. Parents of university students provided a generational difference and they are directly connected to education in both the academic and moral senses. These parents had children that were currently pursuing university studies. Parents also provided a general public perspective, as these participants were not selected for level or education, profession or age. Healthcare providers work closely with medications in the treatment of disease making their perspective on the repurposing of methylphenidate for enhancement of interest to this study. Physicians have been identified as key stakeholders in cognitive enhancement given that they are often described as the *gatekeepers* of the medications used as cognitive enhancers due to their role in prescribing (Chatterjee 2004; Synofzik 2009; Singh and Kelleher 2010). In order to facilitate recruitment and broaden the perspective beyond having the potential to prescribe medications, a healthcare provider was defined as someone having a professional responsibility to care for the health of patients (e.g., doctors, nurses, pharmacists). No particular expertise with methylphenidate was required so that no bias regarding experience with the substance (consuming or prescribing) was deliberately introduced.

Recruitment

The study and the recruitment strategies were approved by the Research Ethics Board (REB) of institutions of the Institut de recherches cliniques de Montréal and the Faculty of Medicine at McGill University[7] (see Appendix B for letters of approval). The flyers and advertisements used to recruit participants can be found in Appendix B. English and French recruitment advertisements were posted in common areas of McGill University and Université de Montréal campuses. Advertisements were featured in general newspapers (Journal Métro and Journal 24 Heures which are

[7] Dr. Roberta Palmour of the Department of Psychiatry at McGill University served as the principal investigator for the project at the Faculty of Medicine.

distributed for free in the Montréal subway system) and student newspapers (McGill Daily, Journal Forum (Université de Montréal), The Link (Concordia University)) as well as online classified sites (McGill Classifieds). E-mail invitations were sent to major student associations and health services at McGill University and Université de Montréal as well as faculty members in healthcare professions (e.g., medical specialties, nursing, pharmacy). Participants received a fifty-dollar compensation for the time involved in preparing for and participating in the focus groups.

Focus group discussion

To minimize recruitment bias and encourage participation of non-experts, participants remained unexposed to the specific subject of the discussion (cognitive enhancement with methylphenidate) until they received the documentation package. The advertisements promoted a discussion about the non-medical use of prescription medications. They mentioned neither methylphenidate nor cognitive enhancement. This package included a print media sample of four articles, a consent form and a short questionnaire (Appendix C). Print media coverage of cognitive enhancement with methylphenidate served as a basis for discussion as it is an important source of information and interaction for the public with regard to neuroscientific innovation (Racine et al. 2005; Racine et al. 2006; Racine et al. 2007). The articles were chosen from a systematic print media sampling of a prior discourse analysis (Racine and Forlini 2010a). To maximize the scope of the focus group discussion, articles were selected to reflect variability in content (e.g., details about how students obtain pills, effects, and testimonials), quality of information, overall coverage of ethical issues, length, and country of origin (Laurance 2003; Zernike 2005; Morency 2006; Ross 2006). After reading the articles, participants were asked to fill out an anonymous questionnaire collecting demographic data and information about prior knowledge of cognitive enhancement with methylphenidate. The complete results of this

questionnaire are reported in Chapter 4. The discussions were audio recorded for transcription purposes and video-taped as a safeguard.

The composition of each focus group was homogeneous. The three stakeholders groups were not mixed in order to create an environment where participants would feel comfortable sharing their opinions and experiences with other individuals in similar situations (Morgan and Krueger 1998).The interview grid for the focus groups was based on the results of prior discourse analysis (Racine and Forlini 2010a). This discourse analysis incorporated perspectives from ethics, public health and the media. As a result, the interview grid is representative of different points of view and not simply derived from the academic ethics literature. Before the focus groups, the grid was tested with three pilot interviews to verify coverage of issues as well as clarity of questions and wording. At the beginning of each focus group discussion, participants were invited to comment generally on cognitive enhancement. This first round of comments collected participants' spontaneous reactions toward cognitive enhancement. Follow-up questions in the second part of the interview grid were focused on specific ethical, social and legal issues related to cognitive enhancement. Participants were also asked to comment on the potential social and healthcare impacts of cognitive enhancement as well as solutions to challenges identified. Finally, participants were asked to give their impression on the media coverage of methylphenidate for cognitive enhancement based on the prompt material. The focus groups were moderated by one of the authors (Eric Racine) to allow spontaneous expression of opinions while ensuring the most possible complete coverage of the topics included in the interview grid. The other author (Cynthia Forlini) assisted the moderator and took field notes.

Coding

Each focus group was transcribed verbatim by the candidate and a research assistant. Transcripts used for data analysis used the

alphanumeric code attributed to the participants at recruitment instead of their names. The transcripts were coded systematically using QSR NVivo 7 software (Doncaster, Australia) according to the coding guide in Appendix D. The coding guide was piloted with the transcript of one focus group to test coverage of nodes and definitions (which serves as inclusion criteria for the nodes) (Neuendorf 2002). The nature of the changes made to the coding guide specified the major nodes with sub-nodes but did not add any major themes. Further coding did not reveal any themes that required the coding guide to be amended. One author (CF) coded the transcripts initially. The other author (ER) reviewed the coding for each node for fit to the data. Disagreements were resolved by deliberation and settled in a consensus between the two authors. Participant comments were included in a node if they met the definitions specified in the coding guide (Appendix D).

The coding guide identified major themes and issues from lay, bioethics and public health discourses on cognitive enhancement and followed the structure of the interview grid (Forlini and Racine 2009a). The first part of the coding guide captured (1) stakeholder reactions to cognitive enhancement; (2) stakeholder views on common analogies; (3) descriptions (definitions) of and views on cognitive enhancement. The second and third parts dealt with ethical, social, and legal concerns related to cognitive enhancement. The ethical, social, and legal issues examined included: (1) autonomy and coercion (2) abuse; (3) authenticity of the individual; (4) cheating; (5) commercialization; (6) illegality; (7) justice; (8) overprescription, and (9) social meaning. The third part, in particular, explored healthcare aspects including physiological effects, psychological effects and safety of methylphenidate use for cognitive enhancement. The final part of the coding guide recorded perspectives on the media coverage of cognitive enhancement based on the prompt materials that were provided.

Figure 6.1 shows the overall methodological approach for coding and analysis specifically for the ethical issues discussed during the focus groups. Within the codes for each of the ethical, social, and legal issues in the second and third parts of the guide, participants' statements were further categorized in order to identify participants' positions on the ethical issues (See section 1B of Figure 6.1). If a participant's statement expressed that the issue in question posed an ethical, social, legal problem or had a significant impact it was coded as an "affirmation". If, on the contrary, a participant's statement denied the existence of a problem or its impact, it was coded as a "negation". Statements that mentioned an issue but neither affirmed nor negated a problem, or represented both points of view were coded as "neutral". Likewise, if the statements clearly indicated that the speaker was uncertain, the code "neutral" was applied.

Analysis

The analysis of coded statements began by breaking down the content of each node by stakeholder group. This step generated large data tables with separate columns for students, parents and healthcare providers and was conducive to comparing the perspectives of the three groups to observe convergences and divergences (Morgan and Krueger 1998). Statements were read and briefly summarized with a few keywords. The summaries allowed statements to be grouped into sub-themes that were explanatory of the position adopted by participants in each stakeholder group. The connection of statements with the themes identified were discussed and agreed upon by the two authors. The themes were compiled in another document which noted the gross proportion (i.e. major or minor view) of themes and identified striking examples. For the content of Chapter 5, the Nivo software was used to carry out fine-grained analysis of the sub-themes regarding autonomy and coercion in cognitive enhancement to identify paradoxes in the points of view of participants.

This analysis used matrices to indicate instances where a participant argued for both autonomous choice and coercive factors.

The analysis of coded statements regarding ethical, social and legal issues in Chapters 5 and 6 was twofold. First, the acknowledgement (or lack of acknowledgement) of a substantial ethical question for each issue was examined to determine *whether* an issue was contentious or not (affirmation, negation and neutral). Then, the specific arguments for each side were examined to determine the *extent* of contention. These specific arguments are presented in Table 6.1 as well as Figures 6.2-6.5. Bold italic fonts provide the broader themes underlying the specific positions taken on particular ethical issues. These themes were identified in the same manner as for other nodes (previous page). The relative proportion and qualitative diversity of the arguments in the affirmation, negation, and neutral categories determined the extent (highly or moderately) to which a specific ethical issue was contentious or not. An ethical issue judged to be "highly contentious" had a comparable number of affirmation and negation statements or a rich variety of qualitative arguments pertaining to either affirmations or negations. Typically, a highly contentious issue contained ethical debate about the underlying reasons for or against cognitive enhancement. An issue was categorized as "moderately contentious" if it was acknowledged as raising ethically significant questions but affirmations or negations occurred without substantial debate on the underlying reasons for or against the ethical issue. In this fashion, a moderately contentious issue indicated either a consensus issue among stakeholders or that the particular issue did not appear to raise a substantial ethical debate (Figure 6.1 section 2A).

The second level of analysis consisted in building a model of the relationships between the ethical issues (Figure 6.1 section 2B). Parsing the arguments given for the affirmations and negations of the ethical issues revealed specific arguments that often had common underlying values (personal effort, honesty, and equality), external factors (legal

regulation, commercialization), or subsequent consequences (education, medicalization) of the non-medical use of methylphenidate. The relationships were determined by looking for overlapping or related arguments from the broader themes identified in the analysis documents and original transcripts to articulate a global understanding of how the ethics issues affected each other.

Limitations

Some aspects of the qualitative nature of this project limit the generalization of the results and should be taken into consideration for the proper interpretation of the results. First, due to the small sample, the opinions expressed in the focus groups cannot be considered to represent general opinions of students, parents and healthcare providers. The results can serve to illustrate some of the potential convergences and divergences between the perspectives of each group but further research and analysis is needed. Second, participants were given four representative media articles to read prior the focus group but despite the range of topics covered in these articles, they represent a specific type of prompt that has its advantages (e.g., real source of information intended for general readership that was not created by the researchers) but also its disadvantages (e.g., not addressing in detail every ethical and social issue related to cognitive enhancement). Also, though the UK and Australia media are represented in this prompting material, the way in which cognitive enhancement was depicted reflected mostly a largely North American phenomenon. Third, focus groups are discussions and not surveys. Thus, not all participants commented on every question. Accordingly, when we report the perspectives expressed, these perspectives should be considered as those that were explicitly and *de facto* expressed – not necessarily all that could be expressed. Fourth, our focus groups were conducted in English (given the English-language prompts) but our recruitment included individuals with different mother

tongues and this could have an impact on how participants expressed themselves. Fifth, some difficulties in data capture (e.g., failed recordings of some comments) and subsequent transcription caused a very small part of participant statements to be unsuitable for analysis. Sixth, the demographic questionnaire that was administered before the focus groups asked participants to specify their professions, however, the questionnaire did not inquire whether the participants had children. Thus, there is no record of the proportion of healthcare providers that were also parents.

CHAPTER 4: Stakeholder perspectives and reactions to "academic" cognitive enhancement: unsuspected meaning of ambivalence and analogies. *Public Understanding of Science*. (2012). 21 (5): 606-625.

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Abstract

The existence of diverging discourses in the media and academia on the use of prescription medications to improve cognition in healthy individuals, i.e., "cognitive enhancement" (CE) creates the need to better understand perspectives from stakeholders. This qualitative focus-group study examined perspectives from students, parents and healthcare providers on CE. Stakeholders expressed ambivalence regarding CE (i.e., reactions to, definitions of, risks, and benefits). They were reluctant to adopt analogies to performance-enhancing steroids and caffeine though these analogies were useful in discussing concepts common to the use of different performance-enhancing substances. Media coverage of CE was criticized for lack of scientific rigor, ethical clarity, and inadvertent promotion of CE. Ambivalence of stakeholders suggests fundamental discomfort with economic and social driving forces of CE. Forms of public dialogue that voice the unease and ambivalence of stakeholders should be pursued to avoid opting hastily for permissive or restrictive health policies for CE.

Keywords: cognitive enhancement, neuroethics, stakeholder perspective, ambivalence, media coverage, focus groups

Introduction

The non-medical use of prescription medications to enhance human cognition (e.g., concentration, memory, alertness) in healthy individuals is often described as "cognitive enhancement" (CE). Studies indicate that methylphenidate (MPH; Ritalin), a common treatment for Attention-Deficit/Hyperactivity Disorder (ADHD), is being used by university students for non-medical CE purposes in proportions ranging from 4% to 11% (Racine and Forlini, 2010; Wilens et al., 2008). Combined with growing bioethics debate and media coverage, these studies on the non-medical uses of stimulants in university students provide a current and well documented example of CE. Proponents of CE in academic bioethics have argued that CE, "has much to offer individuals and society" (Greely et al., 2008). However, others contend that it is premature to declare CE beneficial given existing knowledge gaps (Racine and Forlini, 2009) including limited evidence of its safety and its efficacy in enhancing cognition of healthy people (Barch and Carter, 2005; Bray et al., 2004; Elliott et al., 1997; Mehta et al., 2000). Further,

little attention has been paid to the social context and social factors involved in CE practices. A recent study on autonomy and coercion in CE found that stakeholders (students, parents, healthcare providers) described enormous social pressures to perform, which may in themselves entice use of cognitive enhancers (Forlini and Racine, 2009a). Other studies on the attitudes of the public and stakeholders found general discomfort with CE in the general public and among healthcare providers (Bergstrom and Lynoe, 2008) as well as issues with the justice and fairness of using such medications in competitive environments (Sabini and Monterosso, 2005). Data on how different stakeholder groups view CE on both an ethical and social level is currently sparse but indicate that information about the social aspects of CE may be lacking.

Examining stakeholder perspectives and public appreciation of the ethical and social issues of CE has been suggested to broaden the CE debate and gain further insights into social and contextual aspects of CE (Racine and Forlini, 2009). Currently, stakeholders face a potentially difficult challenge in sorting through the diverging discourses on CE (Forlini and Racine, 2009b). Academic bioethics has generated some optimistic accounts of the impact of CE on society (Greely et al., 2008) despite an unclear understanding of the perspectives of stakeholders and the broader public (Racine and Forlini, 2009) while public health discourses are structured around negative labels like “prescription misuse” and “prescription abuse”. North American and international media have discussed CE as a lifestyle choice referring mainly to the North American context and evoked the issue of ‘pharmaceuticalisation’ with regard to CE (Williams et al., 2008). Research on the media coverage of modafinil, a sleep cycle regulator often associated with CE, has also revealed the use of different frameworks. On the one hand, modafinil is constructed as a “wonder drug” (Williams et al., 2008) and product that can help control sleep (Coveney et al., 2008). On the other hand, media discourses on this topic have voiced cultural and social concerns about the regulation of sleep cycles with modafinil especially for enhancement purposes (Coveney et al., 2008; Williams et al., 2008). Though the different discourses in bioethics, the media, and public health create a rich set of co-

existing perspectives, they may complicate the stakeholders' take on the current controversy surrounding CE. This study aimed to better understand stakeholder reactions to and comprehension of CE for performance enhancement in the academic setting in order to address the need to gather more grounded and social perspectives on CE.

Methods[8]

Participants

Three groups of participants were selected, university students 25 and under, parents of university students and healthcare providers (HCP). The prevalence of the non-medical use of methylphenidate in university student populations has been widely studied (Wilens et al., 2008). The age limit on university students reflects data showing this practice exists among undergraduate students (Babcock and Byrne, 2000; White et al., 2006). Parents of university students reflect a generational difference and are directly connected to university education. Healthcare providers work closely with medications to treat disease making their perspective on the repurposing of MPH for enhancement of interest to this study. A HCP was defined as someone having a professional responsibility to care for the health of patients (e.g., doctors, nurses, pharmacists). No particular expertise with MPH was required.

Recruitment

The study and the recruitment strategies were approved by the Research Ethics Board (REB) of institutions where the study was conducted. English and French recruitment advertisements were posted in common areas of two Montréal area universities and affiliated institutions. Advertisements were also featured in various Montréal general and student newspapers as well as online classified sites. E-mail invitations were sent to major student associations and faculty

[8] The data presented in this article is part of a larger study of which the methodology and other non-overlapping data have been previously published (Forlini and Racine, 2009a).

members in healthcare professions. Participants received a fifty dollar compensation for participating.

Focus groups

Focus groups allowed us to gain insight into stakeholder perspectives as opposed to those of individuals. To minimize recruitment bias and encourage participation of non-experts, participants remained unexposed to the specific subject of the discussion (CE with MPH) until they received the documentation package. This package included a print media sample of four articles, a consent form and a short questionnaire. The articles were chosen from a systematic print media sampling of prior discourse analysis (Racine and Forlini, 2010). To maximize the scope of the focus group discussion, articles were selected to reflect variability in content (e.g., details about how students obtain pills, effects, and testimonials), quality of information, overall coverage of ethical issues, length, and country of origin (Laurance, 2003; Morency, 2006; Ross, 2006; Zernike, 2005). After reading the articles, participants were asked to fill out an anonymous questionnaire collecting demographic data and information about prior knowledge of CE with MPH.

The interview grid for the focus groups was based on the results of prior discourse analysis (Racine and Forlini, 2010) and tested with three pilot interviews. During the focus groups, participants were first invited to comment generally on CE (i.e., propose definitions and react to the frequency and social acceptability of CE) and then express their opinions regarding the ethical, social and legal issues related to CE (e.g., safety, justice and fairness). They were also asked to comment on the potential social and healthcare impacts of CE as well as solutions. Finally, participants were asked to give their impression (i.e., completeness of information, realism) on the media coverage of MPH for CE based on the prompt material. The focus groups were moderated to allow spontaneous expression of opinions while ensuring coverage of the topics included in the interview grid.

Coding

Each focus group was transcribed verbatim. The transcripts were coded systematically according to a previously used coding guide that identified major themes and issues from lay, bioethics and public health discourses on CE (Forlini and Racine, 2009b). In this paper, five themes around the non-medical use of MPH for performance enhancement are reported and discussed: (1) stakeholder reactions to CE; (2) stakeholder views on common analogies; (3) descriptions (definitions) of and views on CE; (4) physiological effects, psychological effects and safety of MPH use for CE; (5) stakeholder impression of media coverage on CE.

Results

Demographic data

Sixty-five individuals participated in one of nine homogeneous focus group discussions: 29 students (mean age 20.9 years; focus groups A, B, C); 21 parents (mean age 53.8 years, focus groups D, F, H) and 15 healthcare providers (mean age 31.9 years, focus groups E, G, I). Each participant was assigned an alphanumeric code (e.g., A1) where the letter identified the stakeholder group they belonged to and the number indicated the order in which they were recruited. Results from the demographic questionnaire (Table 4.1) show that the majority of participants were female (68%; N=44/65; S: N=22; P: N=12; HCP: N=10) and had obtained or were in the process of obtaining undergraduate or graduate degrees (86%; N=57/65; S: N=29; P: N=15; HCP: N=13). The commercial name of MPH, Ritalin, was used in the questionnaire because of its familiarity. The remaining results from the questionnaire are presented in Table 4.1 which include the participant's experience with MPH in the medical (questions 1, 2 and 3) and non-medical (questions 4, 5 and 6) contexts as well as the participant's appreciation of the media and their interest in popular science issues (questions 7 and 8).

Table 4.1: Demographic data and participants' experience with the medical and non-medical contexts of MPH use as well as appreciation of media and popular science

Question	Yes (%)			
	S	P	HCP	Total
1. Do you presently have a prescription for Ritalin?	-	-	-	0
2. Have you ever had a prescription for Ritalin?	-	10	-	3
3. Do you know someone with a prescription for Ritalin?	48	29	53	43
4. Have you ever tried Ritalin for non-medical uses?	24	-	-	11
5. Do you know someone who has tried Ritalin for non-medical uses?	69	5	33	40
6. Had you ever heard/read about Ritalin for non-medical purposes before participating in this project?	90	67	53	74
7. Do you subscribe to a newspaper or magazine?	38	67	33	46
8. Are you interested in reading about popular science? *	93	80	93	89

S: students; P: parents; HCP: healthcare providers *64 respondents answered this question

Stakeholder reactions to the non-medical use of MPH for performance enhancement

Reactions toward the non-medical use of MPH varied across groups of stakeholders (Table 4.2). Some were surprised, even shocked to learn about performance enhancement in the academic setting; others, namely students, were not surprised given the lengths to which students will go to in order to succeed. The perspectives of parents and HCP were marked by the presence of two features. The first was a strong association of MPH exclusively with the medical context, which created some confusion about how MPH could actually be used non-medically. The second was a reaction of surprise caused by the perceived frequency and extent of non-medical use of MPH. Some parents were surprised that the non-medical use of MPH was socially acceptable among students but also stated that it was not the first time substances were used to improve performance. Students suggested that MPH had become a common solution for students wanting to improve their performance but some students were also surprised that a neuropharmaceutical like MPH was being used to enhance performance. The dual reactions of students were interesting because many participants had first hand experience with the non-medical use of MPH. For example, student C10 said, “I would see my roommate crash from it. I knew it was happening.” Many students were aware of CE before attending the focus groups. As a result, among students who were surprised, many referred to their impression regarding MPH use for performance enhancement the *first* time they heard of it (during their studies) and not necessarily their reaction to the focus group and the focus group prompt material.

Table 4.2: Features of stakeholder reactions with qualitative examples toward the non-medical use of methylphenidate for performance enhancement

Features of stakeholders' surprise and shock about the non-medical use of MPH			
Description	Lengths to which students would go to perform well (S, P, HCP)*	Association of MPH with the medical context (P, HCP)	Perceived extent, frequency (P, HCP), and social acceptance (P) of non-medical use of MPH for CE
Examples	"I found out about it last year like students in my classes were taking Ritalin and I was really surprised, like "What do they need this for?" and since then I've known more, not more and more people necessarily, but it seems to be the norm now." (Student A6) "Yes, really. It shocked me, you know, because I never thought it went that far." (HCP I1)	"Well I know that young kids, in primary school, take a lot of Ritalin, and secondary school too. But I thought it was only for medical purpose, given by the doctor. I was shocked." (Parent F2) "I was very surprised because it is like abusing it. It used to be something prescribed. You used to take it for overactive children and now it is used to enhance your ability to perform." (HCP E7)	"I was more shocked than surprised by the moral ambiguity when some people think it is OK." (Parent H5) "I wasn't expecting that students were cheating this way, but sure I thought maybe 0.5% of students, but we have some statistics of 5%, something like that." (HCP E3)

Features of stakeholders' lack of surprise about the non-medical use of MPH

Description	Students will go to great lengths to perform well (S)	MPH has become a common solution for students (S)	MPH is not the first substance to be used to enhance performance (P, HCP)
Examples	"I just found out about this a few months ago but when I found out about it I wasn't necessarily surprised. Just sort of with the pressures of being in university and seeing a lot of friends crack under the pressure. A lot of students will go to great length and do almost anything to sort of enhance their academic achievement." (Student B10)	"I had first heard about it, I guess, half way through my undergrad (...). Back then yeah it surprised me in a "What do you mean? This is so unfair!" way because there was quite a bit of students using it (…). Back then I was surprised but now, quite frankly, it seems that it, everybody, it kind of got out there, got the message." (Student A9)	"Not surprised but in the 1960s and 70's, ah, students used coffee, cigarettes, and nowadays there are a lot of possibilities to use drugs." (Parent F7)

MPH: methylphenidate; S: students; P: parents; HCP: healthcare providers

*Parentheses indicate that this feature was expressed by at least one participant of this group

Table 4.3: Stakeholder reactions to analogies to performance-enhancing steroids and caffeine in reference to the non-medical use of MPH *

	Steroids	Caffeine
Same	Steroids and MPH are used for the same type of goal (S, P, HCP) Taking either MPH or steroids constitutes cheating (S, P, HCP)	Caffeine and MPH both have a risk of dependence and are used to improve performance (P)
Different	Steroids improve physical performance more than MPH improves concentration (S) MPH can be taken occasionally while steroids require long-term use (S) Athletes are more commonly regarded as role models than academics (S) Different regulation for the use of substances in sports and academics (HCP)	Caffeine does not have the same effect on concentration as MPH (S) MPH is not available over the counter like caffeine (HCP)
Ambivalent	Unsure whether the use of steroids in competition and the non-medical use of MPH are both cheating to the same extent (S)	Unsure whether the regulation of caffeine and MPH make them equivalent given that the goals underlying their consumption by students are the same (S)

*Parentheses indicate that this feature was expressed by at least one participant of this group

Stakeholder views of common analogies for the non-medical use of MPH for performance enhancement

Table 4.3 summarizes the different attitudes ("same", "different", and "ambivalent") expressed by stakeholder groups toward analogies between the non-medical use of MPH and the use of other substances like performance-enhancing steroids in sports or caffeine (coffee) in the academic environment. There was no general consensus within and between groups on the similarities and differences between MPH and these other substances. We found the views voiced by stakeholders to be

complex and sometimes paradoxical. In general, stakeholders were hesitant to consider the use of MPH as completely analogous with the use of other performance enhancing substances. The student group was especially ambivalent about whether the analogies of MPH to steroids and coffee were fair or accurate. In addition to Table 4.3, the text below provides qualitative examples of these views to illustrate how stakeholders compared and contrasted MPH to steroids and coffee.

Stakeholders considered MPH comparable to performance-enhancing steroids

Some participants from all three stakeholder groups agreed that using MPH as a study aid was akin to using performance-enhancing steroids in sports because, in both contexts, the goal is to improve performance. HCP E1 described this goal as “hyper-functioning” because “you are functioning and you want to function better.” In further support of this analogy, both sports and academia were viewed as competitive environments. The competition in both fields was compared by Student A2 who said that in sports “[y]ou want to beat the teams (…) otherwise they will replace you” and in academia “you need that ‘A’ because (…) there are so many just like you who can get your spot.” Stakeholders with this point of view also agreed that the non-medical use of MPH to improve performance would constitute cheating. Student C6 qualified this perspective by explaining that, “[i]n both cases it is an artificial chemical enhancement” because “academic performance is sort of based on merit and hard work, which is the same thing in professional sports, based on natural ability and also hard work.” Some participants from all three groups considered that, by virtue, a substance used as shortcut to perform in a competitive environment renders MPH the same as using steroids.

Stakeholders contrasted MPH and steroids

During the focus group, students and HCP identified some aspects that differentiated the contexts in which MPH and performance-enhancing

steroids are used. They described enhancing athletic performance as having implications for professional advancement whereas enhancing academic performance impacted a student's future. Differences were also discussed by students and HCP regarding the nature of competition in sports and academics. For example, sports competitions were regarded as a "celebration of the natural body and how far the natural body can go (…) without enhancement" (Student B8) and as having extraordinary expectations for achievement, "(…) I don't know if you can compare a baseball player taking steroids because he wants to beat the home run record as opposed to a student that takes Ritalin so that he can pass his exam and get a decent job and make a living out of it" (Student A1). However, one HCP highlighted how the "ordinary" nature of academic achievement renders academic success all the more important, "if you are not succeeding in sports you can do other things. (…). If you are failing in school and have low grades your life is quite impaired for a long time" (HCP I1). Another HCP also added the fundamental difference on which sports competitions are currently regulated, "[t]hey know that there is going to be drugs tests and urine tests in baseball" (HCP G4). In contrast, academic competition was described as "how well you want to do and what grade you want" (Student B5) without "a focus on what's natural" (Student B2).

The contexts of academia and sports were further distinguished by students in terms of physiological targets because, "(…) if you're on steroids (…) you can do things that people can't do no matter what if they weren't on steroids. (…) as far as I can tell, Ritalin (…) could [help] achieve the same level of performance [as someone who has not taken MPH]" (Student A4). Another aspect that appeared to influence students' appreciation of the analogies was the frequency of substance use, "you have to keep taking steroids for a very long period of time to keep that muscle mass" but MPH can be used occasionally at "specific times" (Student A5). Some students further distinguished academia and sports by

describing that sports figures are “idols to society” and this may explain “why society thinks that steroid use is negative for athletes” (Student B8). In sum, some participants in all three stakeholder groups thought academic and sports competitions shared a common goal but differences between MPH and steroids in particular were highlighted in terms of the contexts and purposes for which the substances are used.

Stakeholders compared MPH and caffeine

The use of caffeine as an analogy to the non-medical use of MPH was less debated than the steroid analogy yet it yielded some interesting comparisons and contrasts. The similarities of MPH to caffeine were mainly expressed by parents. Methylphenidate and caffeine were both considered substances which have the potential to cause dependence. However, parents recognized that despite this commonality, the contexts of MPH and caffeine use were different. Parent D5 expressed this observation by saying: “[s]ociety doesn’t get upset when somebody uses caffeine to stay awake. Even though it is a drug it is acceptable.” Parents also regarded MPH and caffeine as similar study aids because: “[t]he kids who do not take Ritalin (…) get a huge latté or whatever it is. (…). So if they don’t take Ritalin they will take coffee, they take Red Bull, they take something” (Parent H2). Thus, some parents regarded MPH and caffeine as drugs that are both used in the academic context.

Stakeholders contrasted MPH and caffeine

Students and HCP contrasted MPH and caffeine more than parents did. The first difference was brought up by students who considered the physiological and psychological effects of MPH and caffeine to be different. For example, Student C10 said that, “I don’t think that caffeine helps you concentrate. I just think that it makes you jittery and not able to fall asleep.” Thus, for students, the targets of MPH and caffeine appeared to be different as were the ways in which they can help a student improve

their academic performance. As with steroids, the regulation of caffeine, in comparison to MPH, was the major difference for HCP. They contended that coffee and energy drinks containing caffeine were available over the counter while MPH is a prescription drug that should not be used as readily for enhancement purposes. With potentially different effects on academic performance and involving different regulatory frameworks, students and HCP considered that performance enhancement with MPH was not equivalent to consumption of caffeine.

Various stakeholder definitions of non-medical use of MPH for performance enhancement

Stakeholders offered incongruent definitions of the non-medical use of MPH. Based on a published discourse analysis (Racine and Forlini, 2010), three terms ("abuse", "enhancement" and "lifestyle") were proposed as prompts for the discussion of definitions. Stakeholders associated the non-medical use of MPH with all three terms. Some stakeholders, through the process of elimination, determined which of the three terms corresponded most to their perspective. For example, Student C9 preferred the term enhancement being unsure of, "[going] as far as calling it abuse. Lifestyle sounds kind of soft for [them]. Enhancement [they] think works." Similar rationales are, "(…) abuse (…) sounds too much" (Student C1) or, "(…) that's probably more enhancement than it is abuse" (Student B2). Stakeholders also combined terms giving definitions like, "it kind of falls somewhere in between abuse and enhancement" (Student C6). Finally, some stakeholders maintained that "(…) you [can't] necessarily separate any of these three concepts from the issue (…)" (HCP I3).

Generally, terms were selected in relation to specific features of the non-medical use of MPH. For example, Student A5 explained that, "(…) the difference between these three categories: abuse, enhancement or lifestyle is how [MPH is] taken, how often [MPH is] taken, what are the motives in general." Abuse and enhancement were the definitions most elaborated upon. Some members from each stakeholder group, mostly

HCP, defined the non-medical use of MPH as abuse, i.e., usually defined as the lack of adherence to MPH's medical label. For instance, the non-medical use of MPH was classified, "(…) as abuse just on the fact that [MPH] is a prescription drug. Coffee and Red Bull you can buy in a store and it is legal but I mean [MPH] is under the table. That is what crosses the line" (HCP G7). The use of MPH without a prescription in healthy individuals also troubled stakeholders. HCP E7 elaborated by saying that, "(…) this is abuse or self-medication because they don't use it for the purpose it was made." Included in the abuse definition were the perspectives that non-medical use of MPH was caused by peer pressure and that it constituted cheating.

When defined as enhancement, stakeholders emphasized that the non-medical use was purposeful because, "(…) the first assumption is that people are taking it to better enhance their concentration" (Student B5). The fact that healthy individuals, as opposed to patients, were using MPH was also a feature of the enhancement definition but some stakeholders nuanced that these individuals were building upon abilities they already had because they, "(…) still have to learn the information this just makes [their] brain think in a certain way" (Student C4). Some students highlighted that because non-medical MPH use by students pertained to certain types of goals it was typically occasional and not necessarily constitutive of a student's life. However, some students and HCP explained that the use of MPH to improve academic performance could become a lifestyle choice if a dependence develops, "(…) you are taking these pills and you can't write without taking them" (Student C2).

A few stakeholders combined terms to form a definition. The two most prominent combinations were abuse-enhancement and abuse-enhancement-lifestyle. The association of abuse and enhancement described how students, "(…) might use it once but along the same lines as caffeine (…) caffeine can be abused too. Any drug can be abused and so; if it becomes obsessive then it becomes abuse" (Student C6). When

adding the lifestyle component to a composite definition, stakeholders of this opinion perceived the definition to include a "(…) choice puts you at an advantage over someone who chooses not to do that" (HCP I3). A composite definition could describe the non-medical use of MPH as striving toward an academic goal by making a choice to use a medication in a manner other than it is normally prescribed. Overall, stakeholders defined the non-medical use of MPH mostly in terms of abuse and enhancement.

Table 4.4: Risks and benefits of the non-medical use of MPH for performance-enhancement identified in prompt material and by stakeholders during focus groups

	Prompt material only	Common to stakeholders and prompt material	Stakeholders only
Risks	Depression linked to withdrawal, dizziness, loss of appetite, irritability	Cluttering of the brain, heart attacks, heart palpitations, insomnia, nausea	Anxiety, bad for the brain, depression, drug interactions, general cardiovascular effects, hallucinations, gateway drug, general health concerns, general mental health concerns, lack of self-esteem, missing out on learning skills, negative effects on nervous system, psychosis, stunting growth, sudden death, suicide, teratogenic effects, toxicity, weight loss, withdrawal from drug
Benefits	Accumulate more information in a shorter time, boost brain activity, increase confidence, increase energy, helps to organize thoughts, helps to think rationally, maintain high performance level, minimize fatigue	Boost concentration, increase focus	Person appears more intelligent

Risks and benefits of the non-medical use of MPH identified by stakeholders

Stakeholders identified and discussed a range of physiological and psychological risks and benefits of the non-medical use of MPH. Risks and benefits identified by stakeholders were compared to those found in the prompt material they read before the focus groups. Table 4.4 shows the risks and benefits that were mentioned (1) exclusively in the prompt material, (2) common to both the prompt material and the focus groups and (3) exclusively during focus groups by stakeholders. There were no observable differences between stakeholder groups, but as a whole, stakeholders identified more risks than benefits of using MPH non-medically. The discussion of benefits was more selective in the focus groups than in the prompt material. Stakeholders also discussed risks beyond those that were present in the prompt material. Only a few risks and benefits found in the prompt material were discussed in the focus groups. Thus, our results show that stakeholders emphasized the risks of non-medical use of MPH.

Stakeholder reactions to safety of the non-medical use of MPH

We asked participants whether they thought the non-medical use of MPH was a safe practice or if they had any concerns.. We found a split between the assessments that the non-medical use of MPH had either significant or limited risks. Two major factors contributed to the perspective that the non-medical use of MPH was unsafe. First, stakeholders considered that many risks were still unknown and “from a pharmacological point of view, this drug has not [been] established and they have not studied long term effects” (HCP E3). Of the potential risks, emphasis was put on the, “(…) long-term effects that it would have on your body, especially if you become dependent on it and end up taking it all your adult working life” (Student C6). They added that this type of data would be difficult to obtain because the non-medical use of MPH happens outside of the medical and research

contexts. Stakeholders related this obstacle to a second factor, general lack of medical supervision. This lack was exacerbated by the fact that MPH is obtained notably through illegal channels such that the drug "(…) [does] not come with instructions" (Student A5) whereas "(…) if you were on a prescription presumably your doctor would be vigilant about monitoring the use and any potential side-effects and counter information" (Student C6). Student C6 went on to describe the supervision of a medical professional as a "safety net" which is absent when one is "self-medicating". Furthermore, it was mentioned that without professional instructions or guidance, "(…) you really have to experiment to know how much [the drug] affects you" (Student C10). Thus, some participants feared the potential consequences of self-medication for non-medical purposes.

In contrast to the ill ease with unknown risks, other stakeholder responses showed a sense of security with regard to the safety of using MPH non-medically. This sense of security was explained in several ways. First, stakeholders communicated a trust in substances that are subject to an official approval process, otherwise explained as "(…) a perception (…) that because it's prescription medication and not a street drug that it is pretty safe (…)" (Student B2). An example of this point of view was, "I think when used responsibly it's relatively safe otherwise they wouldn't prescribe it" (Student B1). The second perspective had to do with MPH's reputation as a pediatric medication. Parent F8 explained that, "[t]he fact that this is taken by children, perhaps students think that it is not serious to take this drug, you know. 'If children can take it, it is fine with us.'" It was assumed that the strict approval and prescription procedure for children, makes a drug like MPH automatically safe for other populations such as adults because, "(…) if it is a drug they have been giving to kids (…) that means it's pretty benign" (Student B7). Finally, stakeholders' belief that non-medical use of MPH was safe indicated that regardless of whether a substance is available by prescription or over-the-counter individuals

should consume substances responsibly to avoid dangerous side-effects. To illustrate this point, Student B10 said, “(…) everything is sort of not safe if not taken in moderation even something like caffeine can have some serious effects that people don’t know about (…)”. Many participants with this point of view suggested that the key to responsible use was in moderation of the amount and frequency that a drug like MPH is used non-medically to strike “(…) a balance [in the] amount of times you take it, on a week (…) or how much a day or if you mix it with caffeine” (HCP G3). Accordingly, some participants characterized non-medical use of MPH as “relatively safe” (Student B1), “probably fine” (Student C11), “fairly safe” (Student C9) and “not necessarily dangerous” (HCP I3).

Stakeholder appreciation of media coverage on non-medical use of methylphenidate for performance enhancement

Part of the focus group discussion was devoted to assessing stakeholder appreciation of the media coverage on the non-medical use of MPH based on but not limited to the prompt material. Stakeholder opinions pertained to general aspects of the media coverage, the information contained in the articles and their perspective on the media coverage itself (Table 4.5). The three stakeholder groups, but especially parents, acknowledged that the media coverage on the non-medical use of MPH provided valuable information. However, stakeholders suggested that media coverage may promote the non-medical use of MPH simply by describing the practice. One healthcare provider offered the perspective that professionals who confirm the enhancing effects of MPH could influence the public. Some participants stated that the articles did not present enough reasons to discourage the use of MPH. Though most of the comments on the promotion of the non-medical use of MPH were in the third person, some participants employed the first person to indicate that they would try it. Students, in particular, wondered why media coverage had only recently begun discussing after years of MPH being used non-medically. Students were most critical of the style of the media coverage. For example, one

student said, “it kind of sounded like something that was in [their] high school newspaper” (Student B5).

No stakeholders reported that the information in the articles was complete. Many suggested subjects that they would have liked to see covered more extensively (see column 2 of Table 5). Stakeholders formed a consensus on two information gaps: (1) the lack of information on the workings, effects and efficacy of MPH especially on healthy individuals in the long-term and (2) the debatable quality of the scientific evidence contained in the articles. Topics of interest also included accurate prevalence data, a more developed ethics debate, details about how one uses MPH non-medically and the solutions being explored to reduce the non-medical use of MPH. The last three subjects were specific to students, parents and HCP, respectively.

The last aspect that stakeholders commented on was the perspective of the articles. Some participants from all three stakeholder groups considered the perspective of the articles to be ambiguous. These stakeholders stated that there was not enough discussion of the benefits and social acceptability of the non-medical use of MPH and, consequently, they could not make up their own minds. The majority view indicated the presence of a bias in the media coverage on the non-medical use of MPH. Stakeholders described a negative bias (media emphasized the risks of the non-medical use of MPH) and a positive bias (media focused on the benefits). Only one participant from each stakeholder group said that the articles were well rounded and balanced. A few students and HCP noted that the media coverage was realistic, even if ambiguous, because it reflected the current state of social opinion on the non-medical use of MPH.

