

Research Article

Ethical Framework of Healthcare Delivery to Stigmatized Populations, Implications for Care in Pregnant Women with Substance Related-related Disorders

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ABSTRACT

Background: Policy-making of healthcare delivery to stigmatized populations is one of the most challenging areas in public health ethics. Marginalized people carry societal stigmas as a result of various determinants including their health and social conditions. By creating a framework, which helps to guide decision making towards an ethical provision of optimal healthcare, more trust and solidarity will be built within and among healthcare organizations, and the social support system. Good healthcare planning requires reflection on values because, by far, the defined social determinants of health alone have not been sufficient to provide a continuum of care to vulnerable, stigmatized populations.

Methods and findings: This paper presents an ethical framework for healthcare delivery to stigmatized populations. The framework was developed considering the needs of

these populations and validated through a process involving community agencies and stakeholder engagement. Guidelines of ethical conduct for healthcare delivery by health professionals; community agencies providing care to stigmatized populations, and the public health and social support system is proposed. Application of this framework in the healthcare delivery to pregnant women with substance-related disorder is discussed.

Conclusions: Application of this framework can optimize healthcare delivery to the stigmatized. It will require re-evaluation and refinement because the merits and limits will be revealed when applied to different subpopulations of stigmatized people.

MeSH Headings/Keywords: ethics, substance-related disorders, pregnancy, social stigma

Background

The public's attitude towards stigmatized populations often involves interplay of public lack of knowledge sustained by social organizations, and media. This perpetuates the stigma. Lack of public knowledge involves people's faulty understanding of the scientific definition of these conditions and their treatability, and the damage that negligence of treatment can cause. These things bring to light a number of barriers to treatment, requiring a development of a comprehensive approach to removing the stigma. The need for an ethical framework for care delivery to stigmatized populations is obvious to improve the quality care, which is also influenced by this stigmatization.¹

Evidence of stigmatized populations' lack of access to sufficient healthcare calls our attention to duty to care, reciprocity, equity, and good stewardship.^{1,2} An ethically robust framework for the healthcare delivery to stigmatized populations is of prime importance to guide the provision of a standard care in such settings.

"Healthcare delivery to a vulnerable population with a defined and treatable health condition should never be affected by professional healthcare policy-makers and care deliverers who are influenced by the stigma the patient carries with himself/herself" and "healthcare providers should never be placed in a position of denying treatment to patients without guidance of a policy or protocol."

The proposed ethical framework for healthcare delivery to stigmatized populations in this paper speaks to the relevance of the ethics of healthcare provision to stigmatized populations at the level of point of care and its policy making. It articulates applied/practical ethics and values that are already accepted in the public health sphere.^{1,3-11}

Methodology

Ethical framework for healthcare delivery to stigmatized populations

The framework begins with the premise that policy-making and

delivery of healthcare to stigmatized populations ought to be 1) guided by ethical healthcare delivery processes to improve accountability, thus raising the potential of producing ethical outcomes and 2) informed by ethical values in order to address the ethical dimensions of healthcare delivery.¹²

Ethical process

The ethical process applies democratic justice to the healthcare priority setting, towards a deliberative approach to healthcare delivery in policy-making and institutions delivering health care (Table 1 in annex).^{9,10}

Ethical values

The second part of the framework identifies the key ethical values in healthcare policy-making and delivery to stigmatized populations. Because conflicting values may be relevant to a subpopulation, ethical policy-making and care delivery can be challenging. Accordingly, refined definitions of each value have been introduced with respect to healthcare delivery to stigmatized populations (Table 2 in annex).^{1,12}

Discussion

Healthcare delivery to pregnant women/ mothers with substance- related disorder ~ an example for the framework applicability

Pregnant women suffering from substance-related disorder (PWSU) are an example of a vulnerable and stigmatized population with a treatable societal and/or mental health condition. Optimal healthcare delivery to this population is a current public health issue. The values presented in this ethical framework can help guide the healthcare delivery system in prioritizing public healthcare and social support resources in order to meet the healthcare needs of this population. The value of solidarity, stewardship, and trust would require that policymakers reevaluate priorities to optimize the capacity to help this part of society.

Furthermore, in accordance with the values of duty to provide care, equity, and healthcare providers must overcome the internal dilemma of holding a punishing attitude towards

Table 1: Characteristics of an ethical process in healthcare delivery to stigmatized populations⁸

Value 1: Accountability

Description: Mechanisms to ensure ethical decision-making is sustained through healthcare delivery

Rationale for inclusion: Accountability to ensure: 1. Sustainability in resource allocation for care delivery to stigmatized populations 2. Gaining the trust of target population.

Value 2: Inclusiveness

Description: Decisions made explicitly containing stakeholder's views. Example: The quality of the healthcare delivered to pregnant women with a substance- related disorder should be enhanced by the input of representatives of this population: people drawing from their own experiences, as stigmatized persons, of the quality of healthcare they have received.

