Abstract

In light of preconceived notions in Western society that children make irrational decisions, society often wants to “protect children from themselves” (Doyal and Henning 1994, 771). In Eastern countries, notions of familial hierarchies, respect, and harmony remove children from decision-making contexts and promote non-emotive silence (Wang and Marsh 1992, 85; McLaughlin and Braun 1998, 118). One must be wary of unquestioningly valuing parental choice as it can cause medical, personal, and familial harm while disregarding the importance of children’s autonomy, regardless of how “limited” or “incompetent” it may be. It is unjust to generalise and say that children are inexperienced and thus lack capacity to make decisions. It is also unjust if cultural notions disregard the child’s voice. For children who have been ill their whole lives, it can be certain that they have a greater capacity to understand their situations than they are given credit for—it may even be reasonable for them to “prefer death” and voice that thought (Raymond 1999, 15). I am writing from an “end-of-life” perspective where minors are severely ill, probably have been for a long time, and should
have the opportunity to refuse treatment and have that decision respected. This fact is not mentioned often throughout the essay because although end-of-treatment care for children prompted my research, I believe minors have an overarching ability and right to have a role in their medical decision-making, regardless of the severity of the situation. I am not suggesting that adolescents should make decisions unaided. I do recommend, however, a care ethics approach that calls upon guardians and professionals to assist with the adolescent-patient’s understanding of the situation by contextualising the situation and offering valuable information and teaching via open communication. This enhances and develops patients’ capacity, values it, while also providing the opportunity for professionals and guardians to evaluate their capacity which is currently a difficult process. Contextualised by the current dynamics between parent, child and medical professional, it is clear that a care ethics approach is a beneficial way to rebalance the power between these parties and fix many of the issues integral to a) unjustified overt paternal authority; and b) not acknowledging or valuing a minor’s capacity, for families all over the world from Canada to New Zealand to China, Malaysia and India.

Keywords: medical decision-making, adolescents, end-of-life care, care ethics, China, New Zealand

The Current Dichotomy and Difficulties in Deciding Capacity in Minors

Legally minors are unable to provide informed consent in medical decisions (Kuther 2003, 343). There are some exceptions, as when a child is: (1) emancipated; (2) assessed and labelled a mature minor by a judge or doctor; or (3) seeking medical help for a specific health problem (ibid., 345). Unless challenged through these processes, children are automatically deemed incapable of understanding the complexities of their medical situation, particularly concerning death (ibid., 345). Thus they are thought to lack the components of competency necessary for informed consent.

This legal view, seen in many countries such as Canada, New Zealand, Singapore and Malaysia, is increasingly challenged by medical societies because studies have illustrated the extent to which minors possess capacity. Throughout childhood and adolescence, a minor’s goals “extend to a greater length of time” (ibid., 349), they are capable of asking meaningful questions, and they tend not to naively and automatically agree with parents or professionals (ibid., 347). These abilities are proof of developed/developing skills that arguably enhance the proficiency for making meaningful decisions. Consequently, the American
Academy of Paediatrics states that if a minor has “developing capacity or is capable of providing assent to treatment, his or her wishes should be respected” (ibid., 355).

Reconciling the legal and medical viewpoints is problematic because what these studies conclude, unlike what the law suggests, is that being competent or incompetent is not clear cut when it comes to minors. Undeniably, there are definitions of what it means to be competent. It is required that an individual (ibid., 346):

- understands the situation, factual issues, and vital information including possible outcomes; effectively considers the consequences of each alternative;
- compares alternatives based on one's evaluation of the consequences and an understanding of how each fits within the framework of one's values and goals; and make a voluntary uncoerced decision.

During adolescence, however, the repertoire of skills that enables competent autonomy as described above is developing (Weins 1993, 97). Skills such as “reason, memory … and verbal communication” are progressively being attained and refined (ibid., 98). The degree to which adolescents can fight coercion, ask the right meaningful questions, or express their desires evolves throughout childhood and adolescence; over time, various degrees of capacity are held by one individual. This change also occurs at different rates between minors, meaning children of the same age may be at different levels of capacity. Due to these sources of variability, there is tentativeness surrounding the labelling of minors as competent.

