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The Individualist Model of Autonomy and the Challenge of Disability

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Abstract In recent decades, the intertwining ideas of self-determination and well-being have received tremendous support in bioethics. Discussions regarding self-determination, or autonomy, often focus on two dimensions—the capacity of the patient and the freedom from external coercion. The practice of obtaining informed consent, for example, has become a standard procedure in therapeutic and research medicine. On the surface, it appears that patients now have more opportunities to exercise their self-determination than ever. Nonetheless, discussions of patient autonomy in the bioethics literature, which focus on individual patients making particular decisions, neglect the social structure within which health-care decisions are made. Looking through the lens of disability and informed by the feminist conception of relational autonomy, this essay argues that the issue of autonomy is much more complex than the individualist model suggests. The social system and the ableist ideology impose various forms of pressure or oppressive power that can affect people's ability to choose according to their value system. Even if such powers are not directly coercive, they influence potential parents' decisions indirectly—they structure their alternatives in such a way that certain options are never considered as viable and other decisions must be made. This paper argues that, instead of only focusing on the individual act of decision-making, we need to pay attention to the social structure that frames people's decision.

Keywords Disability · Autonomy · Genetics · End-of-life care · Ableism

In recent decades, the intertwining ideas of self-determination and well-being have received tremendous support in bioethics. Bioethical discussions regarding self-determination, or autonomy, often focus on two moral dimensions—the capacity of the patient and freedom from external coercion. While doctors are experienced in technical procedures and familiar with medical data, many now acknowledge that health-care decisions deal with more than clinical outcomes, such that people who are deemed competent have the moral and legal authority to make decisions regarding their health care. The practice of obtaining informed consent, which provides patients the opportunity to consider all relevant information and determine which health-care alternative best fits their value system, has become a standard procedure in therapeutic and research medicine.

In the face of widespread moral and legal support for patient autonomy and an increasing availability of medical options, on the surface it appears that patients now have more opportunities to exercise their self-determination than ever. Nonetheless, discussions of

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patient autonomy in the bioethics literature, which focus on individual patients' competence or capacity in making particular decisions, neglect the social structure within which health-care decisions are made. Looking through the lens of disability and using the examples of genetic testing and medically-assisted deaths, this essay argues that the issue of autonomy is much more complex than the individualist model suggests. Informed by the feminist conception of relational autonomy, this paper focuses on how the social system and ableist ideology impose various forms of pressure or oppressive power that can affect people's ability to form and choose according to their value system. Even if such powers are not directly coercive, they structure people's alternatives in such a way that certain options are never considered as viable and other decisions must be made.

In this paper, I do not argue for or against the use of genetic testing, selective termination, or medically-assisted death. My goal is more limited than this. I aim rather to critique the individualist framework of autonomy by drawing attention to the experience of disability. While I assume the importance of respecting autonomy, I will show how the traditional framework is inadequate in truly promoting self-determination. Instead of focusing only on the individual act of decision-making, we need to pay attention to the social structure that frames people's identity and decisions.

Centrality of Individual Autonomy in Moral Philosophy and Bioethics

In moral and political philosophy, particularly since the Enlightenment, there is an explicit acknowledgment of the importance of respecting the autonomy of moral agents. Immanuel Kant's principle of respect and John Stuart Mill's principle of individualism, which have shaped the contemporary discussion of autonomy, focus on the inherent capacity and rights of self-determining agents to make their own decisions. The capacity for rationally determining one's own ends or destiny is the locus and origin of one's unique and unconditional value [1]. It helps to explain what the government and other individuals can or cannot do to self-legislators. While the autonomy condition generally does not apply to children and those who are deemed mentally incompetent to make decisions, except perhaps through surrogate decision-makers, adult autonomous moral agents have the epistemic and moral privilege to make decisions regarding their own good. Even if we may disagree with their decisions or believe that they are making mistakes, whether in health-care or other situations, we cannot coercively override their decisions—we can only advise or persuade them when they hold false views, so that they are better equipped to reconsider their decisions [2]. To coerce rational beings even for their own good is to treat them as if they lack the capacity to shape their own lives—it is to deny them the moral status as persons.

The moral requirements of respecting people's autonomy have received tremendous support in bioethics in recent decades. Individuals, including patients, are considered separate from others by boundaries that can be justifiably breached only by the explicit and voluntary consent of self-determining subjects [3]. Such boundaries define what professionals can or cannot do to a patient. Protection of autonomy is considered particularly crucial in health-care settings because illnesses and injuries are physically and emotionally challenging for many patients, especially when the diagnoses are unexpected or grim. As Susan Sherwin points out, patients are often worried about their situation and are ignorant of the particulars of various treatment alternatives, which generally make them dependent on the care and good will of others [4]. Their professional caregivers, on the other hand, are presumably knowledgeable about the disease condition and have some control over patients' access to various procedures—their professional judgment and recommendation determine whether patients would have access to diagnostic and therapeutic procedures that can provide further information, minimize pain, restore health and/or functioning, and extend life. Given such relational framework and power hierarchy, patients are inherently vulnerable to manipulation or even coercion by their caregivers. While many conscientious physicians would traditionally treat patients according to the former's judgment, with the benevolent assumption that patients who lack medical expertise would not know what clinical alternative is best for them, many bioethicists, legal scholars, and professionals now support replacing medical paternalism with patient autonomy, thereby reducing the likelihood of undue influence and power hierarchy. In western bioethics, there is now general acknowledgment that health-care decisions are not simply clinical decisions—they have important implications on various aspects of the patient's personal, professional, social, and family life. As more medical options are now available, it is increasingly difficult for professionals who have limited contact with patients to determine which available option is most compatible with the latter's value system and priorities. This is especially so in diverse societies, where patients may have different cultural values. A strong principle of respect for patient autonomy is thus necessary to counter medical paternalism and protect patients, particularly those who are most vulnerable and/or socially disadvantaged.

