

Introduction: Towards a Critical Bioethics

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The contributions gathered in this volume represent part of a growing movement that seeks to intervene in the dominant ways that bioethics is understood and practised. The need for new and critical approaches to bioethics does not merely reflect recent theoretical scholarship, but is at the heart of unprecedented advances in biotechnology, coupled with current trends in healthcare management and delivery. This is all the more pressing as bioethics itself has been institutionalized as an integral part of mainstream medical management and administration. Written from a variety of disciplinary perspectives, these contributions variously suggest that traditional modes of bioethics are proving incommensurable with burgeoning biotechnologies, medical management systems, and the emergent conceptions of the “self” that have arisen in their midst.

An intervention is called for in times of breakdown or crisis. In the popular sense of the term, to undergo an intervention is to be reminded that we are not autonomous creatures, that our actions affect others and extend in myriad ways into the world around us. To intervene is not necessarily to condemn; the one who intervenes claims only to be unable to continue to live with the way things are. Each of these contributions makes such a claim, reminding us that bioethics is, in its most immediate sense, an ethics of non-autonomous life—of the *bios*—and that what is at stake here are the terms of a liveable life, a good life, and all this might entail. Arguably, mainstream or professional bioethics—from the classroom to the clinic—has forsaken this insight, with all its ambivalence, for an instrumental logic or a set of normative principles that promise consistency, efficiency, and ready implementation. Ironically, these principles often are held to be logically “self-evident” and thus in the last instance constitute a matter of faith that obviates the need for any bioethical reflection in the first place. Indeed, the harsh critic might say that this is the surreptitious goal of bioethics-as-usual: to evacuate ethical decision-making of its ambivalence and discomfort, and to offer a set of best-practice guidelines to produce ethical “outcomes,” to pre-empt lawsuits, and to safeguard the putative goodness of one’s good conscience.

What, then, is a “critical” approach to bioethics? This is an increasingly vexing question because bioethics has become such an integral part of mainstream medical management, and healthcare discourse such an integral part of daily life, that it is difficult to imagine a space from which to wage a critique. While bioethics was originally inspired by sociopolitical and counter-cultural movements in the

1960s, including civil rights and feminism, the terms of bioethical debate have grown increasingly corporate, abstract, and legalistic. Bioethics has become what McKinnie (2004) has referred to as an “affirmative institution”: pro-capitalist, pro-technology, and pro-governmental. As M.L. Tina Stevens argues, bioethics has become a “midwife” to the implementation of technologies: “The bioethics ‘movement’ ... assisted in transforming alarm over exotic technologies into a situation in which ethical experts manage problems—problems generated by technologies seen, ironically, as value-neutral in their creation” (2000, xiii). Consequently, critical questions that take account of power and its effects are virtually impossible to formulate, since these discourses have been neutralized and their language has been supplanted by the depoliticized Newspeak of the “ethical expert” and “manager.” Without an analysis of power and its complexities, mainstream bioethics is ill-equipped to consider social, political, or even economic issues in any robust manner. To begin to wage a critique, we must call into question and resist the reductive binary logic that tends to inform mainstream bioethics: theory/practice, mind/body, subject/object, nature/culture, and so on. Moreover, critics must seek to understand the many broader contexts—sociopolitical, socioeconomic, historical, cultural—that provide the conditions under which mainstream bioethical principles have become authoritative, if not hegemonic. Finally, critique will mean that we work together to find a conceptual vocabulary that will allow us to interrogate the “expert” authoritarianism of bioethics without ourselves adopting a simple antiauthoritarianism (see Murray et al. 2008).

To offer a critique of bioethics is not to suggest that the field is unified or monolithic. Along with professional philosophers, we might dismiss any serious consideration of religious faith-based ethics and distinguish among several more or less systematic bioethical concepts and “methodologies.” Deontologists, such as the philosopher Immanuel Kant, base ethical conduct on rules or duties derived from logical principles, rather than from the consequences of an individual’s actions. In contradistinction, consequentialists, including utilitarians, weigh consequences or effects and hope to maximize the presumably calculable utility of ethical decisions, often summed up as the pursuit of “the greatest good for the greatest number.” On the other hand, virtue ethics, which hearkens back to Aristotle, finds its basis in the virtuous traits that make up an individual’s character (*ethos*); here virtue is defined most often in accord with social values and practical wisdom (*phronēsis*), both of which are socio-historically contingent. Finally, the most popular approach today is principlism, which holds that all human beings share a common morality that can be parsed into a set of ethical principles meant to govern action.