Compounding this issue are the non-standardised ways by which doctors measure minors’ capacity. Definitions do not stipulate what is considered a sufficient level of aptitude for each criterion, nor are there guidelines to aid in “assessing maturity or decision-making capacity” in adolescents (Kuther 2003, 346). In fact, judgments are often subjective and cannot be objectively verified and may lie outside the physician’s expertise. Even if a child is considered mature or is being assessed for that status, doctors are caught in a paradox. Adolescents are deemed to be competent when they consent to a doctor’s proposal, but “incompetent if they reject professional [or potentially parental] advice” (Devereux, Jones, Dickenson 1993, 1460). This dichotomy is partly caused by the legal system which distinguishes and accepts minors’ right to consent to treatment but not their right to refuse treatment (Doyal and Henning 1994, 769). If a minor is judged to be mature, they technically have the same rights as a competent adult, that is, they not only have the right to consent to a treatment but inherently also to refuse to provide that consent (Kuther 2003, 354; Doyal and Henning 1994, 768). If this were false, then the concept of consent
loses all meaning and would only be a “right to agree with the medical practitioner” (Devereux, Jones, Dickenson 1993, 1460). This double standard is simply illogical and oversimplifies and overgeneralises the complexities of capacity. Overall, the inability to provide a concrete answer regarding extent of capacity—due to the fluctuating capacity of adolescents and the difficulties in measuring that capacity—causes physicians or judges to use their professional, subjective judgement to err on the side of caution to “protect” minors (Doyal and Henning 1994, 769). Instead of acknowledging any capacity in minors, medical and legal professionals turn the power of decision-making to guardians and parents as the “natural decision makers” of children (Whitty-Rogers et al. 2009, 745). Similarly, in countries where adolescents’ capacity is almost an irrelevant concept due to social, religious or cultural beliefs, there is a corresponding culturally-driven perception that it is still most appropriate for family members, or one family member, to make medical decisions for minors (Tsoh et al. 2015, 1031).

Examining the Argument for Parental Authority

According to Edwin Hui (2008, 287): “in the West, parental authority is justified on three presumptions: (1) minor children are too immature to make major decisions; (2) parents always act in their child’s best interests due to the natural bonds of affection; and (3) parental authority is essential for maintaining family integrity”. Furthermore, since the family unit is a child’s primary source for learning values and life lessons, judicial systems advocate that parents should be allowed to make decisions for their child which “will permit those values to grow” (ibid., 289). There are obvious exceptions to this general rule, but this concept further substantiates the propensity to trust guardians’ choices (ibid., 289).

As previously discussed, there are arguments for and against the first claim regarding child immaturity. Regarding the second presumption, parents do not always act in their child’s best interests. Foremost, guardians can be subject to many influential variables such as financial factors or obligations to their other children (ibid., 289). Personal emotions such as not wanting to abandon their child may also blind them to their child’s “needs and concerns” (Whitty-Rogers et al. 2009, 746).

Additionally, “best interest” is a subjective concept (Kuther 2003, 244). There are many instances where parents attempt to act in the best interests of their child but arguably fails to do so. Many parents will sugar-coat the truth or lie by omission, in an attempt to protect their child (Whitty-Rogers et al. 2009, 750). Unfortunately, adolescents have shown great intuition in these situations
and often realise that something is wrong (ibid., 750). This not only causes angst and confusion, but also places a burden on the child to not speak about the illness in an open manner (despite her own wishes) for the sake of the parents. The determination of failure to meet a child's best interests arises most often in cases where a parent refuses treatment—such as refusing blood transfusions for Jehovah's Witnesses—in the name of the child's best interests. In such cases, it is clear that the decision is medically harmful to the child and the judicial system intervenes on the premise of negligence. On the other hand, forcing an adolescent to be treated, regardless of the futility of the treatment or the child's physical or verbal reluctance or refusal, can inflict a different sort of harm. Sometimes this harm vastly outweighs any benefit and these types of parental decisions should be examined more prominently in the legal and medical systems. When harm can be caused by acting in one's supposed best interests, judging and justifying best interests becomes difficult. This is because benefits and harms include not only medically objective factors, but also many subjective components of well-being such as beliefs, goals, values and emotions, which are contextually grounded within an individual's life. Ultimately, balancing probabilities of benefit and harm is not “a simple, straightforward task”, even for a parent (Groarke 2000, 219). These difficulties beg the question whether parents can make an accurate best-interests decision for their child based solely on their own “natural” parental intuition and insight.