One important aspect of the mainstream discussions and practices of respecting patient autonomy is that they focus on individual patients making specific decisions regarding their health care, i.e., the making of autonomous *choice*, or the actual governance itself [5: 121]. Autonomy is generally assessed in an individualistic manner by looking at one patient and one medical decision at a time—each case is seen as separate from any other. In the contemporary health care settings, particularly in western countries that take individual rights for granted, respect for patient autonomy is often manifested in the practice of obtaining informed consent and following advance directives. Attending to separate and individual cases, respect for self-determination translates into providing each patient relevant information regarding various available alternatives for his/her particular condition, and then allowing the patient to make decisions according to his/her values. A decision is considered autonomous if a sufficiently competent patient, construed as a "normal chooser," has and understands the relevant information about the available options, and makes a reasonable and intentional choice without coercion from others ([4], p. 26; [5], p. 123). The focuses here are on how others directly involved in the care of the patient may influence the patient's capacity to make that particular decision, and whether the patient temporarily fails to comprehend his/her situation because of illness or depression in that moment.

On the surface, this individualistic focus on each patient's decision-making process appears appropriate, given that different patients in diverse societies have varying values, priorities, and considerations. The patient-cantered approach of contemporary medicine has led many practitioners to focus on each patient's values, perspectives, and preferences. It cautions the possibility that others may exert their power over the patient, and searches for ways to ensure that any potential power hierarchy is not used unjustly to pressure or coerce patients in their decision-making. This individualist approach echoes the mainstream view of power as the power-over or power to dominate another that focuses on refraining instances of direct domination ([6], p. 150). According to this framework, autonomy consists of ensuring that a subordinate agent is not being in the power of a dominant agent who directly imposes choices on him/her.

However, as some feminists have cautioned, while consideration of particular power relationships or individual decision-making process is important, such individualist framework is too narrow and misses the significance of other external powers—it does not address how many subtle and yet powerful forms of influence, particularly the social structure and institutional framework, shape people's decision-making process. The individualist view tends to take restriction of autonomy as a dyadic matter between two individuals—one who is dominant (e.g., physician) and another who is subordinate (e.g., patient). It presupposes that decisions that are not unduly restricted by the dominant agent's actions are autonomous. Nonetheless, as Nancy Hartsock and Iris Marion Young remind us, power and domination are not simply or always individual actions [7, 8]. Rather, they are also structural phenomena, the intended or unintended product of the actions of many people that shape others' choices. Patients' decisions are embedded within a complex set of social relations, practices, and policies that structure an individual's selfhood and can significantly affect people's ability to exercise autonomy with respect to their choices ([4], p. 32). We are socially-embedded beings, such that autonomy often incorporates intrinsically relational or social content, and it is thus impossible to assess patient autonomy without critically evaluating how or whether the interconnected social, political, and health-care structural frameworks often foreclose certain opportunities or pre-determine how individuals approach various health-care situations [9]. Marilyn Friedman, for example, cautions that social conditions can affect a person's ability to decide reflectively to act or behave according to one's reflectively affirmed values, and the individualist view neglects how the collective action and ideology often shape the way people evaluate their options by making some alternatives more costly than others [10]. This individualist view does not ask how the social system ought to be organized to ensure that people have genuinely meaningful opportunities to critically reflect upon their priorities, freely develop attitudes towards them, and make health-care decisions that would realize their life plans accordingly.

Choose from the Menu: Genetic Testing and Autonomy

Take genetic testing as an example. Prenatal and preimplantation genetic diagnoses have been presented in the medical and bioethics literature as a means to produce valuable knowledge about the genetic bases of various human characteristics and the risks posed to the integrity of that genetic material ([11], p. 35]. These procedures have been hailed as liberating for people who have an increased probability of having a child with various genetic traits that are deemed undesirable. In the pre-screening era, people had no secure knowledge of their genetic history, and as a result some worried about becoming pregnant—they were concerned about the possibility of bearing a child with certain undesired genetic dispositions. Others who suspected that they carried certain genetic traits suffered anxiety during pregnancy, often not knowing whether to continue the pregnancy.

Recent genetic screening technologies, however, have made it easier for people to decide to become pregnant. Potential parents can now undergo *in vitro* fertilization, produce multiple embryos, test each of them for various conditions or genetic traits, and only implant those that are free of certain unusual or undesired patterns ([12], p. 319]. Those who are already pregnant can also use various prenatal tests to screen for chromosomal and monogenetic deviations.

