

Shifting Paradigms in Women's Health Care: From Informed Consent to Informed Choice

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Abstract

Context: This article discusses the paradigm shift in health care and bioethics from the concept of informed consent to informed choice.

Evidence Acquisition: Informed consent is linked to the concept of respect for autonomy-one of the four pillars of bioethics. This concept requires health care givers to share information with patients so they can make appropriate health care decisions. However, the concept of informed consent has been critiqued as being paternalistic and not attentive to the complexities of modern health care decisions.

Results: As a result of a paradigm shift in health care and ethics, favoring autonomy over other principles-informed consent evolved to the more patient-centered concept of informed choice. Even so, feminist bioethicists critique the mainstream model of informed choice as being inattentive to inherent power dynamics within health care and society which may influence decision making. Drawing on the model of midwifery in Canada, this paper outlines an approach to health care that incorporates feminist definitions of informed choice.

Conclusions: This paper reviews the necessary criteria for informed choice to be attentive to the individual needs of women. Using the model of midwifery in Canada as an example, this paper demonstrates how feminist approaches to informed choice should be preferred in modern health care settings.

Keywords: Women's Health, Informed Consent, Personal Autonomy, Bioethics, Midwifery, Feminism, Canada

1. Context

Over the past several decades health care in Iran, along with other global regions, has become more patient centered and patient needs oriented (1). The voices of women as consumers of health care are increasingly seen as vitally important to improving the quality of health care in general and maternity services in particular (2). Significant evidence has demonstrated that women do not feel listened to enough in health care settings and want more information and choices in their maternity care (2, 3). Increased choice and control has been demonstrated to improve emotional outcomes for women and increase satisfaction with care (3). Moreover, recent research in Iran suggests that caesarean section rates may be reduced if women are adequately informed and supported in their choices by health care providers (4). Parallel to changes in health care over the past decades, has been the evolution of core concepts in medical ethics. The four key pillars of bioethics, generally accepted in global health care settings, are: beneficence, nonmaleficence, autonomy, and justice (5, 6). Both the principles of beneficence and respect for autonomy are seen to be fulfilled through the process of informed consent. However, as health care has shifted to be-

come more patient centered, informed consent has been critiqued for being insufficient to fully support autonomy and choice (3, 7-9). In response, informed consent has evolved to the more subjective and patient-centered practice of informed choice (10, 11). This paper will provide an overview of the evolution of bioethics and the paradigm shift from informed consent to informed choice in response to client-centered care. This paper goes on to define informed choice within the context of medical bioethics and examine feminist critiques that claim that even informed choice can remain within a paternalistic medical framework. We will outline the key components of informed choice in mainstream medicine and how these are expanded on in the feminist ethical approach to health care. Drawing on midwifery care in Canada, we will elaborate on how a feminist bioethics model allows for a more robust definition of informed choice. As a result, this model is more attentive to client needs and allows for a fuller supporting of patient autonomy-making it more relevant and suitable for modern maternity care settings.

2. Evidence Acquisition

2.1. From Informed Consent to Informed Choice

Respect for autonomy and beneficence are two of the fundamental principles enshrined in medical ethics (5, 10, 12). Beneficence is the principle which obligates health care providers to “do good” or act solely for the benefit of their patients, while respect for autonomy recognizes the inherent right of patients to make decisions based on their own values and beliefs (5). Both beneficence and respect for autonomy are the underlying principles which obligate caregivers to provide patients with informed consent for tests, procedures, interventions or research (5). One can chart the evolution of the concept of “informed consent” from its precursor in the Nuremberg Code of 1947, to the beginning of its current manifestation when it first appeared in 1957 court documents (13). Informed consent obligates care providers to ensure that patients have enough information to make reasoned, uncoerced and autonomous decisions about their health care (5, 10, 14). However, as medicine has advanced, modern health care and decision making have profoundly changed. Modern health care has resulted in the ability to extend life, redefine death, harvest and transplant organs, and enable artificial reproduction. As a result, health care choices are increasingly complex and treatment decisions have a greater potential to impact patients’ long term health and lifestyle—such as the ability to work, care for children or participate in valued life activities (10). As a result of the complexity of decisions, health care choices are increasingly dependent on factors that transcend professional training and knowledge onto those that are related to individual patient values and goals (7). While in the past, informed consent was viewed as sufficient to fulfill ethical obligations of beneficence and autonomy, this model has been critiqued in as insufficient within the context of modern health care. The informed consent model of decision making often skews patient decisions to those emphasized by the physician, based on the physician’s preferences, values, treatment choices and levels of risk aversion (10). The result is that caregiver authority and expertise are preferred over patient values and lived experience (7). Consequently, informed consent focuses more on the ethical obligation of beneficence and undervalues the importance of autonomy (3, 7, 10). As respect for autonomy has become the dominant and controlling principle in medical ethics over the past few decades, consent to physician provided choices is no longer considered sufficient to legitimately support patient autonomy. Instead the emphasis has shifted towards valuing patients’ preferences and sharing information to allow patients to make decisions based on their