As for the third claim, parental authority does not necessarily maintain family integrity. External factors, such as the environment in which medical decisions for a very ill child are made, increase potential points of familial tension. This heightens the potential for family disintegration. For example, parents can disagree on the plan of treatment, causing a divide in the authoritative parental unit (Whitty-Rogers et al. 2009, 753). Consequentially, the integrity of their decisions is questionable. Alternatively, family tensions may already exist, for example, when parents are divorced. Furthermore, despite parental authority, the interests of the child and the parents may conflict. When a “united family front” is superficially maintained through omissions or sugar-coating, children can feel resentment or confusion towards their parents. Problematically, in cases of obvious and severe disagreements between a minor and guardian, there is “a lack of legal criteria governing the matter” to guide parties on how to proceed in such circumstances (Kuther 2003, 354). To resolve many of these issues, the medical professional is required to go to court. This takes time (which may be limited due to the minor’s illness) and it can cause further family instability and strife. It is arguably the parent’s “right of authority” that causes the family unit to break down.
As mentioned, there exists in some Asian societies a different strain of thought that justifies parental authority. Cultural, religious, philosophical and moral factors influence Chinese, Japanese, Vietnamese, Singaporean cultures, among others, to consider familial harmony, reputation, the larger good and filial piety when making decisions (Ng et al. 2013, 2; McLaughlin and Braun 1998, 118; Chong et al. 2015, 420, 424; Wang and Marsh 1992, 85). Such an approach often places the father at the forefront of decision-making because he is at the top of the vertical hierarchy of the family (Wang and Marsh 1992, 85; Cheng, Ming & Lai 2012, 432). The points discussed above are equally applicable even under this different system of reasoning. When making decisions, the child-patient is inadequately informed; finances and obligations to the other members of the family are considered when making decisions; children must often stay quiet; and even though decisions are made with the family in mind, there may be a very real lack of family integrity (Chong et al. 2015, 421, 424). Similar negative effects spring from these actions, and while it is more likely that grievances are not voiced, it does not mean they do not exist (Wang and Marsh 1992, 84). The idea that this type of social structure can facilitate decisions in the best interests of the patient and the family, and that it sustains family integrity, is incorrect. What comes to light is that regardless of the reasoning behind parental authority, similar problems arise in Eastern and Western medical decision-making environments. In both cases, these problems are important to resolve as the development of children’s autonomy and capacity is similarly at stake.

The Need For (but the Harm of) Paternalism on Minors’ Autonomy

The justifications for parental authority are deficient and provide cause to question why guardians are legally or culturally regarded as the most appropriate decision-makers. As demonstrated, parents are not wholly superior to children in making decisions that affect the child because guardians face obstacles—albeit different and potentially more difficult ones—of their own. Furthermore, the structures in which decisions are made, and the decisions themselves, have implications. Many of the harms caused by “best interest-fuelled” decisions taken by parents or the family grow with frequency and intensity as a minor’s capacity develops and she is able to recognise and understand (a) more of the intricacies of the medical situation; and (b) her needs and wants in relation to the medical situation contextualised by her life plan. When considering a minor’s growing capacity for self-determination, the continued value placed on the validity of parental decisions for minors can be argued to be unjustifiably paternalistic.
Autonomy is considered by some scholars as the “greatest good” (Groarke 2000, 209). By the same token, paternalism is an “intrinsic evil because it eliminates autonomy” (ibid.). Constraining autonomy to any degree necessarily harms any individual (Doyal and Henning 1994, 768). For the reasons mentioned in the following paragraph, children require paternalistic protection and guidance, but they can still be harmed by excessive paternalism. Paternalism “ignores the opportunity to assess [and value] children’s level of understanding” and “stunts human realization” (Whitty-Rogers et al. 2009, 745; Groarke 2000, 208). To assume that minors are incompetent means that their capacity is never assessed, even though their insight may not only be surprisingly valuable but necessary to the decision-making process. Problematically, the opportunity for capacity growth via decision-making and critical thinking is never pursued. For example, children brought up in a Confucian familial context “do not know how to choose” (Hui 2008, 292). The ability to choose is an essential skill necessary for autonomy and self-determination, a fundamental right protected by law in many countries. Denying growth of that skill denies the fundamental right that allows an individual to explore, understand and express one’s self; this seems to occur worldwide when concerning children.