Bioethics discussions regarding genetic technologies often suggest that such technologies advance users' autonomy, since they presumably provide potential parents "secure information" that can help them to evaluate their situation and make reproductive decisions accordingly ([13], p. 67]. That is, such discussions follow the common argument for reproductive autonomy, assimilating genetic technologies into the realm of choices among which potential parents can decide. As many have argued, potential parents, particularly women, should have control over their bodies and reproductive decisions—they should have the authority to decide whether they would like to begin, continue, or terminate a pregnancy. After all, reproduction and raising children are some of the most significant events and processes of one's life, requiring some of the most important decisions one will make over the course of that life. Since such processes have tremendous psychological, physical, and financial impact on potential parents and the rest of the family, some people's decision to procreate may depend on the ability to have a healthy child ([14], pp. 152–153). Genetic technologies, which help potential parents monitor and manage their reproduction based on test results, are thus valuable strategies to promote their personal power and decision making ([15], p. 96). Some American courts have ruled that prospective parents might experience "diminished parental capacity" if they are not given the opportunity to decide whether or not to bear a "congenitally defective" child whose birth may cause undue emotional and financial burden for their family ([12], p. 96]. Some bioethicists suggest that failure to enable individuals to obtain relevant genetic information limits people's reproductive freedom, since it restricts their pursuit of important reproductive interests ([16], p. 324). In recent years, many who consider the ethics of health-care resource allocation have proposed increasing public funding for genetic tests so as to expand the number of eligible alternatives for potential parents who are concerned about passing on various genetic traits ([16], p. 208).

Given this background presumption that genetic technologies are desirable and offer individuals more power to control their reproductive decisions, discussions regarding potential utilizers' decision-making processes have often focused on ensuring that each person has relevant information and shows adequate understanding of the available technology. The emphasis on individual decision-making is manifested in concerns about confidentiality in exploring and storing potential utilizers' genetic history, explanation regarding risks and benefits of each relevant genetic tests, and voluntariness of people's consent for these tests. It is generally assumed that the consent process and decisions regarding the use of genetic technologies are similar to other private diagnostic and therapeutic decisions. While many acknowledge that genetic information is often difficult to communicate and understand, given the limited knowledge about the severity and likelihood of various conditions, high level of false positives and negatives, and confusion between genetic susceptibility and genetic disease, it is generally accepted that such challenge is not unique to genetic medicine ([17], p. 179; [18], p. 71). However complex or confusing the information might be, it is the responsibility of physicians and genetic counsellors to employ appropriate communication strategies to inform potential parents of the knowns and unknowns [19]. As long as potential parents are not pressured or coerced by anyone to undergo any particular genetic test, individuals who are given relevant information regarding various available tests for different genetic traits presumably are free to make private, informed, and deliberate decisions that will fit their value system.

Social Structure, Ableism, and Relational Autonomy

Certainly, respect for autonomy and privacy requires that we take the wishes of potential parents seriously in facilitating their decisions regarding genetic tests. Respect for self-determination demands that people are free to form their own preferences, develop their interests, and realize their life plans in ways they deem appropriate. Professionals and others should not exert undue power over the potential parents.

Nevertheless, the micro focus on whether a professional is unduly and unjustifiably coercing an individual, while necessary, is by itself insufficient in assessing whether people are truly free to form and evaluate their reproductive priorities. The dyadic modelling of power and autonomy examines whether the dominant agent (i.e., the physician) acts directly to pressure, manipulate, or alter the action or decision of the subordinate agent (i.e., the patient; [20], chapter 7). However, such focus on the dyadic relationship misses the impact of the larger social structure and ideology in determining potential patients' value framework and available options. Patients routinely act as they do in the medical setting because of the power that professionals have, even though the medical staffs generally do not do anything special to cause patients to adopt or change their actions.

The feminist notion of relational autonomy can guide us in recognizing the political dimensions of the multiple relationships that structure an individual's identity and the ways in which such relational identity determines a patient's authority and credibility in health-care contexts. Autonomy, including matters regarding reproduction, is not simply about presenting and providing options. Many autonomy-protecting measures reinforce the power of medical authority rather than promote patient autonomy, especially the autonomy of socially marginalised patients. As Susan Sherwin cautions, the implicit but well-established power hierarchy secures the compliance of docile patients who operate under the illusion of autonomy by virtue of being invited to consent to procedures the professionals predetermine to be appropriate ([4], pp. 28–29). If individuals have a right to make reproductive decisions for themselves, we need to examine not only whether professionals are explicitly trying to alter the potential parents' decisions. We also need to critically evaluate whether the broader social and cultural framework respects and supports this autonomy, or whether the social context undermines it ([21], p. 226). Direct coercion or explicit use of power over another is only one way to violate people's autonomy. Many other social influences and systemic factors can also significantly distort a person's ability to freely form and make reproductive decisions according to his/her value system. Feminists such as Anne Donchin, Susan Sherwin, Carolyn McLeod, and Rosemarie Tong have all expressed concerns of the long history of powerful social and medical control over the lives of women and marginalized groups [3, 4, 22, 23].

A closer look at the social meaning and contexts of prenatal genetic screening reveals that the individual model of autonomy is incomplete and inadequate in ensuring that potential utilizers of genetic technologies are truly free to decide according to their own values and priorities. In particular, the societal treatment and professional viewpoints of disability continue to shape the meaning of pregnancy and the role of screening programs, pre-determining people's decision-making framework and feasible options while giving the illusion of autonomy. There are also concerns that the widespread use of such technology will affect certain groups, such as people with impairment, and how that may in turn impact individuals making decisions regarding genetic testing [24].