Table 4.5: Stakeholder opinions with qualitative examples on the media coverage of the non-medical use of MPH for performance enhancement (in terms of general appreciation, completeness of information and perspective of the media)*†

1. General comments on media coverage of the non-medical use of MPH

A. Positive appreciation of media coverage on non-medical use of MPH (S, P, HCP)
- "I think it's important to send the message out there you do not need Ritalin to get through things." (Student A9)
- "I found it very interesting to be aware of what is going on on campus because (…) I was not aware of it." (HCP I1)

B. Criticism of the timing of media coverage on the non-medical use of MPH (S)
- "I remember reading about this in a teenage magazine when I was 13. This has been a problem for ages. I don't see why there is news coverage announcing it as a new problem." (Student C10)

C. Media coverage may encourage non-medical use of MPH (S, P, HCP)
- "I don't know if spreading it all over the newspapers is a good idea because quite frankly I think it kind of promotes it." (Student A9)
- "I think unintentionally it would sort of promote Ritalin use to students." (Student B2)
- "I would probably be more likely to take Ritalin now after reading those articles than not because if like the only side effect they can come up with, and I think those articles were slanted pretty negatively, was that my brain can get too full. Like, you know, maybe I'll try it." (Student B7)
- "I don't know why but it made me want to try Ritalin." (Student B8)

2. Comments on incomplete information on the risks and benefits of the non-medical use of MPH

A. Workings, effects and efficacy of MPH (S, P, HCP)
- "I would have liked more content about neuro-physiology and how the pill is actually working. What are the studies that have actually been done? I would have liked more scientific evidence base. (…) I would have liked more things to help me to make my mind up about the medication because after reading the articles it was difficult for me to say yes or no, do I agree do I disagree?" (HCP E2)
- "It was kind of just like a surface of what was going on and not really delving into it or really what Ritalin does." (Student B5)

- "I would be interested to read about the student who took it like recreationally or whatever and something bad happened to them like that's what I really want to know before I try it, like what's the worst that could happen?" (Student B7)
- "it would have been nicer to have sort of stronger scientific view as well or just an article that explains what Ritalin physiologically does to your body because not everybody knows."(Student B10)
- "it is about the short time effect, not the long term effect. There is nothing; there is nothing about long-term effect." (Parent H1)
- "I don't think it addresses at all the retention of the material [learned with Ritalin]." (Parent D1)

B. Scientific evidence (S, P, HCP)
- "all of them basically lacked the scientific information. There was no evidence for somebody who would be looking out for Ritalin and reading more about it. Maybe it might be complicated for an ordinary paper but there has to be at least some scientific evidence to be there because it was mostly anecdotal." (Student A8)
- "sometimes I wondered about the data in these statements and I wondered where it came from and what sample population it was tested on" (HCP G7)
- "it just shows you how bad the media are: no data just impressions, 'I hear that, this and that.'" (HCP G1)

C. Prevalence data (S, HCP)
- "I kind of got a vague feeling of actual prevalence and the actual size of the problem because here's one student from [Quebec], she thinks her friends use it. Here's another student from Ontario… This is not very good sampling really if you want to find out how much we have to be worried about this." (Student B2)

D. Ethics debate (S)
- "(…) other articles didn't really address the ethical issues as much. That is what leapt out at me the most. The articles were more straight on news articles whereas they don't really talk about the nuanced issues about it." (Student C6)

E. Access to of non-medical use of MPH (P)
- "Is it that easy to get those drugs? Do you need a lot of money to get those drugs? We don't know about that, how these people get the drugs." (Parent F2)

F. Solutions to non-medical use of MPH (HCP)
- "(…) where were the solutions? Where were the 'Hey, this is a problem! Why is this going on?' What are we

going to do about it?" (HCP G4)

3. **Comments on the perspective of media coverage of the non-medical use of MPH**
   A. Ambiguous discussion on benefits and acceptability of the non-medical use of MPH (S, P, HCP)
      - "the article in all aspects it is really inconclusive. It doesn't really say where it is good, it doesn't really say where it is bad. All it really says is that it enhances. Does it enhance?" (Parent D5)
      - "I think that there seems to be this recurrent theme that when discussing things like Ritalin and performance enhancement drugs or substances that there does seem to be something intuitively disconcerting (…) people have a lot of difficulty articulating why they feel that it's wrong or why they feel that people shouldn't be doing it. (…) it's hard to come up with some definitive reason as to why it's wrong and that's why I personally think that's why a lot of people indulge. And that's what I think B7 was saying about the articles that they seem to be getting to something about there being some nebulous connotation but nobody could quite pinpoint what as wrong." (Student B1)
   B. Bias in coverage of the non-medical use of MPH (S, HCP) — majority
      - "Another problem that I had with the articles is that they really didn't focus on Ritalin in schools as a social topic. They didn't say that it is a reflection of what we expect from our kids or it is a reflection of the current job market and what they are looking for. It was just like 'they're doing it. It's bad. Save your children!'" (Student C11)
      - "What I didn't like about the articles is that they all made the assumption but it kind of became an assertion that taking Ritalin makes you perform better." (Student A5)
   C. Unbiased coverage of the non-medical use of MPH (S, P, HCP) — minority
      - "I think they were quite neutral at exposing the facts." (HCP E1)
   D. Realistic coverage of the non-medical use of MPH (S, HCP)
      - "I think they kind of portrayed how grey of an issue this is that there are many different takes on it that there are many different aspects to it. I think they did pretty well for being a page and a half each." (Student B1)

MPH: methylphenidate; S: students; P: Parents; HCP: healthcare providers
*Qualitative differences between stakeholder groups are explained in the text
† Parentheses indicate that this feature was expressed by at least one participant of this group

Discussion

This study examined how different stakeholders consider the phenomenon of non-medical use of a common stimulant, a practice often called cognitive enhancement in the bioethics literature. First, though the majority of participants were already familiar with the non-medical use of MPH, many expressed considerable surprise and even reported being shocked when learning about its existence. Second, our study revealed marked ambivalence and pluralism in the perspectives of stakeholders with regard to the non-medical use of MPH to improve performance from both descriptive (what is going on) and normative (what should we do) standpoints. For example, no consensus was reached to the effect that non-medical use of a stimulant like MPH could be described as “cognitive enhancement”, “abuse of a prescription drug” or “a lifestyle choice”. Stakeholders responded to popular analogies of performance-enhancing steroids and caffeine by comparing and contrasting certain features of these substances but hesitated to declare either of them normatively equivalent to the use of MPH. Finally, in contrast to previous studies (Forlini and Racine, 2009a) this study did not find substantial differences in opinion between different stakeholder groups. Media coverage of the non-medical use of MPH was appreciated by stakeholders but also considered as potentially encouraging non-medical use and lacking in certain types of information and a clear or balanced position (mostly by HCP and students).

Limitations

Some aspects of the qualitative nature of this project should be taken into consideration for their proper interpretation. First, due to the small sample, the opinions expressed in the focus groups are not representative of general opinions of students, parents and healthcare providers, especially outside of North America. Though the UK and Australia media are represented in this prompt material, the way in which CE was depicted

reflected a largely North American phenomenon. Second, participants were given four representative media articles to read prior to the focus group. Despite the range of topics covered in these articles, such prompts have advantages (e.g., real source of information intended for general readership) and disadvantages (e.g., not addressing in detail every ethical and social issue related to cognitive enhancement). Third, focus groups are discussions and not surveys. Not all participants answered every question thus when we report the perspectives expressed, these perspectives should be considered as those that were explicitly and *de facto* expressed – not necessarily all that could be expressed. Fourth, our focus groups were conducted in English (given the English-language prompts) but our recruitment included individuals with different mother tongues which could have an impact on how participants expressed themselves. Fifth, some difficulties in data capture (e.g., failed recordings of some comments) and subsequent transcription caused a very small part of participant statements to be unsuitable for analysis.

The results presented in this article bring to light two points that can be further discussed. First, we reflect upon the role of stakeholder ambivalence in the debate on the non-medical use of MPH. Second, we examine how analogies can be useful to dispel ambivalence but can also mislead in the CE debate.

Ambivalence: indicator of indifference and misunderstanding or a reflection of deeper concerns?

Our study revealed fundamental ambivalence and pluralism of stakeholders with respect to descriptive and normative aspects of CE. The ambivalence we noted reflects the coexistence of conflicting reactions and perspectives ("ambivalence, n," 1989) expressed by stakeholders in defining CE, deciding upon its acceptability, and determining its equivalence to common analogies. There are at least two major interpretations of this ambivalence. First, ambivalence may reflect a lack knowledge and exposure to CE among stakeholders. This is likely partly

true as some stakeholders expressed surprise about the sheer existence of CE with MPH or about the extent of this practice. Such an interpretation is consistent with the unidirectional model of science communication which "assumes that researchers are in control of media content and are the primary gatekeepers of scientific knowledge" (Racine, forthcoming). This model also suggests that sound science communication is hindered by an information gap between experts and non-experts (Racine, 2010). However, most stakeholders were familiar with CE before the focus groups (see questionnaire data of Table 4.1) and were still able to elaborate and discuss a wide range of issues associated with CE. Stakeholders in our study demonstrated advanced understanding of the consequences and implications of CE during the discussion, going beyond the prompt material to attempt a definition and discuss the risks and benefits of CE.

A second interpretation is more consistent with multidirectional approaches to science communication. The multi-directional model encourages open dialogue and self-reflection between and among stakeholders (science, humanities, public and media) (Racine, 2010). This approach considers that ambivalence may actually reveal something much deeper than mere lack of knowledge, or expertise. Though there were few dominant opinions, stakeholders provided original perspectives regarding the debate on CE. Thus, the ambivalence may reflect that stakeholders sense that CE could carry substantial issues and constitutes a source of discomfort. Hence, a more compelling interpretation is that stakeholders felt uneasy about the social implications of CE in academic and work environments as well as the larger but vexing role that pharmaceuticals could play in helping individuals cope with increasing social demands for performance. This interpretation, more consistent with our findings, also suggests that stakeholders have felt the scope and far-reaching social implications of changes that broader scale CE would bring about. Given this capacity and interest of stakeholders, several authors have suggested

multidirectional approaches to include stakeholder experiences in debates about ethical and social issues associated with neuroscience (Illes et al., 2005; Illes et al., 2010; Racine et al., 2005). As stated by Leshner (2004), "[t]he unique attributes of the brain as an organ system and its centrality to our concept of our own humanity raise an array of ethical issues that must be resolved in an open dialogue involving both the scientific community and the wider public before we will see widespread application of the fruits of neuroscientific progress."

Interestingly, the ambivalence of our focus group participants contrasts quite radically with the often strong and clear-cut pro and con positions encountered in the bioethics literature. Optimists predict that CE can positively and substantially contribute to society (Bostrom and Sandberg, 2009). They suggest that CE could equalize the natural distribution of abilities and talents at the source of some injustices in opportunity (Savulescu, 2006). Individuals who wish to maximize their performances could decide autonomously to do so (Caplan and Elliott, 2004; Caplan and McHugh, 2007). Using pharmaceuticals for CE has been argued to be "morally equivalent to other, more familiar, enhancements" such as "education, good health habits and information technology — ways that our uniquely innovative species tries to improve itself" (Greely et al., 2008). These points of view lay the groundwork for the public to accept an ideal situation of a society of enhanced individuals but it fails to capture the ambivalence expressed in our focus groups.

The critics of CE have expressed – like proponents of enhancement – strong opinions. One of their main arguments is that CE represents an affront to "human nature" and bypasses the enrichment of life experiences gained by hard work and renders such achievements inauthentic (President's Council on Bioethics, 2003). Sandel (2004) invites us to recognize that, "our talents and powers are not wholly our own doing", a framework he calls "giftedness" and has been dubbed "gratitude" by Parens (2006). Arguments against CE have garnered the reputation of

being inarticulate and largely unpersuasive because they are based on ill-defined concepts such as “human nature” and emotional reactions (Caplan and Elliott, 2004; Caplan and McHugh, 2007; Nature, 2007). As a result, criticism or uncertainty regarding CE has not been brought to the forefront and therefore, much ambivalence that could be expressed in the literature has dissipated under the radicalization of the debate between those in favor and those against CE. Bioethics writings on this topic seem to be driven by what Dewey called a “quest for certainty”.

One exception can be found in the writings of Erik Parens who has attempted to reconcile the academic lenses of optimism and criticism of CE. Parens (2006) describes a “creativity” framework that emphasizes, “our responsibility to be creative, to use our creativity to mend and transform ourselves and the world” instead of accepting the gifts we are handed. Parens (2005) argues that the creativity and gratitude frameworks are superficially opposing yet they have a shared vision of the “moral ideal of authenticity” (Parens, 2006). Consequently, Parens (2005) suggests that the “gratitude and creativity frameworks deserve equal respect and that we should aspire to balance the commitments and insights of both” in order to better consider the issues at stake in CE. In spite of its value for bridging arguments in favor and against CE, Parens’ proposal lacks realism with respect to the motivations underlying CE, especially the socio-economic forces at play and the pressures felt by members of society to respond to increased levels of performance (Forlini and Racine, 2009a). The fear is that, “the self-improvement agenda will be set not by individuals, but by powerful corporate interests” (Caplan and Elliott, 2004). The frameworks of *creativity* and *gratitude* too easily conceal the real politics and economic interests in the development of cognitive enhancers.

Another, more socially-grounded, way to capture the ambivalence of stakeholders can be articulated as a tension between the concepts of “moral acceptability” and “moral praiseworthiness” proposed by Racine

(2010). In *Pragmatic Neuroethics*, Racine proposes two “moral tests” to determine both the moral acceptability (i.e., is it ethically acceptable to pursue CE? Can an individual enhance their cognition?) as well as the moral praiseworthiness of CE (i.e., should an individual enhance their cognition? Is this a moral ideal?). Moral acceptability as proposed by Racine (2010) requires that fundamental scientific, ethical, social and policy criteria be met such as safety, respect for autonomy, fair resource allocation, and development of surveillance for CE. However, being deemed morally acceptable is only one condition to being morally praiseworthy. Moral praiseworthiness goes beyond the wishes of individuals seeking performance enhancement to consider broader goals such as addressing the medical needs of humankind. Following these concepts, the ambivalence of stakeholders reflects their hesitation to declare CE morally acceptable since many conditions of moral acceptability are currently not met. For example, reliable scientific data remains to establish the safety, risks and side effects of cognitive enhancers. Ethical and legal conditions such as the freedom from coercion and mitigation of discrimination as well as cultural and social conditions such as the impact of CE on public health issues and health coverage have yet to be fulfilled (Racine, 2010). In addition, participants are perplexed about the moral praiseworthiness of CE. They are troubled by the prospect of a society where success in education and professional life would rely on or require the use of cognitive enhancers.

The dyads of creativity-gratitude and moral acceptability-moral praiseworthiness proposed by Parens and Racine, respectively, have their own strengths and weaknesses. Their common value is to highlight that the type of ambivalence expressed by stakeholders in our study has potential deeper meaning than simple lack of knowledge. It is a sign of moral unrest, i.e., that ideal morals of gratitude, creativity and moral praiseworthiness are troubled by the prospect of broader scale CE. As both Parens and Racine point out in the CE debate, rarely can all aspects

be explained and supported by only one framework or one moral construct. Both suggest that broader consideration of alternate frameworks is the way forward (rather than settling in one framework or relying on a single "moral test").

At this point in time, it is unclear which lens or moral construct would most accurately capture the experiences and perspectives of stakeholders. Ambivalence on the part of stakeholders may reflect the very nature of the CE debate and the fact that issues at stake are captured in different lenses and frameworks. Therefore, stakeholders and non-experts may carry some important wisdom in sensing what challenges broader scale CE would bring about. They are well positioned to gain contextual knowledge allowing them to assess the impact of CE in *their* context and lives. Those in favor of CE in the bioethics community can speculate how society could be improved but they do not have a privileged position to capture the experience of pressures and discomfort that CE carries. Pressures will mount for clearer and more articulate public opinion and policy approaches. Dismissing public perceptions too quickly may engender yet simply remaining ambivalent about descriptive and normative aspects could demonstrate complicit acceptance of broad scale CE. However, the moral unrest that underlies stakeholder ambivalence about CE may also conceal an additional challenge. Stakeholders must consider and contextualize with sufficient time different features of CE before they can assess what the issues and impacts will be.

Analogies: informing or distorting ethics debates?

We noted various reactions and understandings of commonly-used analogies comparing performance enhancement with MPH to steroids or caffeine in our data. When dealing with fuzzy or difficult to comprehend phenomena, one obvious strategy consists of comparison to an allegedly better known phenomenon. In this regard, analogies are attractive conceptual tools that help grasp a theoretical phenomenon or process

(target domain) by comparing it with a more familiar phenomenon or process (source domain). This approach has been described in great detail in cognitive science by Johnson and Lakoff (1980) as well as in ethics. Proponents of analogical thinking have argued for the prevalence and general worth of these forms of reasoning and thinking in ethics and beyond (Heath and Heath, 2007). By calling upon familiar concepts and experiences, analogies can reduce the need for background information about a phenomenon. They have also been credited with making messages more concrete; favoring their comprehension and assimilation by non-experts.

Stakeholders in our study discussed the use of analogies in comparing caffeine and steroids with MPH. The process of comparing and contrasting a source domain to the target domain helped to dispel some of the normative ambivalence in comparing steroids and caffeine to MPH. Nonetheless and despite their penetrance and convenience as cognitive short-cuts, analogies can become problematic if they lack the crucial features of a target domain and therefore confuse rather than enlighten the understanding of a phenomenon.

First, though analogies can be helpful to highlight features of a social phenomenon like the non-medical use of MPH, they can rarely capture the whole, or truly unique aspects, of the target domain. For instance, social context and social aspects may differ significantly between the source and the target domains. Participants in our study pointed out many differences in the environments and pressures enticing steroid use and caffeine use in contrast to the non-medical use of MPH. However, the analogies of caffeine and steroids to MPH are largely based on comparing the *substances* and not the *circumstances* in which the substances are taken. By focusing on the substance, the analogy may be masking social issues that are proper to the target phenomenon but absent in the source domain while doing further injustice to the broader social issues. For example, a prior study has also shown that social pressures to perform

play a role in the non-medical use of MPH (Forlini and Racine, 2009a). Furthermore, many of the risks and benefits discussed in the focus groups and literature are physiological. Aside from the obvious benefit of increased cognition, there is little data on how CE affects interpersonal relationships. Perhaps these effects could be even more substantial than the physiological effects and risks. After all, if CE does not benefit how we are, who we are and where we are in society why would it even be practiced? Thus, without taking into consideration the social context, current analogies remain loose comparisons with important limitations.

Second, differences in perspective can also compromise the congruency of value-laden analogies to a new phenomenon. Comparison of steroid and caffeine use to MPH provides an example of how analogies can capture opposing values. In our focus groups, steroids are generally frowned upon while caffeine is widely accepted yet both were commonly considered equivalent to MPH use. Using value-laden analogies can prematurely attribute a certain value to an active debate such as CE. The salience and interpretation of value-laden analogies can also depend upon the unique perspective of different stakeholder groups. The importance of regulation of substances played an important role in HCP opinion on the equivalency of analogies to the non-medical use of MPH. Students, on the other hand, focused more on the goals underlying steroid and caffeine use to compare them to MPH. Considering the varying interpretations of analogies by stakeholders, with sometimes contradictory values and opinions, agreeing on a definition is a challenge and evidence of a descriptive type of ambivalence.

The use of analogies in an ethical and social debate such as CE is therefore vexing for several reasons. They are potentially useful discursive devices but also potentially misleading and unreliable grounds to base values and decisions upon. Analogies can lead both descriptive and normative perspectives of the target domain astray. First, a normative perspective on CE can hardly be considered without a multi-faceted

approach to describing and understanding a specific situation, i.e., considering the social context and specific circumstances of the case (Jonsen, 1991). Second, the type of analogies used could also complicate reflection from a health-policy perspective. Consider a public health intervention based on an analogy of MPH to caffeine, a legal and largely accepted substance. On the other hand, consider a public health intervention, which equated steroids and MPH, a substance that is controlled and largely banned for enhancement purposes. The resulting public health interventions would send contradictory and even opposing messages to the public while failing to reflect how CE would actually affect their lives.

Conclusion

This paper reported a study of stakeholder perspectives on the use of MPH for CE. First, we found marked ambivalence in stakeholder perspectives, a clear contrast to most bioethics discourse which stands strongly in favor or against CE. We argued that there is a more profound meaning to stakeholder ambivalence indicating apparent discomfort of stakeholders with the economic and social pressures underlying the drive for cognitive enhancers. Second, we observed that common analogies used by academics and the media in the CE debate could be discursive devices that help dispel ambivalence regarding a new phenomenon (target domain). However analogies may neglect some of the distinct circumstances of CE practices fostering unclear interpretations from a stakeholder point of view and tempering suggestions that analogies are useful in ethical debates. Public dialogue could help voice the unease of stakeholders and also avoid hastily opting for permissive or restrictive health policies for CE without taking into full consideration current concerns in the public domain.

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Concluding remarks on Chapter 4: Ambivalence is an indicator of moral unrest

The divergent definitional approaches and contrasting ethical stances reviewed in Chapter 2 demonstrate how the cognitive enhancement debate is entrenched in multiple frameworks. Each of these frameworks carries recommendations for promotion or restriction of cognitive enhancement. The results presented in Chapter 4 reported the perspectives of different stakeholders on the non-medical use of methylphenidate for cognitive enhancement to assess whether they were comparable to the conclusions of the frameworks discussed in the literature. In particular, Chapter 4 studied the attitudes and reactions of stakeholders toward various definitions of and analogies to cognitive enhancement as well as their appreciation of media coverage on the topic. Analysis of the focus-group discussions revealed ambivalence in stakeholder perspectives regarding these aspects of the cognitive enhancement debate. This ambivalence suggests fundamental discomfort of stakeholders with economic and social driving forces of cognitive enhancement that characterize the different definitional approaches. Popular analogies of cognitive enhancement to caffeine and steroids were found to be value-laden and may be neglecting some of the distinct circumstances of cognitive enhancement practices while fostering unclear interpretations from a stakeholder point of view. In Chapter 4, stakeholder ambivalence was described as moral unrest in order to denote the ongoing struggle of stakeholders to adhere to a framework with a specific ethical stance on cognitive enhancement.

Original contribution of Chapter 4

The results of Chapter 4 unveiled for the first time an important level of moral unrest outside of the academic literature. Moral unrest in stakeholders highlights the potential incongruence of stakeholder perspectives with existing ethical frameworks and assumptions that

cognitive enhancement is widespread, in demand and an accepted practice. This finding contrasts with many perspectives within the academic ethics debate that argue for or against cognitive enhancement based on liberal and conservative values, respectively. A subsequent study by another group has since shown similar ambivalent perspectives[9] specifically among physicians (Hotze et al. 2011). However, this survey was not designed to examine the socio-economic factors underlying cognitive enhancement or to explore definitional approaches, which could be underlying causes of moral unrest (Forlini and Racine 2011b). The findings in Chapter 4 also temper the power of analogical arguments from opponents and proponents. Suggestions that cognitive enhancement should be perceived in the same light as either sports doping or education does not present an imperative to ban or allow it (Gunson 2012). Instead, "one might conclude that precisely because they are analogous, we should think hard before allowing unrestricted private [cognitive enhancers] because there are good grounds for criticizing environmental forms" (Gunson 2012). More needs to be learned about the aspects at the root of moral unrest in discourses about cognitive enhancement and how it may be clarified. Fortunately, this type of moral unrest can constitute a territory for open discussion on the ethics and policy directions of cognitive enhancement.

Examining specific areas of contention in Chapter 5

The analysis in the next chapter hones in on one ethical issue in particular to begin a fine-grained exploration of the sources of moral unrest in stakeholder perspectives. This exploration begins with the issue of autonomy, personal choice and coercion. The review of prevalence studies in Chapter 1 showed that cognitive enhancement was one motive for non-medical use of prescription stimulants and that attending

[9] The results presented in Chapter 4, 5 and 6 are thoroughly compared and contrasted with other existing stakeholder studies at the beginning of Chapter 8.

competitive universities was a risk factor for users. As social pressures to perform are suggested through prevalence data and the ethics debate (Chapter 2), discussions about potential sources and forms of coercion are also emerging. The next chapter examines whether or not stakeholders believe individuals are free to use medications non-medically as cognitive enhancers.

CHAPTER 5: Autonomy and coercion in academic "cognitive enhancement" using methylphenidate: Perspectives of key stakeholders *Neuroethics*. 2009. 2 (3): 163-177.

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Abstract

There is mounting evidence that methylphenidate (MPH; Ritalin) is being used by healthy college students to improve concentration, alertness, and academic performance. One of the key concerns associated with such use of pharmaceuticals is the degree of freedom individuals have to engage in or abstain from cognitive enhancement (CE). From a pragmatic perspective, careful examination of the ethics of acts and contexts in which they arise includes considering coercion and social pressures to enhance cognition. We were interested in understanding how university students, parents of university students, and healthcare providers viewed autonomy and coercion in CE using MPH. We found that perspectives converged on the belief that CE is a matter of personal and individual choice. Perspectives also converged on the existence of tremendous social pressures to perform and succeed. Parents emphasized personal responsibility and accountability for CE choices, and expressed feelings of worry, sadness and fear about CE. Students emphasized the importance of personal integrity in CE, expressed tolerance for personal choices of others, and highlighted the challenge that CE poses to maintaining one's personal integrity. Healthcare providers emphasized the health consequences of CE. These results illustrate: (1) the importance of understanding how context is viewed in relation to perspectives on autonomous choice; (2) the limitations of individualistic libertarian approaches that do not consider social context; and (3) the ethical implications of public health interventions in a value-laden debate where perspectives diverge.

Keywords: cognitive enhancement, autonomy, coercion, public understanding, neuropharmaceuticals

Introduction

There is mounting evidence that methylphenidate (MPH; Ritalin) is being used by healthy college students to improve concentration, alertness, and academic performance [34] a phenomenon dubbed "cognitive enhancement" (CE).[10] Recent data published in *Nature* suggest that this phenomenon is not exclusive to the student population but also pervasive

[10] Studies on the non-medical use of prescription stimulants by university students show that prevalence rates range from 6.9% to 35.3% [14] [20] and up to 11% for cognitive enhancement specifically [25].

in other parts of academia. In this survey, 20% of over 1400 respondents had used a prescription drug for CE [18].

The spread of pharmaceutical CE [21] has caught the attention of medical and ethics communities [7]. One of the key concerns associated with this trend is the degree of freedom individuals have to engage in or abstain from CE. For example, potential sources of coercion on an individual's decision-making have been identified [13]. Competitive environments like the workplace, academia, and the military have the potential to become targets of explicit pressures to require or impose enhancement [1, 10, 13, 32]. Explicit coercion is perhaps likely if this practice becomes more widespread [13]. On the other hand, pressures to enhance could be much more subtle and implicit. Environments, like academia, can constitute "winner take all" situations meaning that slight gains in cognitive performance can translate into substantial benefits. Athletes currently face such situations and, even though they participate in activities that openly call for honesty and fair play, some of them still use performance-enhancing drugs [10]. Implicit forms of coercion are likely and perhaps almost unavoidable in societies that thrive on competition. Chatterjee states that "hand-wringing of ethicists, journalists, and futurists is unlikely to have much of a restraining effect on its development" [9]. Accordingly, the inevitability of CE may simply be brought on because, "[w]hen faced with the analogous ethical concerns in other contexts, we collectively shrug our shoulders" [9].

The emerging view that enhancement may be unavoidable [5, 9] interacts with concerns about coercion in complex ways. Some authors contend that giving everyone a choice may result in some individuals feeling pressured to enhance their cognition [9, 12, 17, 22, 26]. The contrasting opinion is that individuals would consider CE as voluntary self-improvement [8]. Others have suggested legislation to prevent coercion [1] but a ban on CE is viewed by some as equally coercive considering that it denies individuals the choice to improve themselves [13]. While coercion

related to CE may not overtly occur in workplaces, the subject is being discussed [32] in addition to possible models of legislation to regulate its use [1].

From a pragmatic perspective, coercion and social pressures are important to consider in carefully examining the ethics of acts and contexts in which forms of CE occur. Accordingly, we embarked on a study to examine views on this issue and others related to CE. Inspired by pragmatic naturalism [23], we were interested in understanding how different stakeholders and non-experts in ethics viewed CE. We focused our examination on university students, parents of university students, and healthcare providers to determine if they viewed CE with MPH in the academic setting as 1) an individual's autonomous decision; 2) the result of coercion or 3) a combination of both. In this paper we report results of focus groups with students, parents and healthcare providers relevant to this topic. Other issues were discussed, e.g., general comments on CE, concerns for ethical, social and legal issues, social and healthcare aspects as well as media content and the media as a source of information and will be presented in future papers.

Methods

Participants

Three groups of participants were selected, university students 25 and under, parents of university students and healthcare providers (HCP). As mentioned earlier, the prevalence of the non-medical use of methylphenidate in university student populations has been established [2, 4, 28, 29, 34]. Consequently, we identified this group as relevant and interesting to our study. The age limit on university students was enforced because prevalence studies on the non-medical use of MPH reported that the practice exists among undergraduate students [3, 33]. Parents of university students are of interest as they reflect a generational difference

but are directly connected to university education. For the purposes of this study, a healthcare provider was defined as someone having a professional responsibility to care for the health of patients. All healthcare professionals were invited to participate (e.g., doctors, nurses, pharmacists). No particular expertise with MPH was required for respondents to participate.

Recruitment

The study and the recruitment strategies were approved by the Research Ethics Board (REB) of institutions involved in the study. English and French recruitment advertisements were posted in common areas of two Montréal area universities and affiliated institutions. Advertisements were also featured in various Montréal general and student newspapers as well as online classified sites. E-mail invitations were sent to major student associations and faculty members in healthcare professions. Participants received a fifty dollar compensation for participating.

Focus groups

To minimize recruitment bias and encourage participation of non-experts,, participants remained unexposed to the specific subject of the discussion (cognitive enhancement with MPH) until they received the documentation package. Participants generally received this package one week before the focus group. This package included a print media sample of four articles, a consent form and a short questionnaire. The articles were chosen from a systematic print media sampling of prior discourse analysis [25]. To maximize the scope of the focus group discussion, articles were selected to reflect variability in content, quality of information, overall coverage of ethical issues, length, and country of origin. After reading the articles, participants were asked to fill out an anonymous questionnaire collecting demographic data and information about prior knowledge of CE with MPH.

The interview grid for the focus groups was based on prior discourse analysis [25] and captured a wide range of ethical and social issues (e.g., safety, social acceptance) as well as questions to assess media coverage and public understanding of MPH for CE. Three pilot interviews were conducted to test the interview grid tool. During the focus groups, participants were first invited to comment generally on CE then express their opinions regarding the ethical, social and legal issues related to CE. They were also asked to comment on healthcare aspects and media content on CE. Given that the focus group was a discussion and not a survey it is important to note that not all participants expressed opinions on each topic. The focus groups were moderated to allow spontaneous expression of opinions while ensuring coverage of the topics included in the interview grid.

Coding

Each focus group was transcribed verbatim. The content of each focus group was coded systematically according to a previously used coding guide (Forlini and Racine, Disagreements with Implications: Diverging Discourses on the Ethics of Non-medical Use of Methylphenidate for Performance Enhancement, forthcoming). However, for the purpose of this paper, only the themes of autonomy and coercion are reported and discussed.

Results

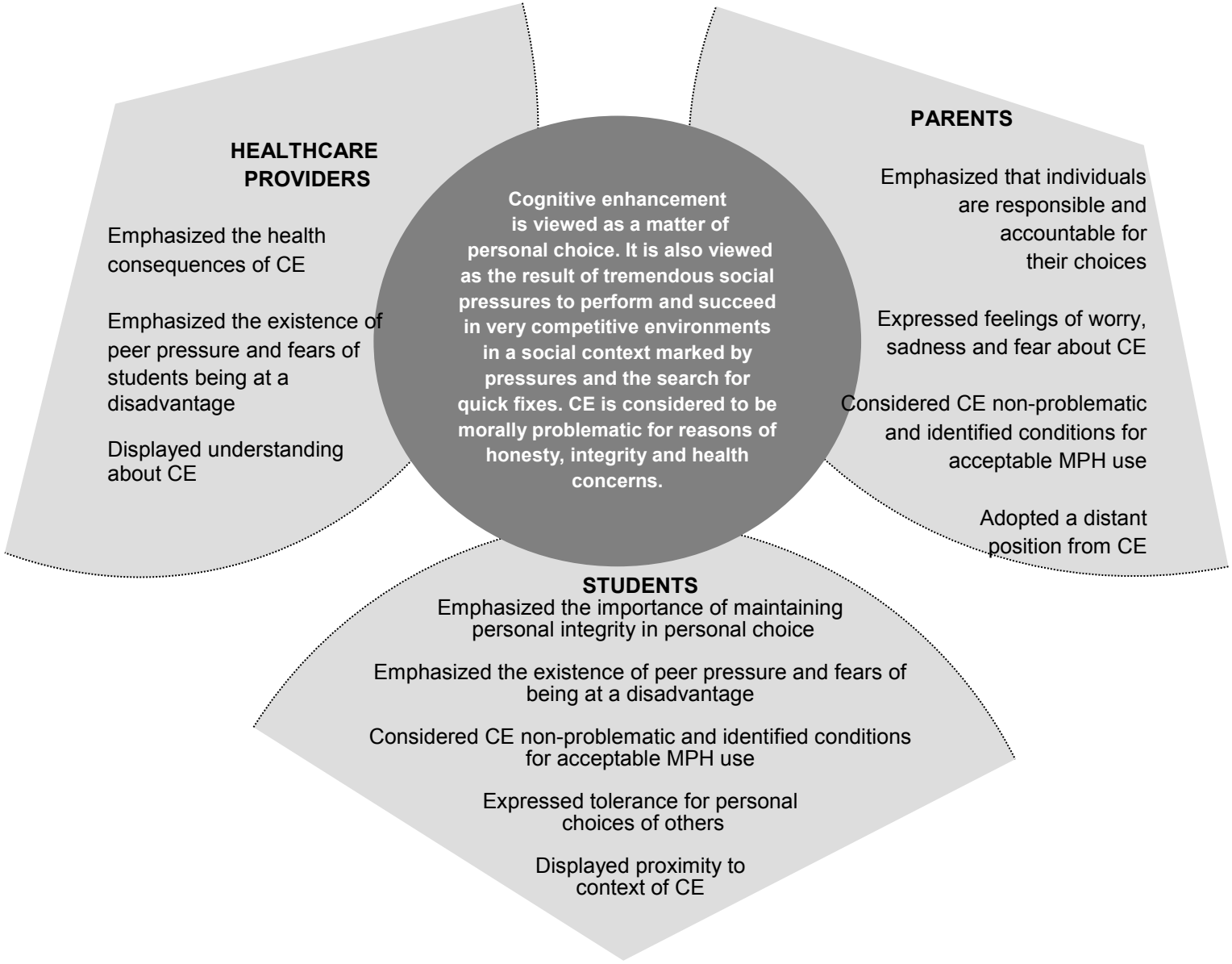
Participants

A total of 65 participants within 9 homogeneous focus groups were recruited: 29 students (mean age 20.9 years; focus groups A, B, C); 21 parents (mean age 53.8 years; focus groups D, F, H); and 15 healthcare providers (mean age 31.9 years; focus groups E, G, and I). Each participant was assigned an alphanumeric code (e.g., A1): the letter

indicating the stakeholder group and the number indicating the order in which the participant was recruited for the group. The majority (68%; N=44/65) of participants were female. The level of education of participants varied, though the majority of participants (59%; N=38/65) had an undergraduate degree that was completed or in progress. Of the 65 participants, 73.8% (N= 48/65) were already familiar with the phenomenon of non-medical use of MPH and 10.8% (N=7/65) of participants had used MPH for CE. Interestingly, none of the participants had a prescription for MPH at the time they completed the questionnaire and only two (3.1%) had had one in the past.

We first introduce converging perspectives between different stakeholder groups regarding the nature of choices and existing forms coercion present in the use of MPH for CE. These “converging perspectives” indicate that some opinions and statements were shared between groups but not that every individual shared or agreed with these opinions and statements. In spite of common perspectives, we encountered several important diverging perspectives between stakeholder groups, notably concerning the nature of personal choice, types of pressures encountered by students, as well as reactions and positions with respect to the use of MPH for CE. Figure 5.1 illustrates both converging and diverging perspectives between stakeholder groups.

Figure 5.1: Converging and diverging perspectives between stakeholder groups on autonomy and coercion in cognitive enhancement using MPH



Converging perspectives on personal choice and coercion in cognitive enhancement

The perspectives of stakeholders converged on several points, including considering CE as a matter of personal choice while considering it, paradoxically, as the result of tremendous social pressures to perform and succeed in very competitive environments. Several participants considered CE to be morally problematic for reasons ranging from honesty and integrity to concerns for health.

Cognitive enhancement is a personal choice

We asked participants whether they considered the decision to use MPH for CE as autonomous and the result of an individual choice. Positive answers (non-medical use is a decision made by solely individuals for themselves) were encountered in all three stakeholder groups. However, this opinion was most prevalent among students and parents with much less representation in healthcare providers. A representative example of this perspective is: "[p]eople make choices. Whatever reasons they use to make their choices, they still make their choices" (Parent D5). Other comments expressed a sense that the decision should remain completely within the purview of the individual: "[s]o if someone chooses to take Ritalin, whatever the reason, to get better grades, better paper, stay awake, if it's their choice. Are you allowed to regulate that? I don't think you can regulate a person's choice" (Student A1). Other participant comments highlighted that as individuals they would also feel free to choose to enhance or not: "[h]ey, if Ritalin does that for me maybe I will make that choice" (Parent D5). The personal choice perspective reflects that stakeholders believed using MPH for enhancement is a voluntary act based on an individual's choice, values and preferences.

Cognitive enhancement is motivated by pressure to perform

In contrast to statements expressing the view that CE was an autonomous individual decision, we found that participants from all three groups expressed opinions that the pressure to perform and succeed strongly supported CE practices and consequently heavily influenced an individual's decision. These pressures were often described as a demand for the individual to be the best in contrast to simply being average. For example, one healthcare provider explained that, "it is the problem of being the best of the best of, you cannot be a failure or an average, you have to be the best" (HCP E7). Success or ideal performance was discussed by all groups in terms of academic achievement and professional goals. Student (A2) justified that "you need that 'A' because you want to get into the best grad school because you want to get into the best program after and get the best job because there are so many just like you who can get your spot." Performing at an average level was felt to be insufficient because "[i]t is not just getting that 'B' because that 'B' is not going to get you very far in life. If everyone is going to university, a 'B' is not going to cut it to get you into the grad school you want to go to or get you that great job straight out of school" (HCP I3). Stakeholders emphasized academic scores and job placement as contributing to the pressure to enhance performance with prescription drugs like MPH.

Stakeholders considered that fierce competition with other students contributed to the pressure to perform and to use MPH for CE. For example, Student A6 said that using MPH for CE was attractive at the academic level: "[j]ust because it is so competitive. It is so cut throat that people do compare themselves to everyone else in the class." The motivation to achieve success in academia and in the job market supported this pressure: "[i]n terms of grad studies, we're getting into a highly highly competitive level where you can be replaced at the snap of a finger purely based on grades." (Student A1). On a more practical level, it was suggested that competition was compounded by the fact that "[w]e

have all these people who are going to university but there aren't enough jobs for educated individuals" (HCP I3).

Social influences for cognitive enhancement

Stakeholders identified social influences and forces that fueled the pressure felt by students to enhance their performance with MPH. For example, Student B7 stated that "the use of non-prescription Ritalin is very much like a symptom of societal problems not like a cause. Like I don't think it's gonna change society I just think people are taking it because there is so much pressure from school and stuff." One frequently mentioned social factor was the fast pace of modern life where "teenagers today or young adults who are on Youtube all night or Tivo, or bombarded, we are bombarded" (HCP G3). The social value of performance surfaced in the discussion of pressures felt by stakeholders to enhance their cognition where "you have raised the level of what is in terms of educational attainment and then by proxy I think you then raise the desire of what is your average kind of life: what is your average job and how well you can do. I think it puts into question whether or not the expectations are just too high" (HCP I3). The perceived high expectations were sometimes criticized as demonstrated by HCP G1 "if you feel you need to get 90% or 95% and without the Ritalin you would get an 88%, then why don't you get an 88. That is your problem." Some stakeholders considered social expectations to be related to "a problem with how we view the point of education" (Student C6), and that "the cause and effect is the other way around that it is the meaning of education has changed that's making social practices change. Like the demands being placed on the student right now is what makes people turn to this kind of thing rather than the university taking the line 'Oh the students are taking Ritalin so we can ask them to do more work'" (Student B2). Some stakeholders postulated that high expectations and subsequent changes in the way education is viewed has created a "bigger culture of 'one-upmanship'" where "people feel like

they don't have a choice" (Student C6) which is not present in other societies where people "just do what they can do and they don't overestimate what they can do" (HCP G3).