In some countries, such as Singapore, while individual autonomy is considered a right, it is still considered more appropriate to ask for the family’s opinion (Chong et al. 2015, 421, 424; Tsoh et al. 2015, 1031). This is because individual autonomy is generally not valued but considered a threat to the integrity of the culture (Wang and Marsh 1992, 83). On the contrary, as developing individuals, minors’ existing capacity should not be oppressed but engaged so that as they reach adulthood, they are experienced and proficient in making meaningful decisions that not only match their identity and life goals but also their cultural beliefs (Kuther 2003, 351). Possessing the ability to think critically and choose can, in fact, strengthen cultural practices.

This is not to suggest that adolescents should have full autonomy to make medical decisions or that parental input is fruitless. The fact of the matter is that patients on the whole are particularly vulnerable because of paternalistic tendencies in healthcare, the overwhelming feeling “when they have to … make decisions on their own” (Ho 2008, 131), and the “dependence of the patient on the expert” (Weins 1993, 95). It has also been argued that the medical system objectifies patients by “shredding [their] sense of identity” (ibid., 130). This vulnerability in the medical system is exponentially worse for children, not because they lack competency but because their current state of development—in terms of identity, rationale, knowledge, etc.—subjects them to be more easily coerced or violated. Furthermore it is important to maintain culturally
important values; this can be accomplished with the help of parental involvement. For these reasons, families should, and must, remain a vital part in the medical decision-making process, but in a different way.

The Need for Balance

There are clear logical, practical and ethical issues in allowing either parents or minors to be the sole medical decision-makers. In New Zealand, there is a complete rights-based focus that involves the child, parent and medical professionals, in determining what they are or are not permitted to do. On the other hand, in some Asian countries, there is a strong cultural focus on the authority of the family and not the child-patient. There is a legitimate need for a systematic compromise that respects all parties' voices because of the benefits that arise from such an arrangement as discussed earlier—benefits for mainly the child but also the family and the associated culture. A care ethics approach can achieve this balance by giving children a voice, allowing them to develop their capacity, as well as solving many of the inherent problems of an approach that makes parents the sole decision-makers.

The Scope of Care Ethics

Care ethics is a feminist concept that focuses on the “relational self” (Ho 2008, 128). Individuals do not exist in isolation but in relation to others to whom they are emotionally or psychologically close, such as parents, siblings and friends (ibid., 129). An individual's actions and decisions affect not only herself but also her relational community. Mutual respect for the autonomy of each individual in the relational community is upheld because each person is a stakeholder in the decisions being made and the consequences that arise from them (Mendel 2007, 68). As a result, each person has equal claim for her unique and valued autonomous voice to be heard (ibid., 74). Even though in the present legal context, the child is not an autonomous decision-making individual, she is still integrally connected to the relational self of the parents who are deciding for her (Kuther 353). It cannot be denied that the child is a stakeholder in a serious medical situation where she is concerned. Thus, the minor becomes an individual whose voice warrants recognition.

The idea is for difficult decisions to be made as a cooperative collective from mutually equal and respectful discussions. Yet, one cannot expect children to speak up simply because there is now the opportunity to do so. It is important to implement measures to prompt children because as not fully-competent,
autonomous individuals, they may need help in voicing their thoughts. Fortunately, care ethics is comprised of concepts that, when acted upon by others (such as parents, guardians, family and professionals), enables a focus on the child’s capacity growth.

The Benefits of Care Ethics: Enabling Capacity for Assent, Maintaining Family Integrity and Attaining an Accurate Best-Interests Decision

The act of caregiving—through listening, conversing, understanding values and beliefs, and offering overall general support—is a means to “empower a care[d]-for person” (Bender 1992, 537–8). For children, this may mean increasing capacity and competency. Exercising decision-making skills (such as in a care ethics-based approach) increases the capacity to make decisions, but it also develops identity. As identity is cultivated, competency for decisions becomes more aligned with identity and thus more rational (Wiens 1993, 98). If Anita Ho’s claim is indeed true and family is at the “centre of the child’s existence” (132), the simple support of family can (a) heighten a child’s sense of identity in an environment where it is difficult to maintain identity, and (b) lead to decisions that more or less coincide with and reinforce personal identity as well as the family’s identity. Realistically, the relational community of parents, siblings, potential extended family members and friends do not just offer support, but remind and educate the child of the larger contextual situation in which she is based. This is why this relational community is so important—family members and friends can ensure that the child considers the various aspects of decision-making, and that the components of competent decision-making are grounded within these aspects. These can include wants, goals, family values, culture, religion, etc. Family involvement has clear benefits for the family (such as making decisions within a cultural, familial context), which makes it suitable for various Asian cultures to adopt (Groarke 2000, 214). More importantly, facilitating the growth of components that are important for a minor’s autonomy capacity (such as decision-making) is an act of caring not only because it sanctions the development of a fundamental human right, but because this development is beneficial to any minor regardless of her culture.