As some have noted, the social domains are weighted against people with impairments and potential parents who choose to continue with pregnancies affected by various genetic traits [21]. The ableist socio-cultural framework is full of negative messages about impairments. It constructs the meanings of a good life according to the able-bodied and able-minded ideals, underlying the social and professional structures within which discussions and decisions regarding various impairments are held. Just as a racist or sexist society assumes one 'race' or sex to be superior and stereotypes or discriminates against people who do not fit that profile, an ableist society assigns lower value or worth to people based on their bio-physical and mental impairments. It treats individuals without impairments as the standard of 'normal' or even ideal living, and builds the social environment and expectations to privilege this population, despite directly or indirectly disadvantaging or disabling people with various impairments [25].

The blanket assumption that a life with impairment is inherently inferior is empirically inaccurate [26]. People with varying levels and types of impairments have diverse experience and abilities, and many can fully integrate into the society when appropriate accommodations and arrangements are available. Many people with impairments also do not think of their life as full of hardship that must be solved through medical interventions. Nonetheless, the ableist society continues to structure our understanding of the social world and quality of life in particular ways, portraying people with impairment "as pathetic, as medical tragedies, as dependent, and as unfulfilled" [21]. While feminist standpoint theory has reminded us that epistemic privilege can be drawn from the position of the marginalized, and that people with impairments report a much higher quality of life than projected by people without impairment, many in medicine and bioethics continue to dismiss or discredit their experience as subjective, mistaken, or simply result of the lowered expectations due to disabilities ([27]; [28], p. 103; [29]). Moreover, biomedical and bioethical approaches generally assumed that impairments are objectively and scientifically defined as species-abnormal functioning, such that those who lack the 'normal' opportunity range cannot have a high quality of life [29–32].

This ableist socio-cultural framework influences how genetic medicine is practiced, determines the way that clinical and other information is delivered or withheld, affects health-care funding priorities, and shapes people's perception of available alternatives. This is not simply a micro concern of specific professionals directly manipulating particular persons making screening decisions. Rather, the salience of this argument is to the society, scientists, and other health-care professionals who reproduce the prejudice by failing to provide accurate and balanced information about living with impairment, even if unintentionally ([21], p. 229).

While professionals are supposed to be non-directive and value-neutral in their explanation of various genetic traits and available options, research has found that many professionals appear to favour the use of genetic screening for various conditions, and many potential parents feel that they have no choice but to take the test [17]. This is perhaps not surprising, given that medicine operates within the existing social structure that favours certain forms of existence over others, and presumes a therapeutic imperative.

First, many professionals have limited interaction with people with various impairments, and their encounters usually occur only in the highly controlled medical setting which focuses on bio-physical symptoms in the individual. Because many well-meaning professionals have also never experienced life with a significant impairment, they inadvertently adopt and reproduce skewed impressions of the lives of people with impairments. Available information regarding the quality of life of people living with impairments and medical descriptions of various conditions and experiences are generally one-sided, selectively representing these conditions in static, absolute, negative, and stereotypical terms ([33], p. 81). While people with varying types and levels of impairment have vastly different experience, probabilities of having different genetic traits are typically presented as *inherent risks* that ought to be avoided at all costs. As one of the co-discoverers of the molecular structure of DNA notes, genetic diseases are "random tragedies that we should do everything in our power to prevent" ([34], p. 225).

This widely-accepted imperative to prevent the occurrence of genetic anomaly highlights the second reason why medical scientists tend to favour using genetic science and selective termination as the solution to the problem of impairment. Medicine is not a value-neutral or disinterested enterprise. Rather, its main goal is to promote the welfare of patients as a population. Many thus believe that health-care professionals have a prima facie obligation to pursue therapies that can promote human health [35]. Medical research and rehabilitative medicine generally aim at using technologies to diagnose and alter the bio-physical status of patients, who are viewed as temporarily or chronically defective. Preimplantation and prenatal diagnostic technologies, for example, aim at helping people have children who will be free from (a predisposition to) genetic conditions which are identified as or with disease. Many genetic experiments also aim at replacing disease-causing genes with therapeutic ones. Health-care pre-professional students and medical professionals take their role to be about preventing impairment from happening and 'helping' the 'vulnerable' people with impairments by 'correcting' their 'defects' ([36], p. 408).

While the therapeutic focus of medicine is understandable, it tends to assume that various conditions are inherent in the individual. The perception that genetic screening is the solution to the problem of impairment or defects reflects the individualist framework—individuals (i.e., potential parents) who carry or may pass on various genetic traits are considered both the loci and the agents of change ([18], p. 68). With the exception of public-health discussions, medical and bioethics literature continues to explore genetic and many other health-care issues as private individual matters, assuming that the potential barrier to opportunity lies mainly or even solely in the genetic makeup of the individual embryo, fetus, or the potential parent. The idea of personal genetic responsibility, which implies that an individual must learn about his/her condition susceptibility and then act to ward off the problem, transfers accountability from society to the individual, particularly to the woman ([18], p. 72). While most conditions are multifactorial, many health-care professionals continue to adopt the medical model of disability that assumes that disability results from bio-physical impairments that inevitably reduce the individual's quality of life and opportunities; that is, they focus on the symptoms of various conditions rather than on other factors such as personal and social framework that are often more important to people's quality of life and reproductive decisions [37]. Despite the rhetoric of patient autonomy, it is not uncommon that women who are offered various prenatal and preimplantation genetic diagnoses have a limited idea of the social or psychological experience of living with a particular condition, even though such issues are often most important to prospective parents ([38], p. 113). While the testimony of people with impairment is invaluable as a source of information for prospective parents of a child with an impairment, the biomedical and bioethical literature marginalises these people's accounts and renders them as subjective and unreliable. It is often assumed that the bio-physical conditions and symptoms alone determine people's experience and identity.