All stakeholder groups also suggested that using MPH for CE may currently serve as a quick fix. One perspective was that using MPH is "the easy way out" (Parent D3) or a shortcut in attaining goals where "you can just kind of pop a pill and focus for 6 hours" (Student B10). This feature was associated with the idea that "in society you have to out-perform, you are always looking for the next quick fix" (Parent D2). The other perspective we encountered adds to the description of MPH as a quick fix but stresses that MPH is a tool or a resource that can help attain a goal. For example, "[b]ut it can also be argued that Ritalin is also sort of a resource. Because in university these days with lectures being recorded and stuff they give you a lot of resources an a lot of help and things like that for you to succeed and it's how well you manage your resources and the thing about Ritalin that gets a lot of people is that it's a quick and dirty way and these days with pressure anybody can read though a bunch of essays and learn how to write an essay but it's the pressure for time" (Student B10). The notion of lack of time was observed by Parent H3, discussing alternative strategies to cope with high pressures, who said "[y]ou show me a university student in this day and age that has time to meditate, I will show you a kid who is not doing much work." The descriptions of the non-medical use of MPH for CE as a quick fix and resource culminate in the idea that demands for high standards of achievement emphasize the end result and encourage the fulfillment of a goal by any means possible. Student A8 articulated this point by saying that "everything is related to on what you cram and present on the final day. (…) The assessment of the student is just based on the final exam."

Cognitive enhancement is problematic

Stakeholder perspectives converged on the topic of MPH use for CE as being problematic, although as we will see later some accepted this practice. Participants stated that the covert nature of the practice was one of the key reasons that made it problematic. This perspective was apparent in qualifying MPH use for CE as "a taboo subject" (Student A2) and "something sort of sketchy (…) a secret so it's bad" (Student B4). Parent D2 elaborated that: "[t]his is nice if it is all in the open, but I assume that this is not really out in the open. I am not going to wear a badge saying 'I take Ritalin.'." Participants viewing CE as problematic also mentioned that it was "not honest" (Parent H5). In relation to dishonesty HCP I3 stated that: "I personally don't think that it is acceptable. I think that it is akin to things like people faking nervous breakdowns before an exam. I think that it takes away from individuals that need the drug (…) but to the extent where you are essentially disadvantaging other individuals who choose not to partake in its abuse then I think it is absolutely unacceptable". Other reasons supporting this view of CE with MPH as problematic were that "it is an illegal drug" (Parent D4); "it is bad for the brain" (Parent F2), and that "it would set a bad example" (Parent H5).

Diverging perspectives on personal choice and coercion in cognitive enhancement

The perspectives of stakeholders generally converged on the topics of personal choice, pressure to perform, social influence and the problematic nature of the use of MPH for CE. This means that, generally speaking, we found a shared perspective that CE was the result of an individual and rather autonomous choice. However, 20 participants answered that taking MPH for CE was both an autonomous and a coerced decision. The source of discrepancy for most participants was first the affirmation of an autonomous choice and then the identification and elaboration on the sources of pressure that may be lead to coercion. This section describes

the differences we observed between stakeholder group perspectives on the nature of personal choice and then on forms of coercion.

Responsibility and accountability in personal choice (Parents)

On the topic of personal choice, parents of university students tended to hold the individual responsible and accountable for the decision they make with regards to using MPH for CE. Much of this responsibility was associated with informed consent about the potential effects of using MPH non-medically. An example of such a statement is “students can take anything that they want. It is better for them if they know. To educate them first and then they can have their choice” (Parents F2). The choice to enhance cognition with MPH was even likened to smoking: “[i]t is like the cigarettes. I mean the cigarettes are there, they know it is bad for their health, and they still do it. It is their choice” (Parent F1). In encouraging the individual to be informed before they decide, the parental perspective made the individual responsible and accountable for the result of that decision.

The emphasis of parents on the accountability and responsibility of students is related to a form of soft paternalism that we observed in the parents’ discussion of personal choice. For example, parents emphasized the values and the role of the parents in the upbringing of an individual and ultimately in the decision to engage in CE. This paternalistic point of view was well illustrated by Parent H8 who asked “[i]s it that we are not allowed to talk about values anymore?” The same parent also expressed a generational difference in saying: “I mean it is not acceptable to get a lower grade if you do it on your own? (…) We are not allowed to tell our kids that they have to do the right thing. It is not important that you always get the ‘A’. (…) We always thought it was more important that the kid should be a good kid and do the right thing, you know, that it was not just about being the best and about winning the medal. It is how you run the race. It used to be anyways.” The role of the parents was discussed in

terms of instilling values but also in terms of parental guidance: “[t]he twenty year old might be too young to decide on their own, but if they were brought up properly maybe they would talk to Mom and Dad. Maybe they would think about it. Maybe they would, well they might do it anyway” (Parent D6).

Tolerance and integrity in personal choice (Students)

Values were an important topic in the student perspective on personal choice as well. However, in contrast to the parents’ responsibility and accountability model, students were more tolerant of the choices of others and expressed a form of libertarian view of personal choice that relied heavily on personal integrity. This tolerance can be seen in the statement “I mean, just knowing that I could go get it too if I wanted to you know what I mean. Like I don’t really mind other people like in my class (…) But if I really wanted to I could find some Ritalin and take it. I just choose not to so…” (Student B7). The notion that CE is a lifestyle choice also reflected tolerance where “I see it more as a lifestyle. You are making this choice to find the easy way out and morally I think that that is someone lifestyle choice” (Student C7). Though students were tolerant they emphasized the importance of integrity and of following one’s own morals and values in the decision to use neuropharmaceuticals like MPH for CE. For example, Student C1 said “I don’t feel comfortable about the word ‘acceptable’ because I don’t think that I am able to judge someone, but I think it is dangerous first of all. Acceptable or not I think that the person has to judge by herself if he or she has a strong body for that or not, if it is going to be good for her or not. I think it is a matter of your own conscience if it is acceptable or not.” Students seemed to accept CE as long as the individual was being true to his or her values: “[t]here’s the type of people that morally feel that it’s OK to do that kind of thing and there are the people that don’t and as long as, I guess, people should just stick to what they feel is right and that’s the best they can really do” (Student A4).

Despite their focus on personal integrity students also reflected the reality of the pressures that are associated with CE and the concessions that one would be ready to make with regard to the risks of using MPH. Goal-oriented students may be of the same opinion as Student A9 who said "fine, there is a side effect but everyone is doing it. Am I going to be the sucker that falls asleep at 2 AM before the exam?" Other students recognized that in spite of information "on what alcohol can do to your body, on what smoking can do to your body even things like use contraception and things like that and a lot of kids or students go ahead and do these things anyway" (Student B10).

Making a health conscious personal choice (Healthcare providers)

Healthcare providers focused their discussion of personal choice on the health aspects of the use of MPH for CE. Contrary to students who were tolerant to the health risks of non-medical use of MPH, the chief concern of healthcare providers was for those individuals who "are willing to risk the health consequences" (HCP I3). This concern was expressed by one HCP G4 who asked "[w]hat is going on in their lives that they are up all night, that they are having a manic episode? This is going to mess with your brain in ways that really concern me in terms of anxiety or depression. Are they working too much?" HCP I1 suggested that "[y]ou have the choice to organize your life without the drug. You can be more organized in your way of studying. You can take yourself in charge and say, 'I am not obliged to take this drug and go into this big stress if I start studying before, before the end- the exam.'" Healthcare providers were very much concerned about the mental health of students. For example, HCP I3 stated that "what is more disconcerting is the amount of anxiety, pressure and feelings of worthlessness that accompany the motivation to use something like this because you feel like you are not doing well enough or you can't handle the stress that is being put on you but you have to. So I think that is the most dangerous aspect of the medication is

that it highlights this kind of underlying, not instability, but a feeling of being uncomfortable, of not being confident of not thinking that your own abilities are enough" (HCP I3).

Worry, sadness and fear of cognitive enhancement (Parents)

Perspectives among stakeholders on coercion differed less widely than those on personal choice. Parents demonstrated the same kind of soft paternalism in discussing coercion as in discussing personal choice. They did not identify any additional types of pressure faced by students than those shared by all stakeholder groups. Parents recognized the pressures students face but wondered whether students recognized the potential impact of CE. An illustrative example of this point of view is: "as you know today, children are faced with a lot of competition, OK, and there is an increasing amount of pressure to succeed, to succeed, to succeed at all costs. It is easy to get up the $5 once a week. How do you address this with a student, an 18, 19, 20 year old student that does not see past tomorrow's exam?" (Parent D4). With regard to the pressures that may be fueling CE, parents had a variety of reactions which were not expressed (at least not as clearly) as in the other groups. The first type of reaction was the expression of worry. Parents were "worried about the people who are working really hard and they are not getting that 'A+'. Then they find out somebody else is getting an 'A+' and they start taking the medication" (Parent F8). The second type of reaction to the pressures faced by students was sadness. Parents said students "always have to be so perfect and they always have to succeed. I feel very, very sorry for them that they have all this pressure on them and they feel like they have to use a chemical substance to get through their exams or perform properly" (Parent H2). Another example of this reaction was the following statement "it is sad, it really is sad. I think that we are losing some of the value system because of it. I would always tell my kids: 'Do your best and I will be happy and I will be proud.' The reality is that you have got to perform or

you are not going anywhere. It is scary but it is true" (Parent H3). The previous example also illustrates the third and last type of reaction which was fear. We observed that parents were fearful that CE would become a new way of living "what I am afraid of is that it becomes the new standard" (Parent D1).

Individuals face peer pressure and being at a disadvantage (Healthcare providers and Students)

Students and healthcare providers emphasized specific pressures to perform and succeed. First, healthcare providers and particularly students felt that students may be put at a disadvantage if they abstained from using MPH for CE: "I think that it has the potential to become one of those things where you say 'I don't really want to but I don't feel like I have a choice.' (…) So again, the more people who take it, I think it relates to the issue of increased demands placed on students and then people who might not otherwise do it feel like they have no choice, if they don't take it they are ruining their own chances" (Student C6). One healthcare provider (I3) offered an interesting perspective about her personal experience with CE: "I wasn't surprised just because I have encountered it while going to university. Although when I was at university and I encountered it for the first time I was shocked. I was surprised at how prevalent it was. It certainly made me feel as though I was at a disadvantage because I wouldn't have taken the Ritalin to enhance my performance."

Second, both students and healthcare providers discussed peer pressure. They highlighted that the influence of other students could contribute to the perceived need for CE. Some participants in these two stakeholder groups lay fault on youth: "[i]t's about the gangs and about peer group and everything: if everyone else is doing it then I will do it too, although that would be kind of sad at a university level. I can understand at the high school level. (…) It's peer pressure, peer pressure. I mean that can happen in the workplace" (HCP G4). In addition to the effect of age, participants also described CE as a trend evoking precedents like cell

phones. One student commented that "[s]ome people were like 'oh I don't want to be dependent on my cell phone I not going to get a cell phone'. People tried to hold off. And then, or like Facebook, people tried to not get it. And then if you don't get it like it could sort of seems like well you need it because everyone else does it so if everyone else is on…Picture everyone at [your university] is on Ritalin and you're the only one who's not. (…) Everyone wants a cell phone now because it's a social norm to just call someone say if you're going to be late or something like that" (Student B4).

Cognitive enhancement is not problematic (Parents and Students)

Some students and parents expressed the opinion that CE was not problematic and perhaps even acceptable. Only one healthcare provider indicated that CE was not problematic. In contrast to the aforementioned perception of CE as problematic, some of these opinions evoked the idea that it was not problematic because individuals have become more forthcoming about using MPH for CE. For example, one student said that "it used to be far more taboo but now I find there is a lot less hesitation for students to just come forward and say 'Yeah I wrote that paper on Ritalin, I don't know how I would have done it otherwise'. And nobody blinks an eye. Nobody really looks at you" (Student A5). The practice was also acceptable on the grounds of respecting the personal choices of others. Representative examples of this point of view are: "(…) when I heard about them doing it I wasn't like "Oh my God!" It was just like, "I drink coffee. They do that" (Student B7) and "[y]ou know, if any of my kids came to me and said they took Ritalin for an exam, I am not going to be upset, not at all. It is what it is" (Parent H3). Interestingly, some of the opinions that CE was not problematic are based on a trend of increasing social acceptance. For example: "I have noticed within the past 2-3 years students say it more and more as if they want to legitimize it, as if it's OK. It's an attitude that I find changed since I found out about it a couple of

years ago" (Student A2). One parent even affirmed that "it has to be acceptable because it is a general rule now" (Parent H1).

In addition to perspectives that the MPH use for CE was not problematic, parents and students specified conditions under which use of MPH for CE could be acceptable. Examples of conditions included "If a university student takes it in a responsible fashion to actually function through an exam or a set of exams and that is it, then I think they are fine" (Parent H3); "it doesn't matter if it is the same or not if you can't get caught" (Parent D1); "I think that moderation is totally key but if it is a drug that they are giving to kids I kind of think that means it's pretty benign I have always been under the impression that it is fairly safe" (Student C9). Other conditions included the acceptance of CE amongst one's peers, and being in a dire situation.

Cognitive enhancement as a challenge to maintaining integrity (Students)

Students reported the challenging dilemma to maintain personal integrity when one may not want to engage in CE with a substance like MPH. Students expressed that "[i]t takes a lot to stick to your values" (Student A8) especially when they felt they may be put at a disadvantage if they would not be using MPH for CE. For example, Student A4 explained that "[i]t's getting harder and harder and that's the problem. I mean, people will always, usually at least, will come in with good intentions. They don't see themselves as the kind of person that would cheat or whatever, give themselves an advantage over others (…) But when more and more people are doing it and you see yourself being put at a disadvantage because of your values you're a lot more likely to think maybe my values are wrong because they're causing me these problems. Like it's hard to stick to values with more and more pressure." The challenge of maintaining personal integrity was described by students as a conflict between personal values and social values where "everyone wants to stick to their values until there's a conflict between core values that you have.

Because for me a core value is being true to myself and honest all the time but another core value is to academically succeed and I can clearly see that when these two come into conflict with each other you have to choose and most people choose to have the advantage and that's where I think social influence has come along and help you choose" (Student A2). Other students saw personal values as somewhat ornamental because "[y]ou're willing to do anything just because you only have so much time and you need those grades. So it's nice to stick to your values but I think that everyone is willing to make exceptions at one point or another" (Student A9). These exceptions may be justified by the point of view that "nobody is going to pat your back for being honest. It's for yourself. If you're honest and you feel good about it it's totally up to you but if you take Ritalin and you do the exam well and get 100% a lot of people will pat your back. It will open a lot of doors in society. So the pressure, society doesn't really congratulate you on your values" (Student A1). Though personal integrity was an important aspect of the autonomous choice to use MPH, constantly adhering to one's values proved to be a challenge for students.

Positions expressed by stakeholder groups

Stakeholder groups expressed different relationships and levels of familiarity with MPH for cognitive enhancement. Parents adopted the most distant position. For example, individuals that may engage in CE were referred to as "they", "people", "kids" and "children". Other examples of parents' statement are: "[t]hey have all this pressure" (Parent F8) "[p]eople make choices" (Parent D5), and "[t]hese kids you know, they are adults" (Parent F1). The distance parents put between themselves and the students who are under pressure to perform is consistent with the soft paternalism observed in the discussions of personal choice and coercion.

Healthcare providers shared, to some extent the same distance as parents but introduced proximity by using the term "you" more frequently.

For example, HCP E1 said “[i]f you want to do a masters or doctoral degree well you have to have the best grade. Otherwise, you don’t get any money, you don’t get any directors”. In this respect healthcare providers spoke more generally and did not necessarily remove themselves from the group of people affected by pressures to perform. Accordingly, healthcare providers also used this term when speaking of health choices. For example, healthcare provider who said “[y]ou choose to take Ritalin to enhance your cognitive ability just like this person chooses to smoke cigarettes” (HCP I3) equated CE to a lifestyle choice. HCP I1 suggested that “[y]ou have the choice to organize your life without the drug. (…) it is very important because it is your life and you have to have it controlled, especially the students.”

Students showed the greatest variability in their position with regard to CE with MPH. The most prevalent way of speaking was the “you” perspective akin to healthcare providers. For example, Student A1 said: “[i]n campuses the pressure is evident when you’re in exam time so you have a good chance to find out what it is.” Student A9 expressed that “[y]ou’re willing to do anything just because you only have so much time and you need those grades.” By providing the most specific examples of situations that might encourage CE and using the term “you”, students introduced a self-inclusive component which positioned them close to CE. Interestingly, the students were the only group to consistently use the terms “we”, “us” and “I”. For example Student A5 said “I worked really hard to do really well in school because I wanted to but it wasn’t because of what other people were doing that motivated me to pull the all-nighters.” Student A10 indicated that students were part of the solution “I don’t know how to change an education system but we have to take off the kinds of pressure that are causing people to do this.” Students did not always keep a consistent position within a statement.

Discussion

Our study revealed that perspectives of stakeholders converged on the belief that cognitive enhancement is a matter of personal and individual choice. Perspectives also converged on the existence of tremendous social pressures to perform and succeed in very competitive environments marked by the search for quick fixes. Despite the overarching belief in autonomy, the conclusion of many participants was that students now had no choice but to engage in CE, especially in a competitive academic environment where their peers might be engaging in CE. Several considered CE to be morally problematic for reasons ranging from honesty and integrity to concerns for health.

Perspectives between stakeholder groups also diverged on some fundamental points. Parents emphasized personal responsibility and accountability for CE choices, and expressed feelings of worry, sadness and fear about it. They tended to distance themselves from CE and adopt a paternalistic position toward students choosing to enhance their cognition. Students emphasized the importance of personal integrity when considering CE, expressed tolerance for personal choices of others, and highlighted the challenge that CE poses to their own personal integrity, while displaying familiarity to the context of CE. Healthcare providers focused on the health consequences of CE and displayed an integrative perspective on CE that built on features of the students' and parents' accounts. Both healthcare providers and students emphasized the existence of peer pressure that could lead students who decide not to enhance to feel at a disadvantage. Some parents and students suggested conditions under which the use of MPH for enhancement could be acceptable. Healthcare providers tended to be staunchly against the practice of CE with MPH and did not formulate any conditions that would make the practice acceptable.

Limitations

Some aspects of the qualitative nature of this project limit the generalization of the results and should be taken into consideration for the proper interpretation of our results. First, due to the small sample, the opinions expressed in the focus groups cannot be considered to represent general opinions of students, parents and healthcare providers, especially outside of North America. Our results can serve to illustrate some of the potential convergences and divergences between the perspectives of each group but further research and analysis is needed. Second, participants were given four representative media articles to read prior the focus group but despite the range of topics covered in these articles, they represent a specific type of prompt that has its advantages (e.g., real source of information intended for general readership) but also its disadvantages (e.g., not addressing in detail every ethical and social issue related to CE). Also, though the UK and Australia media are represented in this prompting material, the way in which CE was depicted reflected mostly a largely North American phenomenon. Third, focus groups are discussions and not surveys. Thus, not all participants commented on every question. Accordingly, when we report the perspectives expressed, these perspectives should be considered as those that were explicitly and *de facto* expressed – not necessarily all that could be expressed. Fourth, our focus groups were conducted in English (given the English-language prompts) but our recruitment included individuals with different maternal tongues and this could have an impact on how participants expressed themselves. Fifth, some difficulties in data capture (e.g., failed recordings of some comments) and subsequent transcription caused a very small part of participant statements to be unsuitable for analysis. Sixth, the demographic questionnaire we administered before the focus groups asked participants to specify their professions we did not, however, inquire in this questionnaire whether the participants had children.

Based on these results, we have identified a number of important points that merit further attention for discussion: 1) the discrepancy between the belief that CE is an autonomous choice and the description of intense social pressures in the academic environment; 2) the impact of the apparent neglect of a social-level ethics approach in contrast to the individual *laissez-faire* attitude generally observed; and 3) the differences observed between stakeholders in their approach to the ethics of CE with MPH suggesting that there are important ethical implications of public health interventions in a value-laden area where perspectives diverge.

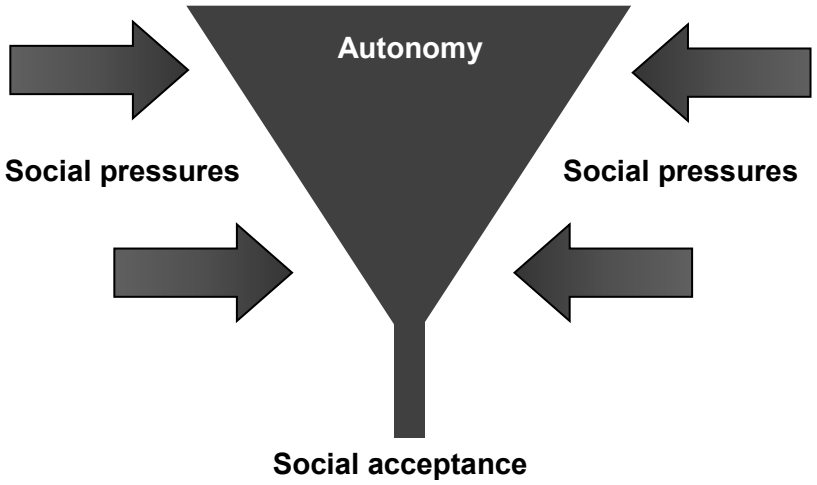
Understanding the Nature of Autonomous Individual Choices in a Context of Intense Social Pressures in the Academic Environment

Our findings show that stakeholders generally perceived the students' decision to use MPH for CE as an individual's choice. This was well reflected in the comments made by participants who believed that this choice was a function of personal ethics and values which created the difficulty of regulating this form of behavior. Consequently, a part of the converging stakeholder perspectives was that individuals had the option to choose to enhance or to abstain thereby reflecting a fundamental belief in individual choice regardless of the different ways in which this choice was described.

However, a vast majority of participants in the three stakeholder groups described the context of CE with MPH as being marked by multiple forms of intense social pressures to perform and succeed. This leads to what we have called a "funnel phenomenon" (see Figure 5.2) where perceptions of social pressures channel toward the social acceptance of MPH use for CE. Accordingly the choice of CE was viewed as autonomous but the social *causes* motivating this practice (e.g., pressures to succeed, highly competitive academic environments, faster pace of life and increased expectations) transformed them into a *reason to do it*. This transition in the discussion (from causes to reasons) was present in many comments suggesting that the sheer pressures of society upon individuals

fatalistically impede any form of preventative regulation because individuals have no choice if they want to succeed. Only a few reactions across groups to this point of view highlighted that causes are not reasons; that ends do not justify the means; and that other strategies could be used to cope with pressures created by the academic environment.

Figure 5.2: "Funnel phenomenon": Social pressures to engage in cognitive enhancement with MPH could lead to social acceptance in spite of beliefs in autonomous choice



Hence, participants highlighted the role of an individual's values as a guiding light in the decision to enhance or not. Paradoxically, stakeholders also felt that social pressures create a form of fatalistic social determinism leading to conformity with social values through a concession of personal values. Though stakeholders maintained that personal values are a substantial factor in decision-making their speedy concession under social pressure leads to the contradictory interpretation that they are unessential and rather ornamental.

But does the "funnel phenomenon" we observed in the discourse of stakeholders have an impact on actual behaviors? Does the belief in fatalistic social determinism influence actual behavior and decision to use

cognitive enhancers? At this point, there is no data to shed light directly on this question but social psychology research suggests that portrayal of contexts as deterministic can actually influence decisions and behaviors [30, 31]. For example a study conducted by Vohs *et al*. on undergraduate students has shown that participants who were exposed to deterministic messages cheated more often on a simple task than their counterparts having read messages promoting free will. We can draw two important messages from this study. First, an individual's belief in determinism can be conducive to unethical behavior. Second, beliefs in free will may be changing and lead to increased cheating and other unethical behavior. A cross-temporal meta-analysis by Twenge *et al.* confirmed this plasticity by finding that between 1960 and 2002 young Americans externalized their locus of control, i.e., they believe that external factors and not their will determines their fate. This belief of recent generations may be bolstered by beliefs of biological determinism through genes but also neuro-essentialist (e.g., we are our brains) and neuro-realist (e.g., we can directly access brain function) interpretations of neuroscience research [24]. It is important to note that from a descriptive point of view the way participants depicted the context of decision-making may be exaggerated. Participants may have overstated the role of social pressures [19] and minimized the possibility of autonomous choices. However, we can not neglect the potential draw of deterministic and fatalistic arguments on the potential acceptability of neuropharmaceuticals with cognition enhancing properties. If deterministic and essentialist interpretations of neuroscience do have implications, then our results suggest a broader social acceptability of this form of technology use potentially impacting future social policies on neuropharmaceuticals.

The impact of the apparent neglect of a social-level ethics approach in contrast to the individual laissez-faire attitude observed (normative-descriptive discrepancy)

As noted above, we found that fundamentally, participants held a strong belief in autonomy and the importance of being guided by one's personal values and ethical principles. In this sense, not only does the choice seemed to rest upon personal values but the acceptability of the phenomenon was generally left up to the better judgment of individuals. In this respect, participants advanced the role of autonomy at the *normative level*. However, at the *descriptive level*, social pressures were abundantly illustrated by an overwhelming majority of focus group participants. Consequently, there is a striking "normative-descriptive" tension in the opinions expressed by stakeholders. The tension we describe does not imply that the presence of strong social pressures would *de facto* disqualify normative beliefs in autonomy. (This would be a "fallacy" not simply a "tension".) Rather, we are highlighting the tension between the description of an autonomous decision to enhance in the presence of strong social pressures constituting a context and an environment which values success. The concerns expressed by participants regarding the social pressures for increased academic performance are not well captured by the normative individualistic stance that was generally put forward by participants.

The individualist stance we encountered resonates with North American writings on the ethics of CE. For example, Arthur Caplan has argued from a liberal perspective that "[t]he answer is not prohibiting improvement. It is ensuring that enhancements always be done by choice, not dictated by others" [8]. A representative of conservative bioethics, Eric Cohen, has expressed different ethical concerns but has also suggested that individuals could have a choice (in this case not to enhance) [11]. However, based on our data, it is unclear whether the issue of choice and autonomy can be discussed outside of specific social contexts. At this point, tenants of liberal bioethics perspectives may wrongly assume that

using neuropharmaceuticals for CE is an individual, context-independent choice. Conservative perspectives may imply that we can easily reject or stop enhancement uses of neuropharmaceuticals also independently of context. Such individualist stances contrast with views that would highlight the need to consider tackling the social context in which CE arises.

In contrast to some predominant perspectives, some approaches underscore the need for attention to context and the social dimensions of individual choices. For our purpose, it will suffice to highlight two points based on the writings of Habermas and Sartre. The first point is that the normative-description tension should be put in the broader context of liberal economies to properly exhibit the forces at play and the need for social approaches. The second point is that historically, other forms of fatalistic determinism have been highlighted as well as their potential to reinforce collective behaviors.

Habermas's writings, in particular "Science and Technique as Ideology" [15] and "Discourse Ethics" [16], provide an interesting connection between the normative-descriptive tension we observed and the impact of liberal economies on public discourse and ethics. Habermas analyzed patterns related to the modern replacement in the public sphere of discourse by strategic rationality, that is, rational modes of productions that progressively replace traditional modes of production and being. Our data, based on the comments of focus group participants, reflect that academic institutions, the education process, and students are under significant pressure for increased productivity and performance. Stakeholders converged on this point and their comments reflect in many respects a phenomenology of modern strategic rationality at work. Nonetheless, there were few, if any, comments suggesting that the forces at play needed to be tackled at a social level because of the intense pressures of strategic rationality on values.

In *L'existentialisme est un humanisme* [27], Sartre identified and criticized deterministic views like those described by our focus group

participants. He argued that individuals were *projects*; human beings were responsible for their own choices and that the refusal to decide and to lucidly come to terms with one's choice was a gesture of bad faith (*mauvaise foi*). Sartre also argued that when we choose for our self (qua individuals), we also choose for ourselves (qua humanity). When we act, we act as part of humanity and engage others to do the same by setting an example. By doing so he contributed to making existentialism a form of humanism with potential universal implications. Clearly this line of thinking is also very different from the perspectives on personal choice we encountered in our focus groups. Sartre's strong stance against individualism is relevant to the context of CE because many participants described that individual enhancements constituted trend-setting and encouraged others to do the same. Clearly, the mere replication of social pressures creates a "vicious circle" that can simply reinforce social pressures and promote implicit coercion, which in return increases pressures to enhance cognition with neuropharmaceuticals.

The individualist perspective we encountered in our focus groups resonates well with liberal moral-political thought which emphasizes that CE should be the decision of individuals. However, it clashes with other approaches like those found in the writings of Habermas on science and technology as well as moderate liberal approaches that underscore the importance of the broader context in shaping decisions. The normative-descriptive tension we observed in stakeholder perspectives suggests the need for an ethical approach that adopts both an individual and social perspective on science and technology to fully capture the social dimensions of individual choices. It would be interesting at this point to further explore how moral political thought could integrate both individual and public autonomy (e.g., public debate on the use of cognitive enhancers) given the potential impact of these practices on the collective pursuit of common goods and public institutions (Racine, Pragmatic

Neuroethics: Improving Treatment and Understanding of the Mind-brain, under review).

Differences observed between different stakeholders in their approach to the ethics of cognitive enhancement with methylphenidate and future public health interventions

Finally, our comparison of contrasting stakeholder perspectives in our focus groups brought to light important divergences namely regarding their views on personal choice and relationships to the phenomenon of CE *per se*. The diverging perspectives of stakeholders in this study may reflect previously described paradigms regarding the enhancement use of MPH [25]. For example, students were tolerant of the choices of others. Even though some stated they would personally not engage in CE themselves, they expressed the view that CE was a lifestyle choice consistent with "the lifestyle choice paradigm" previously encountered in the popular print media [25]. Healthcare providers extensively criticized CE and this coincides with "the prescription abuse paradigm" encountered in the public health literature [25]. We also found that healthcare providers tended to view CE as deeply problematic from a healthcare and ethical perspective while parents and especially students were much more ambivalent. This observation coincides with recent research conducted in Scandinavia showing that healthcare providers are less enthusiastic regarding CE with prescription pharmaceuticals than the general population [6].

One of the lessons we can draw from existing divergences is that the contentious issue of CE generates wide-ranging reactions and opinions. In the context of modern democratic societies, it is important to recognize this pluralism and the multiple factors that generate it. At this point, public debates on current and future CE have been timid. Even professional societies have not engaged extensively in related discussions (Forlini and Racine, Disagreements with Implications: Diverging Discourses on the Ethics of Non-medical Use of Methylphenidate for Performance Enhancement, forthcoming), the British Medical Association

being one notable exception [7]. Though there has been no consensus on the exact role that public health can or should play, there are certainly some areas where interventions could be considered appropriate given the potential impact of CE on collective behaviors and beliefs. The close relationship of CE with healthcare raises the issues of responsible management of prescription neuropharmaceuticals especially in environments where CE is prevalent. Public health authorities must also be aware of enthusiastic media reports on practices potentially having an impact on public health if they want to counterbalance unwarranted messages in the media and better inform the public and stakeholders. If public health information and interventions are eventually considered, the pluralism that we and others have observed will need to be factored in to inform debates and take into account the diversity of current perspectives.

Conclusion

We reported and discussed the results of a focus group study of stakeholder perspectives on the non-medical use of MPH for academic performance enhancement. In this paper, we focused on data that shed light on the issue of autonomy and coercion with the goals of better understanding how these aspects play out in the perspectives of different stakeholders. Our results showed that the perspective of stakeholders converged on the belief that CE is a matter of personal and individual choice. At the same time, perspectives also converged on the existence of tremendous social pressures to perform and succeed. Perspectives between stakeholder groups also diverged on fundamental points (e.g., specific views on personal choice). We discussed how these results illustrated the importance of understanding how context is viewed in relationship to autonomous choice since perceptions of fatalistic social determinism like those we encountered could fuel further acceptance and use of neuropharmaceuticals for cognitive enhancement. We also highlighted the limitations of individualistic libertarian approaches that do

not factor in social context while highlighting briefly a few possible implications of public health interventions in a value-laden area where perspectives diverge. We believe that current discussions on CE need to pay closer attention to the perspectives of different stakeholders and the context in which CE practices arise. How the crucial phenomena of autonomy and coercion play out in reality also needs to be better understood. Further, we call for more engagement of professional societies and public debate to better prepare the terrain for potential future public health policy.

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Concluding remarks on Chapter 5: Individual choice seems to be constrained by social pressure

The results reported in Chapter 5 address the choice of individuals to engage in or abstain from the non-medical use of prescription medication for cognitive enhancement. Perspectives of stakeholders converged on the belief that cognitive enhancement is a matter of personal and individual choice as well as on the existence of tremendous social pressures to perform and succeed in very competitive environments marked by the search for quick fixes. Despite the overarching belief in autonomy, the conclusion of many participants was that students now had no choice but to engage in cognitive enhancement, especially in competitive academic environments where their peers might be engaging in cognitive enhancement. This perspective is consistent with prevalence studies citing attendance of competitive universities as risk factors for non-medical use of stimulants (Chapter 1). The influence of external pressures on individuals contributed to a “funnel phenomenon” with the acceptability of cognitive enhancement despite a fundamental belief individual choice. However, perspectives between stakeholder groups diverged in discussing reasons why cognitive enhancement was problematic with respect to autonomy. These reasons touched upon the topics beyond social pressures such as: personal responsibility and accountability for cognitive enhancement choices, challenges to personal integrity when considering cognitive enhancement, tolerance for personal choices of others, and the health consequences of cognitive enhancement. These considerations suggest a more complex landscape for decision-making regarding cognitive enhancement.

Original contribution of Chapter 5

The analysis of stakeholder perspectives presented in Chapter 5 is, to date, one of the only contributions shedding light on the concrete aspects of beliefs in autonomy and sources of influence in cognitive enhancement.

Beliefs in personal choice and pressures to perform have been reported by other studies with students (Franke et al. 2012b; Bell et al. 2012) but contrast with our results regarding deterministic influences reported (Franke et al. 2012b). The tension between personal choice and the context of social pressures is a striking finding that highlights a moral struggle between what stakeholders value and what they feel they have to do. This normative-descriptive tension is not yet well recognized in the academic debate that may misrepresent the voluntariness of cognitive enhancement by analogizing social pressure with other accepted external influences (Caplan 2003; Bublitz and Merkel 2009) or overstating its influence (Bush 2006). However, stakeholder and academic debates must not lose sight of the possibility for individual choices and actions regarding cognitive enhancement to orient social practice. To date, most studies have been carried on either student or medical professional populations with the exception of one study that compared the perspectives of physicians with those of the public (Bergstrom and Lynoe 2008). The results in Chapter 5 illustrate important differences between different stakeholder groups that suggest the existence of many *publics* as opposed to one public. The context and experience of different groups (socio-economic or cultural) play an important role for individual autonomy in the ethics of cognitive enhancement (Racine and Forlini 2009) and may also impact other salient issues.

Surveying the ethical landscape of the cognitive enhancement debate in Chapter 6

In Chapter 6 the scope of the analysis of stakeholder perspectives is widened to survey the ethical landscape of the cognitive enhancement debate. This approach seeks to compare stakeholder perspectives with existing ethical frameworks (as in Chapter 4) and explore the experience of stakeholders (as in Chapter 5) to clarify the roots of ethical contention. Ethical, social and legal issues identified from a previous discourse analysis of the print media, bioethics and public health literatures (e.g.,

prescription abuse, authenticity of the individual, cheating, commercialization, illegality, injustice and inequalities, overprescription, social meaning) (Forlini and Racine 2009a) are examined individually and in concert based on the perspective of stakeholders.

CHAPTER 6: Added stakeholders, added value(s) to the cognitive enhancement debate: Are academic discourse and professional policies sidestepping values of stakeholders? *AJOB Primary Research*. 2012. 3 (1): 33-47.

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Abstract

Background: The debate on the non-medical use of prescription medication for the enhancement of cognitive function (e.g., attention, memory, concentration, vigilance), accompanied by heated public discussions in the media, has spurred the interest of scholars and the public.
Methods: In this paper, we present qualitative data from a focus group study with university students, parents, and healthcare providers. We identified ethical, social, and legal issues related to the non-medical use of methylphenidate for cognitive enhancement (CE) and closely examined the positions taken on these issues and their supporting arguments.
Results: The ethical, social, and legal issues we identified (e.g., authenticity, cheating) were similar to those identified in a previous discourse analysis of the bioethics literature but indicate the existence of moderately and highly contentious issues as well as factors and values underlying these issues. The model we generated from these findings shows how interplay between values (e.g., effort and honesty) and external factors (e.g., regulation and access) may lie at the root of contentious ethical issues in CE.
Conclusions: Our discussion points to an unsuspected complexity in understanding values of stakeholders and their unclear relationship to academic discourse and professional societies. We propose deliberative or other democratic processes as a way to recognize and incorporate the complexity of the CE debate.

Keywords: cognitive enhancement, neuroethics, focus groups, stakeholder perspectives, professional guidelines, pragmatism

Background

The debate on the non-medical use of prescription medication for the enhancement of cognitive function (e.g., attention, memory, concentration, vigilance) has spurred the interest of scholars (Farah et al. 2004; Hall 2004; Greely et al. 2008; Forlini and Racine 2011) and the public through heated discussions in the media (Forlini and Racine 2009b). Several specific ethical issues surrounding this phenomenon (often called “cognitive enhancement” (CE) by academics) have now been described and discussed at length (President's Council on Bioethics 2003; Chatterjee 2004; Farah et al. 2004; Hall 2004; Mehlman 2004; Bush

2006). Throughout this debate, little consensus exists on the moral acceptability or moral praiseworthiness of CE (Racine 2010). It has been suggested by some authors that cognitive enhancers "should be viewed in the same general category as education, good health habits, and information technology – ways that our uniquely innovative species tries to improve itself" (Greely et al. 2008, p. 702). Yet others consider that "biotechnological enhancement fundamentally alters the essence of what it means to be an individual" (Bush 2006, p. 131). These opposing points of view have been associated with the broader framework of the "culture wars", which underlies many polarized American bioethics debates like stem cell research and end-of-life care (Racine 2010). The entrenched opposition that characterizes the perspectives within academic ethics creates blind spots, resulting in a lack of attention to underlying values and assumptions (Parens 2005) that could have consequences in the development of cohesive policy approaches, irrespective of their liberal or conservative orientations.

A second debate concerns whether CE poses novel and salient ethical issues of its own and what type of attention and response, if any, these issues require. Scholars have voiced healthy scepticism about the novelty of the questions related to CE based on precedent lifestyle use of illicit and prescription drugs (Lucke et al. 2010) or exaggerations about the effects and prevalence of CE[11] (Outram 2010). As such, the nature of the debate and response to CE becomes a phenomenon to reflect on in its own right. This is important in light of comments that the academic debate is overly polarized to the point where *advocacy* – rather than *open scrutiny* – better describes current scholarship, in bioethics generally and in the debate about CE specifically (Callahan 2005; Parens 2005; Racine 2010). Exaggerations of the novelty and prevalence of CE, along with a dubious

[11] Estimates of the proportion of university students using stimulants to enhance academic performance range from 1.3% to 11% (Wilens et al. 2008; Racine and Forlini 2010; Franke et al. 2011).

use of CE terminology within the academic literature, (Racine and Forlini 2010) suggest that academia has not necessarily been an impartial and reasonably objective participant in the CE debate (Hall and Lucke 2010; Lucke et al. 2010; Outram 2010; Forlini and Racine 2011). Moreover, assumptions about the effects and prevalence of CE could prevent open-ended discussion and stifle debate by suggesting that "cognitive enhancement" is by nature an "enhancement" (Racine and Forlini 2010) or that prevalence creates pressures to hastily condone the moral acceptability of CE more generally (Lucke et al 2010).