With the exception, perhaps, of virtue ethics—which is rarely taken seriously in the clinic or the classroom—the approaches above presume that human reason plays the central role in ethical decision-making. Thus, while bioethics is neither conceptually nor methodologically monolithic, its various strands nevertheless take for granted the truth of personhood or subjectivity as it is derived from Enlightenment reason—including the belief that the individual is

a free, autonomous, and rational agent. In other words, the conventional subject of bioethics is presumed to be a stable and coherent self, sovereign in its ethical judgements. The roots of this modern subject stretch back to the early seventeenth century, when philosophers, such as René Descartes, began to conceive of the self as abstract reason (“I think, therefore I am”), a mind divorced from the body (which was soon regarded as “property”).

Nowhere is this cognitivist conceit better demonstrated than in principlism. To offer one example, we turn to Beauchamp and Childress, whose book *Principles of Biomedical Ethics* is an industry standard, spanning over thirty years and six editions. They assert:

All persons living a moral life grasp the core dimensions of morality. They know not to lie, not to steal others’ property, to keep promises, to respect the rights of others, not to kill or cause harm to innocent persons, and the like. (2009, 2–3)

This suggests that to live is, in some sense, no different than to know, that ontology and epistemology are of the same order—or better, that the epistemic principles that stand as “bioethics” emerge naturally, as it were, from the kind of life that one leads—provided that this life is “a moral life.” This begs the ethical question: what, then, qualifies a life as “moral” if not those epistemic principles that would organize that life *ex post facto*? It turns out that the “common morality,” as Beauchamp and Childress call it, is understood as “universal” not by virtue of our common living-together, but according to particular rational principles that have been universalized and presumed to be natural and necessary. In other words, these values are assumed to be trans-historical and trans-cultural structures, yet immanent to one’s “moral” livingness. It is on the basis of this problematic assumption that they derive their four well-known bioethical “principles”: respect for autonomy, nonmaleficence (do no harm to others), beneficence (benefit others), and justice.

While these four principles are not reducible to the first (“respect for autonomy”), each of them ultimately must presume the existence of a modern subject/agent founded in rational autonomy. Arguably, even “respect for autonomy” presumes autonomy not just on the part of the one whose autonomy is respected, but also on the part of the one who respects (respect, almost by definition, would be invalid without it). Derived from the Greek *auto-* (self or own) + *nomos* (law), “autonomy” has come to describe the way that the self is conceived as governing or conducting itself. Thus, the self is considered to be fully autonomous only when it governs itself according to rational principles that have been conventionally recognized as such. One might be recognizably “human,” but one is not considered fully autonomous when ruled by emotions or bodily urges; such an individual might forfeit certain “rights” and risks being ostracized socially and politically. Rational autonomy therefore presumes that one acts and is acted upon in a very particular way. In the medical context, rational autonomy is a strange convention in part because its philosophical underpinnings continue to be dualistic, founded

in a binary logic that sees agency as a mental activity of free will, and bodies no more than resistant, brute matter or a heap of “spare parts.” From the patient’s perspective, we might ask: who—or what—acts, and who—or what—is acted upon? The clinician can be said to act, is the agent who is presumed to know, and yet acts in myriad ways—through words and deeds, through argument and physical actions, in and through bodies, affecting other bodies. And what is the relation between the patient and the patient’s body? Does the patient act? Is the patient acted upon? Or is it the body that undergoes the action—the action of the patient’s own body’s genes, for example, or of a virus, a drug, a surgeon’s scalpel, the persuasive regulatory force of the healthcare leviathan, the insurance industry, loved ones? Could we not declare each of these agents “autonomous,” obedient to—and demanding—a particular logic?