belief systems and goals (3, 7, 10). As a result, philosophies of health care have moved from informed consent to the more complex notion of informed choice (3). Informed choice is increasingly recognised as a more progressive and preferable approach than previous notions of informed consent. Informed choice not only aims to support patient autonomy, but attempts to include processes to ensure patients are not coerced into certain courses of action (15). In so doing, the process of informed choice shifts the balance away from professional dominance and paternalism towards individual knowledge and control (7, 8, 10). This model of informed choice over informed consent values beneficence and autonomy as equally important pillars of ethics. The focus on autonomy is not viewed as being in conflict with the principle of beneficence, but a higher standard of beneficence which works to “do good” for the patient both by providing choices and supporting autonomy to exercise different options (10). Following this model, the role of the health care provider is not that of an authority figure but rather a trusted guide or advisor (16). This represents a fundamental shift in both health care and bioethics from the “historical roles of the paternalistic physician and the compliant patient to a new model of an autonomous, informed, and participatory patient” (10, 17, 18).

2.2. Defining Informed Choice Within Bioethics: The Canadian Model of Midwifery

Both the concepts of informed consent and informed choice are based on several principles of bioethics, namely: autonomy, competence/capacity, disclosure, voluntariness, beneficence and nonmaleficence (19). While the ethical foundations for both concepts are similar, they are distinct approaches to health care decision making and the patient-care giver relationship (7, 10, 20). In response to dissatisfaction with informed consent and recognition of its inadequacies, the midwifery model in Canada incorporated informed choice as a core tenet of care as it developed into a recognized profession (8, 9, 20, 21). The definitions of informed choice in this model not only shift the locus of control from caregiver to patient, but incorporate feminist bioethics principles which further problematize informed choice as it is applied in mainstream bioethics (3, 20). Mainstream bioethicists assert that autonomy can only be effectively exercised when patients have enough information to enable choice (10, 22). Following this, health care providers are required to disclose all relevant medical information to patients so they can make medical decisions based upon their personal beliefs, values, and life goals. Within informed choice as a standard, health care providers must respect patients’ decisions even

when those decisions do not promote their physical well-being or conform with the caregiver's medical judgment (10, 23). However feminist bioethicists recognize that people, and women in particular, are uniquely situated in society and thereby influenced in decision making by roles and power dynamics which are culturally embedded (24). When simply sharing information, there often remains an inherent hierarchal relationship between patient and caregiver- resulting in a kind of guised paternalism. In order to address this, the Canadian model of midwifery actively seeks to both recognize the hierarchy and power imbalances in health care and actively dismantle them through client interactions (24). This model of midwifery has been described as taking a relational approach to the patient-caregiver relationship (8, 9, 20). This relational approach seeks to diminish the hierarchal boundaries between patient and caregiver and actively empower women to enable them to make meaningful choices (8, 9, 21). Part of addressing power imbalances is to recognize women as consumers of health care. Thus, Canadian midwifery prefers the term 'client' over 'patient' (9). This recognizes that the client has choices both within health care and the care providers they seek. In addition, the term 'patient' has been problematized in feminist bioethics as being synonymous with compliance and 'patience', particularly with respect to women's health-where the locus of control remains with the health care provider (24). While informed choice offers patients a range of choices regarding treatment options, in most settings these options are based on what is presented by the caregiver and their own inherent bias (3, 10). When patients refuse recommendations, they are seen as going against medical advice, thereby setting up an opposing relationship between patient and caregiver (10, 20). With an emphasis on promoting autonomy, integral to the midwifery concept of informed choice, patients are equally supported to consent to available options or decline all options presented by caregivers. Within this framework, declining recommendations is not simply 'allowed' but is recognized as a valid and supported option. Recognizing that information sharing alone is not sufficient to fully support autonomy, midwifery in Canada incorporates feminist bioethics principles into its model (20). To this end, the Canadian model of midwifery includes informed choice as a central tenet of care and an obligation of all midwives in the provision of care (25). The Association of Ontario Midwives defines informed choice as, "an exchange of relevant information between client and health care provider, which allows for decision making by the client that is informed, reasoned, and uncoerced. It is a process that leads to the act of informed consent to treatment/procedures/tests or to a choice of refusing treatment/procedures/tests. Autonomy, responsi-

bility, and accountability are the three bases of informed choice" (26). Following this definition, ideally, the principle of informed choice supports a patient-centered ideology of health care, in which the caregiver facilitates a non-authoritarian exchange of information which empowers the patient to function as the primary decision maker (8, 26). Integral to the concept of informed choice is both the nature of information shared and the way in which it is provided. Information should be shared and exchanged in a 'non-urgent, non-authoritarian, cooperative manner'. In this sense is intended to be a process as well as an outcome: a process that both depends on and develops a relationship of mutual trust and respect between the patient and caregiver, and an outcome which results in the patient making the appropriate choices for their health (8, 26). In addition, the inclusion of the patient as an active participant in healthcare moves beyond the earlier and more paternalistic notion of informed consent or informed choice.