These points of contention within academic debates have complicated efforts to map the ethical landscape of CE, while also structuring the debate in ways that may create or perpetuate blind spots. For example, in policies and guidelines about CE produced by two professional societies and a government committee, commonly shared assumptions such as (1) the strong need for professional guidance, (2) the urgent need for social discussion, (3) estimates of high prevalence and widespread demand for enhancers (Outram and Racine 2011) have already been cited as motivators for advice on governance on how to approach CE in an ethical manner (British Medical Association 2007; Larriviere et al. 2009; Commission de l'éthique de la science et de la technologie 2009). There is therefore the potential, as we have argued elsewhere, for the academic debate focused on the ethics of CE to actually perpetuate blind spots with respect to the way that issues are identified, discussed, and approached in the public domain in the development of policies with little reality check and input from non-academic perspectives on CE (Racine and Forlini 2010; Forlini and Racine 2011).

An emerging body of research has begun to shed some light on potential blind spots within academic CE discourse by investigating the perspectives of different stakeholders with regard to the non-medical use of prescription medication. These data create the possibility of better

situating the ethics debate within relevant social contexts and redirecting, if needed, the academic ethics debate to address issues that are important to stakeholders. So far, stakeholders in these studies consist of university students or members of the public (Sabini and Monterosso 2005; Riis, Simmons and Goodwin 2008), healthcare professionals (Banjo, Nadler and Reiner 2010; Hotze et al. 2011) and combinations of these groups (Bergstrom and Lynoe 2008; Forlini and Racine 2011; Forlini and Racine In press). These empirical studies employ methodologies, both quantitative and qualitative, that allowed the authors to identify attitudes, opinions, and reactions to different aspects of CE and CE-related ethical issues. Results have honed in on specific issues (e.g., autonomy, fairness, authenticity), providing more information on how stakeholders grapple with the permissibility of CE. The results of these studies help illuminate the real-world context of CE, adding important facets and realities that inform and enrich academic debates but can also sometimes radically contradict or call into question assumptions made in these debates which may not reflect the real-world context of CE. In a striking study, Riis *et al.* used a series of vignette experiments to show that healthy young individuals are more reluctant to enhance traits that are perceived to be fundamental aspects of their self-identities than those which are believed to be less fundamental (Riis, Simmons and Goodwin 2008). However, attitudes toward legal access are not shaped by this perspective on self-identity but rather by moral concerns (e.g., fairness and authenticity). We have previously reported that both liberal and more "conservative" or prudential academic bioethics positions on CE may err fundamentally in their assumptions about individuals' levels of freedom to either choose or refuse CE; both positions are in radical disconnect with perceived pressures and coercion (Forlini and Racine 2009a). In other studies, healthcare providers emphasized concerns for the safety and efficacy of medications used for CE as well as issues of social justice in terms of distribution and potential insurance coverage (Banjo, Nadler and Reiner

2010; Hotze et al. 2011). These studies show the psychological complexity underlying perspectives regarding the ethics of CE, in contrast to some of the more simplistic assumptions made within the polarized academic ethics debate as well as in discussion of policy and professional associations. This contrast between academic and non-academic discourses is suggestive of parallel debates in the multiple approaches to the ethics of CE (Forlini and Racine 2011).

In this paper, we sought to identify the ethical, social, and legal issues that are most important to stakeholders and to better understand the values at the root of ethical contentions about CE. We present qualitative data from a focus group study that we hope will enrich comprehension of ethical issues in CE with experiential knowledge and perspectives contribute to a grounded understanding of different stakeholder perspectives on CE and the emerging literature on non-academic stakeholder perspectives on CE.

The study was inspired by an open-ended research approach grounded in pragmatism (Racine 2010) as a pathway to develop empirically-based ethical approaches in a context of unclear moral intuitions and pervasive academic debate. The data we acquired contribute to furthering our understanding of social and psychological factors underlying the CE debate while shaping a complex picture of public attitudes to CE. We discuss specifically how academic approaches fall short of capturing values of importance to stakeholders, most notably authenticity. We argue that current policies would benefit from attending to the values underlying public perspectives toward CE, although this would call for non-conventional approaches to develop policies through open deliberation.

Methods[12]

We focused our study on methylphenidate (MPH). Methylphenidate is a prescription stimulant that is used to control the symptoms of Attention Deficit/Hyperactivity Disorder (ADHD) and is more commonly known under the commercial name Ritalin (Canadian Pharmacists Association 2008). This prescription drug is often cited as being used by university students to increase academic performance (Teter et al. 2003; Barrett et al. 2005; Arria and Wish 2006; Teter et al. 2006; Wilens et al. 2008) in spite of unclear evidence about its efficacy (Repantis et al. 2008, 2010, 2010).

Participants

Participants consisted of three groups: university students 25 and under, parents of university students and healthcare providers (HCP). Each group brought a different perspective. The age limit on university students reflects data showing that the practice exists among undergraduate students (Babcock and Byrne 2000; White, Becker-Blease and Grace-Bishop 2006). Parents of university students provide a generational difference and they are directly connected to university education. Healthcare providers work closely with medications to treat disease, making their perspective on the repurposing of MPH for CE of interest to this study. A HCP was defined as someone having a professional responsibility to care for the health of patients (e.g., doctors, nurses, pharmacists). No particular expertise with MPH was required.

Recruitment

The study and the recruitment strategies were approved by the Research Ethics Board (REB) of institutions where the study was conducted. English and French recruitment advertisements were posted in common areas of

[12] The data presented in this article is part of a larger study of which the methodology and other non-overlapping data have been previously published (Forlini and Racine 2009a; Forlini and Racine In press). (

two universities and affiliated institutions. Advertisements were also featured in various general and student newspapers as well as online classified sites. E-mail invitations were sent to major student associations and faculty members in healthcare professions. Participants received compensation ($50) for their time.

Focus groups

Focus groups, as a method, allowed us to gain insight into broader stakeholder perspectives as opposed to those of single individual which could be gathered in a survey approach. To minimize recruitment bias and encourage participation of non-experts, participants remained unexposed to the specific subject of the discussion (CE with MPH) until they received the documentation package. This package included a print media sample of four articles, a consent form, and a short questionnaire. The articles were chosen from a systematic print media sampling of prior discourse analysis (Racine and Forlini 2010). To maximize the scope of the focus group discussion, articles were selected to reflect variability in content (e.g., details about how students obtain pills, effects, and testimonials), quality of information, overall coverage of ethical issues, length, and country of origin (Laurance 2003; Zernike 2005; Morency 2006; Ross 2006). After reading the articles, participants were asked to fill out an anonymous questionnaire collecting demographic data and information about prior knowledge of CE with MPH.

The interview grid for the focus groups was based on the results of prior discourse analysis, which identified salient ethical issues in different literature, including the print media (Racine and Forlini 2010). We tested the interview grid with three pilot interviews to gauge the appropriateness and comprehension of our questions. During the focus groups, participants were first invited to comment generally on CE and then express their opinions regarding the ethical, social, and legal issues related to CE. They were also asked to comment on the potential ethical, legal, social, and

healthcare impacts of CE as well as solutions to these issues. Finally, participants were asked to give their impression on the media coverage of MPH for CE based on the prompt material. The focus groups were moderated by one of the authors (ER) to allow spontaneous expression of opinions while ensuring coverage of the topics included in the interview grid. The other author (CF) assisted the moderator and took field notes.

Coding

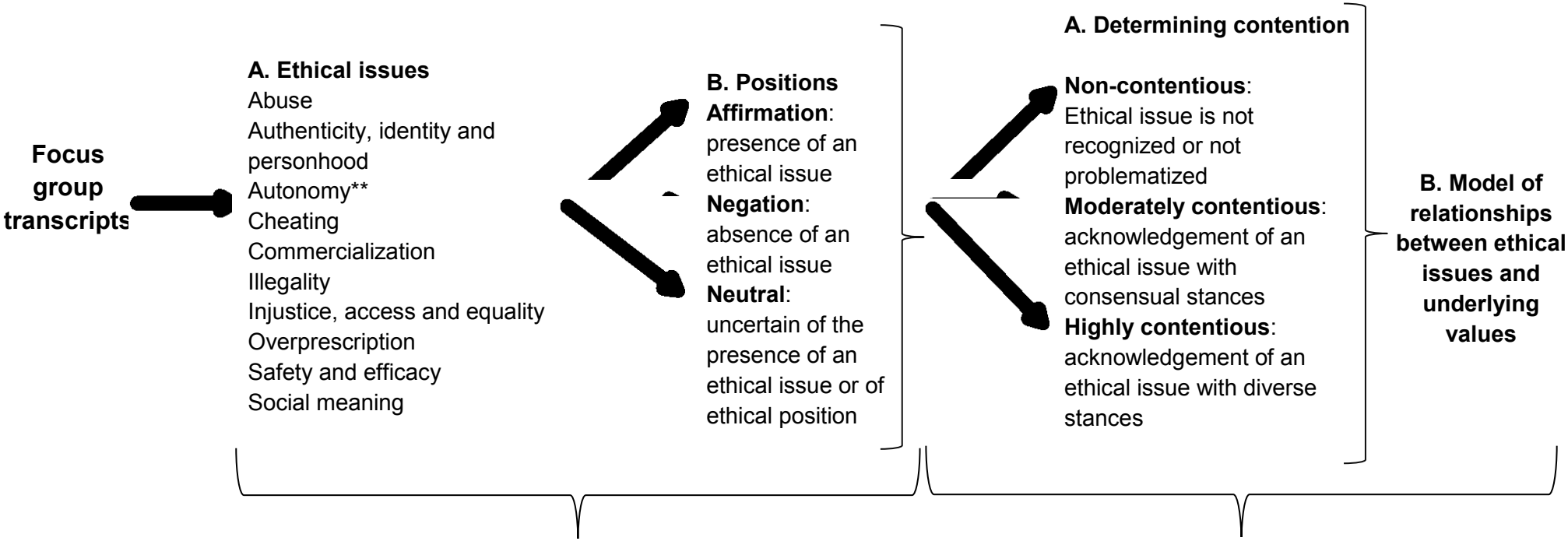
Each focus group discussion was recorded and transcribed verbatim. The transcripts were coded systematically using QSR NVivo 7 software (Doncaster, Australia) according to a previously used coding guide that identified major themes and issues from lay, bioethics, and public health discourses on CE (Forlini and Racine 2009b). This previous coding guide, used to analyze academic discourse and print media content, was modified and enriched to reflect the novel perspectives of focus group participants, especially regarding reactions toward CE and the media coverage, through pilot coding by both authors. The full transcripts were then systematically coded by one author (CF) and verified by another author (ER). Disagreements were settled by discussion and the achievement of consensus.

Figure 6.1 shows the overall methodological approach for coding and analysis of the ethical issues discussed during the focus groups. The complete coding guide captured many facets of the CE debate that were also part of the interview guide and focus group discussions. The first part of the coding guide captured stakeholder reactions to CE where they proposed definitions and reacted to the frequency and social acceptability of CE. The second part dealt with ethical, social, and legal concerns related to CE, including safety and efficacy, legality, potential risks and benefits, and other issues related to academic performance (e.g., authenticity and cheating). The third part explored social (e.g., abuse, autonomy, social meaning) and healthcare aspects (e.g., overprescription,

commercialization and injustice). The final part of the coding guide recorded perspectives on the media coverage of CE based on the prompt materials that were previously provided.

Within the codes for each of the ethical, social, and legal issues in the second and third parts of the guide, participants' statements were further categorized in order to identify participants' positions on the ethical issues (See section 1B of Figure 6.1). If a participant's statement expressed that the issue in question posed an ethical, social, legal problem or had a significant impact it was coded as an "affirmation". If, on the contrary, a participant's statement denied the existence of a problem or its impact, it was coded as a "negation". Statements that mentioned an issue but neither affirmed nor negated a problem, or represented both points of view were coded as "neutral". Likewise, if the statements clearly indicated that the speaker was uncertain, the code "neutral" was applied.

Figure 6.1: Methodological approach for coding and analysis of ethical, social and legal issues* identified and discussed during focus groups.



**issue not reported in this paper

* Ethical, social and legal issues are abbreviated as “ethical issues”.

In this paper, we report results on the following aspects of the debate over the ethical, social, and legal issues[13] around the non-medical use of MPH for CE: (1) abuse; (2) authenticity, identity and personhood; (3) cheating; (4) commercialization; (5) illegality; (6) injustice, access, and equality; (7) overprescription; and (8) social meaning. Issues of autonomy and potential for coercion to use medications for CE (Forlini and Racine 2009a) as well as stakeholder views on the safety and efficacy of using MPH for CE (Forlini and Racine In press) have been reported elsewhere (See Section 1A of Figure 6.1). These data are largely non-overlapping but the nature of qualitative data does mean that there are small convergences between the general data set reported here and more specific pieces of data previously published (Forlini and Racine 2009a; Forlini and Racine In press).

Analysis

The analysis of coded statements was twofold. First, we examined the acknowledgement (or lack of acknowledgement) of a substantial ethical question for each issue to determine *whether* an issue was contentious or not. We then examined the positions taken (affirmation, negation and neutral) for each coded ethical issue as well as the specific arguments for each side to determine the *extent* of contention. . These specific arguments are presented in Table 6.1 as well as Figures 6.2-6.5. Bold italic fonts provide the broader reasons underlying the specific positions taken on particular ethical issues. The relative proportion and qualitative diversity of the arguments in the affirmation, negation, and neutral categories determined the extent (highly or moderately) to which a specific ethical issue was contentious or not. An ethical issue judged to be "highly contentious" had a comparable number of affirmation and negation statements or a rich variety of qualitative arguments pertaining to either

[13] Subsequent mentions of "ethical issues" in the text should be taken to encompass ethical, social, and legal issues.

affirmations or negations. Typically, a highly contentious issue contained ethical debate about the underlying reasons for or against CE. An issue was categorized as “moderately contentious” if it was acknowledged as raising ethically significant questions but affirmations or negations occurred without substantial debate on the underlying reasons for or against the ethical issue. In this fashion, a moderately contentious issue indicated either a consensus issue among stakeholders or that the particular issue did not appear to raise a substantial ethical debate (Figure 6.1 section 2A).

The second level of analysis consisted in building a model of the relationships between the ethical issues (Figure 6.1 section 2B). Parsing the arguments given for the affirmations and negations of the ethical issues revealed specific arguments that often had common underlying values (personal effort, honesty, and equality), external factors (legal regulation, commercialization), or subsequent consequences (education, medicalization) of the non-medical use of MPH. The relationships were determined by looking for overlapping or related arguments to articulate a global understanding of how the ethics issues affected each other.

Results

Sixty-five individuals participated in one of nine homogeneous focus group discussions: 29 students (S) (mean age 20.9 years; focus groups A, B, C); 21 parents (P) (mean age 53.8 years, focus groups D, F, H) and 15 healthcare providers (HCP) (mean age 31.9 years, focus groups E, G, I). The groups varied in size from three to eleven participants. Each participant was assigned an alphanumeric code (e.g., A1) where the letter identified the stakeholder group they belonged to and the number indicated the order in which they were recruited. Results from the demographic questionnaire showed that the majority of participants were female (68%; N=44/65; S: N=22; P: N=12; HCP: N=10) and had obtained or were in the process of obtaining undergraduate or graduate degrees

(86%; N=57/65; S: N=29; P: N=15; HCP: N=13). None of the participants was currently using a prescription for MPH, but 3% had had a prescription in the past and 11% of the sample had previously used MPH for non-medical purposes (Forlini and Racine In press). The commercial name of MPH, Ritalin, was used in the questionnaire because of its familiarity.

We first present the content of the issues stakeholders viewed as contentious and non-contentious. Then, based on our focus group data, we propose a model to describe the relationship between the ethical issues identified. Stakeholders identified many ethical, social, and legal issues related to the non-medical use of MPH for CE. For all issues identified, stakeholders more often "affirmed" and discussed the existence of problematic ethical aspects of an issue than "negated" these aspects. We segregated the issues in relation to how contentious they were – highly, moderately or non-, contentious. None of the issues were deemed non-contentious or unproblematic. (See the methods section above for the classification method.) Table 6.1 and Figures 6.2-6.5 indicate whether arguments were made by students, parents, or HCPs, but no significant qualitative differences in the discussion of the ethical issues between these groups were observed.

Moderately contentious issues: Commercialization, overprescription, illegality, and abuse

Our analysis shows that commercialization, overprescription, illegality, and abuse were essentially moderately contentious issues; participants tended to agree on the existence of a problem without strong quantitative or qualitative differences between affirmation and negation statements. Table 6.1 contains a summary of arguments made by participants on these moderately contentious issues and features some illustrative qualitative examples providing further context for each argument. No students expressed that potential commercialization of cognitive enhancers would be non-contentious, and participants across all groups agreed that the non-medical use of MPH was illegal.

Table 6.1: Qualitative examples illustrating stakeholders' perspectives on moderately contentious issues around the non-medical use of methylphenidate

Issue	Negation	Affirmation
Illegality	**Enhancement with MPH is likely illegal (S, P, HCP)** "The way I see it is pretty straightforward. If it's prescribed to you then you can use it if not it's illegal (…)." (Student A6) "They are being sold on the black market so that in and of itself is illegal." (Student D7)	**Regulation about the use of MPH for enhancement is unclear (HCP)** "I hope it is illegal. But I never heard of any law that said you can't take Ritalin if you don't have the prescription." (HCP E1)
Abuse	**Enhancement can be a proper use of medication if occasional and does not disrupt daily life (S, P, HCP)** "(…) we've applied substances that we already know about to solve new problems so maybe this is just another classic problem that has to be solved. Abuse is a dangerous term." (Student A7)	**Enhancement is an improper use of medication (S, P, HCP)** "I think it is abuse in this case, when you use the medication for another thing besides the purpose it is described." (HCP E7) "Any drug can be abused and so, if it becomes obsessive then it becomes abuse." (Student C6)

Commercialization	**Medications for enhancement may not be lucrative since they cannot be marketed (P, one HCP)** "I am not sure that this would be such an enormous money maker for the pharmaceutical companies. Students don't want to line up to a kiosk and take drugs on a regular basis. Nobody wants to live like that." (Parent H3)	**There is a profitable market for medication used for enhancement (S, P, HCP)** "If companies can put on market something that work even better than [Energy] pills and Redbull, then I am sure there would be a lot of people buying it." (HCP G3) **There are many conflicts of interests in the commercialization of medications (S, P, HCP)** "you've got this whole pharmaceutical industry that's living off of creating diseases." (Student A9) "There is also the pressure of the pharmaceutical companies on the doctors. They just want the doctors to prescribe this now because the doctors and the companies will benefit from it." (Student C7)
Overprescription	**Overprescription is a misconception (one P, two HCP)** "My girlfriend she is a teacher and she has 28 kids in her classroom and only one child in her classroom in on Ritalin. Ritalin has not taken over the classroom. It has not." (Parent H2)	**Medications used for enhancement, like MPH are readily available (S, P, HCP)** "I think overprescription does have something to do with it because there are a bunch of people that are willing to sell their pills. So someone who gets it who really really really needs it for them self doesn't have pills to spare." (Student B2)

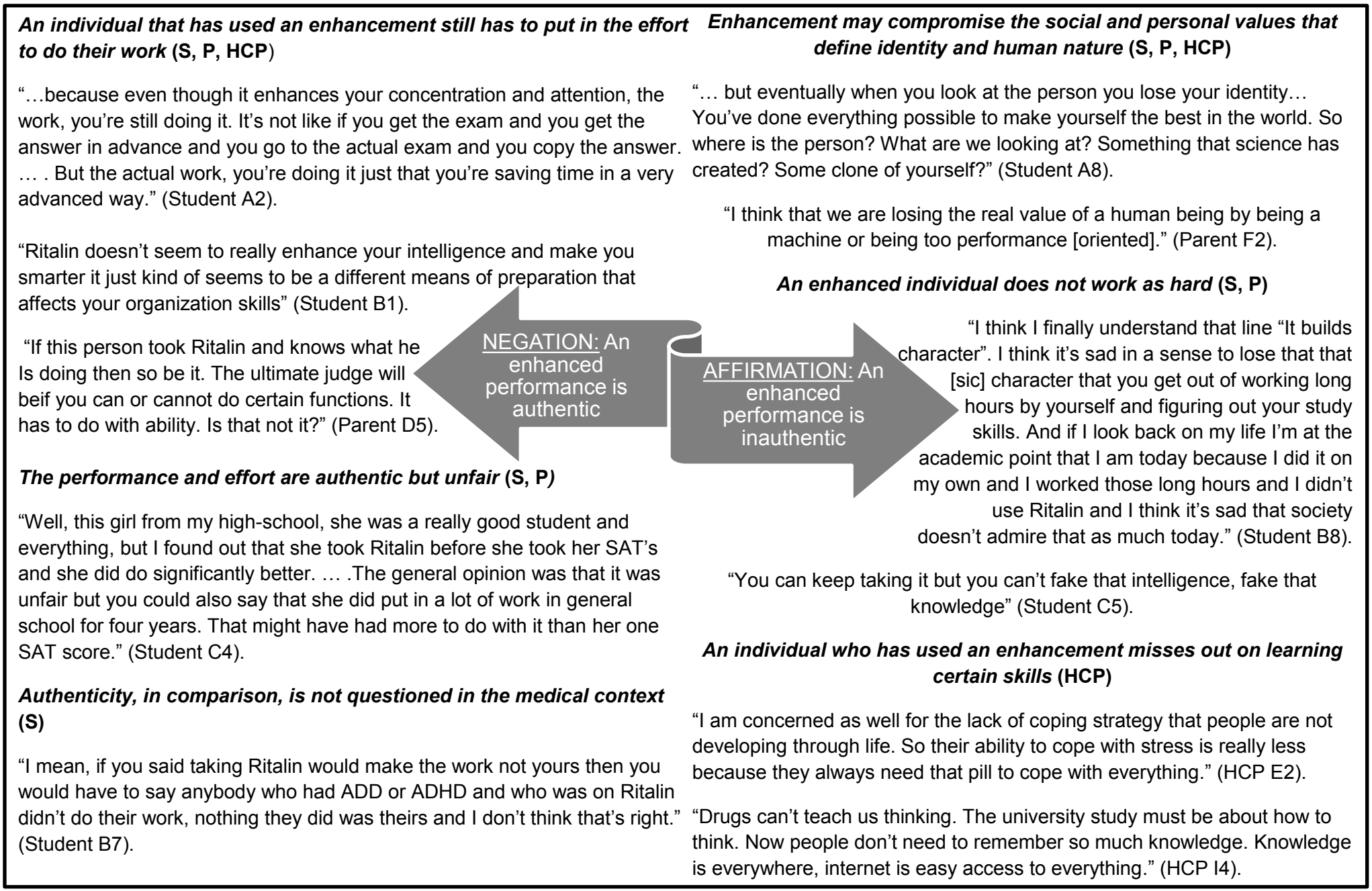
*Neutral statements are not presented here given their marginal quantitative and qualitative salience. S: Students; P: Parents; HCP: Healthcare providers

Highly contentious issues: Authenticity of the individual, cheating, injustice and inequalities, and social meaning

Authenticity, cheating, injustice and inequalities, and social meaning were highly contentious issues. Figures 6.2-6.5 show the contention about these issues in greater detail. In addition, discussion of two issues (authenticity and cheating) featured ambivalence. First, authenticity was discussed almost in equal proportion as a problematic (affirmation) and non-problematic (negation) issue. Authenticity was of interest across all stakeholder groups and produced arguments that were qualitatively oppositional (see Figure 6.2). In this case, the coexistence of conflicting perspectives on the issue of authenticity suggests that globally, ambivalence is the source of contention for this issue. We described this type of ambivalence as *substantial* ambivalence in contrast to *informational ambivalence* (i.e., ambivalence caused by rather superficial misunderstandings, as has been discussed elsewhere (Forlini and Racine 2011)).

Second, participants manifested ambivalence, but perhaps more accurately indecision, regarding the issue of cheating (Figure 6.3). This issue was discussed as mostly problematic, but we observed a high number of “neutral” statements. With the other issues we examined, neutral statements were marginal (quantitatively and qualitatively), but in the case of cheating, neutral statements were salient (quantitatively and qualitatively). In these open-ended neutral statements, participants neither affirmed nor negated that cheating was problematic, and this suggests that indecision is globally prevalent as opposed to the articulated statements of ambivalence for the issue of authenticity. The neutral statements on cheating also showed that participants found it difficult to determine if using MPH was cheating as compared to other substances and practices.

Figure 6.2: Qualitative examples illustrating stakeholders' perspectives on the impact of non-medical use of MPH and the highly contentious issue of authenticity



*Neutral statements are not presented here given their marginal quantitative and qualitative salience. S: Students; P: Parents; HCP: healthcare providers

Figure 6.3: Qualitative examples illustrating stakeholders' perspectives on the impact of non-medical MPH use in the academic context on the highly contentious issue of cheating

***Enhancing performance with a cognitive enhancer can be considered a study tool like any other* (S, P, HCP)**

"I don't know, it doesn't sound like cheating. If you take a cup of coffee or a Red Bull like they say, nobody is going to say you were cheating." (Student C1)

"It is hard for me because I can't say that it is cheating because you are under pressure and you need to perform." (HCP E2)

"They still teach these things that people would maybe argue are aids to cheating but with Ritalin because you can't see it on the surface, that's where it becomes controversial." (Student B10).

***An individual who has used an enhancemenstill does the work (related to authenticity)* (S, P)**

"Cheating means more like copying the work from the other person, this way you are still doing the studying, it is just that you have enhanced powers, if you want to call it that …." (Parent F1)

***There are no rules to say that an individual cannot enhance their performance* (P)**

"I think that there is no standardization. There is no academic law that says you can't use this. Then you are not cheating." (Parent H3)

NEGATION: An enhanced performance is honest and does not constitute cheating

AFFIRMATION: An enhanced performance is dishonest and constitutes cheating

***Enhancing performance is unfair because it is dishonest and a shortcut in learning (related to authenticity)* (S, P, HCP)**

"It's basically like a replacement for doing work in certain instances, but it is a poor replacement." (Student C8)

"I find that a lot of students who end up taking Ritalin in the arts program is because they never went to class. … people who actually work and have that work ethic in them are not going to want to take the drug, they don't need to." (Student C2).

"If I took it and went to the exam and did well on that exam, I would have the biggest guilt complex. … . I would think that it was all the drug." (Student C5).

"And the easy button to press for something without longer work for it." (HCP I4)

***Enhancing performance puts others at a disadvantage* (S, P, HCP)**

"Although when I was at university and I encountered it for the first time I was shocked. I was surprised at how prevalent it was. It certainly made me feel as though I was at a disadvantage because I wouldn't have taken the Ritalin to enhance my performance (…)." (HCP I3)

***Enhancing performance is against the rules/law* (S, P)**

"It is if it's against the law. You weren't supposed to, you did it, it's cheating." (Parent D6)

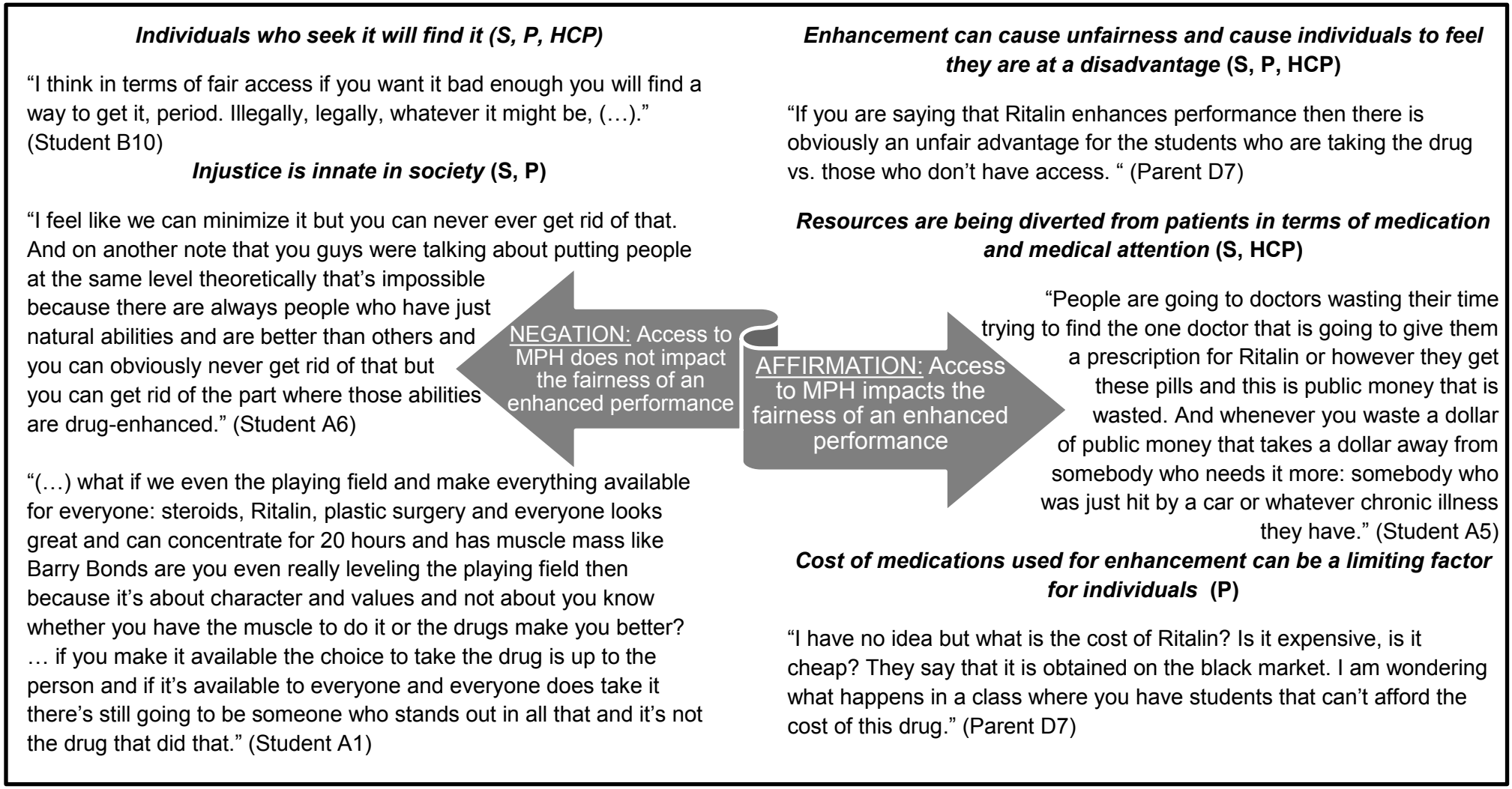
NEUTRAL: It is unclear whether an enhanced performance is honest and constitutes cheating or not

"I have known so many people [in university] who have had panic attacks and stuff…It just seems impossible and how much pressure is put on these students…And if you know there's an easy way to just help you pass because you've just got to pass that class to graduate, well, you know…" (Student A10)

"… no one's going to tell you not to have a cup of coffee before and exam or no one's going to tell you not to buy a special program to put on your laptop that makes referencing the sources on your paper easier. No one's going to tell you not to help yourself other ways just that it's in a pill form and that's what sort of gets everyone… It's a drug but so is coffee" (Student B4).

S: Students; P: Parents; HCP: healthcare providers

Figure 6.4: Qualitative examples illustrating stakeholders' perspectives on the impact of non-medical MPH use in the academic context on the highly contentious issue of justice*



*Neutral statements are not presented here given their marginal quantitative and qualitative salience. S: Students; P: Parents; HCP: healthcare providers

Figure 6.5: Qualitative examples illustrating stakeholders' perspectives on the impact of non-medical MPH use in the academic context on the highly contentious issue of social meaning*

The changes in education are a part of a natural progression of assimilating new technology (S, P)

"Like all the advances that we have and like technology and medicine and like literature and a lot of it and stuff is because people have time to do other things because we have technology because people don't have to spend hours looking in a dictionary because we have spellcheck so you know (…) ." (Student B7)

NEGATION: Enhancement of academic performance with MPH is not bringing about changes in society

AFFIRMATION: Enhancement of academic performance with MPH is bringing about changes in society

Society is already performance-based (P, HCP)

"It is already performance based, school right now is performance based. If you want to do a master's or a doctoral degree well you have to have the best grade. (…) it is already based on performance. I am not sure that Ritalin is going to change that because it is already like that." (HCP E1)

Enhancement is bringing about changes in the goals of education (S, P, HCP)

"I think that it has taken education and made it equivalent to performance. (…) you take a course, you go to university, or you finish a class and six weeks later you don't know what you have learned. You don't have to know what you have learned because the whole point was to pick up that information, regurgitate that information on a test, spit it out on the essay, put it in the final (…)." (HCP I3)

Enhancement may have an effect upon professional life beyond school (S, P)

"When they will graduate they will go on the market and they will keep on having trouble and they will have learned to solve their problems with the drug so I think that is a social problem that these students that are abusing don't learn." (Student A2)

"I think it's an interesting thought to wonder if maybe you can enhance the performance of certain professionals maybe like I guess a brain surgeon. … . Like if you're more alert and focus better like maybe it'll help your purpose." (Student B1)

Social emphasis on performance (S, P, HCP)

"I am concerned about the tolerance that, not the tolerance but if we get used to the feeling of being on Ritalin, (…) . I wonder how they are going to conceptualize human performance, just the normal human performance. (…) . I am afraid that there is going to be a new norm of performance … ." (HCP E2)

Using medication for enhancement medicalizes performance and acts as a "quick fix" for problems that are not necessarily biological (S, P, HCP)

"For many many of our common, everyday problems we have: the solution resides in the pill." (Student A5)

Changes caused by availability of prescription medications for such uses (S, P, HCP)

"It just hit me right now maybe this whole situation with Ritalin is the canary in the coal mine. Shouldn't we be worried about how readily accessible pharmaceutical drugs are to the population? … . Obviously this system isn't working that well if we're having a whole conversation today on how easily accessible a prescription drugs is to students to take for a non-prescription purpose." (Student A5)

Concern for the public health messages that are being sent through enhancement practices (S, one P)

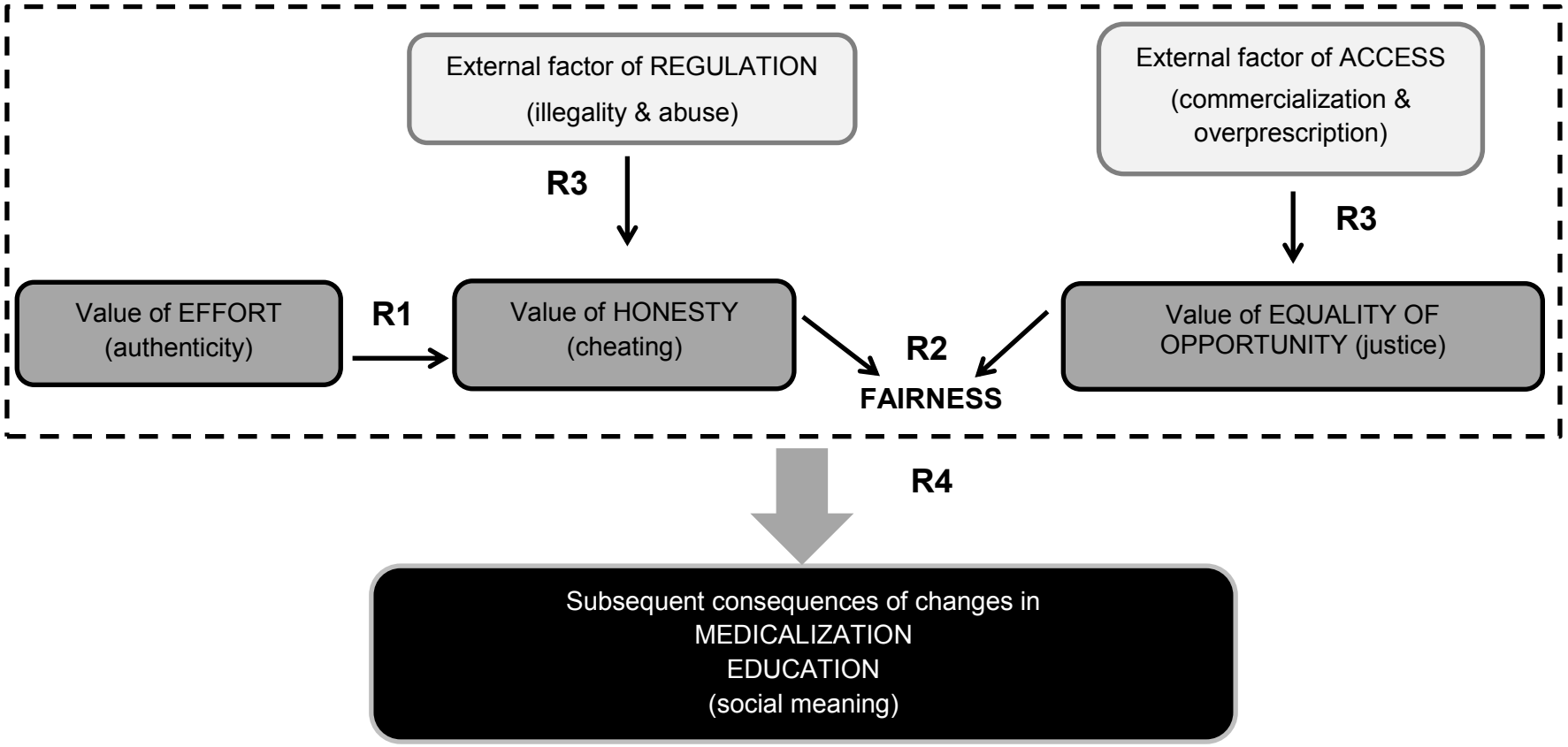
"I would have a problem with society sending the message that you need this drug to do your best. And that's ultimately the message that's being sent if you make it open, available like candy jars full of Ritalin." (Student B8)

*Neutral statements are not presented here given their marginal quantitative and qualitative salience. S: Students; P: Parents; HCP: healthcare providers

Identifying a model describing the relationships between ethical, social and legal issues

In discussing the ethical, social, and legal issues related to the non-medical use of MPH for CE, participants in our focus groups expressed that these issues were inextricably linked to certain values, external factors, and subsequent consequences. Specific values contributed to positioning issues as problematic or not. Figure 6.6 captures the relationships between issues and specific values. In conjunction with Figures 6.2-6.5, this model demonstrates how the highly contentious issues (authenticity, cheating, justice, and social meaning) represent values that affect individual and social decisions, while the moderately issues seemed to act more as external factors (legislation, markets, medicine) that affected these decisions. We further describe the relationships schematized in Figure 6.6, and readers should use the figure as a guide to the following explanations on the four relationships described in the model.

Figure 6.6: Model of ethical, social, and legal issues and the underlying values identified by stakeholders that cause these issues to be contentious



Effort-authenticity relationship (R1): Effort is linked to the underlying belief that work put into an activity contributes to shaping personal identity and being an authentic individual.

Honesty-equality of opportunity relationship with fairness (R2): Fairness is defined by the values of honesty and equality of opportunity responds to social and interpersonal aspects of CE (i.e. the effects of an individual's behaviour on that of others).

External factors relationship (R3): The regulation derived from legislation and medical practice that dictate what constitutes a proper use of a medication and the channels through which performance enhancers are accessed are two key factors that shape the values of honesty and equality of opportunity. These factors are different from the values discussed earlier because they rely more heavily on norms established by government, professional societies, and the pharmacological industry.

Society-performance relationship (R4): The complex ethical landscape of the non-medical use of prescription medication for performance enhancement is causing problematic social changes and creating an overarching concern for the altered meanings of performance and achievement as well as the role of medicine (medicalization) and education.