An important part of making a decision within a medical setting, however, is the acquisition and understanding of medical information. Yet adults can be as equally overwhelmed as children in healthcare settings. Therefore medical professionals (particularly nurses), as the informants and communicators to minors and their families, are an integral part of the relational community,
because they can educate and provide important medical information to both
the patient and the family (Whitty-Rogers et al. 2009, 754; Wiens 1993, 103).
For minors, this may involve offering information in “developmentally appropri-
ate ways” to enhance their capacity to understand so as to “maximize their
quality of decision making” (Kuther 2003, 347; Doyal and Henning 1994,
770). Medical professionals can empower a minor by providing information that
will generate a specific medical context to be placed alongside the broader,
personal framework offered by family and friends in which the thought processes
are grounded. Care ethics’ focus on aiding individual autonomy grounded in a
narrative results in parents and professionals attempting to increase the minor’s
awareness of the complexities in a specific situation. This is important for
capacity growth.

It should be noted that within this process, parents and medical professionals
are not striving for capacity in adolescents which will enable fully informed
consent. Instead, they strive for a lower standard of competence—assent—which
requires a lesser degree of understanding or reasoning ability (Whitty-Rogers
et al. 2009, 758; Kuther 2003, 351). In fact, the American Medical Association,
American Association of Paediatricians and the Canadian Paediatric Society have
all stated that physicians “have an ethical duty to promote the autonomy of
minor patients by involving them in the medical decision-making process to a
degree commensurate with their abilities” (Whitty-Rogers et al. 2009, 748; Kuther
2003, 351). This respect for the extent of their capacity despite their age enables
an appropriate level of participation by adolescents while still recognising that
there are potential limitations to their capacity; the complexities regarding extent
of capacity is finally acknowledged in theory and practice.

There are other benefits to care ethics discussions as well, such as maintain-
ing family integrity without absolute parental authority. Communication forces
parents to deal with their own thoughts and emotions. Instead of omitting
information, parents must have a frank conversation about the realities of the
situation; children will no longer be burdened to remain silent for their parents’
sake. It also means that a child’s unanswered questions, lingering fears or desire
to be acknowledged are addressed as viable and logical concerns that are
important in the child’s world, not simply brushed away as utter silliness
(Ho 2008, 134). Ideally, there will be family integrity because there is respect
between all parties. Alternatively, family integrity will be maintained because
initial conflicts can be diffused through caring discussion that enables the
respective parties to have a better understanding of one another.

Most importantly, a more accurate decision can be reached with this
approach. Instead of a single parent guessing what is in the child’s best interests
or being blinded by other variables such as family, the adolescent has a say in the best interests of her own life. The adolescent’s view is weighed accordingly, along with everyone else’s thoughts, concerns and ideas. The diversity of individuals within a relational community means there are many perspectives regarding best interests—what are the components of best interests, what are the benefits and harms, how can one balance them, etc.—that can be discussed and evaluated. For example, the determination of life and death in terms of sanctity of life or quality of life can be discussed, and a goal can be mutually agreed upon (Bender 1992, 527). Is the relational community striving for life, dignity, or simply maximising a child’s autonomy or happiness in the end stages of her life? Ideally, a consensus is reached “based on the shared values” of the group (which are likely to exist because the individuals of the community have relationships with one another, whether socially, personally, culturally or religiously) (Mendel 2007, 71). It is likely that the decision will be more aligned not only with the patient’s best interests but the community’s as well. Moreover, since both Western and Eastern families consider external factors, whether consciously or unconsciously, this is of benefit to all.