So when, from within this nexus, the patient “consents” to a medical procedure, is this an act of the patient’s sovereign and free will, based on rational knowledge, or does the body not also “consent” or resist, in its own way, ambivalently, perhaps? We need only reflect on the body in illness and pain to understand that the rational and coherent subject is a conventional fiction: in practice, this subject is fragmentary, radically uncertain, contradictory, and embodied. Any “autonomous” decision takes place between the patient and a vast healthcare complex in the face of which the patient can hardly be said to be “rational” or “free.” Moreover, ethical decision-making is also self-reflective, which means that it involves the patient’s self-relation—often a relation of emotional and intellectual doubt, in which the subject’s “autonomy” is questionable at best. After all, the terms of the patient’s self-understanding will surely call upon a wide range of possibly alien(ating) discourses, from genetics, biomedicine, and risk management, to popular literature, personal narratives, and infomercials promoting everything from a cleaner colon to a better sex life—even the desire for “good health” is highly wrought and discursive. The gap that opens up in the subject’s ethical self-relation cannot be bridged by positive knowledge alone: it is also—and perhaps primarily—both an affective space and a relational space that is marked by intersubjective relations of care. Must we presume that these relations and actions are rational (or even reasonable) and that those who, in some sense, “do” them, as well as those to whom, in another sense, they are “done,” are governing themselves accordingly? It is too simple to say that the patient “wilfully” cedes autonomy since the will itself is implicated. And is any of the patient’s ambivalence mitigated if we now call that patient a “client”? Does this “empower”? Or are we just looking for new ways to try to instantiate this person’s putative autonomy? Who will judge? Will bioethics decide, will it govern this governance, and if so, how, and according to whose terms? And how will we ensure that the demand for autonomy is not itself experienced as a kind of violence when autonomy is the *sine qua non* of personhood, dignity, rights, and full “citizenship”?

The contributions in this volume variously suggest that there is something wrong in the way that bioethics asks—or refuses to ask—these questions: the intelligibility of its discourse presumes a model of rational autonomy that is

intrinsically problematic, even if it were not also fast becoming obsolete. Several contributions here point to recent advances in biomedical technology in order to demonstrate how rational autonomy is deeply troubled; others point to the operation of healthcare complexes themselves, from academe to the clinic; still others draw on recent philosophy, political theory, and cultural studies to make their case. The challenge, of course, is how to imagine an ethics that need not seek recourse to an autonomous, rational, liberal subject. In other words, if we dispense with rational autonomy, what then could serve as the foundation (if this is the right metaphor) for ethics? How might we conceive of responsibility without our current understanding of personhood and free will? This is no small challenge because our terms bear the weight of history and its ossified conventions; there is considerable resistance when it comes to remaining genuinely open to the new. And yet if we glance beyond medicine, we can begin to see that nearly every facet of life in the West presumes—and relies on—the fiction of this modern, rational, autonomous subject: our legal and judicial systems, so-called “free market” capitalism, democracy, and education, to name just a few. In coming years, these pillars of Western culture will need to be overhauled to keep pace with advances in the biosciences. Thus, we face a moment of crisis and breakdown. Presuming that ethics is a relation, the terms of this relation are not yet invented; we hope to chart what is an emerging field of inquiry, one that will have implications not just for healthcare but for post-industrial economies, consumer culture, militarism, law—all forms of governance that presume the givenness of an autonomous, rational subject.

The four sections of this volume should in no way imply that there are only four kinds of interventions into mainstream bioethics-as-usual. We have sought interdisciplinary and thought-provoking contributions; our aim is to foster further dialogue in the field. Each of the four parts reflects a distinct sphere in which the terms of ethical self-relation and autonomy are called into question. These include biomedicine in the clinical setting, the biopolitical dimensions of healthcare, representations of gender and the body, and cultural constructions of biomedical subjectivity. In each of these spheres, we find that the fiction of the liberal, autonomous subject is repeatedly (re)constituted; however, we argue that these spheres are also sites of ethical resistance, productive ambivalence, crisis, and intervention. The contributions gathered in each part seek to deconstruct the authoritative grip of rational autonomy operating within each sphere to intervene in the debates, to engage the reader’s imagination, and to suggest new terms for ethical relationality.