Effort-authenticity relationship (R1): Effort is a constitutive element of an authentic academic performance

University students, parents, and healthcare professionals largely defined authenticity in terms of the effort that an individual has to exert in order to achieve and succeed. Effort is linked to the underlying belief that work put into an activity contributes to shaping personal identity and character (Figure 6.2). Consequently, when prescription medications are used as cognitive enhancers, the effort-authenticity relationship is jeopardized and perhaps discounted. A discounted effort, in turn, potentially results in an individual who betrays his or her current personal values and beliefs. It also affects the "future" individual who has not gained the experience of effort he or she would have had without the enhancer. The difficulty, however, remains in how to measure the effort and its distinctive contribution to the authenticity of a performance. In the words of HCP I3:

> [Y]ou have individuals that, you know, definitely start out with a deficit and Ritalin let's say brings them up to average. Then you have individuals who are starting out as average and it brings them up above average. Then you have individuals who are above average and it brings them up to another level. So, I mean, it is such a sliding scale in terms of, is it still your performance?

The effort-authenticity relationship we have outlined in our analysis largely relies on the assumption that ethical judgement is an individual and internal norm. It also assumes that an individual would be conflicted in the choice to take an enhancer or not and that effort is the only way to develop or change one's identity authentically.

Honesty-equality of opportunity relationship with fairness (R2): Honesty and equality of opportunity confer two distinct meanings to fairness

Fairness was identified by stakeholders in our focus groups as a major issue. Analysis of the use of "fairness" showed that it referred to two values: honesty and equality of opportunity. On the one hand, fairness was defined by the value of honesty and the issue of whether using MPH

to enhance academic performance constitutes cheating. On the other hand, fairness was defined in terms of equality of opportunity to obtain MPH (or other such cognitive enhancers) and opportunities deriving from its use.

Fairness as defined by the values of honesty and equality of opportunity responds to social and interpersonal aspects of CE, that is, the effects of an individual's behaviour on that of others. For example, questions of fairness arose when the performance of an individual using a prescription medication was compared to an individual who did not in terms of (1) the perceived effort required and (2) whether both parties had the opportunity to access the prescription medication. The comparison of the outcomes of individuals who engage and abstain from using prescription drugs to enhance cognitive performance is what, in this case, seems to render what has been considered a personal choice ethically problematic. Those who enhanced their performance and succeeded were perceived by a group of participants to (1) not have put valuable effort into their performance and (2) gained an advantage because of an opportunity that was not available to all.

External factors relationship (R3): External factors affect individual and collective ethical opinions and behaviours

Another component in the model of interaction between issues and underlying values are the external factors that participants identified as influencing the ethics of the non-medical use of prescription drugs for CE. Participants identified two key factors: (1) regulation derived from legislation and medical practices that dictate what constitutes a proper use of a medication and (2) the channels through which performance enhancers are accessed. These factors are different from the values discussed earlier because they are norms or practices established by government, professional societies, and the pharmacological industry. In the first case, regulation had a substantial impact on what was perceived as fair. For example, some stakeholders questioned whether their

perspectives about fairness might be different if the regulations were clearer. As one student commented,

> "[m]y gut instinct is to say it is cheating, that is what I would go for first and foremost. The question I would have for everyone is if these pills were legal and available would it be ethical to take it? Is it the illegality that makes it seem unethical to us? Is it the availability, is that all?" (Student C9)

The other external factor, access, illustrates that stakeholders expect that the pharmaceutical industry and the prescription practices of some physicians could be causing an increase in access to drugs like MPH, which, in turn, increases the prevalence of the non-medical use and results in further social consequences.

Society-performance relationship (R4): A subsequent consequence of broad social use of cognitive enhancement is a change in the meaning of performance and achievement

Our data pointed to many ways that participants believed that the non-medical use of prescription medication for CE was both bringing forth and resulting from broad social change. Stakeholders described CE as a problematic social change and expressed an overarching concern for how the non-medical use of prescription medication for performance enhancement changed what it means to perform well and achieve. There were concerns that the non-medical use of prescription medications encouraged the medicalization of performance and ultimately, medicalization of health more generally. In contrast, it was also suggested in the focus groups that health concerns should actually be focused on mental health more broadly and not on the pressure to perform using cognitive enhancers. In the words of a student participant discussing the use of Prozac for enhancement purposes: "I haven't seen a focus group about students who are depressed, which I think might be an even bigger problem because with depression you can't even get out of bed and do your work" (Student C2). Furthermore, according to participants, the

importance of authenticity seemed to impact how society approaches education and training for the workforce.

Discussion

In this study we identified ethical, social, and legal issues (e.g., authenticity, cheating) related to the non-medical use of MPH for CE from the point of view of university students, parents, and healthcare providers. In addition to identifying and describing these issues in depth using a qualitative methodology, we closely examined supporting arguments from these stakeholders. These arguments informed the positions taken by stakeholders to affirm or negate that these were ethical issues (Figures 6.2-6.5). Our results suggest that the ethical issues we identified in the focus group discussions with stakeholders were similar to those identified in a previous discourse analysis of the bioethics literature (Forlini and Racine 2009b). This previous analysis showed that stakeholders had divergent perspectives about the acceptability of CE as a practice based on conceptions of autonomy of the individual; however, they recognized the potential constraints of personal choice based on social pressures for performance (Forlini and Racine 2009a). These findings framed the way in which stakeholders value personal integrity (authenticity) for the individual and his or her performance but also acknowledged that there are social causes and consequences to CE.

However, in this paper, closer observation of the nature and proportion of arguments in stakeholder perspectives on a broad range of ethical issues allowed us to deepen our understanding of the perspectives on authenticity, social meaning, and other issues, while observing the existence of two levels of contention as well as factors and values underlying the issues identified (Figure 6.6). In the following section, we explore the underpinnings of different levels of contention, highlighting the important role that the concept of self-identity plays in stakeholder perspectives alongside the values of authenticity, honesty, and equality of

opportunity. We then explore how such concepts and values are or could be captured in policies about CE.

The limitations of our focus group study have been discussed in previous publications of other data (Forlini and Racine 2009a; Forlini and Racine In press). This paper presents distinct data and incorporates an added level of analysis for identifying moderately and highly contentious issues. As a result, the model of interaction depicted in Figure 6.6 may be considered as a model for use in hypothesis generation as opposed to hypothesis testing.

Understanding the underpinnings of the different levels of contention in stakeholder perspectives on the ethics of CE and the central role of authenticity

In our study, moderately contentious issues (i.e., commercialization, overprescription, illegality and abuse) were typically issues where there was consensus among stakeholders about whether a substantial ethical problem existed. For example, participants agreed that access to prescription drugs used as cognitive enhancers is ethically problematic because it is currently facilitated (in their view) by overprescription by physicians and increases the potential for further commercialization of these drugs. At a deeper level, we observed that moderately contentious issues were tightly coupled with external factors (Table 6.1 and Figure 6.6). For example, issues such as overprescription and commercialization showed how the external factor of access to medications can jeopardize the value of equality of opportunity. Likewise, the issues of illegality and abuse were associated with the external factor of regulation that influences what is considered honest. In this fashion, the moderately contentious issues and the factors they are identified with seem to exert an external influence on the ethics of CE that may make stakeholders feel like CE is highly prevalent in their environments.

In contrast to moderately contentious issues, highly contentious issues (i.e., authenticity of the individual, cheating, injustice and

inequalities, and social meaning) prominently featured ethical debate about the effects of non-medical use of MPH and how these effects might shape the arguments for or against their use. On these issues, stakeholders debated intensely between competing arguments. An example of this type of debate is whether CE can be considered cheating. On the one hand, a cognitive enhancer could be comparable to another study tool and which still requires the individual to do the work themselves. On the other hand, CE could be dishonest, constitute a short-cut in learning, and put others at disadvantage (Figure 6.3).

As indicated in our methodology, the designation of "highly contentious" hinges more on the existence of a rich variety of *qualitative* arguments pertaining to either affirmations or negations and not necessarily a strong *quantitative* disproportion between the two types of statements. Contentious issues like cheating and social meaning raised questions revolving around the perhaps more intrinsic questions of "Who are you?" and "Who do you want to be?" The answers to these questions can draw upon both individual and socio-cultural preferences. These questions address the prominent concern that stakeholders in our study had for the effect of the substances used for CE on their academic performance and ultimately their self-identity and authenticity.

We suspect that the link with the personal concept of self-identity and authenticity could partly explain what distinguishes or even causes an issue to be highly contentious. Our own study, because of its design and limitations, falls short of answering this question. However, other stakeholder studies have specifically examined the issues of authenticity, fairness, and autonomy and provide support for this hypothesis, which helps to explain different perspectives and understanding of these issues among stakeholders. The concern for authenticity has been shown to impact stakeholder willingness to use and ban enhancers and has important interactions with other values (Sabini and Monterosso 2005; Riis, Simmons and Goodwin 2008). Enhancement of mood, emotions, and

memory are seen to have more of an impact on self-identity than enhancement of attention and concentration, just as enhancement by prescription medications were thought to have more of an impact than *natural* means (e.g., natural products and mental training exercises (Sabini and Monterosso 2005; Bergstrom and Lynoe 2008; Riis, Simmons and Goodwin 2008)). In scholarly writings, the value of effort which contributes to authenticity also has great importance, and it binds opposing opinions on the broader ethical landscape of CE (Parens 2005). Both proponents and critics of CE agree that self-identity should be preserved but diverge in their perceptions of whether it is damaged by an intervention that enhances any aspect of cognition.

An issue like authenticity could become even more important and complex when it is put into a social context to consider equality of opportunity. Our qualitative analysis (Figure 6.6) suggests that fairness was defined by a relationship between effort and honesty, as values, with the value of equality of. In other words, a complex combination of internal and external influences appears to shape perspectives on fairness. Our own data does not allow us to go further than generating this hypothesis, but a survey study by Sabini and Monterosso provides additional perspectives. They asked undergraduate students at the University of Pennsylvania to rate the fairness of certain academic situations involving performance enhancement with medications. The majority of students that participated in that study thought that using a substance was fair if it acted as a *normalizer* to help the bottom 10% of the population as opposed to an *enhancer* that helped normal or high functioning individuals (Sabini and Monterosso 2005). In this respect, students felt that it was fair to help underperforming individuals gain access to opportunities that normal or high performing individuals can access.

The concept of a normalizer can be taken one step further in that a cognitive enhancer can also be considered an “enabler of one’s true self” (Riis, Simmons and Goodwin 2008, p. 505) to realize one’s full potential as

a way to gain fair access to desired opportunities and achieve goals. This argument about the acceptability of normalizers as opposed to enhancers has also been voiced in the bioethics literature (Sandel 2004; Levy 2007). However, the choice to use a cognitive enhancer has been described by stakeholders and popular works of fiction as influenced by pressures to compete and succeed in society; external factors are therefore important considerations in the choice to enhance or not (Forlini and Racine 2009a; McKenna 2011). In this fashion, the authenticity-related question of "Who do you want to be?" is in part dictated by the pressure exerted by these external factors (e.g., "What does society want me to be?" and "Who do I need to be to perform, succeed and to some extent comply with social expectations?").

The stakeholder perspectives we gathered suggest that CE challenges certain fundamental values held by individuals as well as society. We argue, based on our own data and that of others, that a high level of contention surrounding issues in CE may be explained, at least in part, by the important value of effort and the related value of authenticity. However, an issue such as fairness likely introduces interplay between both the internal and external factors reflected in our data. Our discussion points to a perhaps unsuspected complexity, when compared to academic debates, in understanding the relationship between different values and issues brought forth in the CE debate as well as an important role of certain core values in opinions about CE. The next section examines current policies on CE and whether it is at all possible to capture the current complexity of stakeholders' perspectives about CE in them.

Shaping policy with stakeholder perspectives?

The important academic debate surrounding CE, coupled with substantial media coverage of prevalence studies and opinions about the efficacy of medications used for CE, have led different professional and regulatory bodies to further examine policy and regulatory aspects of CE for

clinicians and society at large. For example, the British Medical Association surveyed some of the ethical issues associated with CE and developed a discussion paper on CE, although the goal of the paper was perhaps less intended to guide clinicians than to contribute to fostering public discussion on CE. The report of the Commission de l'éthique de la science et de la technologie from Québec, Canada (Commission de l'éthique de la science et de la technologie 2009) issued a report that was developed as a contribution to public debate but also offered specific recommendations for governmental authorities and clinicians. The report recommended increasing education for clinicians about CE and ensuring monitoring of the current public health situation (Outram and Racine 2011). Perhaps the most concrete and directive guidelines were proposed by the American Academy of Neurology (AAN), which was created specifically to inform and guide neurologists in their practice in response to requests from adult patients for cognitive enhancers (Larriviere et al. 2009). But even the AAN left ample room for individual clinicians to determine their own positions and understanding of the ethical acceptability of CE by stating that "prescription of medications for neuroenhancement occurs within the physician-patient relationship" and that CE is neither legally nor ethical obligatory in addition to being legally and ethically permissible (Larriviere et al. 2009, p. 1408). Given its more concrete and specific focus, the attempt of the AAN to counsel clinicians is perhaps the best starting point to examine if and how concerns of stakeholders are and can be taken into consideration in policies.

The guidelines published by the AAN about CE were innovative and among the first to advise a group, in this case medical professionals, on how they might approach requests for neuroenhancement. In the end, the AAN's position was largely non-directive, putting the onus on individual neurologists to evaluate the request of the patient, much in the style of a request for medical treatment. From this perspective, these guidelines adopted a *moral acceptability* approach by examining CE, "within an

existing framework while respecting social and legal obligations" (Racine 2010, p. 124). A moral acceptability approach captures *extrinsic sources of morality* such as the law, social consensus, and socially accepted norms. This stance brings forth questions of what clinicians *can* do instead of whether or why they should be involved.

In seeking to map out what is permissible, guidelines and policies like the one proposed by the AAN do not clearly capture the full complexity of substantial values and concerns like those brought forth by the CE debate and discussed by stakeholders (and in this case patients). For example, we found that effort and authenticity as well as self-identity are very important considerations for stakeholders. The salience of these issues intersects with the existence of an important body of theoretical and philosophical literature on CE on the topic of authenticity and self-identity (Parens 2005; Bolt and Schermer 2009; Bublitz and Merkel 2009). Some of the more *intrinsic sources of morality* (of both clinicians and patients) may have been skimmed over in the AAN guidelines. Intrinsic sources of morality (e.g., empathy and self-reflection) are key in determining *moral praiseworthiness* and deciding, "if we should morally and ideally pursue cognitive enhancement" (Racine 2010, p. 125). In contrast, the AAN guidance is rather procedural and leaves different options open, doing little to arrive at the crux of what may cause moral unrest for clinicians and patients.

Our analysis should not be read as direct criticism of the AAN's guidelines as such but rather as pointing out that guidance by professional bodies like the AAN can only be a partial response to a problem which calls for a more comprehensive and global approach. We wish to highlight the difference between what the guidelines set out to do and the type of reflection we observed among our participants. This difference brings us to recognize a potential limitation in the reach of debates held within specific contexts, such as the medical context of the AAN. Perhaps the AAN guidelines or the physician-patient relationship are simply not the venue to

discuss values like effort and self-identity. However, in spite of this limitation, we should not understate the importance of opening up clinical conversations to different attitudes and opinions about CE as proposed by the AAN in its guidelines. This is considerable progress in contrast to a more paternalistic or authoritative stance that would state for patients and clinicians what is the best ethical decision to make, or even worse, simply dismiss the topic of CE.

At the same time, one can only be partially satisfied by the procedural nature of such guidance given the stakes at hand. Examining the moral acceptability of CE as the AAN has done is an initial way to determine the morality of CE. However, it is but a partial answer to the CE problem and its complex nature. We have ourselves commented that this guidance seemingly lacked awareness of the broader ethical and social issues surrounding such requests (Racine and Forlini 2010) despite the guidelines' authors maintaining that these factors were considered during the genesis of this publication (Larriviere and Williams 2010). Indeed, issues like autonomy and justice were mentioned in the guidelines but lacked the type of consideration that would have been informed by a second moral parameter looking at moral praiseworthiness by incorporating some reflection on contentious values or even the external factors which indirectly relate to the type of socio-economic environment in which CE is developing (Racine 2010).

Consider, for a moment, how the AAN guidance may have changed if some of the values outlined in Figure 6.6 that are pertinent to the medical context were part of the recommendations. Neurologists are encouraged by the AAN to rule out any underlying medical condition in a suspected request for cognitive enhancers. Once this is done, the physician-patient conversation exits the realm of the core traditional goals of medicine, bringing in a host of other questions of a more social nature to determine whether CE is appropriate not only for the patient but perhaps also for the profession and society. In the case of patients, such a

request may be motivated by social pressures to perform in academic or professional environments (Teter et al. 2005; Rabiner et al. 2008; Forlini and Racine 2009a). According to the AAN, physicians, as the gatekeepers for medications, are not ethically obliged to prescribe or withhold cognitive enhancers for CE and thus must also reflect upon how to deal with requests motivated by social pressures within their practice. These questions go beyond what is presented in the AAN's discussion of patient autonomy and the clinician's responsibility to protect the patient from the potential harms of CE related to the medications, of which the side-effects are unclear.

As found in our study, a related contentious issue of importance to stakeholders is that of medicalization. The AAN defines "neuroenhancement" as "prescribing medications to normal adult patients for the purpose of augmenting their normal cognitive or affective function" (Larriviere et al. 2009). However, what is missing from this definition is a discussion of how the definition of health has changed and may continue to change over time. The committee might have taken the opportunity to clarify their position on the treatment-enhancement distinction and the goals of medical practice within neurology.

The strict discussion within the context of neurology brings yet another contentious issue to the surface, that of justice and the value of equality of opportunity. The AAN guidance recognizes that CE may fall into the "lifestyle drug" category that is available to those who can afford it. However, even before that, access to the neurologists who prescribe these drugs could be limited in certain healthcare contexts. These are but a few possibilities that illustrate how the values articulated by participants in our study might lead to policies that are not circumscribed by what is acceptable in existing legal and ethical frameworks.

More open-ended and societal efforts could help develop creative ethical approaches to CE. The goal would be to not only ensure a form of moral acceptability (like the AAN guidance) but to also capture deeper

questions about the moral praiseworthiness of CE to bring both extrinsic and intrinsic sources of morality into the debate (Racine 2010). Recent empirical research about the values held by stakeholders in their reflection on the ethics of CE could inform such thinking.

Dewey's concept of social intelligence, or democracy, is an apt concept to capture how stakeholder values are important to consider in ethical debates such as the one around CE. The ways in which individuals will arrive at these actions, Dewey proposes, is through deliberation which is, "an experiment in making various combinations of selected elements of habits and impulses, to see what the resultant action would be like if it were entered upon" (Dewey 1922, p.190). In this sense, deliberation requires that issues be considered as a function of the different values of those involved, an endeavour more akin to seeking moral praiseworthiness than moral acceptability or "what is expedient, politic, prudent, measured by consequences" (Dewey 1922, p. 189).

The data we collected through focus groups is evidence that stakeholders are still engaging in deliberation about the ethics of CE and are far from making a choice about whether CE will become a custom. However, the concerns and values of the stakeholders do not come through if one relies only on professional groups for guidance regarding CE. Perhaps what is needed is a subsequent collaboration of professional associations with the humanities for a joint deliberation such that moral acceptability and praiseworthiness are examined jointly from both points of view. Bioethics is an appropriate venue to bring these perspectives and disciplines together.

Conclusion

Our findings bring to light contentious issues in the ethics debate around CE and their underpinnings from the point of view of stakeholders. Issues that were moderately contentious were found to be associated with external factors while these external factors shaped perspectives on the

set of highly contentious issues. Highly contentious issues were accompanied by divergences in fundamental values such as effort, honesty, and equality of opportunity that stakeholders thought had a broader impact on health and education. The collision of these values and external factors in the deliberation of stakeholders brings a new dimension to the CE ethics debate that calls for reconsidering the directions of the debate in academia and policy. These discourses have been limited to mainly examining the moral acceptability of CE yet have been interpreted as a global response to a question that research has shown to be much broader and deeper than “can we or can’t we?” One such new direction is to turn the gaze of current ethics discourses toward the moral praiseworthiness of CE that would pay closer attention to different sources of morality and the values that accompany them when determining the possibilities for the best ethical approach to CE.

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Concluding remarks on Chapter 6: Complex relationships between values are at the root of ethical contention over cognitive enhancement

The broad scope of Chapter 6 showed how the ethical, social and legal issues arising from the non-medical use of prescription medication for cognitive enhancement interact, and this, from the perspective of stakeholders. Through their arguments, stakeholders affirmed or negated that issues were problematic from ethical, social or legal standpoints. This style of fleshing out ethical arguments mirrors the overview of the polarized ethics debate on human enhancement from Chapter 2. In Chapter 6, two levels of ethical contention emerged from these arguments — moderate and high. These levels of contention were determined by factors and values underlying these issues. Differences in contention suggest that moral unrest is not pervasive to the same extent within the all stakeholder perspectives on cognitive enhancement and that stakeholders may have more definitive opinions with respect to *certain* issues such as autonomy of the individual, discussed in Chapter 5. The two levels of contention are also significant when considering the interplay between issues (Figure 6.6). Highly contentious issues represented personal and social values that affected decisions while the moderately contentious issues seemed to act more as external factors that affected these decisions. These results add another layer to the social pressures to perform described in Chapter 5 and portray more complex argumentation behind an individual's choice to use a prescription medication to enhance cognitive performance. Conflicts in stakeholder values seem to be at the root of ethical contention and need to be taken into consideration when assessing not only whether cognitive enhancement can be pursued but whether it should be pursued on individual and collective levels.

Original contribution of Chapter 6

The survey of the ethical landscape of cognitive enhancement in Chapter 6 is novel to the literature insofar as it identifies sources of ethical

contention and proposes a model for interaction of ethical issues. Though other studies have examined issues of authenticity (Riis et al. 2008) and fairness (Sabini and Monterosso 2005; Dodge et al. 2012), none have explicitly discussed the relationship between the underlying values of effort and honesty. Furthermore, the influence of existing frameworks such as regulation of pharmaceuticals, commercial interests and prescription practices have not been discussed in an empirical setting as factors that can influence the context of cognitive enhancement. The same applies to the academic ethics debate that has tended to address ethical issues within specific frameworks such as “lifestyle use” and “prescription drug abuse” (Forlini and Racine 2009a). Few texts integrate issues to discuss their relationships and influence on decisions (Bublitz and Merkel 2009; Lev 2009). As a result, the values of stakeholders may be falling into blind spots beside these frameworks (Racine and Forlini 2010a). Recognizing the issues that are important to stakeholders is key in discussing the normative stances that could eventually inform policy. In turn, policy discussions could benefit from a shift away from whether cognitive enhancement is permissible (moral acceptability) toward whether it is ideal (moral praiseworthiness) by creating room for deliberation about stakeholder values in relation to existing normative stances.

Asking whether moral acceptability is a sufficient condition for widespread cognitive enhancement in Chapter 7

The reflections in Chapter 7 address the subject of moral praiseworthiness in policy on cognitive enhancement. The AAN was the first (and still the only) medical professional association to provide guidance on how to respond to requests for cognitive enhancement from patients. This guidance determined that prescribing medications for cognitive enhancement to healthy individuals is ethically and legally permissible but not ethically or legally obligatory (Larriviere et al. 2009). Thus, prescribing medications to healthy individuals satisfies the standard of moral acceptability. The reflection in Chapter 7 examines the Canadian context

of healthcare to highlight certain features of moral acceptability that are in conflict with the standard of moral praiseworthiness. The resulting recommendation is that physicians should not prescribe medication for cognitive enhancement even though they can.

CHAPTER 7: Should physicians prescribe cognitive enhancers to healthy individuals? Canadian Medical Association Journal. doi:10.1503/cmaj.121508

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Key Points:

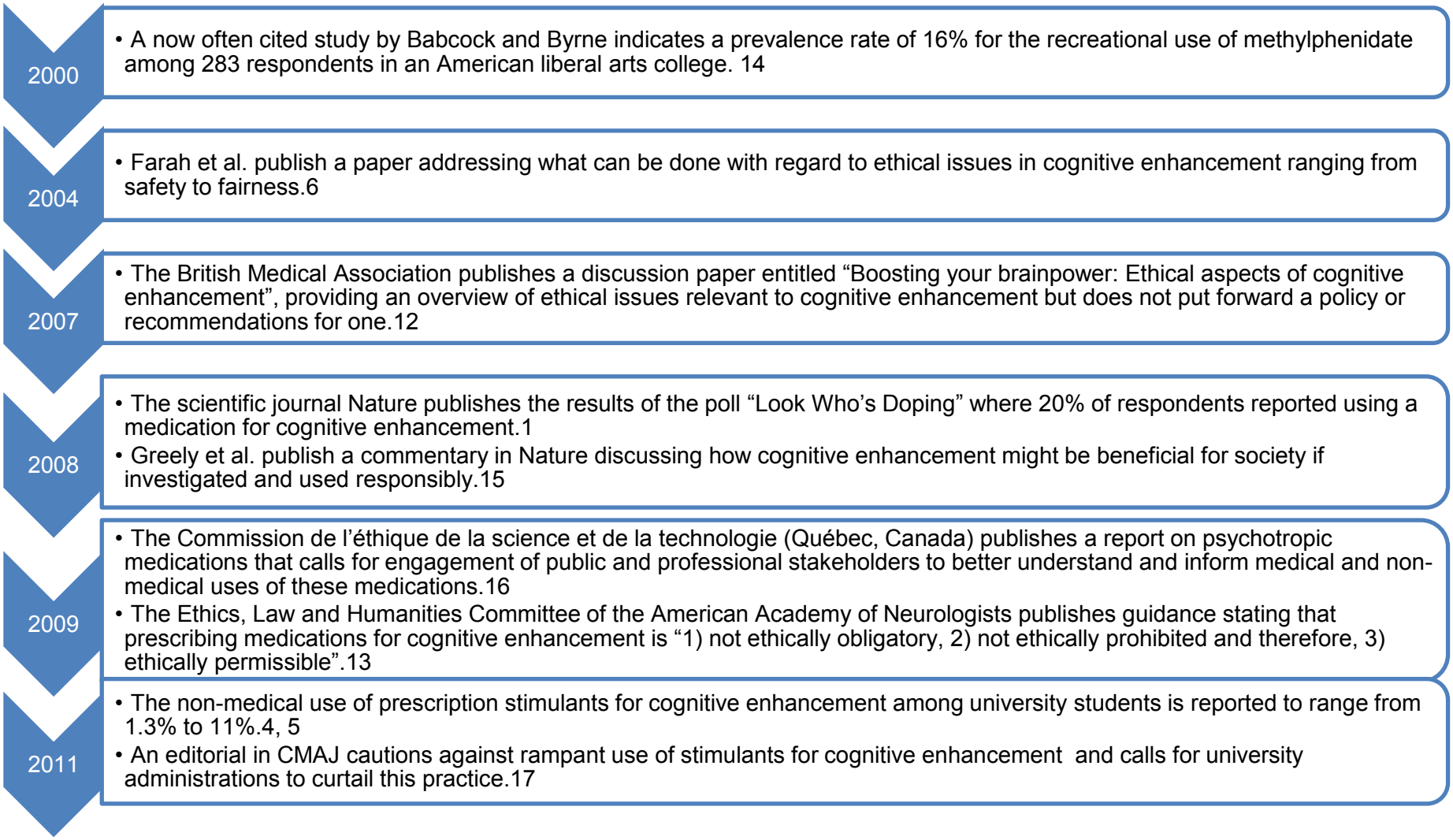
- Physicians should not prescribe medications for cognitive enhancement to healthy individuals.
- Clinical and social benefit of medications for healthy individuals using medications for cognitive enhancement is not well supported by scientific and professional literature.
- Physicians have a responsibility of stewardship to distribute finite and shared resources equitably and prudently, which should lead to prioritizing beneficial treatments for patients.
- Diverging perspectives on how cognitive enhancement aligns with medical professional integrity indicate that cognitive enhancement is not yet a general or an accepted medical practice.

Background

Various studies have reported that prescription stimulants (e.g., methylphenidate, dextroamphetamine mixed salts) and other neuropharmaceuticals (e.g., modafinil) are used by healthy individuals without any diagnosed attention deficit disorders to enhance concentration, memory, alertness and mood, a phenomenon often described as "cognitive enhancement" (CE) or "neuroenhancement".[1, 2] Originally, this term was developed to "mark the limits of professional obligations to pursue biomedical interventions that achieve goals beyond medicine's" and therefore to identify appropriate and legitimate "treatments" in contrast to "enhancements".[3] However, as of late, the term has captured the effort to deliberately develop means to augment performance in healthy individuals and has therefore been criticized for its implicit assumptions that "enhancers" will be beneficial to healthy individuals. In contrast, the terms "non-medical use" and "prescription drug abuse" are used in public health literature. [4] The prevalence of such uses by students on university campuses ranges from 1% to 11%.[4, 5] This practice has spurred important ethical and societal questions concerning the freedom of individuals to engage in CE and whether CE is fair practice

in academic and professional environments [6] (see Figure 7.1 for a timeline of landmarks in the CE ethics debate).

Figure 7.1: Landmarks in the ethics debate on cognitive enhancement



Physicians are important stakeholders in CE, given the risks and regulations of prescription drugs and the potential for requests from patients for "cognitive enhancers".[7, 8] As a result, it has been suggested that "[t]he real question is not whether enhancement should be legitimized or not but *under which circumstances* and which role *physicians* should play".[8] However, physician obligation to grant, decline or redirect requests for CE has not been discussed extensively (see Box 7.1 for additional medical context). In this analysis paper, we argue that uncertain measures of benefits and harms, limited healthcare resources, as well as the professional integrity of physicians, constitute three good reasons why physicians should not currently prescribe cognitive enhancers to healthy individuals. We hope our analysis prompts reflection in the Canadian medical community about the international discussions on CE.

Box 7.1: Medical context of cognitive enhancement
Current prevalence data indicate that students more commonly obtain stimulants for enhancement purposes from other students than from medical professionals.[9, 10] Among those who do obtain prescriptions, it is unclear what the content of the clinical conversation is – whether they are feigning symptoms of attention deficit/hyperactivity disorder or clearly requesting a cognitive enhancer. Cognitive enhancement in the general population is less well characterized both in terms of prevalence and its relationship to medical practice. In a survey of general and specialist physicians sponsored by the American Medical Association, Hotze et al. reported that 61.7% of respondents (n=633) received requests for cognitive enhancement by healthy individuals monthly or more often and 36.7% prescribed medicines for enhancement monthly or more often.[11] The survey did not specify whether enhancement requests targeted cognitive or other physical attributes. However, 12.3% of respondents received enhancement requests daily. The phenomenon of CE prompted the American Academy of Neurology and the British Medical Association to publish guidance on how physicians might approach the ethics of cognitive enhancement and requests for medications.[12, 13]

Why "can" is not enough

Limited normative guidance supports physicians in their response to patient requests for CE. Based on the guidance from its Ethics, Law and Humanities Committee, the American Academy of Neurology (AAN), a leading neurological society, has stated that prescribing medications for CE is "1) not ethically obligatory, 2) not ethically prohibited and therefore, 3) ethically permissible".[13] Likewise, the AAN specified that refusing to "prescribe medications for neuroenhancement is ethically and legally permissible".[13] Thus, according to the AAN guidance, physicians can, but are not obliged to, grant requests for CE.

The AAN was the first professional association to issue specific guidance for physicians on the subject of CE, which has served as a backdrop for further discussion of physician responses and obligations.

The AAN position values the physician-patient relationship as the appropriate locus for addressing and responding to requests for CE. The AAN guidance answered the initial and very important question: "Can physicians prescribe medications for CE?" based on the *moral acceptability* of CE within the existing legal and medical frameworks. However, another question is: "Should physicians prescribe CE to healthy individuals?" This question asks whether CE is a *morally praiseworthy* (not solely acceptable) practice for physicians and summons broader obligations and responsibilities of physicians to their profession and the community.[18] Accordingly, we examine three questions which help us discuss whether physicians should prescribe cognitive enhancers.

Are there benefits for patients?

In investigating a request for cognitive enhancement from a patient, physician must assess what is (are) the chief complaint(s) of the patient and the benefit(s) they expect from a cognitive enhancer. These two questions can be answered in a conversation between the physician and patient as encouraged in the AAN guidance and other ethical frameworks.[8] However, the physician must determine whether a medication can actually produce the benefit the patient expects. The main concerns here relate to genuine benefits and proper patient information. The Canadian Medical Association (CMA) Code of Ethics states that physicians must recommend "only those diagnostic and therapeutic services that [they] consider beneficial to [their] patients or to others" and provide their "patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of [their] ability".[19] Currently, it is unclear how physicians would fulfill these responsibilities with respect to medications used as cognitive enhancers.

The AAN has also suggested that the assessment of benefit for the patient be based upon "relevant medical principles and available evidence, including the pathophysiology of the disease, pharmacologic properties of

the medication, studies or case reports in the professional literature or professional experience" in keeping with the evidence base for prescribing off-label treatments for medical conditions.[13] However, the permissive position recommended by the AAN seems contradictory because it grants CE the status of moral acceptability without clear and decisive evidence. Reviews have not found substantive evidence to support use of medications like acetylcholinesterase inhibitors, antidepressants, and stimulants as cognitive enhancers in healthy individuals.[20-22] The use of stimulants is perhaps the best documented example of the putative cognitive enhancers. Their effects seem to be most prominent in spatial working memory as well as long-term declarative memory, in lower-performing individuals.[22, 23] However, medical uses of stimulants are associated with risks of dependence, cardiovascular outcomes and psychosis. [24] In a non-medical context, these risks are compounded by outcomes caused by the unawareness of individuals regarding dosing and medical contraindications [25] in addition to those that may arise, have not yet been studied or documented.[26] In addition, current studies and medical professional literature have not captured outcomes such as "being more efficient in work or school" or "getting better grades", illustrative of real-world enhancement goals outside of the laboratory environment. How physicians might reconcile these types of non-standardized goals with medical indications and whether the (in)ability to meet these types of goals might eventually be pathologized by enhancement practices remain impending questions. With uncertain benefits and a clearly established set of harms, it is difficult to support the notion that physicians should prescribe a medication to a healthy individual for enhancement purposes.

What is the impact of CE on healthcare resources?

A recurrent question is whether cognitive enhancers should be readily available to all in the same way treatments are and, therefore, whether CE is part of the genuine goals of medicine.[3] The AAN expresses related

concerns that “neuroenhancement therapies are likely to be seen as ‘lifestyle’ drugs and therefore are unlikely to be covered by third-party payers. Their use might thus be limited to a relatively small segment of the population”.[13] The concern that those who cannot afford the medications for cognitive enhancement will be at a disadvantage is relevant. First, the results of two studies show that physicians and members of the public are reluctant about cognitive enhancers being covered by insurance and especially by public funds. [11, 27] Second, healthcare resources are finite and access could be inequitable even if CE were affordable. Recent shortages of generic drugs have illustrated that there can be issues in access for affordable medications. In the Canadian context, the Commission on Ethics, Science, and Technology (CEST) has cautioned that “given the likely increase in the use of psychotropic drugs caused by expanded ‘medical’ and ‘lifestyle’ uses, the Commission is concerned about the impact of this increase on access to medications”.[16] Moreover, the costs of cognitive enhancement would likely entail significant human resources. For example, the AAN arguably recommends full thorough assessment of patients requesting cognitive enhancers. However, the CEST has unveiled a “vicious circle” of wasted human health resources where:

> a medical consultation is a precondition for a person (potentially) to get a prescription. In a context where the health and social services network [in the context of Québec in this report but with broader Canadian relevance] is hardly able to meet demand, health professionals could promote a drug therapy ‘by default’ so as not to leave people without care.[16]

This phenomenon would have a detrimental impact on the handling of “legitimate” needs of patients already diagnosed with mental and neurological illnesses by diverting health resources, both pharmacological and human, toward CE.

Physicians act as gatekeepers to healthcare resources for individual patients and also maintain a role of stewardship with respect to

the collectivity of users of the healthcare system. [28] Consistent with this responsibility of resource stewardship, Canadian physicians must promote "equitable access to healthcare resources" and use "healthcare resources prudently".[19] Currently, the limited evidence of benefit and undefined professional experience with cognitive enhancement make it difficult to argue that CE is an appropriate use of health resources. When put into a context where health resources are shared and the use for CE may come at the detriment of patients who need treatment, it is even more difficult to sustain this argument. The libertarian ethical position articulated in the American context by the AAN may not be a good fit for Canadian healthcare systems based on principles of equal access and solidarity.

Is cognitive enhancement coherent with medical professional integrity?

It is unclear at this point if physicians are willing to integrate CE into their clinical practice and if they think it respects their professional integrity. Consequently, as hasty as it seems to consider, it has been suggested that CE is within the "domain of other socially useful practices that are acceptable to the profession and society".[13] A low response rate to a survey of general practitioners on the topic has led to the hypothesis that, "the issues were too foreign to their daily experiences and not perceived as clinically relevant".[27] Hotze et al. (2011) reported that physicians showed "considerable ambivalence around the issue of enhancement" when questioned about their willingness to prescribe a hypothetical enhancement intervention. In half of the situations, physicians responded that they might prescribe the intervention but "with reservations". Likewise, Banjo et al. presented results showing that willingness of physicians to prescribe existing medications (e.g., methylphenidate, modafinil, sildenafil) for the potential use of enhancement was low.[29] These findings suggest a less favourable involvement of physicians in CE than was believed. The surveys by Hotze et al. and Banjo et al. also reported major concerns for safety on the part of physicians, which may explain some of the reticence

to prescribe medications for enhancement based on the harm(s) that may befall otherwise healthy individuals. Consistent with these data showing reticence of physicians to prescribe cognitive enhancers, Rosenfield et al. published an editorial in the *Canadian Medical Association Journal*, where they maintained that academic institutions, not medical professionals, should be leading efforts to prevent stimulant abuse in universities.[17] However, this latter approach should not pre-empt an in-depth conversation about the involvement and integrity of healthcare professionals. In contrast to much of the literature, it has been suggested that physicians might be inclined to grant patient requests in order to keep a good relationship with them.[30] In this type of scenario, the CMA Code of Ethics might lead to the recognition of the responsibility of physicians to indicate to the patient when they are presenting "an opinion that is contrary to the generally held opinion of the profession".[19] This divergence of opinions on how to best uphold professional integrity when dealing with requests for CE might also indicate that physicians should not pursue a practice as scientifically and ethically contentious as CE.

Conclusion

An international bioethics discussion has surfaced on the ethics of cognitive enhancement and the role of physicians in prescribing cognitive enhancers to the healthy. We discussed three reasons why positions based on the concept of moral acceptability (e.g., AAN) do not fully capture important considerations related to moral praiseworthiness. Physicians should reflect upon competing obligations such as the need for evidence of benefit, and upholding equitable and prudent use of resources as well as professional integrity in conjunction with professional guidance. These obligations also need to be considered in light of the changing face of medicine where physicians can be bypassed by direct to consumer availability of medications. We acknowledge that our reflections could be modulated by the evolving state of science and that future advances (e.g.,

documentation of inter-individual differences of positive or negative pharmacological response to cognitive enhancers) could impact the current discussion. [23] Given the current state of limited evidence on medical, scientific, social and ethical aspects of cognitive enhancement, we call for greater attention to its appropriateness within existing Canadian healthcare systems.

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Concluding remarks on Chapter 7: Physicians should not prescribe medications to healthy individuals for cognitive enhancement

The publication of the AAN guidance was a landmark in the ethics debate on cognitive enhancement. By suggesting the moral acceptability of prescriptions for cognitive enhancement, this guidance affirmed the gatekeeper role of physicians and inserted cognitive enhancement within the purview of medicine (see Chapter 2 for background discussion on this topic). However, relying on moral acceptability might overestimate the involvement of physicians in dispensing medications for cognitive enhancement given that prescription diversion is common (see Box 7.1). It may also underestimate their responsibility to pay attention to the social consequences of healthcare (Racine and Forlini 2010b). The arguments made in Chapter 7 are directed toward holding cognitive enhancement to a higher moral standard than mere moral acceptability. Satisfying the conditions for moral praiseworthiness would include producing evidence of benefit to the patient while minimizing harm, making provisions for just distribution of resources and ensuring the integrity of the medical profession. Until these conditions are met, cognitive enhancement may be moral *enough* but would not be morally praiseworthy in a context such as Canadian healthcare.