The Case of Down Syndrome Screening

A look at one of the most widely screened conditions can shed light on how the ableist presumptions of many scientists and medical professionals continue to dominate the system and constrain people's reproductive decision-making power. The dominance of the technological imperative and the ableist socio-cultural framework cannot be understood as acts of one person coercing another—such influence is pervasive and structural. Despite the promises of non-directiveness and individual autonomy, prenatal tests are not simply particular screening procedures taken by isolated individuals who seek such services. Rather, they are increasingly institutionalized within standard protocols for 'routine' maternal and prenatal care that govern all potential parents. For example, the American College of Obstetrics and Gynecologists (ACOG), the Society of Obstetricians and Gynecologists of Canada, and the National Screening Committee in the United Kingdom now recommend that all pregnant women, regardless of age group and family history, be offered screening for assessing their likelihood of having a child with Down Syndrome. In particular, the Society of Obstetricians and Gynecologists of Canada recommends *automatically* giving pregnant women over the age of 40 amniocentesis [39].

Since these tests are supported by professional associations and understood to be routine, they send the normative message that the diagnostic technologies are legitimate, inherently good, desirable, or even necessary, such that acceptance is expected and/or recommended as part of prenatal care ([11], p. 45; [40]). As screening is normalized, genetic testing is no longer simply a matter of particular potential parents seeking information about their genetic history. Rather, under the framework of routine testing, it seems that potential parents are considered risk carriers until proven otherwise, and it is up to these 'self-determining' women to decide and act appropriately. These organizations and their messages predetermine the setting in which commands are issued and obeyed—they form people's beliefs regarding genetic testing and construct an environment in which they act on them ([6], p. 156). They shape the way professionals communicate about such technologies and influence the way potential parents come to interpret and accept the information. Despite the promise of freedom to determine one's reproductive goals and act accordingly, routine screening in the name of the fetus' or pregnant woman's good makes it difficult and intimidating for women to ask for more information or seriously deliberate whether they want to accept or refuse the recommended test ([41], p. 56). After all, the innate characteristic of "routine" testing is to secure compliance of not only those women who would have elected to be tested, but also others who would not have specifically chosen to be tested [42]. As Susan Sherwin and Abby Lippman caution, in the context of prenatal testing, the informed consent procedure here gives the illusion of autonomy, since it amounts to assuring potential mothers of the opportunity to accept a procedure they are socially encouraged to choose ([4], pp. 28–29). It is designed to discourage women from challenging the existing framework, and sets the stage for social control and for blaming those who do not follow professional advice for their future child's health ([18], p. 72).

There has also been evidence that people are not only encouraged if not expected to undergo genetic tests; on the contrary, there are further pressures if a test result is positive, indicating the presence of presumably undesired traits ([43], p. 676). Language regarding a diagnosis of Down syndrome is generally negative, and pregnant women often do not receive information on support groups [44]. Even though a desire to know about the status of an embryo or fetus does not necessarily translate into an intention to refrain from getting pregnant or to terminate an existing pregnancy, health-care providers have historically operated under the assumption that an agreement to screening implies a belief that having a child with Down syndrome would be an undesired outcome and a wish to terminate an otherwise wanted pregnancy. Some obstetricians have been reported to be directive in their advice to pregnant women, advocating termination of fetuses with a range of genetic conditions [45, 46]. While termination rate by itself does not provide a full picture of reasons behind such decisions, it is worth noting that a review of international data between 1980 and 1998 shows that 92–93% of women terminated their pregnancy following a prenatal diagnosis of Down syndrome [47]. In recent years, some bioethicists have argued that people who carry the risk of passing on various genes that can contribute to certain disabling conditions have a duty to get tested and not bear children if they are in such 'high-risk' groups. Those who ignore such duties are considered negligent, selfish, or irresponsible [48, 49]. While the availability of genetic technology is supposed to give women more power to make reproductive decisions based on their own value system, we need to ask if routine genetic testing operates within and simultaneously reinforces an environment in which women believe that they have no choice but to take such a test and terminate a pregnancy upon certain results. Women who may want to exercise their autonomy and resist geneticisation or medicalisation of their pregnancy may worry about doing so ([18], fn 8), since following professional advice and utilizing the latest genetic technology are presented as simply the responsible things for each potential parent to do.

While most feminists concerned about the screening process focus on its implication for women's reproductive autonomy, rather than of its implications for people with various genetic conditions, their underlying principle that the personal is political is helpful here. The medicalisation of ableism and individualisation of impairment are of crucial moral and political importance, given the social dominance of the medical profession. When medical professionals reinforce the therapeutic imperative and reproduce the idea that it would have been better if someone with an impairment had not been born at all, it sends the message that selective termination is simply a scientific or clinical procedure to solve the problem of impairment, without acknowledging various social contexts that make such option the only viable alternative. Such a viewpoint repackages and reduces complex diseases and social experiences to individual genetic traits which can and should be prevented by individual medical actions [18]. In addition, it shapes the discussions about genetic screening and determines how such technology is perceived, marketed, funded, and recommended.