The chapters in Part I, “Clinical Interventions,” take a critical look at clinical bioethics. Each begins in the clinical setting, discussing a concrete instance in which the principle of autonomy is in crisis. The first chapter is a passionate contribution by Kim Walker, written from the perspective of a nurse and an academic. Walker tells the story of his sister, Donna, from the moment she is diagnosed with terminal breast cancer. To what extent, he asks, does it make sense to speak of Donna as an autonomous subject? And how do we locate the personal and highly affective narrative of the patient/client/subject within the dominant discourse of evidence-

based practice (EBP)? While EBP has strongly influenced the clinical healthcare agenda across the discursive territories of policy, research, and scholarship, Walker contends that in practice EBP's much touted ideal of patient autonomy and "patient-centeredness" cannot be realized. His contribution dramatizes the ethical tension between academic and clinical discourses, on the one hand, and a deeply existential and affective narrative, on the other. If the terms of these discourses are incommensurable, Walker suggests it is just this irreconcilable tension that the patient is forced to navigate. A critical bioethics would abandon the onerous language of autonomy and the logic of EBP within contemporary acute care practice, and turn instead to a reappraisal and a reinstatement of case-based healthcare decision-making.

The chapter by Jennifer M. Poole and her colleagues presents novel and potentially disturbing research on cardiac transplantation. Poole and her team are in the early stages of a project called PITH (Process of Incorporating a Transplanted Heart), which employs a qualitative visual methodology to study the effects of transplantation on the recipients. They hope to discover why such a large number of recipients report the experience of "otherness," a disruption of identity, a sense of loss and distress, and even dreams of the donor—not only immediately after the transplant, but well into the "recovered" phase, 3–5 years later. These phenomena cannot easily be explained under the rubric of a positivist, Cartesian biomedical model; consequently, these experiences are usually ignored or psychiatrized. Their research challenges the "spare parts" view of the body that is consonant with a belief in rational autonomy, suggesting instead that an embodied, phenomenological model is more appropriate. They trace the ethical implications of their preliminary findings, responding to conventional bioethics and its insistence on autonomy, confidentiality, and consent; but they also look towards a "postconventional" ethic of intercorporeality drawing on the phenomenology of Maurice Merleau-Ponty.

Roanne Thomas-MacLean's contribution draws on data from the *Visualizing Breast Cancer* project. She offers a reading of several interviews in which Aboriginal women with breast cancer discuss their clinical experience. Focusing on these illness narratives, Thomas-MacLean explores the ways an increased attention to the lived experience of illness—the meaning of which is often taken for granted—might lead to a more ethical and affirming clinical experience. While institutional structures can reinforce and perpetuate a model of healthcare that privileges rational autonomy, she argues that clinicians have a duty to engage with patients in ways that do not reduplicate the dominant ideologies of free choice, autonomy, and paternalism in medicine. Such an approach would serve as an antidote to biomedical orientations and would allow for the recognition of marginalization. Moreover, by turning to the politics and practices of everyday life, she argues that clinicians could better understand how ethical practice emerges from within the intersubjective dimensions of human experience.

Part II, "Biopolitical Interventions," presents chapters that examine the political dimensions of bioscience and its ethical oversight and regulation. While science

and technology are frequently presented as apolitical and value-neutral—a move that is often politically strategic—these contributions point to the underlying and hidden powers at play in the governance of life itself. This section opens with a chapter by Ann Robertson, who examines the case of pre-implantation genetic diagnosis (PGD). Robertson defines key biopolitical terms and issues, suggesting that emerging biotechnologies have created a world in which the principle of autonomy can no longer serve as the foundation for governance or for ethics. Based on the Hashmi case in the UK, and using a Foucauldian perspective, her contribution raises some crucial bioethical questions concerning the transformative possibilities of PGD, including the spectre of “saviour siblings” and “designer babies.” The ethical implications are discussed further in terms of “biopower” and the notion of “biological citizenship” in the context of a prevailing neoliberal political rationality.

In his chapter, Bradley Bryan discusses the ways that individual subjects—falsely promoted as autonomous—are called into being through biotechnology and biopolitics. Bryan examines how biotechnology arises against the backdrop of an urgent need to manage the conditions that set upon human beings in their very livelihood, including health, illness, and the other vicissitudes of biological existence. Following the insight of French Marxist philosopher Louis Althusser, he argues that “interpellation” or “hailing” is the way the modern subject comes to understand itself as a biological entity. By looking at the preconditions and rhetorical modes of biotechnology, this chapter suggests that individuals recognize themselves as biopolitical subjects in the moment of “being hailed” by biotechnology’s (promised) cures.