Original contribution of Chapter 7

The reflections in Chapter 7 follow-up on two points that were not included in the original AAN guidance to enrich the debate about the role of physicians as gatekeepers to enhancement technologies. First, in the absence of equivalent Canadian guidance, one of the goals of Chapter 7 was to attempt to add an international dimension to the AAN guidance. Reference to the relevant articles of the Canadian Medical Association Code of Ethics showed incongruence between the contexts of American and Canadian healthcare. Thus, the ethical permissibility of cognitive enhancement in the American context differs values embedded in

Canadian healthcare. Second, Chapter 7 revisited the AAN guidance in light of subsequent data on physician perspectives that did not exist at the time of its publication. Two survey studies, in particular, demonstrated ambiguity (akin to the ambivalence reported in Chapter 4) (Hotze et al. 2011) and hesitation (Banjo et al. 2010) on the part of physicians regarding prescription of medication to healthy individuals for enhancement purposes. Reframing the AAN guidance in light of the Canadian context and recent data on stakeholder perspectives may not contradict the moral acceptability of cognitive enhancement. However, it may provide good grounds for a principle-driven and evidence-driven stance against the moral praiseworthiness of cognitive enhancement.

CHAPTER 8: Contextualizing stakeholder perspectives within empirical evidence and normative theories regarding cognitive enhancement

The data and reflections presented within Chapters 4, 5, 6 and 7 have aimed to bring experiential and practical perspectives to the ethics debate on cognitive enhancement. The data was gathered to identify the ethical and social issues regarding the emerging practice of cognitive enhancement as perceived by key stakeholders (university students, parents of university students, healthcare providers). Stakeholder perspectives were gathered with focus group discussions using the example of the non-medical use of stimulants medication to improve academic performance. The data reported in Chapters 4, 5 and 6 provided qualitative data elucidating reactions and perspectives on ethical and social issues of key stakeholders. In Chapter 4, stakeholders expressed marked ambivalence and pluralism in their perspectives from both descriptive (what is) and normative (what should be) standpoints. This ambivalence was observed through hesitation in establishing terminology to define the practice as well as identifying with analogies with steroid and caffeine use. Autonomy of the individual stood out as a significant issue for stakeholders as reported in Chapter 5. These results described how social pressures to perform in competitive environments might lead to increased acceptability of cognitive enhancement despite a fundamental belief in the value of individual choice. A more exhaustive picture of ethical issues in cognitive enhancement and their relation to each other was provided in Chapter 6. The analysis of stakeholder perspectives in this chapter revealed that ethical issues are inextricably linked through underlying values and are contentious to different degrees. The insights gained through these data about stakeholder perspectives on cognitive enhancement suggest a cautious and complex approach to using medications to enhance cognitive performance that is far from the polarized positions in the academic ethics debate described in Chapter 2.

The data in Chapter 4 also responded to another objective of this thesis to assess print media coverage. Stakeholders considered the media discourse on cognitive enhancement to be informative but identified scientific and ethical issues that could be elaborated upon. A concern was also raised about media coverage being a double-edged sword because it may promote cognitive enhancement by providing optimistic accounts of benefits. This sub-set of data identified the media as an influential stakeholder in the cognitive enhancement debate. In addition to contributing empirical data to the ethics debate, the results presented in this thesis are consequential at a policy level. The ambivalence in stakeholder perspectives indicates that it is perhaps too early in the debate to be committing to policy while certain moral boundaries remain unclear for stakeholders. The second element of significance concerns the way the values important to stakeholders are represented (or not) in existing and future policies. One important direction in policy and neuroethics scholarship is the relationship between cognitive enhancement and the practice of medicine. The reflections in Chapter 7 used current data and guidelines to put forward a recommendation for clinical practice. These reflections have constructed a case for protecting the healthcare resources that can be used for enhancement based on safety and efficacy of medications but also on the responsibilities of physicians to their profession, individual patients, and the community. The stance in this chapter disentangled some of the assumptions about the responsibilities of physicians as gatekeepers of enhancement technologies.

The data and reflections presented in this thesis give information on the values of stakeholders on cognitive enhancement and the values that might be upheld in future policy. These values represent the preferences that guide what stakeholders consider to be an appropriate outcome or action in approaching the ethical dilemma. However, whether these are the values that *should* be promoted to serve as the foundation of our

society and our actions is another area of inquiry. In this last discussion chapter, I address the larger question of how the conclusions of this study and other empirical evidence on stakeholder perspectives contribute to the normative ethics debate on cognitive enhancement. I adopt a three-step approach to situate these data within the ethics debate around cognitive enhancement and begin a discussion about why information on stakeholders is needed. The first section of this final chapter will compare the specific results of this project with data from other empirical studies reporting stakeholder perspectives on the ethics of cognitive enhancement in order to highlight convergences and divergences in their findings. A review of research on stakeholder perspectives has not yet been undertaken and can help to ascertain the general approach of stakeholders as well as which issues are most urgent and contentious for stakeholders. The second section uses the review of stakeholder perspectives to consider how empirical data on cognitive enhancement align with the values discussed and principles prescribed by traditional normative ethics positions. Significant differences exist between the empirical and normative perspectives on cognitive enhancement and can be a hindrance for approaches to cognitive enhancement aiming to respond to the key values of both different normative academic viewpoints and the experience of stakeholders. The third section refines the role of bioethics in bridging divergent academic ethical perspectives with each other and with empirical data. The proposed role of bioethics rests upon a deliberative approach that can help to explain and understand diverging perspectives as opposed to accepting or rejecting a set of principles. An ethics debate that unifies expertise can more productively work toward finding solutions for action.

Toward a general idea of the acceptability of cognitive enhancement for stakeholders

Since the beginning of the study reported in this thesis, the pool of empirical evidence on stakeholder perspectives regarding the ethics of

cognitive enhancement has grown. Studies have mainly[14] examined student (Sabini and Monterosso 2005; Riis et al. 2008; Franke et al. 2012a; Franke et al. 2012b; Bell et al. 2012) and physician perspectives (Bergstrom and Lynoe 2008; Banjo et al. 2010; Hotze et al. 2011). To say that any normative conclusions could definitively be drawn uniquely from the study presented in this thesis would be to submit to the critique of the "is-ought problem" (see Chapter 3 for definition). A method for translating empirical data into normative thought within ethical inquiry is still the subject of debate (Hurst 2010). However, a first step in discussing the contribution of empirical evidence is to consider the range of existing evidence to obtain an idea of which types of experiences and conclusions have been reported in relation to current normative thought. The combined force of empirical studies may contain practical wisdom useful in normative inquiry whether by supporting the normative principles already put forth, qualifying these principles or proposing new ones. The purpose of this section is not to provide a comprehensive review of data regarding stakeholder perspectives on cognitive enhancement but rather to connect the findings of the focus-group study reported in Chapters 4, 5, and 6 as well as the reflections in Chapter 7 with other studies that vary in method, sample, culture and frame to gain a sense of tone in stakeholder perspectives. The common thread of the studies reviewed here is that the results speak to the opinions, attitudes and values of stakeholders.

Chapter 4 focused on the reactions of stakeholders to cognitive enhancement. Its major finding was the substantive ambivalence of stakeholders on cognitive enhancement, analogies and safety showing that stakeholder perspectives are not as clear-cut as those of authors in the academic ethics debate around cognitive enhancement. Other studies have reported results where there was coexistence of conflicting perspectives about the nature of cognitive enhancement and its

[14] Bergström and Lynoë's survey (2008) includes perspectives from the general public.

acceptability in medical and academic environments. For example, a majority of physicians answering questions about hypothetical cognitive enhancers "demonstrated some ambivalence, agreeing that the medicine should be allowed but not encouraged" (Hotze et al. 2011). In another sample, physicians seemed to be uncomfortable prescribing even existing medications (i.e., methyphenidate, modafinil) for cognitive enhancement purposes (Banjo et al. 2010). However, this sample of physicians was increasingly willing to prescribe a hypothetical enhancer as the patient age increased from 25 to 65 years of age and the purpose shifted from enhancement toward restoration. Students felt much the same way in Sabini and Monterosso's study where the participants discussed how cognitive enhancers might be fair but "under no circumstances was a drug given a ringing endorsement" (Sabini and Monterosso 2005). In these studies, stakeholders acknowledged and considered the possibility of cognitive enhancement in their environments, but this did not lead them to think that it should be encouraged. The hesitation of physicians to prescribe medication for enhancement was considered in the recommendation proposed in Chapter 6 that physicians should not grant patient requests for enhancers.

Ambivalence was also noted in Chapter 4 with regard to analogies of cognitive enhancement with steroid use in sports and routine caffeine consumption. Just like the focus group participants, a sample of Australian students concluded that cognitive enhancement could be compared to sports doping on a competitive basis, but that the two situations were different because of the magnitude and locus of effect of steroids compared to current cognitive enhancers such as caffeine or prescription stimulants (Bell et al. 2012). These students likened cognitive enhancement more to drinking coffee or alcohol considering it "just one way to study" (Bell et al. 2012). A small majority (56%) of a sample of German university students drew no *moral* difference between pharmacological cognitive enhancement and the use of caffeinated

substances (Franke et al. 2012a). However, 44% said there were general differences between the use of prescription stimulants and caffeine that were based on the side effects and medical risks as well as the legal consequences of using a regulated substance non-medically. Furthermore, an even proportion of these students either *did not* or *could not* differentiate the two types of substances. Being unable to produce definitive opinions on common analogies used to depict cognitive enhancement with prescription stimulants is an indication that stakeholders are also uncertain about what type of policy framework is most appropriate. Neither permissive nor restrictive policies seem to adequately respond to the type of action stakeholders foresee.

One area where other stakeholder studies diverge with respect to the results of Chapter 4 is on the issue of safety of using pharmaceuticals non-medically for cognitive enhancement. The results from Chapter 4 show that the sample in this focus-group study was ambivalent about using approved substances for cognitive enhancement displaying both a sense of security as well as some reservations. Interestingly, in other studies, safety was a chief concern for participants who were careful about the potential risks of using a prescription medication for cognitive enhancement. Banjo *et al*. (2010) reported that, “physicians mistrust safety claims regarding pharmaceuticals” such that it remains a concern despite being presented with a hypothetically safe cognitive enhancer in the study. For these physicians, the safety concerns “were not offset by the benefit afforded the individual” (Banjo et al. 2010) putting emphasis on “the balance between safety and benefit” for individuals. Similarly, Hotze *et al*. (2011) reported that safe hypothetical cognitive enhancers, “least often approved by physicians were interventions that could easily be argued as dangerous to the user,” whether due to the side effects caused or the behaviour produced (e.g., making a soldier more aggressive). In two studies by Franke et al., safety was a deciding factor for German students and pupils. Approximately 80% of the sample “agreed that such

substances must not lead to long-term damage or addiction if they were to consider using them" (Franke et al. 2012a). In the other study, researchers found that students "cited physical and mental side effects as important factors in their decision on using caffeine or stimulants" (Franke et al. 2012a). From the results of other empirical studies it seems that other stakeholders were more cautious and decisive about safety than those in Chapter 4.

The results presented in Chapter 5 show a normative-descriptive tension in stakeholders' discussion of the values involved in making an autonomous choice to use a cognitive enhancer (or not) and their actual experience. No other study has demonstrated the same type of tension but some have echoed results on either the descriptive or normative levels. Australian students put forward a similar belief in personal choice (Bell et al. 2012). Two other studies characterised personal choice from the perspective of the legitimacy of motive. German "students primarily focussed on their individual situation and on how to best achieve their ends" reinforcing the supremacy of personal choice (Franke et al. 2012b). In contrast, Bergström and Lynoë's study of Swedish general practitioners and members of the public showed that they are more attuned to the consequences of their personal choices as "socially related reasons seemed to be more acceptable than the merely egoistic ones" (Bergstrom and Lynoe 2008). Health consequences also figured into the perspectives of physicians who emphasized the responsibility of the physician to favour the benefit of using a cognitive enhancer for the individual over and above the safety of the medication (Banjo et al. 2010). This finding agrees with the finding that the healthcare providers in Chapter 5 who thought it the responsibility of the individual to make health-conscious decisions regardless of pressures to enhance performance. It is also relevant to the discussion of ensuring benefit to patients as an obligation of physicians in Chapter 7. On a more descriptive level, in Franke et al.'s study of users and nonusers of stimulants for cognitive enhancement, peer pressure

seemed to not be among these pressures as “66% answered that they would ‘under no circumstances’ or ‘probably not’ use cognitive enhancers if others did” (Franke et al. 2012b). This finding comes in stark contrast to those in Chapter 5 that cited peer pressure as a motivating factor for using stimulants as cognitive enhancers and may constitute a cultural difference in North American and European attitudes. However, in the same study, the authors report that users of stimulants viewed “life as subject to chance circumstances beyond their control” (Franke et al. 2012b), which resonates with the determinism reported in Chapter 5. While the results in Chapter 5 remain the most detailed examination of the issue of autonomy in the cognitive enhancement debate to date, results on personal choice and peer pressure from other studies have added some specifications about stakeholder perspectives on autonomy that echo the individualistic nature of the decision to enhance one’s cognition but acknowledge influences.

Values were found to be at the root of ethical contention in the debate around cognitive enhancement in Chapter 6. The same values surfaced in many other empirical studies on stakeholder perspectives. The issue of authenticity of the individual was highly contentious in Chapter 5 and associated by participants with the value of effort that is put into a performance. Results from other studies on stakeholder perspectives have shown less contention around this point. Students in a study by Riis et al. showed reluctance to enhance traits believed to be fundamental to self-identity such as social comfort as opposed to concentration, which they considered to be less fundamental to self-identity (Riis et al. 2008). However, this reticence to enhance fundamental traits changed when enhancers were framed as *enablers* of one’s true self-identity. Other stakeholders shared this view in demonstrating more tolerance for enhancing attention as opposed to memory or mood (Sabini and Monterosso 2005; Bergstrom and Lynoe 2008). Arguments negating the authenticity of an enhanced performance similar to those in Figure 6.2

were given by 63% of physicians in Hotze et al.'s study who strongly agreed that that enhancement "poses a threat to the value of human achievement and 58% who were concerned about physicians "playing God" (Hotze et al. 2011). A variable response from Australian students was that an enhanced performance was "not a true reflection of the person's ability" (Bell et al. 2012). Few counter arguments to the inauthenticity of an enhanced performance were presented in other stakeholder studies yet the value of effort emerged as an important consideration in determining whether cognitive enhancement was ethically acceptable.

Fairness was discussed in two ways in Chapter 6. Though the same distinction between cheating and distributive justice was not made in other studies, the values of honesty and access resonated with other stakeholders. Discussions of cheating refer to whether cognitive enhancement confers a competitive advantage whereas distributive justice refers to the ease in gaining access to cognitive enhancers. Majorities of both Australian and German samples considered an academic performance enhanced with stimulants to be cheating (Franke et al. 2012b; Bell et al. 2012). Interestingly, some students in two studies made concessions for lower performing classmates to be allowed to use substances to equalize their academic performances with higher performing peers (Sabini and Monterosso 2005; Franke et al. 2012b). Access to enhancers was a major concern for physicians. The majority of Hotze et al.'s sample agreed that if medical enhancements were allowed they should be equally available to everyone (Hotze et al. 2011). Paradoxically, a majority also said that if medical enhancements were allowed, they should not be covered by insurance. Scandinavian physicians shared the same perspective about cognitive enhancers (Bergstrom and Lynoe 2008). This finding about access to medications agrees with the recommendation put forward in Chapter 7 for physicians to maintain their roles as stewards of healthcare resources making sure they

are allotted to those who are in need of them. Only 1.9% of German students interviewed by Franke et al. noted that enhancers should be inexpensive (Franke et al. 2012b). The combined perspectives on distributive justice reveal what is perhaps another normative-descriptive tension where the value of equal access is promoted but is not necessarily translated into the practical aspects such as cost and insurance coverage. The combined empirical evidence shows that fairness is a contentious issue when considering access but was considerably less contentious on the subject of cheating.

The social meaning of the outcomes of cognitive enhancement was a highly contentious issue in Chapter 6 but was not prominent in the results of other empirical studies. The clearest discussion of social impact is seen in Hotze et al.'s survey of physicians where the authors questioned participants on whether certain types of enhancements should be encouraged, allowed or discouraged (Hotze et al. 2011). Though their concerns are qualitatively different from those for medicalization and education seen in Chapter 6, physicians in this study show awareness for the social impacts of medical technologies especially when considering the impact on certain professions. For example, respondents discouraged the use of enhancers to "make soldiers more aggressive", "reduce fear in people with dangerous jobs" or "make factory workers works faster" (Hotze et al. 2011). What these social impacts have in common is the concern for changing standards of performance and whether pharmacology is a laudable way to meet these standards.

The empirical evidence on stakeholder perspectives has shed light on issues in the ethics debate around cognitive enhancement. These perspectives can help formulate some general observations that might help to inform normative reflection on the acceptability of cognitive enhancement as a whole. Synthesizing the results and reflections presented in Chapters 4, 5, 6 and 7 with other qualitative and quantitative studies reporting stakeholder perspectives this section will be used in an

attempt to give a general account of acceptability. Only two studies concluded on the topic of acceptability of cognitive enhancement. Banjo et al. (2010) reported that physicians have a conservative stance on the acceptability of cognitive enhancement. The students in Sabini and Montetosso's sample were "eager to have the drug banned if it affected everyone" (Sabini and Monterosso 2005). No study encouraged or concluded that cognitive enhancement was acceptable in any form and under any circumstances. Only 15.6% of a sample of German students said they would use an enhancer under any circumstance (Franke et al. 2012b). Instead, what can be observed is a negotiation of reservations with regard to acceptability or conditions under which cognitive enhancement would be acceptable. For example, cognitive enhancement could be acceptable if use is controlled and moderate (Forlini and Racine 2009b; Bell et al. 2012). Other types of conditions are found in the perspectives described in the paragraphs above. Distinctions in acceptability were made between using medications as an *enhancer* versus an *enabler* (Riis et al. 2008), *normalizer* (Sabini and Monterosso 2005) or *restorer* (Banjo et al. 2010) of cognitive function. The cognitive ability targeted for enhancement (e.g., mood, memory or concentration) was also an area where acceptability varied through a connection with authenticity of the individual (Bergstrom and Lynoe 2008; Riis et al. 2008). Access and benefit (outcomes) for patients were additional mediating factors for stakeholders in evaluating the acceptability of cognitive enhancement (Bergstrom and Lynoe 2008; Banjo et al. 2010; Hotze et al. 2011; Forlini and Racine 2012b). Physicians' conditional acceptance of enhancement brings into question the place of enhancement within medical practice and challenges the gatekeeper role (Chatterjee 2004; Synofzik 2009). What becomes clear in looking at the empirical evidence on the ethics of cognitive enhancement is that the acceptability of the non-medical use of prescription medications to enhance cognitive function is a matter of degree. However, which issues and considerations determine

the degree of acceptability is not merely a question of large-scale demand and consensus but also a question that is inclusive of thoughtful ethical reflection of a theoretical kind. Empirical findings about degrees of acceptability for cognitive enhancement may not fit neatly into the principled approach of normative ethics. This type of incompatibility could stifle ethical inquiry by creating a stalemate. To avoid this type of situation, it is important that within ethical inquiry, empirical findings are contrasted and compared with the tenants of normative thinking to create a space for deliberation where convergences can be explored and divergences bridged. The next section will use the finding of degree of acceptability to set the agenda for deliberation between empirical and normative ethics in the cognitive enhancement debate.

Bridging empirical and normative in the cognitive enhancement debate

The general need for both empirical data and normative reflection in bioethics is non-controversial (Borry et al. 2005; Salloch et al. 2012). Contention arises in trying to derive normative conclusions from empirical findings despite the conceptual and methodological gaps to surmount. A conceptual gap exists in the polarization of the academic normative ethics debate between bioconservative and bioliberal approaches to enhancing cognition that was reviewed in Chapter 2. A second gap also seems to exist between the academic ethics debate and empirical data from studies with stakeholders (Forlini and Racine 2011a). The goal of this second section is to critically examine the relationships between the data reviewed above and the relevant principles defended by both bioconservative and bioliberal normative ethicists in the cognitive enhancement debate. Recognizing these relationships and finding common ground is a first step in understanding how empirical data and normative reflection come together and contribute to fruitful conclusions (Frith 2012). Finding common ground ensures that normative ethicists and stakeholders are using commensurate terminology to refer to concepts of importance (Ives

and Draper 2009). The common ground is essential if one of the goals of the ethics debate is to propose policy whether for prevention, promotion or an option in between. A discourse analysis has already shown that academic and lay literatures portray cognitive enhancement using different terminology, prioritize different issues and recommend different policy approaches (Forlini and Racine 2009a). An examination of normative and empirical perspectives might yield the same result. The relationships between data and relevant principles are discussed in this section by addressing dominant values that form the common ground between normative and empirical perspectives. Then, apparent normative-descriptive tensions that arise will illustrate obstacles in finding common ground. Finally, this section considers whether any wisdom for taking action in the cognitive enhancement debate can be gleaned from convergences and divergences in normative and empirical perspectives. The endeavour is not to propose a new method for combining normative and empirical ethics. Instead, the goal is to take stock of common ground and begin to cultivate a more unified debate on cognitive enhancement that recognizes and uses the interplay between normative and empirical expertise to work through sources of ethical contention.

Values in the cognitive enhancement debate

The previous section of this discussion revealed that the values present in stakeholder perspectives on the use of prescription medications for cognitive enhancement erred on the conservative side of the ethics spectrum. Beliefs that an enhanced performance is inauthentic, unfair and dishonest making cognitive enhancement a generally unacceptable practice were common. More liberal stances that would consider an enhanced performance authentic, fair and honest were not as prominent. Personal choice emerged as one of the strongest liberal values to figure in stakeholder perspectives, though was compromised by other contextual factors such as social pressure to perform and succeed. Interestingly, the

seemingly conservative values of stakeholders challenge the perception that current prevalence rates are an indicator of demand for cognitive enhancement from the public (Farah et al. 2004; Greely et al. 2008). How can cognitive enhancement be prevalent or in demand if stakeholders uphold these conservative values? Perhaps a partial answer to this question is present in conditions described by stakeholders that increase the acceptability of cognitive enhancement to certain degrees. The different degrees of acceptability suggest that, according to stakeholders, the ethical landscape around cognitive enhancement is more diverse than it initially appears and that stakeholder values are neither firmly conservative nor liberal. The particularities of stakeholder values will be explored further in subsequent sections of this discussion and should be investigated by future empirical research. One potential difficulty for normative ethics is reconciling potential widespread approval or dissent for cognitive enhancement among stakeholders with other important ethical practices and principles. The same reasoning can be applied to navigating ambivalence in stakeholder perspectives.

A common limitation of empirical ethics studies is the inability to generalize the results of a study to represent the perspective of the majority of a population of interest. However, even a poll with a large representative sample cannot force a certain course of action to respond to an ethical dilemma unless the principles and values behind these opinions are justified (Leget et al. 2009). Furthermore, ethical reflection would be superficial if bioethicists, both empirical and normative, “come to broad moral conclusions on the basis of fine-grained data” (Parker 2009). The individual studies reviewed above can be considered fine-grained both in the scope of issues and the populations studied, and thus not suited for generalization. However, contrasting and comparing the results of these empirical stakeholder studies as was done in previous chapters is a first, and valuable, step in establishing a more complete understanding of the ethical landscape of cognitive enhancement. This step provides a

larger and more varied body of evidence to consider. Still, discovering conservative values among stakeholders translates neither into a rejection of liberal principles nor adoption of any pro-conservative policy regarding cognitive enhancement. Instead, the conservative values aid in "recognizing which moral principles are most at stake in given contexts" (Solomon 2005). The issues at stake can be the ones that are most often discussed or even those that are in need of clarification. Safety emerged as an issue of prime importance for stakeholders just as it has been in the academic ethics debate. On the other hand, discussion of authenticity, an issue that is often dismissed in liberal perspectives (Buchanan 2009), emerged as a fundamental issue in the acceptability of using medications for cognitive enhancement. In contrast, most of the moderately contentious issues identified in Chapter 6 were not explicitly discussed as ethical issues in other studies. Examining the level of contention of ethical issues rather than looking for clear-cut partisanship with existing frameworks could be a more productive approach to distilling the morally significant values for stakeholders in the context of an ethical debate.

Empirical ethics and normative ethics both use values and principles as tools for reflection. Normative ethics can exist in a purely theoretical domain. However, normative reflection as a policy endeavour has an interest in being empirically driven. Empirical data helps those doing normative research to (1) have an idea about what stakeholders' views might be; (2) "explore whether some intuitions are held more strongly than others or are perceived to take precedence over others"; and (3) "explore the extent to which some intuitions are unshakeable" (Ives and Draper 2009). Ives and Draper (2009) insist that it "is no use a theorist engaging in [normative policy or practice oriented bioethics] making assumptions about intuitions in place of taking these three steps." Similarly, empirical researchers must not lose sight of the influence of normative ethics research on data gathering. Empirical ethics is deeply infused with theory that may lead to biased assumptions (Frith 2012).

Recent psychology studies have made use of normative stances to investigate attitudes on cheating. In one study, researchers showed that participants who read deterministic passages about free will were more likely to cheat than those who did not (Vohs and Schooler 2008). In another study, researchers used a vignette based on sports doping in comparison to another vignette on academic doping to study attitudes on cheating in cognitive enhancement (Dodge et al. 2012). These two studies provide evidence that implicit normative principles can color empirical approaches (i.e., determinism and stigma of sports doping). There are some traces of a "conservative normative infusion" in empirical discussions on the issues of autonomy in cognitive enhancement. Chapter 2 reviewed stances that maintain (1) there are influential factors in academic and professional environments to engage in cognitive enhancement; (2) individuals will succumb to these influences and (3) it will be against the individual's personal values to do so. Stakeholders have echoed some of these sentiments but have also opened up discussions of tolerance and the personal choice to resist these coercive pressures as values that are morally relevant in their experience with cognitive enhancement. Another example might be found in the results of the "Look Who's Doping" poll conducted by the scientific journal *Nature* (Maher 2008). These data are used to support widespread general prevalence and approval of cognitive enhancing medications in addition to be preceded and followed by commentaries with libertarian undertones (Sahakian and Morein-Zamir 2007; Greely et al. 2008). How would results from a similar poll conducted by the President's Council on Bioethics be presented and discussed? The conservative sway of stakeholder perspectives begs the question whether these results are a true reflection of the values of stakeholders or an artefact of research questions with embedded normative assumptions. It is beyond the scope of this thesis to answer this question but reports of stakeholder perspectives are a reminder that normative principles are essential in empirical ethics and

could stand to be more openly discussed and declared as integral parts of empirical studies (Parker 2009; Salloch et al. 2012). As a result, biases might be better identified and the results situated within the normative context they were collected.

Normative-descriptive tensions in the cognitive enhancement debate

Empirical ethics research not only studies the normative values upheld by stakeholders but also describes their actions and behaviours in situations calling for a moral choice. The stakeholder studies reviewed above revealed two instances of normative-descriptive tension where the outcomes of moral decisions (i.e., "is") were not in line with participants' normative values (i.e., "ought"). The first was an important finding in Chapter 5 of pressure to perform which left participants feeling they had "no choice" but to use cognitive enhancers despite their belief that this choice was an individual and personal matter. The second example was brought to light in the review above. Inequalities caused by differences in access to existing and future enhancement technologies are a contentious topic for bioconservatives and bioliberals (Chapter 2). However, when asked about practical considerations that would permit equal access, stakeholders were inconsistent. They were reluctant for enhancement to be covered by insurance or for collective resources to pay for individual preferences. These are two examples where the solutions suggested by evidence of "is" do not fit neatly into the principles of "ought" (e.g., autonomous decision-making and distributive justice). The dissonance is perhaps an indication that something other than values is guiding the actions of stakeholders in their experience with cognitive enhancement. It has been suggested that "[w]hen faced with an ethical dilemma, people do not always think about what they ought to do in isolation from what they are currently doing" (Ives and Draper 2009). Neither, then, should normative ethics be prescribing what "ought" to be done without considering what "is" being done.

An individual's decision to use a medication to enhance their academic or performance is often multi-faceted". An individual may follow ethical norms which "are not biological laws but rules created by human society" (Racine 2008b). Ethical norms, however, can vary according to culture and era. The norms followed by a group of people at a particular time are subject to change. For example, Franke et al.'s samples (2011, 2012b) seemed to resist the pressures to use prescription medications as cognitive enhancers more than focus-group participants in the results of Chapter 5. Furthermore, human society is a complex phenomenon that does not always follow the prescription of ethical norms. Indeed, "bioethics analyses often assume an implausible degree of rationality in human motivation and action" (Solomon 2005). When stakeholders speak about cognitive enhancement there is often mention of what "has" to be done in order to compete, succeed or be happy. Thus, "should" does not always translate into "can" (Racine 2008b; Ives and Draper 2009). Sometimes other socio-economic infrastructures can be prohibitive, which was discussed briefly in the case of limited health resources in Chapter 6. However, in this case, we see that the moral praiseworthiness (should) is rendered unacceptable (cannot). In the case of the normative-descriptive tension related to justice it is easy to see how "getting from an ideal vision of the good to an embodiment of those ideals in practice depends as much on structural factors like power, money, and socializations as on espoused values and ideals" (Solomon 2005). These structural factors might also be relevant for the normative-descriptive tension with autonomy but another option is also possible. The deterministic attitudes of stakeholders mirror the academic discourse predicting the inevitability of cognitive enhancement that "It's too late to 'just say no' to biomedical enhancements: They're already here and more are on the way" (Buchanan 2010). With this ominous message, stakeholders may believe that their values do not stand a chance against the assimilation of cognitive enhancement technologies into social practices. Then again,

stakeholders might also be paying lip service to generally accepted values while acting according to structural factors in their respective contexts. There is still work to be done to understand the roots of normative-descriptive tensions but recognizing differences in values and actual possibility for acting according to prescribed values could be an area of focus for deliberation between normative and empirical ethics.

Normative-descriptive tensions such as the ones that can be observed in the ethics debate on cognitive enhancement are an obstacle for bioethicists, both normative and empirical. Empirical data helps bioethicists to understand the values of stakeholders so that theory and subsequent policies can be relevant and effective (Ives and Draper 2009). If principles “are too abstract or practically not feasible” then normative ethics has failed in its role to guide action (de Vries and Gordijn 2009). Until normative-descriptive tensions are unwound it would be difficult to carry out a constructive discourse that tends toward policy. As more and more empirical data on stakeholder perspectives about the ethics of cognitive enhancement emerge, normative bioethicists may have to revisit prior discussions of principles to reframe the debate for two reasons. First, this process may help create a negotiated space between what people “ought” to do and what they actually “can” do within socio-economic frameworks. Second, empirical data may uncover unethical behaviour that does not abide by traditional social values. If, for example, it were discovered in a study certain professional environments were obliging employees to take safe cognitive enhancers to be more productive there would likely be a normative objection to this behaviour on the grounds that it was coercive. This is an extreme example but it illustrates that even though behaviours exist, they do not provide grounds to discard a certain set of values. Normative ethics might also have the task of reinforcing values and promoting ethical behaviour. Working through normative-descriptive tensions is a way to contextualize values, both those of

stakeholders and bioethicists, into the description of behaviours reported by empirical data.

How does information about values and actions inform prescriptions for ethical action?

Translating normative theories or empirical data into any type of general statement about the best policy or approach to cognitive enhancement is a complex endeavour. This last subsection will highlight characteristics of the current cognitive enhancement debate that hinder empirically informed prescriptions for action. The first characteristic is the moral unrest expressed by stakeholders that traverses many issues in the debate. The second is the apparent incompatibility of certain values that are upheld by academic and stakeholders with the predicted outcome of adopting one principle over another. Ethical deliberation would be a key step in navigating these moral and practical obstacles to moving forward with the cognitive enhancement debate.

Also called “ambiguity” (Hotze et al. 2011) or “ambivalence” (Chapter 3), moral unrest consists of coexisting conflicting reactions and perspectives. Analogies to caffeine and sports-doping offer embedded values and outcomes, but stakeholders are unwilling to commit to either of these established normative-descriptive profiles. Stakeholders use complex and conflicting arguments to discuss issues of authenticity, fairness and general acceptability often without definitive conclusions about what can be done about the ethical dilemmas posed by cognitive enhancement. This moral unrest is evidence that the ethical perspectives of stakeholders are not being captured by a specific framework (Parens 2005; Racine 2010). Perhaps this is also an indication that stakeholders are not ready to draw moral lines across ethical issues on the grounds of a specific moral argument or a contextual factor. More time and deliberation might be needed to debate and prioritize contentious issues in cognitive enhancement. Deliberation is not only about ranking issues but also discussing the relationships between these issues as they dictate what

"should" be done and affect what "can" be done. The model depicting relationship between ethical issues in the cognitive enhancement debate featured in Chapter 5 (Figure 5.6) is, thus far, unique in the empirical data and could serve as an example of the type of attention that needs to be paid to the interaction and interplay of issues in order to work through moral unrest. This model showed that the ethical issues in the cognitive enhancement debate do not exist in a vacuum and that values are neither exclusive to one issue nor easily teased apart from one another.

The relationship between safety of cognitive enhancers and the autonomy of an individual to choose to use them is an example of how normative principles and empirical ethics can highlight incompatibilities between what (1) normative ethics says "should" be done, (2) empirical ethics describes "is" being done and (3) socio-economic infrastructures say "can" be done. As previously explained, the actions and decisions of stakeholders often follow the third option. The possibility of unknown or serious side effects of substances used as cognitive enhancers is often used as an argument in the bioconservative stance against allowing uses of medications for cognitive enhancement (Heinz et al. 2012). Autonomy of the individual is an argument that is used to support the liberal perspective believing cognitive enhancement should be allowed and the individual free to incur the level of risk they are comfortable with. It is clear that both camps would be against an enhancer that was unsafe or associated with coercive use. It can be suggested that the conservatives would only allow an innocuous enhancer (but would likely still be concerned with levels of coercion for individuals to use them). However, the likelihood of an enhancer that was completely safe is slim and studies proposing hypothetically safe enhancers show that safety remains a concern nonetheless (Banjo et al. 2010; Hotze et al. 2011). In their extremes, the issues of safety and autonomy do not seem to intersect. However, most of this chapter is dedicated to discussing how the reality described by stakeholders does not seem to fit extremes. It is perhaps

more pertinent to explore how the relationship between these two issues becomes more complex and perhaps incompatible according to *degrees* of safety.

What level of risk is appropriate for an individual to incur for cognitive enhancement and to what extent do individuals need to be protected from this risk? A substance that had few side effects is not likely to be banned simply on the basis of safety. Caffeine is a common example of a substance that is not regulated nearly as strictly as the types of cognitive enhancers that are being discussed in this thesis but produces unpleasant and harmful side effects (Moore 2011). These side effects are non-negligible but individuals are still allowed to consume caffeine freely. The relationship between safety and autonomy becomes more complicated as side effects become more moderate but not serious. Alcohol and nicotine carry with them moderate risks of chronic illness (compared with caffeine) and yet access is allowed, albeit restricted to adults. These examples show that there are compromises to be made. Deliberation in ethics can help find an "ethics tipping point" for issues with unclear relationships and diverging fundamental values. The idea of an ethics tipping point recalls Juengst's use of the term enhancement as a moral "boundary concept" (Juengst 1998). An ethical tipping point would be found at the intersection of one or more issues that established boundaries in acceptability. In the case of cognitive enhancement and the two issues of safety and autonomy, the goal would be to establish a certain range of risks where the individual was protected from self-inflicting harm but was at liberty to freely choose to enhance their cognitive performance. Tipping points have already been referred to in relation to both autonomy and safety. Instead of unconditionally condoning or opposing cognitive enhancement based on autonomy, Hildt and Metzinger suggest that the "interesting and demanding task lies in *limiting* this freedom in an intelligent way, in minimizing potential individual suffering and the overall psychosocial cost to society as a whole" (Hildt and

Metzinger 2011). Freedom, after all, “is not a condition in which there are no obstacles to action” (Gouinlock 2002). Instead, an important element to freedom is the ability to function according to preferences (choice) and this can be within an established framework. Harris proposes what can be thought of as an ethical tipping point with regard to the safety of human enhancements. He says that, “[s]afe always means safe *enough*” (emphasis added) (Harris and Chatterjee 2009). Using the example of methylphenidate, he maintains that since regulatory bodies and consumers have deemed the medication safe enough for children and young people over long period of time these criteria should be sufficient to justify its use in healthy adults. In reality, the evidence for the efficacy of methylphenidate as a cognitive enhancer in healthy individuals is sorely lacking but Harris’ argument opens up the issue of safety to establishing what level of evidence would be sufficient.

Establishing the ethics tipping point should be a joint venture of normative and empirical bioethicists to favour recognition of the limitations for stakeholders in concert with the values and principles that are important for society. Cooperation is especially important when considering that any such tipping point could be affected by other considerations. For example, might the tipping point change if the risk is collective and not only individual? Would the landscape change if safety were discussed in terms of benefit as opposed to risk? Perhaps then, the relationships with autonomy would be less tense than the relationship with regard to safety and social outcomes. One way to study ethical tipping points empirically (quantitatively or qualitatively) would be to present vignettes with varying levels as options for response. Each level can be an incremental shift from conservative to more liberal points of view or varying probabilities of outcomes. Rather than looking for unilateral support of conservative or liberal approaches in empirical data, normative ethics could look further into discussing, establishing and re-evaluating ethical tipping points to navigate cases of moral unrest.

Even on common ground normative and empirical perspectives remain somewhat divided. This divide has lead bioethicists studying cognitive enhancement to make three mistakes that were discussed in this section. First, it was expected that stakeholder perspectives would conform to one ethical framework or the other. Second, normative-descriptive tensions were ignored and the debate remained fixed in normative positions that have not considered practical reasons for action. Third, relationships and (in)compatibilities of values have been overlooked which contributed to moral unrest. Those working on the ethics of cognitive enhancement must revisit these points for the debate to work through a normative-empirical stalemate where action-guiding recommendations are difficult to make. Through this task, however, there is a danger of committing a fourth mistake. All too often it is assumed that principles and practices remain static- that concepts or experience will not change with time. Solomon (2005) comments that sometimes practice "guidelines persist, taking a life if their own, while the conditions that motivated them change." It is thus the responsibility of bioethicists to "formulate and reformulate our ethical theories" (Frith 2012) that are at the basis of these policies in order to keep debates and reflections current and relevant.

Renewal of the deliberative role of bioethics for fighting the culture wars

In an early definition of the field of bioethics, Potter advanced that the goal of bioethics should be to "generate wisdom, the knowledge of how to use knowledge for social good from a realistic knowledge of man's biological nature and of the biological world" (Potter 1971). Potter envisioned bioethics to be inherently deliberative and to serve as a meeting place for the biological sciences and the humanities. Other early scholars in bioethics also stressed this role for bioethics viewed as an open-ended field (Callahan 1976). Historically, bioethics has opened up ethical debates to different perspectives by serving as a meeting place. There are several

examples where bioethics has bridged ethics, medicine, science, and public perspectives in times when consensus was needed and points of view diverged on “biological knowledge and human values” (Potter 1971). Even before the official establishment of bioethics, the Nuremberg Code and Declaration of Helsinki called for broader social and ethical perspectives on medicine and the biological sciences. More recent examples like the Belmont Report, the British Nuffield Council on Bioethics and the American Presidential Commission for the Study of Bioethical Issues illustrate how the field has materialized in more interdisciplinary forms. Historical and newer centers dedicated to teaching and scholarship in bioethics along with professional societies have contributed to establishing bioethics as an interdisciplinary field and a meeting place, although this goal has not been fully attained (Pellegrino 2006). The key to both the historical and more recent examples is that bioethics reached out to connect different perspectives and generate new knowledge on the ethical issues in scientific research and medical practice. This final section aims to discuss some of the characteristics and benefits of a deliberative approach to bioethical inquiry that is founded on the interplay between empirical and normative ethics. Deliberation requires that (1) data and theory mutually inform each other, (2) venues be created to foster opportunities for consideration of data and theory, and (3) the focus be on producing feasible outcomes rather than validating one framework over another. With a more deliberative approach, modern bioethicists can reinvigorate Potter’s vision for the field.