The individualist framework assumes that, insofar as prospective parents have the final legal authority in the decision-making process about testing and selective abortion, if no particular person is directly and explicitly coercing them, then they are free to agree or disagree with a medical professional's recommendation [50]. However, as the concept of relational identity reminds us, this framework ignores how various messages and suggestions regarding having children with impairments indirectly or even directly tell potential parents what they must do. Reproductive decisions and recommendations, when made within the context of institutionalized genetic technologies, implies that pregnant women are not making decisions as isolated individuals, but as part of a social movement. Genetic technology such as Down syndrome screening is not value neutral—it represents and signals a valuable opportunity for potential parents to select for desirable outcomes. Medical information is also value laden—professionals exercise their own personal and professional judgment in determining what information is disclosed, and how it is delivered. Even though most states and societies do not coerce or legally require people to seek genetic tests and selective termination for Down syndrome and other genetic conditions, the widespread professional support for these technologies communicates the message that those who do not 'choose' such options are denying their children something valuable and neglecting their responsibility.

If we only consider individual cases of genetic counselling and prenatal screening, it may appear that people's reproductive autonomy is respected, since explicit pressure or coercion is rare. It is also uncommon for blatantly eugenic statement to arise from those designing or advocating genetic screening programs ([21], p. 228). However, if we are genuinely concerned to protect people's right to make reproductive decisions according to their own values, it is insufficient to ask if any particular professional directly exerts manipulating influence onto his/her patient. As noted earlier, social forces are significant in shaping our identity, development, and desires, sometimes inhibiting patients' ability to shape their world [4: 35]. If we consider the widespread use of such technology and critically attend to the social messages that are given about living with impairments, we can begin to see how the social contexts and the technological imperative may have changed the meaning of becoming pregnant and made it difficult for women to opt for a pregnancy without genetic testing. Declarations of neutrality by various professional associations should not be regarded as automatically self-substantiating, particularly since the implicit purpose and role of various genetic screening programs are to reduce the incidence of impairment.

Social Resources and the Choice Context

Many bioethicists and scientists focus on how various genetic traits by themselves affect people's quality of life; however, a look at the social structure would reveal that other systemic matters often have even greater impact on people's life prospect and reproductive choices. As we saw earlier, some American courts recognize that many potential parents may not want to have a child with various genetic conditions because of financial burden. However, what the courts did not address is that such concerns are not simply individual matters. Rather, they are partly social and political issues that structure people's reproductive choices. Many societies still lack social services and directly or indirectly exclude people with impairment from social and economic participation, marginalizing and disabling them. Potential parents also lack necessary economic and practical assistance [51], making it less feasible for them to continue pregnancy potentially affected by various genetic conditions. If social support were available to ensure that parents of children with impairments will not be driven to financial ruins or exhaustion, these potential parents would have a more meaningful opportunity to fully evaluate if having a child with various genetic traits would fit with their life plans.

In other words, it is insufficient to consider only the particular moment of decisions. We need to examine the social basis for decisions regarding genetic testing at all levels, including how the set of available options is constructed. When adequate and appropriate information and social resources are not available to support parents with children with impairments, certain reproductive options that potential parents might have preferred are foreclosed, making their decisions constrained, even though there is no other specific agent directly pressuring or coercing them. Without examining how such constraint makes it very difficult for people to realize various alternatives (e.g., to bear and raise a child with impairment) according to their value system, the individualist framework of autonomy ignores some very important factors that affect people's decision-making.

Autonomy and End-of-Life Discussions

The individualist notion of autonomy, the ableist framework, and their accompanying problems that underlie discussions of prenatal genetic screening also shape the discourse of medically-assisted death. It is generally presumed that patients now have a right to decide whether they want various life-sustaining measures either through direct consent/refusal or advanced directives. Court cases and legislations in the last few decades have been pushing various countries to consider the right of people who are terminally ill or disabled to also seek medically-assisted death. The Canadian example of Sue Rodriguez, the American case of Dax Cowart, and discussions regarding Dr. Kevorkian are often presented to demonstrate the intolerable suffering of people with disabilities or terminal illness, and to assert that it is sometimes morally permissible for health-care professionals and family members to facilitate the death of the patients. The autonomy argument for medically-assisted death generally appeals to patients' right to make decisions about their lives and well-being in ways they deem appropriate [52–56]. After all, under the current practices of informed consent, patients have the right to refuse any procedure that counters their value system and priorities, even if that may result in the patient's death. The autonomy argument also challenges the alleged distinction between killing and letting die that is sometimes said to allow only certain life-ending measures but not others. The assumption is that if people believe their impairments are rendering their lives unbearable and if medical technology cannot cure their 'defects', they should be allowed to end their suffering in a dignified way via assisted death.