Stuart J. Murray’s chapter invokes the research of Stanley Milgram, the Yale University social psychologist made famous by his experiments on obedience to authority in the early 1960s. Murray argues that an analogous obedience to scientific authority characterizes contemporary Western healthcare, which operates politically according to three interrelated forms of “fascist” ideology: (1) biomedicalization, (2) the political economy of neoliberalism, and (3) biosocial or biocultural discourse. The constellation of these three “fascisms” he terms “biofascism,” which is discussed in relation to the phenomenon of genetic screening or “pre-diagnosis.” Murray concludes with a discussion on “genetic subjectivity” and offers one way that we might begin to imagine an ethic that would be commensurable with emerging biotechnologies and the kinds of subjects that they foster.

In his chapter, Michael Orsini compares the legal strategies adopted by opposing activist groups in Canada and the USA advancing an autism agenda. One set of groups is appealing to the UN to have people with autism considered a national minority that should be protected from discrimination, while the other is trying to use the law to argue that the state has a duty to cover the costs of applied behavioural therapy, which many parents of autistic children believe can “save” their children from autism. The first group, made up mainly of adult autistics, believes the therapy can be harmful and instead espouses the view that people

with autism are “neurodiverse”: they are hard-wired differently than the average person. The second group, in contrast, believes that withholding access to this treatment from parents who cannot afford the prohibitive cost is discriminatory. Orsini’s contribution deals with the ethical question of who is permitted to speak on behalf of autistic citizens, what treatment(s) should be chosen, and by whom. The debate calls into question what counts as an autonomous person, a person who is presumed to enjoy the right to choose—and to refuse—treatment.

Part III, “Gendered Interventions,” takes aim at the ongoing gender bias in biomedical discourse, including the ways the gendered body is represented biomedically and within medico-legal discourse.¹ The gendered body is a site where autonomy claims are played out and fixed, but also troubled and contested. Shelley Wall’s contribution is written from the perspective of a biomedical artist. Wall demonstrates that medical illustration in the West shares a long and intimate history with cadaveric dissection, clinical examination, and other medical practices with the body as their object. Her contribution proposes that there is a disconnect between the subjective experiences of patients and the objectifying visual rhetoric of medical and patient education—the clinical gaze. What happens, she asks, when these illustrations function not just as a map, but as a mirror? How do they work to organize the experience of the gendered body? Her discussion takes as its exemplars depictions of sexual anatomy, critiquing them with reference to gender theory, intersex activism, phenomenological accounts of embodiment in healthcare, and the history of medical illustration. It also considers the possibility of alternative—more ethical—visual practices: How can medical illustration rethink the body from the inside out, and better reflect the embodied experience of patients?

Sarah Burgess offers a chapter that reflects on the ways that concepts of autonomy and consent get played out between medicine and the law. Her discussion follows a reading of the UK’s Gender Recognition Act (2004). An act that grants rights and a state-issued “gender certificate” to transsexual people according to their “acquired gender,” it requires that individuals demonstrate that they have been “living in” a particular gender and plan to do so permanently—a way of being that Parliament refused to clearly define. This chapter explores how this refusal shapes and limits the type of evidence available to subjects who wish to apply for a gender certificate. More specifically, it investigates the effects of removing surgery or other forms of bodily alteration as conditions for a gender certificate. Reading the parliamentary debates and the language of law itself, Burgess argues that this provision introduces a moment to critique how medical evidence is employed (or deployed) in legal and political debates. Such critique is ethically important because it re-defines how a gendered subject is seen and heard within medical contexts.

1 For a thorough discussion of gender and postconventional bioethics from a feminist perspective, see Shildrick and Mykitiuk 2005.

Christabelle Sethna and Marion Doull's chapter discusses the ethics of reproductive choice, reporting on a qualitative study of abortion access that tracked the travels of 1,000 women to the Toronto Morgentaler Clinic for the purposes of pregnancy termination in the spring of 2006. The authors demonstrate that access to abortion services has become more difficult since the late 1970s. In light of feminist analyses of reproductive rights, they ask whether the experience of travelling to access pregnancy termination reflects, reifies, and/or exacerbates sociocultural disparities among women. This chapter opens up for discussion bioethical issues of reproductive choice in relation to women's autonomy and women's inequality in Canada. Their data suggest that these women do not experience themselves as autonomous and free.