The three gaps between normative and empirical ethics highlighted in the preceding section suggest that bioethics has not created a desirable meeting place for the cognitive enhancement debate. Normative ethics perspectives and stakeholder perspectives represented through empirical studies seem to be inspiring distinct reflections. The impression is that the distinct foundations cause debates on cognitive enhancement to run on separate parallel tracks and potentially evolve independently. This divide

between stakeholder data and ethics theories on cognitive enhancement is in addition to the academic culture wars already debating conservative versus liberal positions. Indeed, there may be two battles in progress: one where “is” confronts “ought” and another where one vision of “ought” challenges another vision of “ought”. Separate evolution of normative debates and empirical perspectives could have consequences that lead to differences in how academic ethics and other stakeholders: (1) prioritize and assign importance to different ethical issues; (2) justify individual and collective decisions and policy options, and (3) incorporate complex and evolving ethical thinking represented in the form of substantial moral ambivalence. Parallel debates may be evidence of a broader and more general disconnect between academic ethics and broader stakeholder perspectives that may create pitfalls in policy-making and practice-oriented scholarship if they are not linked.

One potential explanation for these separate tracks is the complex relationship between different types of expertise. If expertise is understood as “some superior and/or exclusive form of knowledge and competence in particular field which can be acquired through training and experience” (Schicktanz et al. 2012) both ethicists and stakeholders can be considered experts in their own right. Ethicists *help* make decisions at both the individual and collective levels using theoretical and methodological reflection. Stakeholders experience the decisions they make. Challenges arise when it is expected that one expertise take precedence over another to inspire a solution for an ethical issue (Nadler and Reiner 2010). The categories of *ethicist* (expert) and *stakeholder* (lay citizen) fail to capture two important characteristics of these two groups. The first is thatexperts in academia are not fully objective and possess their own moral intuitions in addition to formal knowledge of ethical theories (Ives and Draper 2009). The second is that stakeholders do not follow the “deficit model” of public understanding of science (Wynne 1993) presuming that “the public usually has considerable lack of knowledge on and understanding of science”

(Schicktanz et al. 2012). Instead, stakeholder groups and members of the public can have valuable knowledge and experience to share in ethical inquiry. One might reframe this distinction as not between the “know” (expert) and “know not” (stakeholder) but rather between the “know something” and “know something else.” Schicktanz et al. (2012) reinforce this point by stating that “[t]here is no clear demarcation line between lay moralities and ethical (academic) reflection, but rather a continuous interactive spectrum: both involve normative reasoning and discussion, albeit to a different extent and on different levels of theoretical sophistication.” Integration of different types of expertise in ethics can generate new wisdom that creates a meeting point between parallel debates in cognitive enhancement founded on competing sources of expertise.

Recognizing and collecting the various sources of expertise that are needed to generate new wisdom is another joint venture for normative and empirical ethics. Amid the “empirical turn” in bioethics there have been critiques that, “there is a paucity of reliable and valid empirical data regarding the considered moral opinions of the public or other key stakeholders who are not empowered to sit at the table” (Kim et al. 2009) (Gutmann and Thompson 1997; Racine 2003; Macpherson 2004). The “participatory turn” (Schicktanz et al. 2012) in bioethics responds in part to this critique about exclusion of stakeholders by inviting members of the public and stakeholder groups to be part of deliberation and not merely be objects of research (Schicktanz et al. 2012). However, the more crucial aspect of responding to this critique is determining who should be empowered to sit at the table, why, and how their perspective might advance ethical inquiry (Salloch et al. 2012; Schicktanz et al. 2012). These are questions of a normative nature and, if answered exhaustively, can include all relevant expertise. Groups with relevant expertise also contribute to setting the agenda for research priorities on both normative and empirical fronts (Secko et al. 2008; Salloch et al. 2012). Thus far in

the cognitive enhancement debate there is evidence that some stakeholders have been overlooked. In an editorial published in the Canadian Medical Association Journal, Rosenfield et al. (a group of physicians) call upon academic institutions to actively engage in preventing the non-medical use of stimulants by university students (Rosenfield et al. 2011). However, few reflections, neither normative nor empirical, have explored the perspective and role of academic institutions. This example is interesting because members of one stakeholder group (physicians) identified by both normative and empirical ethics (Chatterjee 2004; Banjo et al. 2010; Singh and Kelleher 2010; Hotze et al. 2011) passed the onus that had been put on them onto another stakeholder (academic institutions). In the case of cognitive enhancement, the scope of stakeholders, their expertise and respective contributions do not seem to have been fully explored. Bringing the parallel tracks to an intersection would involve recognizing and integrating relevant and available expertise.

Bioethics is already an interdisciplinary field, but its deliberative role could be reaffirmed and better established more generally (Gutmann and Thompson 1997; Racine 2003) and specifically in the cognitive enhancement debate (Forlini and Racine 2009a; Racine 2010). Bioethics could reinvigorate its role as a meeting place for the traditional academic ethics debate on cognitive enhancement and the more experientially based approach of stakeholders. In order to play this role, Callahan has urged that, “if bioethics is to retain its vitality and be taken seriously, it will have to find a way to extricate itself from the culture wars” (Callahan 2005). Indeed, the type of wisdom about using knowledge for social good that Potter advocated could be generated *within* a bioethics that, as Callahan proposed, “expect[s] and welcome[s] struggles between opposing viewpoints” (Callahan 2005). The meeting place fostered by bioethics could help build a two-way bridge between the different theories in normative academic ethics and between stakeholder perspectives, which would enrich the broader cognitive enhancement ethics debate by

representing the value-added of each perspective. This two-way bridge could help incorporate the human values reflected in the experience of stakeholders to “recognize the importance of the manifold factors that affect human welfare” (de Melo-Martin 2010). In the other direction, academic ethics can provide a framework to understand the principles that stakeholders are using and valuing in their experiences with cognitive enhancement.

The ethics debate around cognitive enhancement has not shied away from entertaining opposing viewpoints, as Callahan suggests, but does seem to have become stuck in battles between conservative/liberal normative views and empirical data. One aspect that propagates these culture wars in cognitive enhancement might be the pursuit of a solution to the ethical issues that aligns with a particular framework by rejecting or abandoning general ethical principles (Parens 2005; Ives and Draper 2009; Parker 2009). Trying to commit to one ethical framework seems to be another contributing factor in the multi-track cognitive enhancement debate. The previous section of this discussion explored some of the reasons why it has been challenging to come to some agreement on the cognitive enhancement debate mostly due to the incompatibilities between the descriptions of “is”, “ought” and “can”. Deliberation that recognizes and involves the diverse and relevant expertise that contribute theoretical and experiential perspectives can result “in a response to the real possibilities of the situation, rather than to a partial or mistaken view; so it also results in a much greater likelihood that conduct will be consummatory” (Gouinlock 2002). Here, the concept of consummatory signifies a meaningful experience, the result of considering principles and personal intuitions leading to an acceptable and laudable mode of action. Dewey’s criticism does not propose to do away with normative inquiry. As Gouinlock explains: “[p]rinciples are embodiments of much past experience, and as such they provide useful and often wise suggestions for conduct. But in any case they function as hypotheses, not absolutes”

(Gouinlock 2002). Indeed, deliberation can put forth the hypotheses in the form of existing normative frameworks with empirical data that can be tested in ethical practice. Similarly, empirical data may also generate new hypotheses or raise red flags with regard to issues that have been overlooked by existing principles (O'Doherty and Burgess 2009). This process of deliberation may not provide a universal truth, but proposes explanations of the relationships between principles and experience that are observed (Frith 2012). Unanimity is not a necessary outcome of deliberation (Gouinlock 2002; O'Doherty and Burgess 2009), "but the effort can be made to construct a solution to the situation which will be as widely acceptable as possible" (Gouinlock 2002). Deliberation is sensitive to different expertise and the relationships between issues such that is seeks to understand the type of ethical tipping points discussed earlier and the negotiated space ("can") between what "is" and what "ought" to be. Solutions that result from deliberation between complementary expertise resemble a treaty more than they represent the victor of a battle of principles and experience.

Efforts are being made in bioethics to deliberate upon contentious issues in hopes of bringing divergent perspectives closer and working toward solutions to ethical problems in research and medicine using different methods. Participatory research has been one approach toward engaging members of stakeholder groups and the general public in ethics deliberation (Secko et al. 2008; O'Doherty and Burgess 2009). Within academia, workshops have been employed as a method to create a venue for deliberation. Several examples exist within neuroethics addressing topics ranging from deep brain stimulation to neuroimaging (Kimmelman et al. 2009; Racine et al. 2011; Vincent et al. 2011; Wardlaw and Schafer 2011; Schlaepfer 2012). In fact, one of the seminal papers on cognitive enhancement was the product of this type of work group (Farah et al. 2004). Other, non-academic stakeholders (e.g., professionals, patients and members of the public) can also expand the scope of expertise that

contribute to deliberation. However, the challenge remains in bringing the non-academic expertise into these deliberative activities as an equal contributor instead of being reflected through data gathered from stakeholders and interpreted by ethicists. Deliverables of a workshop typically include recommendations for research, practice and policy. An important point to note is that the goal of a workshop need not be to prescribe a course of action that will do away with all the ethical conflict. The contribution of workshops can be more incremental in the spirit of the hypotheses Dewey suggests can be formed from ethical principles. Workshops can produce a recommendations and guidelines that impact practice (consummatory) just as they can suggest courses for added normative and empirical inquiry (hypothesis generating).

The literature review in Chapters 1 and 2 demonstrated a lack of evidence to fully support efficacy or refute safety yet expectations related to the use of existing medications by healthy individuals for cognitive enhancement persist in academic and lay circles. This tension has been responded to by calling for efficacy research on the enhancement uses of these medications. The manuscript in Appendix A is the result of an application of a deliberative method to clarify the ethical justification and responsibilities for oversight of cognitive enhancement research as well as the role of evidence in the ethics debate. During an interdisciplinary workshop, ten academics interested in the ethics of cognitive enhancement reflected on the possible upstream and downstream implications of cognitive enhancement research. This workshop initially set out to explore the ethical profiles of possible approaches to permit or prevent (or neither) cognitive enhancement research (See Table A.1 in Appendix A). Exploring these options created the opportunity to review and consider current evidence for safety and efficacy of existing medications used as cognitive enhancers together with the theoretical reflections and empirical data available in the ethics debate. Deliberation about what the three ethical profiles consisted of brought the group to

recognize three important points in the current ethics debate around cognitive enhancement that housed scientific and ethical assumptions, and implicit values underlying different approaches to research. These are (1) the relationship between demand and prevalence, (2) the responsibility of stakeholders, and (3) the social outcomes of cognitive enhancement research. The group decided not to support a particular stance toward cognitive enhancement research but opted to put forward a reflection about what different stances would mean for research and society. In addition, the three aforementioned points represent avenues for future normative and empirical inquiry that need to be explored in order to continue considering the ethics of cognitive enhancement research.

As a field, bioethics has the potential to foster deliberation that can tune dissonance between empirical and normative ethics perspectives. Just as it can help choose an ethical stance that follows established normative principles, bioethics can be a venue of discovery, negotiation and compromise. The debate in the ethics of cognitive enhancement, especially, needs the field of bioethics to fulfill this deliberative role. Data on stakeholder perspectives has shown that groups of students, healthcare professionals and members of the public are cautious about the ethics of using medications non-medically for enhancement purposes but are not entirely against the practice in all its forms. Some of the major findings presented in the data chapters of this thesis evoke significant challenges in unifying normative and empirical ethics created by divergences in the priority of values, possibility to implement principles, and establishment of moral boundaries. These challenges are obstacles to formulating ethical reflection that can effectively inform policy. However, if these challenges can be surmounted with deliberation the ethical inquiry around cognitive enhancement could be one that reflects the values of both stakeholders and ethicists with clearer moral boundaries that guide action.

CONCLUSION

This thesis comprises research and reflections based on the premise that the non-medical use of prescription medication for the enhancement of cognitive function in healthy individuals is laden with ethical issues of social, professional, medical and scientific relevance. In Chapter 1, prior to examining the range of issues in cognitive enhancement, I reviewed evidence for the efficacy of medications in healthy individuals and the prevalence of the non-medical use of prescription stimulants. These two sets of evidence were shown to provide only weak support for the persistent expectations for individual and social benefit, which impacts one of the major arguments in favour of cognitive enhancement and indicates a potential public health problem. In Chapter 2, I focused on the strong philosophical and social underpinnings of cognitive enhancement. I showed that the normative academic debate around the issues raised by cognitive enhancement exhibits significant blind spots due to diverging definitional approaches and terminology, which shape perceptions of benefits, harms, and the involvement of the medical profession. These ethical blind spots were the impetus for exploring cognitive enhancement from the experiential point of view of key stakeholders. Thus, in the first part of this thesis I put forth a vision of cognitive enhancement that contains multiple normative discourses but little connection to how ethical issues may be confronted in academic and professional environments.

In Chapter 3, I described the focus group study serving as the basis for the qualitative research project I presented in this thesis. The qualitative data in this thesis provide insight into the perspectives of key stakeholders on cognitive enhancement in an effort to enrich the ethics debate. In the results presented in Chapter 4, stakeholders demonstrated marked ambivalence in reactions toward cognitive enhancement in matters of definitions, analogies, safety and media coverage. General moral unrest was identified in stakeholder perspectives and noted to be in stark contrast with the divergent and decisive frameworks of the normative

ethics debate. This finding suggests a significant disconnection between academic and stakeholder perspectives. In Chapter 5, stakeholders reported the existence of a tension between the value of personal choice and the coercive social pressures that might promote the acceptability of the non-medical use of prescription medications for cognitive enhancement. The analysis of stakeholder perspectives in Chapter 6 supported further clarification of the values at the root of different levels of ethical contention. The model in this manuscript that illustrates the interactions between stakeholder values and external factors showed how ethical issues are inextricably linked. In sum, the stakeholder perspectives that I reported in Chapters 4, 5 and 6 have not provided a resounding endorsement for the acceptability of cognitive enhancement, which I suggest reflect a more prudential approach than the expectations for widespread use found in the literature reviewed in Chapter 1. The prudential approach of stakeholders in this qualitative study also supports the recommendation put forward in Chapter 7 to prevent the diversion of healthcare resources toward enhancement despite professional policies and practices that permit the prescription of medications to healthy individuals.

The research and reflections featured in this thesis contribute to neuroethics scholarship by delineating context-specific issues in the ethics of cognitive enhancement. I have demonstrated that, for stakeholders, these context-specific issues are interrelated and are not easily tackled by normative reflection or policy independently of one another. I have also shown the complexity in the relationships between the normative academic debate and the values of stakeholders in an area where what ought to be done does not always represent the range of possible actions.

In light of the complex ethics relationships I present in this thesis, I synthesized empirical and normative perspectives on cognitive enhancement in Chapter 8. I proposed that some novel challenges remain for an ethics debate that would aim to guide individual and policy action on

cognitive enhancement. These challenges included navigating the different values of normative and empirical perspectives, addressing normative-descriptive tensions caused by socio-economic constraints and clarifying the ambivalence caused by trying to adhere to specific ethical frameworks. In order to tackle these challenges, I recommended an approach that renews the deliberative role of bioethics to develop frameworks reflecting stakeholder values and normative priorities.

There is an overarching question that future reflection and research can begin addressing following the contribution of this thesis. Better understanding the efficacy of putative cognitive enhancers and the motives that drive their use as explained in Chapter 1 is a necessary step to inform some of the ethics questions but remains secondary to the question of: is cognitive enhancement valuable? Some authors warn against the "over-valuation" of enhancement technologies (Rajczi 2008) and are critical of the value they would add to human existence (Tänssjö 2009). Implementation of emerging technologies is not justified solely because they are *possible* (Rose 2005). One component of the answer to the question of value can be provided by gathering and examining the perspectives of individuals and groups that would live with and experience these technologies, as this thesis showed. The face of the ethics debate on cognitive enhancement might change dramatically if it is determined through normative and empirical inquiry that the technology or its use in improving cognitive performance at certain levels is not valuable for individuals or society (Ferrari et al. 2012). The words of Huxley opened this thesis to introduce the idea that the advancement of science affects human individuals, a point that was illustrated through the data presented. As science advances, the development, repurposing, and implementation of technologies can be guided by ethical inquiry that helps understand and manage the effects of technology on individuals and society.

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APPENDIX A: Ethical issues in research on cognitive enhancers for healthy individuals

Ethical issues in research on cognitive enhancers for healthy individuals

EMBO Reports (accepted)

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Abstract

Discussion of the possible widespread use of prescription medications by healthy individuals to augment mental performance (i.e., cognitive enhancement) raises several ethical and scientific questions. Expectations for benefits and concerns about risks linger in academic and public circles despite a lack of evidence for the efficacy and safety of cognitive enhancing medications. Calls have been made to further investigate the effects of these medications in healthy individuals but discussions have been focused mainly on regulatory and practical aspects, leaving open the actual ethical justification and responsibilities for oversight of this research. In this paper, we seek to broaden the discussion by examining the ethical underpinnings of possible stances with respect to cognitive enhancement research and discussing their strengths and weaknesses regarding their possible implications. We identify and discuss three important points that may help uncover scientific and ethical assumptions and implicit values underlying different stances to research on cognitive enhancers. These points are: (1) the nature of "demand" and how it relates to the notion of "prevalence" of use; (2) responsibility of stakeholders in requesting and conducting ethical cognitive enhancement research; and (3) the social outcomes of cognitive enhancement research. Our analysis suggests that adopting a stance on cognitive enhancement research depends upon the ethical priorities of those involved and that better understanding the contextual factors that motivate healthy individuals to use prescription medications could be a precursor to efficacy research.

Keywords: cognitive enhancers, prescription medications, efficacy, neuroethics, research ethics

1. Introduction

In recent years, we have witnessed the emergence of opinions and commentaries calling for greater attention to the possible benefits and risks of so-called "cognitive enhancers" [1]. This latter term usually refers to different technologies generated by neuroscience research that purportedly augment cognitive performance or modulate mood and behaviour in ways that improve performance in otherwise healthy individuals [2]. The discussion on cognitive enhancers has focused on existing pharmaceuticals (e.g., prescription medications) and, to a certain extent, new drugs and technologies which could be developed with the explicit purpose of enhancing cognitive function in the healthy [3]. Interestingly, the terms "cognitive enhancer" and related "cognitive

enhancement" seem to imply that there is good evidence that existing drugs have these effects in healthy individuals and provide clear cut benefits [1, 4, 5]. In fact, recent reviews [6-11] have found insufficient evidence for the efficacy and safety of most cognitive enhancing medications in healthy populations. At the same time, calls for further research have been made on various grounds [12, 13] but in a context where public expectations about cognitive enhancers seem to be continuously shaped by a "melioristic misconception" rather than genuine scientific confirmation of benefit [14, 15]. Critics of cognitive enhancement have argued against further funding and promotion of this research due to multiple ethical concerns [16].

As such, current and future research on cognitive enhancers by healthy individuals raises several ethical and scientific questions. For example, should research be promoted to better understand the efficacy and true benefits, if any, of pharmaceuticals used for cognitive enhancement? Results could confirm the benefits individuals have self-reported or perhaps shed light on side effects that increase the risk of disease spurring a public health problem. Or should another type of research (e.g., public health and epidemiological studies) be carried out mainly with the aim of mitigating risks to public health and actually circumventing such behaviours? Should research be prevented or restricted, given the possible social and healthcare consequences of the potentially rapid uptake of these drugs if research supports their efficacy? The risk of this scenario is that cognitive enhancers would increasingly be traded on a black market should the practice persist. Depending on answers to these questions, research on the efficacy of cognitive enhancers might be actively promoted, restricted or prevented, or left untouched (See Table A.1).

Discussions of the ethics of research on cognitive enhancers in the academic literature [17] have focused on regulatory and practical aspects, leaving the ethical justification and responsibilities for oversight of this

research largely unexamined. Closer examination of questions and implicit ethical assumptions about safety, efficacy and demand [16, 18, 19] could help to ensure that a future stance on cognitive enhancement research is based on clear scientific and ethical justification. In this paper, we seek to broaden the discussion by examining the underpinnings of possible stances with respect to cognitive enhancement research and discussing their strengths and weaknesses with respect to their possible implications. We also identify and discuss three important points that may help uncover scientific and ethical assumptions as well as implicit values underlying different stances with respect to research on cognitive enhancers. This paper does not take a position on the appropriate path to be taken. Its more modest goal is to lay out different stances in a context where the discussion of cognitive enhancement research has not been the object of systematic attention and analysis. Our focus is restricted to pharmacological research on already approved drugs. We acknowledge that current safety data on long term effects of many drugs potentially used as cognitive enhancers is deficient [20] and that safety would also merit further attention.

Table A.1: Rationale, strengths and weaknesses of three stances on research on the efficacy of medications used for cognitive enhancement of healthy individuals.

	Stances on research on the efficacy of medications used as cognitive enhancers		
	Promote research on the efficacy of cognitive enhancers.	**Neither promote nor restrict research on cognitive enhancers.**	**Prevent research on the efficacy of cognitive enhancers.**
Rationale	Expected benefits of cognitive enhancers justify pharmacological research on cognitive enhancement.	Cognitive enhancement is not a serious public health issue and research neither promises to yield benefits nor poses distinct research ethics issues.	Research on cognitive enhancers raises significant ethical and social challenges and should be restricted as a precautionary measure.
*Strengths**	• Allows pursuit of knowledge to discover if medications produce enhancement to dispel speculation about efficacy. • Provides evidence base for decisions about cognitive enhancement in academic, professional, public health and medical contexts.	• Cognitive enhancement research is allowed on case-by-case funding and standard ethics review without change to policies. • Fosters an incremental acceptance or rejection of cognitive enhancement research without the consequences of drastic changes in research policy.	• Curtails discussion of difficult ethical issues by preventing the collection of efficacy data. • Redirects research efforts to more “legitimate” needs in health or patient-oriented research.

*Weaknesses**	• Research to establish efficacy and risks may not have high research priority given more important health needs and lack of support from strong epidemiological data. • Research on cognitive enhancers could inadvertently promote such use by creating a "melioristic misconception" by publishing early results. • Research ethics challenges created by research on the healthy (e.g., equipoise, benefit/risk calculus) must be tackled.	• Case-by-case approach can leave aside the big picture issues created by research on cognitive enhancement (e.g., equipoise, benefit/risk calculus) and social outcomes of research. • Creates regulatory loopholes and variable decisions because of the lack of attention to cognitive enhancement research as a category.	• Prevents research and thus choices and decisions based on evidence. • May over-estimate the ability to curtail the use of cognitive enhancers (e.g., black markets). • May stigmatise therapeutic uses of these drugs. • May foster "disease mongering" if research is reframed as therapeutic or clinical research based on expanded diagnostic categories.

2. Ethical profiles of stances that promote, restrict or remain neutral toward cognitive enhancement research

In the Table A.1, we present three possible stances on cognitive enhancement research. The first stance consists of promoting research, the second of working within the current situation of neither promoting nor restricting cognitive enhancement research, the third attempts to restrict or prohibit cognitive enhancement research. These stances are compared on rationale, strengths and weaknesses to expose and clarify ethical priorities within each stance but not weighed against each other. The Table A.1 also highlights that arguments are not exclusively either a strength or weakness. In some cases, a particular argument is strength for one stance but a weakness for another. Also, the argumentative and qualitative value of strength can sometimes take precedent over a simple weighting of strengths and weaknesses. Therefore, it is important to consider the context and ethical justifications of a stance toward cognitive enhancement research. It is important to note that the stances do not reflect the opinion of a single author or group in the literature, but rather assemble current and possible arguments in cohesive positions for the sake of clarity and discussion. We acknowledge that further discussion can lead to qualifications and nuances leading to other options than the ones we have put forth.

One general caveat about current stances is that the possible outcomes and impacts of promoting or restricting research on the efficacy of cognitive enhancers are largely speculative. Rationales also have embedded assumptions that may color predictions about outcomes and impacts. For example, the stance promoting research takes for granted that having access to more information is value neutral while the opposing stance assumes that any information showing efficacy of cognitive enhancers in healthy individuals will likely lead to change in social practices. Further, a middle stance might assume that there are meaningful methods for studying the enhancement effects of medications

and that current research ethics frameworks are well equipped to review and oversee enhancement research. Nonetheless, each stance demonstrates that the way in which cognitive enhancement research might, or might not, develop leads to considerations beyond gathering data on efficacy.

3. Points to consider about stances on research on cognitive enhancers in healthy individuals

We now discuss three key issues which inform, to different extents, the arguments found in different stances on cognitive enhancement research: (1) the nature of "demand" and how it relates to the notion of "prevalence" of use; (2) responsibility of stakeholders in requesting and conducting ethical cognitive enhancement research; and (3) the social outcomes of cognitive enhancement research. At this time we would like to make a few observations about the current terms of the debate.

First, it is important to recognize that the terms "cognitive enhancement" and "cognitive enhancers" imply the very efficacy that research still needs to confirm or refute. This language could be equivalent to problematic claims of therapeutic efficacy describing unproven and non-validated interventions such as stem cell "therapy" for stem cell injections and gene "therapy" for somatic cell nuclear transfer. Second, the standard definition of cognitive "enhancement" as the opposite of "treatment" is ambiguous [21]. Although intuitively useful, the treatment-enhancement distinction may be better thought of as designating a spectrum rather than mutually exclusive terms. The scope of what is a cognitive enhancement is still a subject of debate, with more expansive classifications of cognitive enhancement technologies encompassing education and computer technologies [1]. Third, given the ambiguity and lack of clarity in vocabulary, it is possible that what cognitive enhancement research consists of will also be unclear. For example, which aspects of cognition (e.g., attention, alertness, memory) are to be enhanced, to what extent and by which means (e.g., pharmaceuticals, devices, software)? Finally,

the term cognitive enhancement lends itself to confusion with existing treatments for impaired individuals (e.g., with depression, schizophrenia or dementia) that are in some cases described as cognitive enhancers and that could also be repurposed into cognitive enhancement for healthy individuals. A similar ambiguity can arise if the “restoration” of cognitive abilities (for example memory in aging) is also considered to be a type of cognitive enhancement [22].

3.1. Prevalence does not equal demand

The different stances summarized in the Table A.1, like the overall debate on cognitive enhancement, have identified high estimates of prevalence of cognitive enhancement as a possible justification to promote or restrict research in this area. Often demand is equated with prevalence [1] but this equation is at best an approximation and, at worst, misleading. First, current prevalence data have been criticized [18, 23] for lack of shared methodology and relying on methods which capture broader uses than only enhancement (e.g., experimentation and recreation) and most often in selected populations (e.g., high school and university students) [24, 25]. Second, the causes underlying the use of cognitive enhancement do not necessarily become demands unless prevalence is seen as revealing motives for using medications in this way and acceptability in academic and professional environments. However, this understanding is problematic since prevalence is a measure of the distribution of a practice like cognitive enhancement and such studies are silent on the greater desire for such drugs. Further, it is problematic to assume that public demand for cognitive enhancers is the same as a demand for research on the efficacy of existing medications as cognitive enhancers.

In spite of this qualification, in the view of some, the justification of demand is linked to the belief that cognitive enhancement is inevitable and likely to become widespread given current prevalence data [1, 3]. Within this perspective, the demand for research is based on at least three major

related, but distinct, rationales: (1) cognitive enhancement research would respond to the prevalence of the non-medical use of medications with efficacy data, (2) it would foster more informed ethical decision-making and regulation based on efficacy data, and (3) it could lead to the development of effective preventative measures if cognitive enhancement proved harmful or ineffective.

The first rationale is grounded in the use of prevalence rates from studies of the use of stimulants on university campuses [26, 27]. Often cited in support of this rationale is a methodologically debatable poll in *Nature* which has been misinterpreted as evidence that the non-medical use of medications for cognitive enhancement is already widespread and a public health concern [1, 28]. Such perception of widespread demand fuels the need for information in order to protect the current and future health of individuals who seek cognitive enhancement. Knowing what the risks and benefits are would support risk assessment in the populations that seek cognitive enhancement [29].

The second rationale stipulates that information on efficacy is needed to promote informed ethical decision making by individuals, organizations and society collectively. The assumption is that such information is required for individuals to exercise genuinely informed consent. Regardless of what findings about efficacy are, research would yield important information for policy and regulation [12]. Long-term effects of the medications used for cognitive enhancement by healthy individuals are already a concern in the guidance issued by the American Academy of Neurology to neurologists who are considering prescribing cognitive enhancers or who are faced with patient demands for cognitive enhancers [30].

The third rationale captures the fear that cognitive enhancement will be widespread and that research is justified to prevent a potential public health issue. Although prevention may appear as an inherently ethical approach, it may lead to premature policy initiatives and also prevent

public debate about what the public wants based on poor understanding of the prevalence of or demand for cognitive enhancement [31]. Collecting data on prevalence of use and separately on demand would therefore be important precursors to researching the efficacy of cognitive enhancers and understanding how data on efficacy could respond to current practices [20].However, estimating demand for cognitive enhancement research is a multi-faceted task involving complex challenges of determining who actually demands cognitive enhancement and why.

3. Ethical responsibilities of stakeholders in research

The research process involves many steps and stakeholders (e.g., funding bodies, researchers and pharmaceutical companies; government and research ethics committees; and clinicians). It is less obvious how the different ethical frameworks of these stakeholders would be integrated to support a specific stance on cognitive enhancement research. Surely, to be ethically justified, cognitive enhancement research must be scientifically meaningful and generate sound results, hopefully in connection with requests for further evidence. Accordingly, research must be planned in a way that clearly and transparently establishes that the study focuses on enhancement, assesses enhancement (quantitatively or qualitatively), and is plausibly linked to a real-world performance.

As long as medications are believed to have some kind of enhancing effect and are only available by prescription, the medical profession will likely have primary responsibility for their use. Studies on the perspectives of physicians show that they do receive some requests for cognitive enhancement and that harms/benefit ratio and justice are major concerns for them [32-34]. Current evidence for the efficacy of enhancers is weak and research is only beginning to shed light on awareness among clinicians and on if (and how) enhancement is discussed in clinical conversations [32]. What constitutes a proper use, in terms of cognitive enhancement, is currently largely within a clinician's

judgment [4]. However, some authors have expressed concern about whether physicians can adequately assess a harm/benefit ratio and maintain their duty to the patient without better evidence and whether medicine is acquiescing too readily to social expectations for enhanced performance [35, 36]. Therefore, research on cognitive enhancement would be useful to clinical practice.

Funding bodies play a role in another aspect of research. Funding decisions are typically made through a combination of open (bottom-up) investigator-initiated competitions where excellence is paramount and through strategic funding and requests for applications (top-down) in specific areas of research identified as priorities. Currently, funding for cognitive enhancement research appears to have been generated through general research funding mechanisms and to our knowledge, few specific funding programs have been developed for enhancement research in this area. In the US, the *Defense Advanced Research Projects Agency of the Department of Defense* (DARPA) established an "augmented cognition" program, which funded research dealing with a range of enhancement technologies, some generating military interest [37]. Within strategic funding, cognitive enhancement research would be competing with other priorities. Some authors condemn "the use of scare resources to carry out this research" [16] but as more is learned about the demand for cognitive enhancement, funding agencies may be more inclined to allocate funds toward it. Also, cognitive enhancement research could be funded because it promises to increase economic prosperity in aging developed nations with struggling economies to augment their "mental wealth" [38]. This more societal perspective could eventually conflict with primary responsibilities of clinicians to their patients.

The design of protocols exploring enhancement is the responsibility of researchers in both the private and public sectors. The intents of cognitive enhancement research should be clearly stated so that cognitive enhancement research is not covered as the control arm or the preliminary

phase of a clinical study. Clearly stating the rationale for cognitive enhancement research, objectives and motivations would ensure a proper review of the quality of the scientific goals and their ethical and funding merits. Pharmaceutical companies could also have a role in initiating and funding cognitive enhancement research. However, the motivations of privately funded research are complex and subject to criticism, especially if their intentions can be characterised by critiques as “disease-mongering” [39]. Also, such activity could conflict with responsibilities of healthcare systems to prioritise patients who clearly need treatment.

Another stakeholder is ethics review and mechanisms which ensure ethical oversight. It is unclear how well current informal and formal oversight of research protocols and publication examine the ethical and scientific value of research generally. Research ethics committees that attend to the scientific and ethical validity of protocols as well as regulatory bodies (e.g. Federal Drug Administration, Health Canada) that approve substances would potentially be partly responsible for this assessment. However, current research and regulatory guidelines do not provide specific guidance on enhancement research or non-medical uses of medication more generally. For example, the recent report of the Presidential Commission for the Study of Biomedical Issues [40] provides limited insights on how to deal with enhancement research in the USA. In Canada, the recently revised research ethics guidelines, the Tri-Council Policy Statement, does not discuss this scenario [41]. The scientific value of cognitive enhancement research could be more clearly overseen and regulated if thresholds for efficacy were established as was illustrated by meta-analyses on anti-depressant clinical trials [42]. The comments in this section highlight how different goals and responsibilities of stakeholders could generate important conflicts and dilemmas with respect to enhancement research.

3.3. Awareness of the social values and outcomes of cognitive enhancement research

The stances summarized in the Table A.1 differ with respect to the social outcomes of cognitive enhancement research. Improved knowledge about the efficacy of cognitive enhancement may be considered value-neutral because it potentially informs positions both in favour and against the use of cognitive enhancement. But, research findings can also be selectively used to support or oppose cognitive enhancement. So far, there has been a loose relationship between evidence and claims made about cognitive enhancement in the peer-reviewed literature [23, 43, 44]. The knowledge sought and generated can also have consequences for science, regulation and social practices. It is important to ask not only *what* type of research should be done but also understand *why* it is justified (or not) from a broader social standpoint.

Benefits to society have often been cited in favour of cognitive enhancement [5, 45]. This argument takes for granted that cognitive enhancement studies will necessarily unveil beneficial effects even though harms are also a possible finding, given experience with therapeutic pharmaceutical drugs. Furthermore, precisely what is meant by social benefits (or social harms) is often unclear. Some claim that increased productivity and intelligence are likely social benefits of cognitive enhancement. In this view, cognitive benefits to individuals will also benefit society at large by making them more productive [46, 47]. On the contrary, changes in productivity may be considered a significant social harm, especially given the potential for abuse in an international context [8, 19]. The effects of cognitive enhancers on individual productivity and intelligence have yet to be demonstrated, much less the contribution that enhanced individuals make to improving overall social well-being.

If we are to promote, prohibit or remain rather neutral toward cognitive enhancement research based, at least in part, on its social benefits or harms, we must be able to evaluate what this may mean

beyond “having a better life” [48]. How may improved concentration translate into social benefits? Who and how (i.e., peer committees, regulatory agencies) might the social benefits and drawbacks of cognitive enhancement be assessed? A recent review of national and international research ethics guidelines revealed contradictory views on whether and how social outcomes and consequences of research are considered within or outside the purview of conventional research ethics [49]. For example, the International Conference on Harmonisation, Good Clinical Practice states that “The IRB [Institutional Review Board] should not consider possible long-range effects of applying knowledge gained in the research (for example, the possible effects of the research on public policy) as among those research risks that fall within the purview of its responsibility.” The Declaration of Helsinki, by contrast, suggests that before research begins, there should be an assessment of “foreseeable benefits to the subject or to others.”

Very different options have been proposed to capture the ethical assessment of the social outcomes of research: expanding the research ethics mandate, resisting expanding the research ethics mandate and adopting the status quo, and opting for new alternative peer and community review strategies [49]. In traditional healthcare, quality adjusted life years (QALYs) and disability adjusted life years (DALYs), are used to measure the impact of treatments on years of quality life. Could equivalent measures be developed for enhancement research? These challenges in assessing the social benefit or harm of cognitive enhancement research should be acknowledged. Current mechanisms for oversight are not clearly oriented to capture and address possible future social outcomes of research. One approach that may help gauge and even contribute to overseeing the social aspects of cognitive enhancement is to involve stakeholders in deliberations about the most appropriate approach to social outcomes of cognitive enhancement research [50]. A more modest proposal, given difficulties in predicting long term social outcomes, might

lie in *monitoring* these consequences through different measures and approaches such as ongoing surveillance of prevalence, adverse social effects, and motivations of cognitive enhancement users.

4. Conclusion

In this discussion paper on the ethics of cognitive enhancement research, we have conveyed the reflections of a group of interdisciplinary scholars with various backgrounds. Our goal was to characterize and analyse from an ethics standpoint, the different stances toward research on cognitive enhancement in a context where the debate is opening to this question. Although we do not intend, at this stage, to recommend a specific stance, we did feel as a group that restricting research was likely to be difficult given the compelling need for better prevalence data and safety and efficacy data. Perhaps a higher strategic priority should be given to research that establishes prevalence and aims to understand better the motivations for use rather than to undertake research on efficacy. Regardless of the stance adopted, an explicit and transparent acknowledgment of the goals of cognitive enhancement research should be communicated throughout the research process. We hope our contribution brings greater awareness of the choices available to the scientific community and emphasises the need for a culturally-sensitive international discussion about the direction of cognitive enhancement research that is representative of the best scientific methods and takes due account of pluralist public perspectives.

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Appendix B: Research approval letters and advertisements

IRCM
Institut de recherches cliniques de Montréal

la formation et la recherche pour la vie

Le 19 juin 2007

Comité d'éthique de la recherche

Cher Docteur Racine,

Le comité d'éthique de l'IRCM a approuvé votre projet intitulé "**Examining stakeholder perspectives and public understanding of the ethical and social issues of cognitive enhancement using methylphenidate** ", daté du **19 avril 2007**. Vous trouverez ci-joint le document attestant de cette approbation

Numéro d'approbation : **2007-05**. Vous devez identifier toute correspondance ou document pertinent à ce projet par ce numéro.

Date d'approbation : **19 juin 2007**

Date d'expiration de l'approbation : **19 juin 2008**

Rapport au comité d'éthique dû : **mai 2008** ou à la fin du projet, si le projet se termine avant.

Le comité d'éthique désire vous rappeler que l'investigateur a la responsabilité de :

- Transmettre au comité d'éthique de chaque institution où se déroule ce projet le protocole de recherche et le formulaire de consentement du projet tel qu'approuvé par votre comité d'éthique ainsi que le document attestant de cette approbation

- Informer promptement le comité d'éthique de tout changement au protocole et/ou au formulaire de consentement en cours d'exécution du protocole, de tout événement intercurrent sérieux survenu au cours du protocole et de toute information ou résultat susceptible de modifier l'évaluation des risques et des bénéfices pour les sujets qui participent à la recherche et leur consentement à y participer

- Demander au comité d'éthique la réapprobation du projet un mois avant la date d'échéance de la présente approbation s'il y a lieu, en fournissant au comité d'éthique un rapport intérimaire sur le travail effectué dans le cadre de ce projet. À défaut de recevoir une telle demande de votre part, la présente approbation deviendra automatiquement caduque à la date d'expiration indiquée ci-haut.

N'hésitez pas à contacter le secrétariat du comité d'éthique au 987-5742 ou au 987-5636 si vous désirez de plus amples informations à ce sujet.

Veuillez agréer, cher Docteur, l'expression de mes salutations distinguées.