It is beyond the scope of this essay to explore in detail whether there are morally significant differences between various means of medically-assisted death, ranging from removal of life support to lethal injection, such that some of these measures are more legitimate than others. My question is limited to whether the common autonomy argument in these cases is adequate in capturing people's decision-making framework. As in the case of prenatal genetic screening, I argue that the autonomy argument for medically-assisted death takes the individual decision-making process for granted without examining the contexts of people's desire to seek death. Certainly, autonomy is an important matter in end-of-life decisions, such that competent patients' right to consent to or refuse any treatment, including life-sustaining procedures, ought to be respected. Nonetheless, the question of whether people with impairments would choose death if they truly were free is often omitted in discussions regarding medically-assisted death ([36], pp. 411–412]. It is often assumed that these people would choose to die because their impairment *itself* creates too many barriers or too much suffering, rendering them unable to enjoy life. While some people with serious impairments may face extraordinary hardship and genuinely have a categorical preference for death over living with their situation, there are no statistics to support the assumption that such preference is prevalent among many people with impairments. In fact, various court cases show that some people with impairments who seek assisted death would want to live if social support and opportunity-enhancing arrangements are available, *even if their physiological condition remains unchanged* ([36], p. 412; [57, 58], p. 141).

Some well-publicized examples can shed light on this issue. Elizabeth Bouvia, Larry McAfee, and Kenneth Bergstedt are three Americans who went to court to request medically-assisted death. McAfee and Bergsterdt, who became quadriplegic after a motorcycle accident and swimming accident respectively, sought court authorization to turn off their respirators. Bouvia, who had severe cerebral palsy and degenerative arthritis, sought an order prohibiting a hospital from nourishing her artificially. Their respective courts agreed that the state had no overriding interest in interfering with the natural process of dying among citizens whose lives were irreparably devastated by injury or illness and could only be sustained by 'radical' intervention. The courts presumed that the quality of life was poor for all these individuals and thus found that it was reasonable for them to think of their situation as hopeless, useless, unenjoyable, and frustrating. And since these were competent adults, protection of individual autonomy supposedly meant they had the right to refuse artificial methods to extend their lives that were full of suffering.

However, missing in all these discussions were the larger contexts of these people's suffering. It was generally presumed that these individuals felt no hope in their lives because of their impairment. However, a close look at their experiences reveals that their "desire" to die was embedded within a complex set of social relations, policies, and circumstances that foreclosed living options they might have preferred and made death the only plausible means to end their suffering. While the court focused on Bouvia's physical condition, it was noteworthy that the then 26-year-old graduate student in social work was dealing with a miscarriage and a failing marriage, and was told that she would never be employable ([57], p. 123). Larry McAfee wanted to die because his Medicaid coverage would not support him to live at home with attendants—he was given no choice but to live in a hospital or nursing home. When it eventually became possible for McAfee to use his engineering talents and to get home care rather than state institutional care, he no longer wanted to die ([57], p. 126). Bouvia also changed her mind.

Bergstedt's case had a different ending. Becoming quadriplegic as the result of a swimming accident at age ten, Bergstedt lived another 21 years of what appeared to be a satisfactory life under his father's care and wrote poetry. However, when his father became terminally ill, he wanted to die, worrying that the society would "cast him adrift in a sea of indifference" and force him into a nursing home after his father's passing ([59], p. 628). The trial court granted Bergstedt's petition, and he died after the respirator was disconnected.

What makes Bergstedt's case noteworthy for our discussion is the fact that even the Nevada court recognized that Bergstedt's desire to die was closely connected to his fear of lack of social support, and that if Bergstedt had found an appropriate substitute caregiver, he might not have wanted to die. Nonetheless, instead of getting to the cause of his desire to die by helping him to find such support, the court only focused on the right to have his respirator disconnected. Together with Bouvia and McAfee, these examples show that the individualist view of autonomy is too narrowly delimited to ensure that people can genuinely make end-of-life decisions that fit their value system. This individualistic notion of autonomy focuses on whether an individual is making a rational or reasonable decision among the available options without considering if some desired alternatives have already been restricted by the social structure in the first place. Certainly, paternalism or interference with self-determination of competent individuals should be prevented. However, the individualist model ignores the multiple ways in which one's autonomy and well-being can be compromised, such as by existing institutional arrangements and practices in the health-care and social system. Those who launch autonomy-based arguments for assisted death neglect how *social* factors, such as the availability of home-based services and social support, significantly affect people's desire to live or die. These authors think that the question that arises about one's autonomy is a purely moral one concerning an individual's reasoning capacity, rather than also a political question regarding distributive justice and marginalization of various population groups. Furthermore, they generally do not consider how society can provide such resources in order to accommodate people with impairments, so that they can truly decide according to their value system.

Just like reproductive autonomy in the genetic age appears to be restricted to the alleged opportunity to undergo genetic testing and selective termination, it seems that autonomy to end one's suffering is limited to the alleged right to choose death and effect one's choice without the state's interference, even if other people are needed to be the instruments of such decisions. Historically, people with impairments have been marginalized and treated as "others"—their preferences and beliefs regarding their welfare are generally ignored, trumped, or not even solicited [60]. It is perhaps ironic that their 'desire' is 'respected' only when they seek to die and because the state deems their lives to be hopeless and useless. Without addressing the social context within which people may find no feasible option but to seek death, the autonomy argument for assisted death reinforces the status quo by not questioning whether imposition of isolation, abandonment, and lack of support and opportunity make life seem not worth living to people with impairments. By failing to ask whether current social arrangements enable or prevent people with impairments to be free, the individualist model of autonomy cannot ensure that the ‘desire’ to die truly reflect people’s preferences.

So… Not Autonomous?