Care ethics is particularly beneficial in Asian countries for a few reasons. First, in China it will give professionals a voice as it makes them a part of the relationship. They can then challenge the sometimes complete authoritative-ness of the father. Second, in countries such as the Philippines, where people are hesitant to discuss emotions and problems with healthcare workers, care ethics provides a structure where a) family members can at least talk to one another, and b) medical professionals can try and facilitate discussion between all parties in order to illustrate the benefits of doing so (McLaughlin and Braun 1998, 120–1). Third, it can give a voice to children-patients and women, two groups that are reluctant to form any opinion, even in a moderate familism context (Hui 2008, 288). Fourth, it illustrates that focusing on individual growth is not denying family input or influence. On the contrary, it embraces it. There is an understanding that the individual’s health and welfare is not independent of that of the family’s (Wang and Marsh 1992, 85). The family, and the family’s way of thought, is still prominent and influential in how an individual’s autonomy functions. Family integrity can indeed be strengthened in the process.

Ultimately, perhaps an ethics of care approach can help combat the idea that that “Eastern” and “Western” values are dichotomous entities. Self-determination and family-determination are not in conflict with one another (Cheng, Ming, & Lai 2012, 435). Rather, individual autonomy and critical thinking must be developed for family autonomy and integrity to have the best results (ibid., 437). At the end of the day, the West could learn from Asian values regarding
communitarian-based decisions and family autonomy. The East could also learn from valuing and respecting the autonomous growth of individuals. Each system is of value in order to balance out the framework (Tsōh et al. 2015, 1036).

**Concerns with Care Ethics and Extant Issues**

As one can see, a care ethics approach helps fix some of the issues inherent in sole parental medical decision-making. There are, however, concerns with a care ethics approach. How broad the definition of community/family should be and who to include in the discussions is still undecided (Mendel 2007, 71; Ho 2008, 129). Depending on the culture and family dynamics, this requires decisions on a case-by-case basis. In addition, it is debatable whether a consensus can be reached within a given community and if not, it is difficult to know how to proceed. Placing various weight on the opinions of individuals may result in voices being oppressed, likely those of the children, which would go against the values inherent in feminist care ethics.

There are also practical difficulties. Depending on the culture and society, patients and families may be more prone to not question medical professionals, to not express thoughts and feelings, and to completely agree with the doctors as authoritative, all-knowing, to-be-respected individuals (McLaughlin and Braun 1998, 118–9). There is a reliance on these authority figures and a care ethics approach discussion may not be forthcoming (Wang and Marsh 1992, 89). Therefore, it is also important that these medical professionals help facilitate communication with the family and promote all of their voices. These professionals should have adequate training in their education to understand various cultures and be able to facilitate the care ethics dynamic despite different cultural beliefs (ibid., 83). While training may help, enabling communication for cultures that do not tend to be open—either to professionals or family members—will still be a challenge.

There are also existing issues that care ethics does not resolve. Measuring a child's capacity is still an extant issue. The ethics of care process is ultimately a lengthy capacity assessment, albeit one with greater context, accuracy and harmony. However, when these adults are required to make a judgment regarding “proportionate involvement”, they may be less inclined to involve adolescents than is warranted due to the same complexities in assessing whether a child is competent. There is also the concern that family members might be coercive or oppressive under the guise of loving familial bonds (Ho 2008, 133). Medical professionals have a duty to ensure that the right of “being heard” and “having weight in the decision” is not abused (Bender 1992, 535). It is thus also
necessary to consider whether the position of each individual—particularly the child—is really their own or if they are acting out of pressure (Ho 2008, 129). Physicians too, as the “expert informant” for both the guardian and the minor, may abuse their power and become overly paternalistic or authoritarian. This problem is briefly discussed in the last section.

It is because of this potential abuse of powers that I stress that the care ethics approach is not meant to replace rights-based discussion on this topic. Rights are an important legal concept and are necessary in order to know the limitations of one’s rights, when they have been violated, what one can rightly expect, and how to govern one’s actions in relation to another individual’s rights. Rights can be too abstract though, and care ethics contextualises the rights of each individual through discussions of caring, love and understanding within the framework of relationships to the other individuals in the relational community (ibid., 534, 536). Both frameworks have their place and function, but perhaps exploring more specific rights and duties within care ethics can help solve the aforementioned issues. As Susan M. Wolf said, for justice to be obtained, situations should “always be examined through both care and rights lenses” because it will ultimately provide a “more holistic treatment context” (Raymond 1999, 14; Mendel 2007, 68). It is thus important that the legal system in any society ensures the health rights of these individuals.