Rationale for inclusion: Social distancing (by health practitioners) from a stigmatized population creates an unrealistic need assessment of them. Inclusiveness within the healthcare delivery process ensures values of transparency, trust, and stewardship.

Value 3: Openness and transparency

Description: Decisions should be publicly defensible and open to public scrutiny. Caregivers and stigmatized care receivers should have access to the basis upon which the decisions have been made.

Educational plan: for healthcare providers and the public in general, for awareness about the treatability of mental health conditions. This should be addressed in medical and societal spheres.

Communication plan: to ensure that the refined policies of healthcare delivery can be effectively disseminated to affected stakeholders, including healthcare professionals, the social support system, and families with a stigmatized patient. This way the stakeholders know where and how to get access to healthcare.

Rationale for inclusion: Transparent and honest communication builds trust and fulfills the moral obligation of health care providers to deliver care. It also respects the liberty of the population in need that receives the care.

Value 4: Reasonableness

Description: Decisions should be based on reasons comprised of evidence, principles, and values that stakeholders can agree upon which meet the health needs of stigmatized patients

Decision makers should be credible and reliable. Example: they must provide a rationale for redirecting limited human resources from other subpopulations of society, which do not have an apparent, stigmatized condition towards the stigmatized population.

Rationale: Reasonableness can overcome the barriers to healthcare access related to the inappropriate exercise of autonomy by the public: holding a blaming attitude towards stigmatized people and disapproving of the redirection/allocation of public healthcare resources toward this subpopulation

Value 5: Responsiveness

Description: Evaluation plans should be designed to revisit and revise the process and outcomes of decisions made by the healthcare delivery system involving stigmatized populations. Example: if there is a longer waiting time in hospitals, there should be a formal mechanism for stakeholders (ex: the mothers and health care professionals delivering care to them) to voice any concerns they may have about this decidedly longer waiting time.

Rationale for inclusion: Responsiveness is necessary for ethical conduct of individuals and institutions in the process of healthcare delivery to stigmatized patients

Table 2: Ethical Values to guide decision-making (listed in alphabetical order)^{1,2}**Value 1- Duty to provide care****Description:**

The duty to provide care and to respond to suffering is inherent in all healthcare professionals' codes of ethics. Healthcare providers must respond to the needs of these marginalized people, as per their duty, and not let the societal stigma rule their response/decisions.

Decision-makers should:

Work collaboratively with stakeholders, community agencies, and social support system to:

- *Establish practice guidelines for healthcare delivery to stigmatized populations.
- *Develop fair and accountable methods to resolve disputes
- *Provide support to ease the burden of internal moral paradox in those with the duty to provide healthcare
- *Develop means through which healthcare institutions can handle appeals or complaints, especially in regard to delayed or denied access of healthcare to stigmatized patients

Example / conflict resolution:

Healthcare providers and policy makers serving stigmatized populations must go through the internal, often subtle, dilemma between the urge to deny healthcare as a way of condemning a stigmatized population (which is an unconsciously approved societal attitude towards stigmatized populations) and the obligation to provide unconditional healthcare to all those in need. This dilemma conflicts with healthcare professional's liberties. Education for healthcare providers regarding these treatable conditions, in addition to antistigma programs can help resolve such conflict.

Value 2- Equity**Description:**

The principle of equity holds that, all things being equal, all patients have an equal right to required healthcare. Respecting this right requires deciding whether, and how many, additional resources (relating to both healthcare and social support systems) should be allocated to the equitable treatment of vulnerable subpopulations

Decision-makers and health care providers should strive to:

- *Preserve as much equity as possible between the interests of patients from the stigmatized population and those who apparently do not carry/discard any stigma.
- *Ensure procedural fairness in policy-making, resource allocation, and delivery of healthcare to stigmatized populations.

Example / conflict resolution:

In allocating scarce resources, the value of equity help guide the development of fair criteria for resource allocation. Consideration would also be given to the stigmatized populations' compensation for any diminution of resources caused by public disapproval

Value 3- Privacy**Description:**

Individuals have a right to privacy surrounding their healthcare information. Such right becomes more critical in the instances of mitigating this privacy through unwanted sharing of their healthcare information to collaborative institutes that are in contact with their point of care institute. Such disclosure of privacy can jeopardize other rights of the owner of information such as custody of their children or employment. In care delivery to stigmatized populations, there should be a robust proportionate response to the level of confidentiality before releasing any of their healthcare information

Decision-makers should:

- *Disclose private information that is only relevant to achieve legitimate and necessary public health goals, and only if there are no less intrusive means
- *Determine whether the good is significant enough to justify the potential harm from suspending privacy rights, (e.g. the harm from stigmatization of individuals who disclosed their condition in order to get the appropriate healthcare)
- * Provide care providers with appropriate education to be critically conscious of their own biases towards stigmatized conditions and to deliver a safe, standard healthcare devoid of internal and influential societal biases to these particular communities

Example / conflict resolution:

Care delivery in various institutions known to the public might disclose patients' health information with the intention of protecting individuals' or cumulative public welfare. Care delivery should be given with the least disclosure to public in healthcare institutions. The need to put societal distance in specific wards must be weighed against the potential harm of exposing individuals to more stigmatization and emotional distress.