Part IV, "Cultural Interventions," includes three chapters that variously address medical cultures. Medical discourse has become popular and widespread, informing the terms by which we understand ourselves and others in sickness and in health. The first chapter, by Twyla Gibson, returns to the Hippocratic *Oath*, which has for 24 centuries served as the cornerstone of professional ethics in medicine and the model for all subsequent revisions to ethical codes of conduct. Gibson points out that there has until recently been a significant barrier to new interpretation of this foundational ethical treatise. Applying new findings from the comparative study of ancient literature, she offers an intertextual reading of Hippocrates and Plato in order to bring new meanings to bear on our understanding and interpretation of the *Oath* and the Hippocratic tradition of ethics in medicine. Intertextuality calls into question the autonomy of both author and reader, suggesting that in order to understand ethics, we must turn to the wider communicative, cultural, and historical contexts of our tradition's foundational texts. In so doing, we gain a better understanding of bioethical debates and clinical decision-making today.

Deborah Lynn Steinberg's contribution examines the cultural reception of the gene and genetic science. Steinberg takes as her case study Nancy Kress's popular feminist science fiction novel *Beggars in Spain*, which tells the story of a world in which a class of human beings has been genetically engineered to function without sleep. She reads the work as a parable of emergent values attached to the gene in the late modern era, in particular the uncanny convergence of genetics and neoliberal political economics. Arguably, these are our social values too: a body politics that promises perfect health and beauty, frictionless efficiency, and 24/7 productivity. Attending to the narrative and rhetorical structures of Kress's novel, Steinberg re-vision conventional bioethical discourse with its rigid focus on regulative models and its uncritical affective orientation to scientific progress. She suggests an alternative ethics of ambivalence founded in the "feeling structures" of bodies and knowledge.

Finally, David L. Clark's contribution discusses the world's foremost female Jungian analyst, Marion Woodman, who has long been a vocal critic of conventional biomedical understandings of health and illness. It lies within the power of our respective imaginations, Woodman argues, to make our bodies and minds whole again. Yet Woodman's confidence faced an extraordinary crisis

when she was herself diagnosed with and treated for uterine cancer, a process she describes in vivid and moving detail in her memoir, *Bone: Dying into Life* (2000). The triumph of mind over matter that lies at the heart of her health regime threatens at various key points in her autobiographical narrative to devolve into its obscure semblance—namely, an asceticism of the sort that her psychoanalytic project had long railed against. This chapter seeks to show how Woodman’s text is haunted by conflicting strata of awareness in which the psychoanalyst’s resistance to conventional biomedicine inadvertently quickens a will-to-nothingness that “skeletalizes” the psyche rather than nourishes and enriches it.

It is true that the contributions gathered here do not make an explicit prescriptive ethical claim. But they are not intended to be policy papers. In other words, they do not respond to the crisis in bioethics by offering a moral code or by delineating a set of moral practices or tests. This would render ethics as a piece of positive knowledge, an object within the grasp of an autonomous and free subject, an object to deploy at will. Rather, it is hoped that these contributions will make their claim on the non-autonomous subject, on each of us whose lives are lived alongside—and sometimes for, together with—the lives of others, in sickness and in health. Ethics is not about applying a rule. As Jacques Derrida has said, “There are ethics precisely because ... there *is* no rule. There are ethics because I have to *invent* the rule; and there would be no responsibility if I knew the rule ... That’s where responsibility starts, when I *don’t* know what to do” (2003, 31). Ethics is premised, then, on the productive failure of the autonomous “I,” beginning where it and its faith in its own knowledge arrive at an impasse, an aporia.

This book hopes to offer more than a consideration of the constitutive social, political, and cultural dimensions of the bioethical field. We hope that readers find in these pages some imaginative possibilities to begin to think and experience bioethics beyond the limits of mainstream bioethical proceduralism—beyond the impasse of liberal voluntarism, autonomy, and rationalism—and toward a critical assessment of the ways that bioethics must respond if it is to meet the complex emerging challenges to healthcare, medicine, the body, and society. More than a critical intervention, then, together these contributions open toward a critical invention—the invention of new modes of ethical relation, new discourses, and a new political ethos that must be forged in virtue of our common and inescapable living-together.

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