One note of caution here. My concerns regarding the impact of oppressive social structure on people’s identity and decision-making framework should not be construed as arguments for the denial of people’s moral agency. While it is important to keep in mind how the ableist socio-cultural framework often precludes certain options from being considered and reshapes a person’s value system, we need to refrain from treating people with impairment paternalistically in end-of-life care. In discussions of medically-assisted death, some reject the application of the autonomy argument *specifically* for people with impairments, arguing that these people constitute a vulnerable group that requires special protection [61]. They distinguish two classes—those with impairment and others without impairment. While people without impairment are presumed to have the capacity to make their own reasoned choices regarding end-of-life care, such that interference with their self-determination should be avoided, those with impairment are presumed to be vulnerable and thus call for special procedural safeguards. The underlying assumption is that people who have impairments or are terminally ill are incompetent, *as a class*, to assess their own well being.

Putting aside the issue of whether it is always possible to clearly distinguish two classes of patients, particularly in end-of-life cases, there are remaining questions of what it means to recognize the oppressive nature of the ableist socio-cultural framework. Certainly, we need to acknowledge the impact of such social structure on people’s despair, and to ensure that the autonomy language does not mask the barriers of oppression. Feminist concerns regarding how oppressive conditions may deny marginalized people the opportunities for self-determination or prevent them from pursuing goals different from those who have influence or authority over them are certainly valid. As in the case of gender socialization, which aims at having women internalize society’s standard, social control of disability-related decisions is most effective when norms of quality of life and ability are securely internalized in people’s attitudes toward themselves ([62], p. 95; [63], p. 391). In such an oppressive environment, an agent’s attempt to develop an authentic self and make autonomous decisions accordingly may be compromised.

Nonetheless, I argue that we need to refrain from acting paternalistically towards those whose choices may have been shaped by the ableist socio-cultural framework. While we need to lift social barriers and promote a motivational system that exhibits bi-directional integration and critical assessments, a system within which people can make informed and voluntary end-of-life decisions, it would be extraordinary to contend that oppression destroys the status of individuals with impairments as moral agents, rendering them disqualified to evaluate their overall situations and exercise judgment accordingly [64, 65]. Granted, people make end-of-life decisions within a social framework—their desire for medically-assisted death is shaped by the broader familial, social, economic, historical, and cultural contexts, some of which have reinforced the idea that a life with impairments is burdensome or even not worth living. There may also be other moral and social arguments against suicide. However, prevention of medically-assisted death *particularly* for people with impairment, through denial of self-determination based on speculation about social manipulation, treats the targets of protection as less than persons. It violates their moral agency, isolates them, and perpetuates their inferior status by allowing dominant agents to override their expressed wishes and act paternalistically towards them ([58], p. 135). This façade of the care discourse, which denies the “others” as equals who deserve equal moral standings, constructs those with impairment as inferior, in need of the paternalistic guidance and rule of their non-disabled superiors to promote their welfare ([66], p. 135). In extending special protections, such paternalistic measures reinforce and yet conceal epistemic oppression and self-serving relationships of power and domination.

When the concern of autonomy is a matter of social environment, respect for autonomy should be about removal of such social barriers or empowerment through social restructuring rather than paternalistic protection. Instead of giving people with and without impairment different treatment regarding medically-assisted death, which reinforces the symbolism of otherness and perception of vulnerability, it is more important to carefully assess the cultural framework that defines and shapes people's life experience. To ensure that we do not further marginalize or patronize people with impairments, we should accept their subjective interpretation of their own situation, while providing additional information and alternatives as appropriate. A full account of autonomy ought to ensure that alternatives that would otherwise exist have not been made less accessible by the influence of social institutions ([13], p. 166). It is only when a system acknowledges the input of people with impairments and guarantees a fair process to determine adequate access to effective and affordable palliative, home-care, and hospice services that people can be genuinely free to construct and decide according to their value system.

Conclusion

It is often argued that, since health care decisions can have tremendous impact on people's familial, social, financial, and psychological well being, a commitment to autonomy requires that professionals respect patients' preferences and values. Certainly, such commitment is necessary. Nonetheless, to protect autonomy, we cannot only consider specific health-care decisions or the moment of medical decision-making. As many feminists have reminded us, we also need to think about the oppressive potentials of the social contexts in which people make their reproductive and end-of-life decisions. The fact that the ableist socio-cultural framework has shaped people's decisions regarding the use of various genetic technologies and medically-assisted death shows the inadequacy of an individualist model of autonomy in promoting patients' self-determination. People's capacity to form and realize their life plan is constrained by an ableist socio-cultural framework that marginalises the experiences and viewpoints of people with impairment. While people supposedly retain the legal right to make their health-care decisions, whether it is about beginning or end of life, it is important to note that dyadic power relations are not the only barriers that may affect people's autonomy. Rather, the social contexts regarding impairments often shape people's "desire" and/or decisions in receiving genetic tests, undergoing selective termination, and requesting medically-assisted death.

In his recent political campaign in the Canadian province of Ontario, home of the most comprehensive newborn screening in Canada, Premier Dalton McGuinty argued for the expansion of prenatal testing. While McGuinty did not say that all women should have prenatal test, or that all parents ought to screen their newborns, promotion of genetic testing by a political leader seems to reinforce the assumption that testing is in everyone's interest and desire. In an ableist society, we need to ask whether or how many personal decisions are shaped by the dominant culture. To truly promote autonomy, we need to restructure the social framework to ensure that people's preferences are not foreclosed because of discriminatory attitudes and oppressive social structure.

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