A Broader View: Oppression of Women and Femininity in Medical Decision-Making for Minors

A feminist ethics approach such as care ethics often incorporates into its framework an analysis of how the current handling of medical decisions for minors directly relates to the oppression of women (Tulloch 2005, 157). Deciding to treat a child or let her die is a burden on the primary caregiver, who is usually the mother (Ho 2008, 132). It is difficult for the mother to let the child go as her maternal instincts clash with the idea of “abandoning” her child. On the other hand, if she decides on treatment, she is often left caring for a severely ill child. This is painful and difficult for both parties because it is often futile. Yet, if she decides that it is in her child’s best interests to forgo treatment, it is considered socially unacceptable because it goes against society’s beliefs concerning maternal instincts. This forms a vicious circle. Since “caregiver” is a gendered role that is culturally reinforced, women are forced into making a decision where either option is potentially a harmful burden to her and her child (ibid., 68). Societal and legal expectations demands for a specific decision to be reached, meaning her autonomy is restricted within this gendered role.
If parents are to know a child’s best interests—which is what society currently suggests—then this restriction to autonomy is unwarranted because the mother is making the tough, but correct decision.

Interestingly enough, despite mothers typically being the primary caregiver, there is a pattern in law, as shown by cases like the Quinlan case, where the father or a male guardian *ad litem* is given guardianship prior to, and rather than, the mother (Raymond 1999, 3). This tendency is clearly culturally prominent in certain Asian cultures, though not necessarily stated in a legal formality. These systems further reduce the mother’s autonomy. Speculation suggests that tendencies to see women as less fit decision-makers—because they are less rational or more emotional in comparison to men—are still prominent. Ironically, the mother is not given a choice because of her gender, yet she is still burdened with the responsibilities (as described above) resulting from the decisions made by males. Ethics of care can offer due voice to the mother, giving her autonomy as she asserts her right to an equally valued voice. Further, neither the care of the child nor the decision to forgo treatment will be a burden solely on the mother. Ideally, it will be shared amongst the other members of the community in which the decision is made, making the caregiving role gender-neutral.

Feminist ethics also seeks to empower and “promote the development of individual agency”, not only for women but for all oppressed individuals (Wallace 1994, 3). This is of particular importance when paternalistic tendencies in medicine “feminise” patients regardless of age or gender (ibid., 4). Feminine attributes, such as passivity, weakness and irrationality, are imposed on patients or mothers by the medical system. Through a care ethics approach, these concepts are combatted by restructuring the power relations via information-sharing. Enforcing the sharing of information between all parties (but particularly from the medical profession to patients and families) gives patients and other feminised individuals the power of knowledge to contemplate and offer rational input and judgments. Historically, these would be tasks that only a doctor—a male-dominant profession—would fulfil. The increased informed autonomy of these individuals decreases the doctor’s justification for authoritative and paternalistic power and the power dynamics begins to balance out. Ultimately, it is the acting out of these tasks that enables an active, de-feminised patient to exist in the medical environment. Alternatively, it illustrates that femininity does not hinder an individual when allowed—and given—the tools to be autonomous.

On a larger topical scope, the relevance of a patient’s gender in end-of-life treatment and euthanasia requests has been analysed by feminist scholars (Raymond 1999, 4). For example, women are held to a high standard in relation to evidence for requests to die, whereas men are “undertreated” and their
wishes for death are “acceded to over females” (ibid., 11). It would be interesting to continue that analysis of gender in children’s cases; unfortunately it is not within this essay’s scope.

**Conclusion**

If a care ethics framework were to be more commonly applied in medical decision-making, then society as a whole would become better at navigating moral issues and contemplating specific outcomes (ibid., 73). As people are educated, informed and familiarised with ethics in medical situations within small relational communities, it becomes a more prominent topic in larger societal groups. At some point, this knowledge would then be applied beyond medical issues to social and political ones as well. In fact, the long-term, outward-expanding effects of an ethics of care approach highlights how its concepts can be reasonably implemented through tangible actions. This is because this framework does not require a utopia to already exist in order for its concepts to be implemented and its goals to be achieved. The positive changes that can result from ethics of care—not only for women but for other vulnerable groups (children, the elderly and patients as a whole)—while existing within the current state of affairs cannot be denied. We only have to look at this example to see how that is true and why an implementation of care ethics in the medical field across various cultures warrants serious contemplation.

**References**