Madeleine Roy

Madeleine Roy M.D., M.Sc.
Secrétaire
Comité d'éthique

110, avenue des Pins Ouest, Montréal (Québec) Canada H2W 1R7

Téléphone : (514) 987-5[illegible]
Télécopieur : (514) 987-5[illegible]
Courriel : isabelle.blais@ircm.q

McGill

Faculty of Medicine
3655 Promenade Sir William Osler
Montreal, QC H3G 1Y6

Faculté de médecine
3655, Promenade Sir William Osler
Montréal, QC, H3G 1Y6

Fax/Télécopieur: (514) 398-3595

February 5, 2008
REVISED: March 26, 2008

Dr. Roberta Palmour
McGill University
Department of Psychiatry
1033 Pine Avenue - #410
Montreal, Quebec H3A 2A7

Dear Dr. Palmour:

We have received the request for review by the Institutional Review Board, Faculty of Medicine of the research proposal entitled "Examining Stakeholder Perspectives and Public Understanding of the Ethical and Social Issues of Cognitive Enhancement Using Methylphenidate", submitted on behalf of Eric Racine.

As this study involves no more than minimal risk and in accordance with Article 1.6 of the Canadian Tri-Council Policy Statement of Ethical Conduct for Research Involving Humans and U.S. Title 45 CFR 46, Section 110 (b), paragraph (1), we are pleased to inform you that approval for the study and study instruments (January 2008) and consent forms (1/10/2008) was provided via an expedited review by the Co-Chair on February 5, 2008 valid until **February 2008**. The study proposal will be presented for corroborative approval at the next meeting of the Committee and a certification document will be issued to you at that time.

A review of all research involving human subjects is required on an annual basis in accord with the date of initial approval. The annual review should be submitted at least one month before **February 2009**. Should any modification to the study occur over the next twelve months, please advise IRB appropriately.

In addition to the continuing review requirements, the investigator is responsible for ensuring that all documents approved by this IRB meet the standards in force at the institution where subject recruitment occurs and/or where study data is collected. The investigator must contact the individual Research Ethics Boards or Research Ethics Offices in order to fulfill this obligation.

Sincerely,

Lawrence Hutchison, M.D.
Co-Chair
Institutional Review Board

cc: Eric Racine – IRCM
Lyse Bourgon – DH
Sheldon Levy – MUHC: MCI/MGH/MNI/RVH
A02-E02-08A

PARTICIPANTS RECHERCHÉS
POUR UNE ÉTUDE SUR L'ÉTHIQUE ET L'UTILISATION DES MÉDICAMENTS SUR PRESCRIPTION

L'Unité de recherche en neuroéthique de l'Institut de recherches cliniques de Montréal cherche des :
- étudiants universitaires de 25 ans et moins
- parents d'étudiants universitaires
- professionnels de la santé

pour participer à une étude.

La discussion se déroulera en anglais et portera sur l'éthique et l'utilisation des médicaments sur prescription.

La participation inclut :
- lecture de 4-5 courts articles de journaux
- réponse à un court questionnaire
- participation à une discussion en groupe

40 ans 1967-2007

IRCM
Institut de recherches cliniques de Montréal
la formation et la recherche pour la vie

cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 poste 3356

The Neuroethics Research Unit of the Institut de recherches cliniques de Montréal is looking for:

- university students under the age of 25
- parents of university students
- healthcare providers

to participate in a research study.

The discussion will be held in English and is about ethics and the use of prescription drugs.

Participation involves:

- Reading 4-5 brief newspaper articles
- Answering a short questionnaire
- Partaking in a group discussion

40 years 1967–2007

IRCM
Institut de recherches cliniques de Montréal

Training and Research for life

cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356	cynthia.forlini@ircm.qc.ca 514-987-5500 ext. 3356

Newspaper advertisements

Healthcare providers needed for research study on ethics and prescription drugs

The Neuroethics Research Unit is seeking healthcare providers (e.g., nurses, doctors, pharmacists, psychologists, nutritionists, and others) to give input on the ethics of prescription medication misuse by students. No particular expertise required. Participation involves reading 4 brief newspaper articles, completing a short questionnaire and attending a 90 minute audio-taped discussion. Participants will be compensated $50 for their time.. Please contact Cynthia Forlini Cynthia.forlini@ircm.qc.ca or (514) 987-5500 ext 3356.

Parents of university students invited to take part in discussion groups

The Neuroethics Research Unit is seeking parents of university students to take part in an ethics discussion about the consumption of prescription drugs by university students. Participation involves reading 4 brief newspaper articles, completing a short questionnaire and attending a 90 minute audio-taped discussion. Participants will be compensated $50 for their time..Please contact Cynthia Forlini Cynthia.forlini@ircm.qc.ca or (514) 987-5500 ext 3356.

Healthcare providers needed for ethics discussion on prescription drug use. $50 compensation. Cynthia.forlini@ircm.qc.ca or (514) 987-5500 ext 3356.

Parents of university students sought for ethics discussion about prescription drug use. $50 compensation.

Cynthia.forlini@ircm.qc.ca or (514) 987-5500 ext 3356.

APPENDIX C: Materials received by focus group participants

Cover letter

Dear Participant,

Thank you for agreeing to participate in our focus group. This package contains the materials and procedure you need to prepare for the focus groups.

Step 1: Read the consent form. If you have any questions about this document do not hesitate to contact us. Do not forget to bring the form to the focus group. It must be signed on site.

Step 2: Enclosed are 4 newspaper articles from Canada, the U.S. and U.K. about a common subject. These articles are:

1. Article 1: “Abuse hits students looking for an exam kick”.
2. Article 2: “The difference between steroids and Ritalin is…”.
3. Article 3: “Students turn to smart drugs for exam help”.
4. Article 4: “More students abusing Ritalin as study aid”.

Please make sure that you have all the articles on the list. Reading of these articles prior the focus groups is mandatory.

Step 3: Once you have read the articles please fill out the pre-identified questionnaire. Put the completed questionnaire into the envelope included in this package. Do not put the consent form in the envelope. The sealed envelope is to be handed in upon your arrival to the focus group.

The two hour discussion will be held at the Institut de Recherches cliniques de Montréal (see map) on Thursday May 1st, 2008 at 18h00.

If you are missing any of the documents, have a question or wish to withdraw from the study please contact us.

Kind regards,

Cynthia Forlini
Master’s student, Neuroethics Research Unit
Institut de recherches cliniques de Montréal
110, avenue des Pins Ouest
Montréal, Qc H2W 1R7
(514) 987-5500 ext: 3356

IRCM
Institut de recherches cliniques de Montréal

La formation et la recherche ... la vie

Consent form

TITLE: Examining stakeholder perspectives and public understanding of the ethical and social issues of cognitive enhancement (CE) using methylphenidate

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

CO-INVESTIGATORS AND COLLABORATORS: Cynthia Forlini, M.A. student, IRCM; David Bouvier, Neuroethics intern and PhD student, IRCM, Nicole Palmour, MSc, Research Coordinator, IRCM.

DESCRIPTION: You are invited to participate in a research study to explore public understanding of ethical issues related to non-medical use of methylphenidate. We are interested in your views about the legitimacy of healthy people using methylphenidate (Ritalin). Your insight will help us understand the gap between popular press coverage and respective academic literature on this subject. We feel that is information will be crucial in addressing practical ethical challenges related to non-medical use of prescription drugs.

CONFIDENTIALITY: Your identity will be kept as confidential as possible, as required by law. Your identity and the information you provide will remain entirely confidential through an alphanumeric coding system that we have developed and that will be available to the investigators. Information about the coding system will be kept in a secure location and access limited to research study personnel. Only the investigators and their research personnel will have access to the study data. The original data will be kept in a locked filing cabinet. Data analysis will be performed on a password-protected computer. All research data will be destroyed after completion of study. Your individual privacy will be maintained in all published and written data resulting from the study. Although we will make every effort to protect the confidentiality of your personal data and will avoid identifying participants, breaches of confidentiality are possible.

RISKS AND BENEFITS: There are no known risks or benefits to you associated with participation in this study other than the breach of confidentiality. We will offer you 50$ if you complete the interview and questionnaires. Updates on the project will be available on our website: http://www.ircm.qc.ca/neuroethics/en/.

TIME INVOLVEMENT: The filmed focus group session will take approximately two hours. You will be asked to read 9 articles on non-medical use of methylphenidate from popular press sources prior to the focus groups. These articles will serve as the basis of a group discussion on ethical, social and legal aspects of non-medical use of prescription drugs. You will also be asked to complete a questionnaire after having read the articles.

110, avenue des Pins Ouest, Montréal (Québec) Canada H2W 1R7
Téléphone : (514) 987-5500
Télécopieur : (514) 987-5878
Site Web : http://www.ircm.qc.ca

FUNDING: Fonds de la recherche en santé du Québec; Institut de recherches cliniques de Montreal

SUBJECT'S RIGHTS: If you have read this form and have decided to participate in this project, please understand that your participation is voluntary. You have the right to refuse to answer particular questions. If you first agree to participate and then you change your mind, you are free to withdraw your consent and discontinue your participation at any time. Please inform the principal investigator if you wish to withdraw from the study.

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

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

You do not waive any liability rights for personal injury by signing this form. For further information, please call or write to the IRCM research ethics board, Dr. Madeleine Roy at (514) 987-5742.

In addition, if you are not satisfied with the manner in which this study is being conducted or if you have any questions concerning your rights as a research study subject, please contact the IRCM's Research Ethics Board at the same address and telephone number.

The parties acknowledge that they have agreed that this consent form be drafted in the English language.

Les parties reconnaissent avoir convenu que ce consentement soit rédigé en anglais.

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

_____ _____

Signature of Subject Date

*Person Obtaining Consent

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

_____ _____

Signature of Person Obtaining Consent Date

REB Approval Date: REB Expiration Date

Version 6/19/2007

Article 1: “Ritalin Abuse Hits Students Looking for an Exam Kick”

A NEW kind of drug abuse is sweeping university campuses in North America and is expected to come to Britain. Faced with the pressure of exams and essay deadlines, students are abandoning the traditional stimulants of coffee and cigarettes for Ritalin.

Unlike their parents who "blew their minds" on recreational drugs in the Sixties and Seventies, today's American students are using chemical substances in pursuit of peak performance.

Ritalin is a stimulant drug, best known as a treatment for hyperactive children. It has found a ready black market among students who are desperate to succeed. Users say it helps them to focus and concentrate.

In Britain, drug agencies say anecdotal reports suggest abuse of the drug is just beginning and British campuses should be prepared. The traditional crutches of coffee, Pro-Plus caffeine pills and cans of Red Bull are being ditched in favour of the new chemical aid.

The Ritalin craze has sparked a debate on the ethics of using drugs for cognitive enhancement. Some experts say students who use Ritalin are doping with "brain steroids" and gaining an unfair advantage. But the students say it is no more unfair than hiring a private tutor or paying for exam coaching.

"These drugs are study tools," one said. The trend has caused alarm on campuses across America, Canada and Australia. A study at the University of Wisconsin suggested as many as one in five students had tried Ritalin or the similar drug Adderall. At the University of Miami, posters around campus warn against the new type of drug abuse.

At McGill University in Montreal, Pierre Paul Tellier, director of health services, said: "We can't quantify it but our impression is that it is being abused just like anywhere else."

David Green, a student at the University of Harvard, told The Washington Post: "In all honesty, I haven't written a paper without Ritalin since my junior year in high school."

Matt, 19, a business finance student at the University of Florida, claimed Adderall had helped him improve his grades. "It's a miracle drug," he told The Boston Globe. "It is unbelievable how my concentration boosts when I use Adderall."

The search for a short cut in learning has worried teachers. But doctors have confirmed the potential benefits of the drugs, unwittingly encouraging the trend.

Eric Heiligenstein, director of clinical psychiatry at the University of Wisconsin, said: "Caffeine is fine. This is better. Students are able to accumulate more information in a shorter time. They minimise fatigue and help maintain a high

performance level."

Some students have reported Ritalin parties where the drug is crushed to a powder and snorted, giving the user an amphetamine-like boost. But in most cases it has been used to help students stay awake during last-minute cramming sessions or while writing essays.

The black market has spread to Australia, where the National Drug and Alcohol Research Centre has reported that single Ritalin tablets are being sold for between AS$ 1 and AS$ 20. The Royal Australian College of GPs said: "Students are using this to keep awake ... There is no question it is being diverted. The kids are selling. It's been happening more in the last couple of months."

The trade is being fuelled by the prescribing of the drug to children diagnosed with attention deficit hyperactive disorder (ADHD). Research has shown that in some American schools up to a third of boys are on Ritalin even though many of them do not have ADHD. Wealthier parents are choosing to give the drug to their well behaved but underachieving children to enhance their performance. What is good for the children, some students are concluding, must be good for them too.

At a conference in New York in June on the ethics of cognitive enhancement, delegates suggested that students in the future may have to be dope-tested and asked to hand in a urine sample with their exam paper to prove their results were down to hard work and not pharmacology.

Martha Farah, of the University of Pennsylvania's Centre of Cognitive Neuroscience, who co-chaired the conference, told The Lancet: "In my classes, everyone knows someone who is using or selling (Ritalin) and I hasten to add that this is not unique to Penn. Research shows it is nationwide." A study of 2,200 students at an unnamed university in North America, published in Pharmacotherapy earlier this year, found 66 of them (3 per cent) admitted abusing Ritalin in the previous year. "Illicit use of prescription-only stimulants on college campuses is a potentially serious public health issue," it said.

Ritalin, the brand name for methylphenidate hydrochloride, was introduced in 1956 and appears to influence the way the brain filters and responds to stimuli. It increases energy as well as confidence and has been compared to cocaine. Possible side-effects are typical of stimulants and include, insomnia, loss of appetite, dizziness, and depression on withdrawal.

A spokeswoman for the British drug charity Drugscope said: "Ritalin abuse does seem to be becoming more common but we are not aware of its use in universities."

FIVE WAYS TO STAY AWAKE
RITALIN
The drug of choice for the hyperactive child, and now for the under-active student. The huge increase in (legitimate) prescribing to children in the US in recent years - more than eight million are said to be on the drug - means it is readily available on the black market. Users say it helps them focus and aids

concentration.

STRONG COFFEE
The first resort of generations of bleary-eyed students. Packs a punch proportional to the strength of the brew but an average cup of filter coffee contains 100mgs of caffeine. Some research suggests that long-term coffee drinking may increase heart disease, but that it is not linked with the caffeine it contains.

PRO-PLUS PILLS
The truly instant coffee. Each pill contains 50mgs of caffeine. The instructions say take one or two with water, no more than two in any hour or 12 tablets in 24 hours. But students tend to ignore instructions. Last year, a chemistry undergraduate at Cardiff University consumed four cartons of Pro-plus (384 pills) and died.

SPEED
Amphetamines are among the most effective medicinal stimulants and have for decades occupied a place in the drugs lexicon, mostly for clubbers who want the energy to dance all night. But they have a big downside - the unpleasant side-effects which include anxiety, restlessness, headache, palpitations and insomnia.

RED BULL
....and similar caffeine laden energy drinks have increasingly substituted for coffee among the young. One survey suggested more than half of under 24s had tried them. Red Bull contains 80 mgs of caffeine in an 8 fl oz can, compared with 35 mgs of caffeine in a standard 12 oz can of Coke. Hence the kick...

Article 2: “The Difference Between Steroids and Ritalin is...”

At the Congressional hearings last week investigating steroids and baseball, players were scolded not just for taking substances that are unsafe, but for doing something immoral. Those who use performance enhancing substances were called cheaters, cowards, bad examples for the nation's children.

But if baseball players are cheating, is everyone else, too?

After all, Americans are relying more and more on a growing array of performance enhancing drugs. Lawyers take the anti-sleep drug Provigil to finish that all-night brief, in hopes of concentrating better. Classical musicians take beta blockers, which banish jitters, before a big recital.Is the student who swallows a Ritalin before taking the SAT unethical if the pill gives her an unfair advantage over other students? If a golfer pops a beta blocker before a tournament, is he eliminating a crucial part of competition -- battling nerves and a chance of choking?

Beyond baseball and steroids, where do you draw the line on the use of performance-enhancing drugs? President Bush said in his 2004 State of the Union speech that steroid use in baseball "sends the wrong message: that there are shortcuts to accomplishment, and that performance is more important than character."

That is easy to say about steroids. After all, the mystique of the major leagues requires that home run records be set without the help of artificial enhancements. And major league players have some responsibility not to encourage teenagers to use a harmful substance.

When it comes to other drugs, and other kinds of endeavors, the lines aren't so clear. Bioethicists, who don't even all agree about whether taking steroids is wrong, are even less clear about everything else.

Some say the use of performance-enhanced drugs simply reflects progress -- better living through chemistry -- and to be human is to strive to be better.

"We've gotten very used to already assisting ourselves in other ways," said Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania. "No one's going to say, 'Don't drink coffee before the SAT.' No one's going to say, 'Don't smoke cigarettes before the SAT.' And most of the drugs we're talking about are far less harmful than nicotine."

But others lament that a performance-enhanced society is giving in to a culture that prizes the achievement over the journey. Many Americans already get that message from a young age, said Denise Clark Pope, author of "Doing School: How We Are Creating a Generation of Stressed Out, Materialistic and Miseducated Students."

When surveys ask students which is more important, to be honorable and get a low grade or to cheat and get a high grade, she said, more students choose the

A. "The parents will say 'no, no, no,' but the message they're sending says the opposite."

The use of performance enhancing drugs reflects a society where stress and striving have become the national pastime. Ms. Pope calls it the "credentialism society," exemplified in her book through a high school student who describes life as a quest to get the best grades, so you can get into the best college, so you can get into the best graduate school, so you can get the highest-paying job, which brings you happiness.

So where people once took illegal drugs like cocaine to escape or stimulate creativity, they now take legal drugs to focus better and achieve more.

The danger in that, said Carl Elliott, the author of "Better than Well: American Medicine Meets the American Dream," is that not performing well will be seen as a medical condition -- one that needs to be treated.

"The lines between treating an illness and enhancing a performance are so blurry," said Dr. Elliott, an associate professor at the center for bioethics at the University of Minnesota. "Most people don't conceptualize it as performance enhancement; most people conceptualize it as a treatment for an illness."

But others think there's no problem. Norman Fost, the director of the medical ethics program at the University of Wisconsin who has long said that the danger of steroids are overstated, similarly sees nothing wrong with taking drugs like Ritalin or Provigil solely to enhance performance.

"We all would like to do better at what we're doing, whether athletic or intellectual or musical," he said. "There's nothing inherently immoral about performance enhancement. It's what everyone does, or would try to do, for their children. We shouldn't be obsessed with the fact that it's a drug, as if it's a drug like cocaine or heroin."

Dr. Caplan mocks the handwringing over self-enhancement drugs. To him, it is all technology: "The lawyer who's taking a pill to stay up is also carrying a computer or P.D.A. to help his brain remember things. Are we going to throw away our calculators?"

Certainly, there is no guarantee that performance enhancement delivers happiness.

As Ms. Pope notes, at the same time stimulants like Ritalin are becoming more popular among high school students, college campuses are reporting a new drug of choice. It used to be marijuana. Now it's Prozac.

Article 3: “Students Turn to Smart Drugs for Exam Help”

STUDENTS preparing for end-of-term exams are using a new generation of "smart drugs" such as Ritalin, which can boost brain activity and keep healthy adults awake for more than 36 hours at a time.

Experts have told The Scotsman that the use of such medication by young people - commonplace in the United States - is becoming an increasing cause for concern in Scotland.

The smart drugs, also known as nootropics, include a range of powerful prescription medications. But they can also be bought over the internet - about GBP 8 for a month's supply - without a prescription.

The top three drugs are methylphenidate, marketed as Ritalin and prescribed for children as a treatment for attention deficit disorder (ADHD); Donepezil, used to help Alzheimer's, and Modafinil, used for chronic sleeping problems such as narcolepsy.

Experts say that the potential market for cognitive enhancers is huge, appealing to a range of people including professionals under pressure to perform in the workplace and shift workers wanting to control sleeping patterns, as well as students under pressure to do well in exams.

A survey of 119 colleges last year by the American College Health Association found on certain campuses that up to 25 per cent of respondents had misused ADHD medication.

A number of clinical studies have shown that such smart drugs can produce significant mental gains in normal, healthy subjects.

Donepezil has been found to boost the brain function of healthy people by increasing the concentration of a neurotransmitter called acetylcholine, boosting the power of certain electrical transmissions between brain cells.

But neuroscientists warn that the long-term effects on healthy people are difficult to predict. Over time, they might cause people to remember too much detail, cluttering the brain and making it difficult to shift attention to a new task.

Short-term effects can range from nausea and irritability to heart attacks in extreme cases.

Professor Neil McKeganey, from the centre for drug misuse research at the University of Glasgow, said: "The growing use of nootropics, or smart drugs, is a problem which people in the arena of drug usage are becoming increasingly concerned about.

"There is a growing perception among groups such as students that these drugs, which were developed for the clinical population, can be used to improve task performance and for exams."

John Arthur, manager of Crew 2000, the Edinburgh-based drug advice group, said his organisation and sister agencies across Europe had become aware of the trend for taking smart drugs, especially among students.

He said: "I think part of the reason for them taking these drugs is the pressure on them to succeed."

A spokesman from the Medicines and Healthcare Products Regulatory Authority warned against people taking prescription-only drugs unless prescribed by a GP.

Article 4: “More Students Abusing Ritalin as Study Aid”

When Valerie needed a boost during her final exams at Concordia University, she didn't brew a pot of strong coffee or open a can of the energy drink Red Bull. Instead, she popped a powerful little pill.
"It helped me focus for eight hours straight," said Valerie, who spoke on the condition that her real name not be used.

"I didn't even notice time go by. I didn't eat, I didn't sleep, I didn't even move. It really organized the thoughts in my head so I could retain all of the information I was studying."

The drug the Concordia graduate relied on to get through five mid-terms in one week is Ritalin - known in the medical world as methylphenidate - and is commonly used to treat people with attention deficit hyperactivity disorder. The drug, which stimulates parts of the brain by increasing dopamine and noradrenaline activity, goes by several aliases like R-Ball, Vitamin R, and Smarties, and is increasingly used as a study aid among stressed out university students.

Jeffrey Levitt, Concordia's co-ordinator of clinical training and supervision, says Ritalin is abused by about five to 10 per cent of Concordia and McGill University students.

According to the Partnership for a Drug-Free America, in the past year, 10 per cent of young people in the United States have misused Ritalin or its sister drug, Adderall, which was recently banned in Canada after being linked to 20 sudden deaths. A 2002 University of Wisconsin survey revealed that one in five college students take the stimulants.

Concordia's health services educator, Owen Moran, believes these numbers are on the rise.

"There has definitely been a surge in use among students in the past couple of years," Moran said. "This certainly wasn't a problem 10 years go." He added that Ritalin misuse has become more prevalent because students have easy access to the drug.

"It's really not that hard to get hold of," he said. "Some doctors are more likely to prescribe Ritalin, and people will tell their friends. They go doctor shopping. Once they have their prescription, many people will keep half their pills and sell the rest."

For Valerie, it was as simple as asking her best friend, who has ADHD, for one of her pills.

But is it safe to take Ritalin without a prescription? And does the drug - which some students crush into powder and snort in order to increase the amphetamine-like effects - even help students to perform better?

According to Moran, any drug that is taken without a prescription has the potential to do harm. "Ritalin in particular can cause heart palpitations and keep you from sleeping," he said.

Moran also has some doubts concerning Ritalin's effectiveness as a study aid.

"It's important to keep in mind that Ritalin, like any other medication, doesn't necessarily work for everyone who takes it," he said.

And he has qualms about the use of stimulants in general.

"Seeing students coming in and asking for Ritalin prescriptions, or even those who take caffeine pills or Red Bull, makes me wonder.

"What kind of stressors do they have to make them turn to these sorts of stimulants?

"Obviously, it's a problem in our society. We think we have to do more to be better, and if this pill will give us an edge, we'll take it."

Valerie says she took Ritalin only once ("as an experiment"), but there are students who really think they need that extra edge, and use the stimulant regularly.

Sean Toomey, who did not want to name the Quebec university he attends for fear of tarnishing its reputation, says that many of his peers rely on the pill to stay focused in school.

"I've never done it personally," said Toomey, who's majoring in business. "It goes against my drug policy. But I've noticed that it's surprisingly common, even among people who you'd think would never indulge in such practices."

Toomey said some students have leftover Ritalin prescriptions from high school, which results in "a somewhat lucrative underground trade" that peaks around mid-terms and final exams, when these students sell pills to friends for about $ 5 each.

It's alarming that Ritalin - a drug most people probably associate with hyperactive children at summer camp - is being illicitly used and sold by university students, Toomey said, adding that some of his peers swear by it.

"People say that it makes them think more rationally, and they can sit down and study for seven or eight hours straight, which is especially crucial for repetitive subjects, like history," he said.

Levitt says Ritalin misuse is linked to society's obsession with band-aid solutions. "I think students are more desperate these days. There's more competition, and kids are looking for a quick fix," he said.

Moran said deep breathing exercises, relaxation, and hot baths are excellent for helping stressed-out students calm down and concentrate. Ritalin does the exact opposite. "It puts your nerves all over the place, and gives you no time for a breather," he said.
"It's just a shame that people aren't coping effectively," Moran said. "Ritalin actually prevents people from coping in a healthier way."

Questionnaire

1. Participant: _____
2. Age: _____
3. Gender
   □ Male
   □ Female

4. Level of Education (completed or in progress):
   □ High School
   □ CEGEP
   □ University
      □ Undergraduate
      □ Master's
      □ PhD
      □ MD

5. Occupation: _____
6. Do you subscribe to a newspaper or magazine:
   □ Yes
      which one(s):
   _____
   □ No

7. Are you interested in reading about popular science?
   □ Yes
   □ No

8. Do you presently have a prescription for Ritalin?
   □ Yes
   □ No

9. Have you ever had a prescription for Ritalin

   □ Yes
   □ No

10. Do you know someone with a prescription for Ritalin?
    □ Yes
    □ No

11. Have you ever tried Ritalin for non-medical uses?
    □ Yes
    □ No

12. Do you know someone who has tried Ritalin for non-medical uses?

    □ Yes
    □ No

13. Had you ever read/heard about Ritalin used for non-medical purposes before participating in this project?

    □ Yes
    □ No

14. If not, do you feel like it is something that you would have wanted to know about?

    □ Yes
    □ No
    □ N/A

APPENDIX D: Interview and Coding Guides

Interview grid

	Questions
Part 1: General comments on cognitive enhancement	1. (10 mins) What are these articles about? **a)** Is this abuse? **(why/why not?)** b) Is this enhancement? c) Is this a lifestyle choice? 2. (5 mins) Were you surprised that this is going on? a) Do you think that it is frequent/rare? b) Do you think that is acceptable/debatable?
Part 2: Concerns for ethical, social and legal issues related to cognitive enhancement	3. (12 mins)Do you have any concerns about what is described in the articles? Why? Why not? a) Is it safe? b) Is it illegal? 4. (12 mins) Are there any risks? a) Physiological risks? b) Psychological risks? c) Are these practices supported by scientific research? (reliability of research) 5. (12 mins) Are the practices described in the articles different than those used in sports to enhance performance? How? a) Is it cheating? b) Is the performance yours (authenticity)?

Part 3: **Social and healthcare aspects**	6. (12 mins) Should Ritalin be available to everyone for non-medical use? Why? Why not? a) Will it change social practices and institutions? How? (social meaning) b) Could there be issues with fair access? (injustice) c) Are these practices due to commercial interests? (commercialization) 7. (12 mins) Is this phenomenon a social problem? a) Will it lead to abuse? b) Could this be caused by overprescription? c) Will it lead to coercion? (autonomy) 8. (5 mins) Do you think there are measures that can be taken as to prevent or solve this phenomenon? (regulation)
Part 4: **Media content & media as an information source**	9. (5 mins) Based on your reading and the content of this discussion what is your impression of the articles? a) Are the articles biased? b) Do the articles present a well-rounded perspective? c) Are the articles realistic? d) What do you think of the quality of the scientific information? 10. (5 mins) Do you feel that information was missing from the articles?

Summary question: (3 mins)

a) Begin with key findings.
b) Acknowledge different points of view
c) Possibly offer an interpretation
d) What was not said that might have been expected?
e) Cite key phrases used in the discussion.
f) Ask “Is this summary complete?”

(2 mins) Is there anything we should have talked about but didn’t?

Coding Guide

Node	Sub-node	Sub-sub-node	Sub-sub-sub node	Definition
Articles				
	Media criticism			Critical perspectives on media coverage of the use of methylphenidate in the academic context as inspired by the articles provided to the focus group participants as prompts for the discussion
		Bias		More prevalent representation of a perspective regarding the use of methylphenidate for enhancement
			Bias affirmation	There is more prevalent representation
			Bias negation	One perspective is not more prevalently represented
		General comments		General observations about media coverage on methylphenidate or media coverage in general
		Incomplete information		Perspectives on the amount and quality of the information in the media articles
			Information gaps	Presence of information gaps which impacted the understanding of the phenomenon
			No information missing	Amount and quality of information in the articles was satisfactory

		Media encouraging practice		The type of reporting in the media could encourage readers to engage in the use of methylphenidate for enhancement
		Perspective		Discussion of social and ethical approval
			Ambiguous	Difficult to tell whether using methylphenidate for enhancement is good or not
			Skewed	Article declares that using methylphenidate for enhancement is good or bad
			Well-rounded	Balanced discussion of pros and cons of taking methylphenidate for enhancement
		Quality of scientific information		Statements about the quality and quantity of scientific information in the media articles
			Bad quality information	Scientific information is insufficient or not from a reliable source
			Good quality information	Scientific information is sufficient and from reliable sources but also well-explained
			Satisfactory information	Scientific information is sufficient and from reliable sources
		Realism		Relation of media coverage to the current state of events
			Realism affirmation	Articles reflect the reality of methylphenidate use
			Realism negation	Articles do not reflect the reality of methylphenidate use
	What are the articles about			Brief summary of the content of the articles
Cognitive				

enhancement				
	Definitions			Based on media articles, how can university students' use of methylphenidate be defined
		Abuse		Methylphenidate is being used for something for which it was not intended
		Enhancement		Methylphenidate is used to improve performance
		Lifestyle		Using methylphenidate corresponds to a lifestyle choice
		Abuse-enhancement		(Combine definitions above)
		Abuse-enhancement-lifestyle		(Combine definitions above)
		Abuse-lifestyle		(Combine definitions above)
		Lifestyle-enhancement		(Combine definitions above)
		Descriptive terms and synonyms		Use of any equivalent terms without a formal definition
		Uncertain definition		Difficult to define. Unsure about which (if any) combinations of terms are valid.
	Social description			Social aspects of the use of methylphenidate for enhancement
		Extent		Frequency/rarity of the phenomenon of cognitive enhancement with methylphenidate
			Frequent	use of methylphenidate for enhancement is frequent among students or other populations
			rare	use of methylphenidate for enhancement is rare among students or other populations

		Social integration		Degree of acceptance by various social groups
			Social integration affirmation	Methylphenidate use for enhancement is an accepted part of social practices
			Social integration negation	Methylphenidate use for enhancement is a marginal social practice
			Social integration neutral	Unable to determine whether methylphenidate use for enhancement is an accepted or marginal social practice
		When		Temporal continuity of the phenomenon of cognitive enhancement with methylphenidate.
		Where		Places (counties, institutions, context) where cognitive enhancement with methylphenidate is taking place.
		Who		People or groups of people who use methylphenidate for cognitive enhancement.
	Treatment-enhancement			Discussion of how using methylphenidate for enhancement relates to the treatment-enhancement debate
		Treatment-enhancement blurry		It is difficult to distinguish treatment from enhancement in this context
		Treatment-enhancement definition		Use of methylphenidate in this context can be defined by either treatment or enhancement
Comparisons				
	Coffee etc			Comparison of methylphenidate use for

				enhancement to other natural substances like coffee
		Different than coffee		Methylphenidate use and coffee consumption (even in the academic context) are different phenomena
		Same as coffee		Methylphenidate use and coffee consumption (even in the academic context) are similar phenomena
		Undecided-comparison to coffee		Unable to determine whether methylphenidate use and coffee consumption (even in the academic context) are similar or different phenomena
	Sports			Comparison of methylphenidate use for enhancement to the use of steroids in sports competitions
		Different than steroid use		Methylphenidate use and steroid use are different phenomena
		Same as steroid use		Methylphenidate use and steroid use are similar phenomena
		Undecided-sports comparison		Unable to determine whether methylphenidate use and steroid use are similar or different phenomena
Effects of methylphenidate				
	Addiction			Statements on the methylphenidate dependency. Such statements may include **warnings** about a dependency or desensitization.

		Addiction- general comments		General comments on the potential to develop a dependency on methyphenidate
		Physiological addiction		Individuals can develop a physiological dependency on methylphenidate (ex. appearance of withdrawal symptoms)
		Psychological addiction		Individuals can develop a psychological dependency on methylphenidate (ex. low self-esteem about performance without methylphenidate)
	How does methylphenidate work			Statements on the causes of the physiological and psychological effects of methylphenidate or why it produces such effects.
	No negative effect			Methylphenidate use for enhancement has no negative effects whatsoever
	Physiological effect			Statements on how methylphenidate affects the biological processes of the user
		Physiological positive effect		Statements on how methylphenidate positively affects the biological processes of the user. Such effects may include prolonged wakefulness, increase in energy level, or lack of negative effects of other stimulants i.e. the diuretic effect of coffee.
		Physiological negative effect		Statements on how methylphenidate negatively affects the biological processes of the user. Such effects include heart palpitations, increase in blood pressure, and loss of sleep and appetite.
	Psychological effect			Statements on how methylphenidate affects the

				behavior of the user
		Psychological positive effect		Statements on the positive effects of methylphenidate on the behavior of the user. Such effects include increases in alertness, concentration, memory, and confidence.
		Psychological negative effect		Statements on the negative effects of methylphenidate on the behavior of the user. Such effects include depression with withdrawal, psychosis, aggression, anxiety, hallucinations and paranoia.
Ethical, Social and Legal Issues				
	Abuse			Statements on the misuse of methylphenidate but different from the dependence upon the drug i.e. used for anything other than the treatment of ADHD. The statements must be explicitly qualified as abuse. This category includes warnings of potential abuse from health professionals. Ideally, statements contrast what it is intended to be used for and the form in which it is being misused.
		Abuse affirmation		Methylphenidate is being abused in the context of enhancement
		Abuse negation		Methylphenidate is not being abused in the context of enhancement
		Abuse neutral		Unable to determine if methylphenidate is being abused in the context of enhancement or not

	Authenticity, identity and personhood			Changes in authenticity, identity and personhood
		Authenticity, identity and personhood affirmation		An individual who takes methylphenidate for enhancement remains authentic
		Authenticity, identity and personhood negation		An individual who takes methylphenidate for enhancement is not authentic
		Authenticity, identity and personhood neutral		Unable to determine whether authenticity changes as a result of taking methylphenidate for enhancement or not
	Autonomy, individual rights and coercion			Impact on the autonomy, individual rights and coercion as a result of using methylphenidate for enhancement
		Autonomy, individual rights and coercion affirmation		Using methylphenidate for enhancement is a an autonomous choice
		Autonomy, individual rights and coercion negation		Using methylphenidate for enhancement is not an autonomous choice
		Autonomy, individual rights and coercion neutral		Unable to determine if using methylphenidate for enhancement is a an autonomous choice or not
	Cheating			Statements on the issue of whether or not using methylphenidate for enhancement provides an unfair advantage.
		Cheating affirmation		Using methylphenidate for enhancement provides an unfair advantage

		Cheating negation		Using methylphenidate for enhancement does not provide an unfair advantage
		Cheating neutral		Unable to determine whether using methylphenidate for enhancement provides an unfair advantage or not
	Commercialization			Potential for commercial forces to drive methylphenidate use for enhancement
		Commercialization affirmation		Commercial forces to drive methylphenidate use for enhancement
		Commercialization negation		Methylphenidate use for enhancement is not driven by commercial forces
		Commercialization neutral		Unable to determine whether methylphenidate use for enhancement is driven by commercial forces or not
	Illegality			Legal perspective of the use of methylphenidate for enhancement
		Illegality affirmation		Using methylphenidate for enhancement is illegal
		Illegality negation		Using methylphenidate for enhancement is legal
		Illegality neutral		Unable to determine whether using methylphenidate for enhancement is legal or illegal
	Injustice, access and equality			Potential for issues of injustice, access and equality in the use of methylphenidate for enhancement
		Injustice, access and		There are elements of injustice, issues of

		equality affirmation		access and equality in the use of methylphenidate for enhancement
		Injustice, access and equality negation		Using methylphenidate for enhancement is just and there are no issues of access or equality
		Injustice, access and equality neutral		Unable to determine whether there are issues of injustice, access and equality in the use of methylphenidate for enhancement or not
	Overprescription			Statements on the prescription habits of physicians for methylphenidate
		Overprescription affirmation		Methylphenidate is overprescribed and that contributes to its use for enhancement
		Overprescription negation		Methylphenidate is either not overprescribed or overprescription does not contribute to its use for enhancement
		Overprescription neutral		Unable to determine whether methylphenidate is overprescribed and whether overprescription contributes to its use for enhancement
	Regulation, governance and policy			What types of regulation is needed to frame methylphenidate use for enhancement and whose responsibility should it be
	Reliability of scientific data			Characterization of the scientific data available to support the use of methylphenidate for enhancement
		Reliability of scientific data affirmation		Scientific data available to support the use of methylphenidate for enhancement is reliable
		Reliability of scientific data negation		Scientific data available to support the use of methylphenidate for enhancement is not reliable

		Reliability of scientific data neutral		Unable to determine whether scientific data available to support the use of methylphenidate for enhancement is reliable or not
	Safety			Safety of methylphenidate as a drug used for enhancement
		Safety affirmation		Methylphenidate is safe for enhancement use
		Safety negation		Methylphenidate is unsafe for enhancement use
		Safety neutral		Unable to determine whether methylphenidate is safe for enhancement use or not
	Social meaning			Statements highlighting the impact of cognitive enhancement with methylphenidate on social values and practices. Impacts include the medicalization of the human condition and the emergence of a social pressure to perform.
		Social meaning affirmation		The use methylphenidate for enhancement changes social practices
		Social meaning negation		The use methylphenidate for enhancement does not change social practices
		Social meaning neutral		Unable to determine whether the use methylphenidate for enhancement changes social practices or not
	Social pressure			Influence of social pressures which encourages use of methylphenidate for enhancement
		Social pressure affirmation		Social pressures encourage use of methylphenidate for enhancement
		Social pressure		There are no social pressures that encourage

		negation		use of methylphenidate for enhancement
		Social pressure neutral		Unable to determine whether social pressures encourage use of methylphenidate for enhancement or not
How are students procuring methylphenidate				
	Black market			Students using methylphenidate for cognitive enhancement are buying pills illegally on the black market.
	Buying pills from students			Students using methylphenidate for cognitive enhancement are buying pills from students that have legitimate prescriptions.
	Feigning symptoms			Students are going to doctors and faking the symptoms of ADHD to get legitimate prescriptions for illegitimate use.
	Internet pharmacies			Students using methylphenidate for cognitive enhancement are ordering pills from internet pharmacies.
	Other			Ex. Stealing
Information on ADHD				
	Statistics on occurrence			How many people suffer from ADHD
	What is ADHD			Details on the symptoms and diagnosis of ADHD
Prevention				

	Challenges			Challenges faced by parties seeking to prevent or reduce use of methylphenidate for enhancement.
		Prevention challenges		Challenges in making rules about MPH regarding enhancement (includes scientific challenges) and enforcing such rules
		Allowing challenges		Challenges in permitting free and widespread use of MPH for enhancement
	Solutions			Description of the measures university administrations and law enforcement agencies are taking in order to prevent abuse from starting and spreading.
		Restricting		Solutions that involve restricting access to MPH for enhancement uses; finding alternatives or resources that would reduce the need for performance enhancement. Factors that prevent implementation of viable solutions.
		Allowing		Solutions that involve allowing widespread access to MPH for performance enhancement
Reactions				
	Not surprised			Stakeholders were not surprised that students are using methylphenidate for enhancement
	Surprised			Stakeholders were surprised that students are using methylphenidate for enhancement

	Other reaction			Various reactions to the use of methylphenidate for enhancement by university students (excluding surprise)
What is methylphenidate used for				
	Academic use			Methylphenidate is used as a study aid
	Medical use			Methylphenidate is used as a treatment for Attention-deficit/hyperactivity disorder
	Recreational use			Methylphenidate is used in party contexts