3. Results

3.1. *Criteria for Informed Choice: Cultural Sensitivity; Dismantling Power Imbalances and Valuing Relational Care*

Within a mainstream framework of bioethics, there are three main criteria necessary for informed choice to occur. Firstly, the patient must be informed, secondly the decision making must be reasoned and finally decisions should be non-coerced. However, within feminist bioethics and the midwifery concept of informed choice in Canada, the three criteria required for meaningful informed choice are autonomy, responsibility, and accountability (21, 26). While these differences may seem subtle, they are profound in the impact on choice and the patient-caregiver relationship (20, 21). In an effort to support respect for autonomy, the informed consent framework requires that patients be fully informed. This refers to the caregiver providing adequate information regarding the nature and foreseeable consequences of all available options (19). The information should include a full discussion of objectives, risks, and benefits of each option including the option of not choosing the treatment/procedure(s). The goal of providing information is to recognize that patients have the right to self-determination (5, 10). However within midwifery, drawing on feminist bioethics, respecting autonomy involves more than the disclosure of relevant information. The relational approach to informed choice used in this model recognizes "the influence that the woman's broader nexus of social and familial relations may have on her decision making process and how even the desire to 'please the midwife' may come into play" (21

pp.73). As a result the process of information sharing requires caregivers to provide accurate, objective and relevant information that is also culturally appropriate and considers the individual client's values and goals as well as their social context (20, 21, 27). This provision recognizes that in some cultures 'patient-centered' care involves the family or even defers decisions to family members (15). In order to provide culturally sensitive care, "the midwife is further called to engage in a reflexive monitoring of the stereotypes she holds towards other cultures, and how these may unduly restrict the autonomy of her clients." (20 pp. 42). While the second criteria of informed choice is that decision making must be reasoned, the midwifery model moves beyond this to incorporate the criteria of 'responsibility'. Within mainstream bioethics, reasoned decision making recognizes that caregivers sharing all the information they know may not be feasible or even desirable (10). Rather, information shared should be that which a 'reasonable' person would want to know, while not burdening patients with minutiae (19). However, this framework remains paternalistic in that the caregiver is seen as the 'expert' and the patient as a passive recipient of knowledge and choices presented (7, 21, 24). Midwifery incorporates the element of responsibility to emphasize that both the caregiver and client share responsibility in decision making. It requires that the midwife and client are both active participants in the process of informed choice (8, 20, 26). An essential element of mutual responsibility is the development of a relationship of trust between the caregiver and client (8, 20). In addition both the expert knowledge of the caregiver and the knowledge women bring to the client-caregiver relationship are valued-further minimizing hierarchy in the relationship for a more robust respect for autonomy (20). As part of this model, there is a recognition that relationship building is a process that takes time and space and requires client-midwife appointments and visits to be unhurried. Finally, the last requirement of informed choice in mainstream bioethics is that decision making should be uncoerced. This is related to the ethical concept of voluntariness. In order to be meaningful, patients need to feel free in making choices that are the most appropriate for themselves. As a result patients should not be subjected to undue pressure or coercion. This refers to both overt attempts at persuasion and force, and subtle forms of pressure and coercion (19). This provision recognizes the influence that physicians or caregivers may have over patients as a higher authority. In a model of truly informed choice, the role of the physician or health care provider is not that of an authority figure but rather a trusted guide or advisor (16). Again, incorporating a feminist bioethics approach, the midwifery model moves beyond the requirement of non-coercion to include the

component of accountability. Accountability recognizes that the midwife, as caregiver, is legally and professionally accountable for client care. However, it also implies that the midwife is accountable for recognizing the potential power imbalances in client-caregiver relationship which create 'coercive' circumstances. Within this framework, midwives empower clients to exercise autonomy skills and be active participants in their own care (8, 20, 21).

4. Conclusions

With the rise of bioethics as a distinct discipline, the core concept has emerged: the respect for autonomy, exercised through the process of informed consent (5). However, as modern medicine and bioethics have progressed, traditional models of informed consent have been critiqued for being overly paternalistic. Informed consent is seen as particularly inadequate as the complexity of choices in health care have increased and as patient autonomy has become favored over other ethical principles such as beneficence and nonmaleficence. As a result, informed choice has become the more favored process for decision making in health care and supporting autonomy is actually seen to enhance beneficence, instead of being in contrast to this principle. Midwifery in Canada has incorporated informed choice as a core principle within its model of care. This model of care draws on feminist bioethics principles, which assert that the mainstream shift from informed consent to informed choice is still insufficient to support true autonomy and remains within a paternalist framework of medicine. Drawing on feminist bioethics, midwifery in Canada takes a relational approach to healthcare and the process of informed choice. In reviewing the key principles of informed choice from a feminist bioethics framework, this paper argues that this model is more client-centered and relevant in modern maternal health care settings.

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