Value 4- Reciprocity**Description:**

Reciprocity requires that society supports care providers who face a disproportionate burden in protecting the public good, and takes steps to compensate for such burden in other ways. They may face increased work place risk such as infection and violent behaviour, and go through emotional and physical stress.

On the other hand, admission to separate institutions and wards may impose significant social, economic and emotional burden on stigmatized patients.

Decision-makers, institutions and healthcare providers are responsible for:

- *Easing healthcare providers' burden
- *In coordination with other social support systems, improving stigmatized patients' and their families' experience in hospitals and institutions
- * Ensuring the safety of health care providers

Example / conflict resolution:

Safe disposal of needles and vaccination to prevent Hepatitis B are examples of supports required to ensure the safety of care providers who are in contact with patients suffering from a concurrent Hepatitis B condition.

Value 5- Solidarity***Description:***

Healthcare delivery to stigmatized populations with societal determinants as the cause of their condition should heighten the social awareness of the need for interdependence between healthcare and social support systems. This requires solidarity across systemic and institutional lines in addressing serious public health conditions. Healthcare delivery to stigmatized populations will not only necessitate social solidarity, it will require a vision of solidarity within and between social support and healthcare systems as interconnected sectors of care delivery to these populations.

Solidarity requires:

- *Open and honest communication between different sectors of delivery of care
- *Open collaboration in a spirit of common purpose, within and between care delivery institutions (health care and social support systems)
- *Sharing public health information across sectors, the stakeholders and the public
- *Coordinating healthcare delivery, social support delivery, and deployment of human and material resources in delivery of care to stigmatized populations

Example / conflict resolution:

Territoriality between hospital departments, healthcare delivery institutions and the social support system (Ministry of Child and Family Development and Social Development) needs to be overcome by good communication and avoiding budget compartmentalization. In order to provide equitable care across jurisdictions, a sense of common purpose must be embraced. Institutions of care delivery might have conflicts within their own organization as a reflection of their obligation to their organization for their often-scarce human and material resources and obligation to the public welfare of the society they function in. Conflict can be resolved by treating stigmatized populations as part of the public whom are in need of interdisciplinary support without territoriality barriers.

Value 6- Stewardship***Description:***

In our society, both institutions and individuals are entrusted with governance over scarce resources such as hospital beds, healthcare materials, and even healthcare providers. In healthcare delivery to stigmatized populations, difficult decisions about how to allocate resources have to be made, and there may be collateral damage as a result of resources being redirected towards a “less societally acceptable” subpopulation. Policymakers should be guided by the notion of stewardship, which should manifest trust, ethical behaviour and good decision-making.

Decision-makers have a responsibility to:

- *Avoid and reduce collateral damage that may result from resource allocation/redirection decisions
- * Maximize benefit for all, while allocating resources of healthcare delivery to stigmatized populations
- *Protect and develop resources where possible
- *Consider good outcomes; benefits to both stigmatized populations and the public, and equity of a fair distribution of benefits and burdens across subpopulations and care delivery sectors

Example / conflict resolution:

A decision to assign a separate ward in hospital for the stigmatized patients must consider whether this is an effective way to deliver healthcare. Also to be decided is where the money for this ward would come from and whether that money or ward (beds) could be put to better use elsewhere.

Value 7- Trust***Description:***

Establishment of trust is essential between: healthcare providers and stigmatized people; between healthcare providers and care delivery institutions; between the public and healthcare providers/policymakers; among organizations within the care delivery system (health, social support). In the process of healthcare delivery, the stigmatized population may perceive public health measures as a betrayal of trust (e.g. when access to care is denied, delayed, or delivery for non-stigmatized patients seems to be favoured), or as abandonment at a time or area of greatest need. Decision makers will be confronted with the challenge of maintaining these populations’ trust while at the same time serving them with a comprehensive, supportive care delivery program. It takes time and effort to build trust.

Decision makers should:

- *Take on the difficult task of building trust with an already mistrustful and stigmatized population
- * Ensure to those affected stakeholders, such as the patients, and caregiversthat policymaking and healthcare delivery processes are ethical and transparent.

Example / conflict resolution:

Engagement with stakeholders while providing education about their stigmatized condition may go a long way in strengthening stakeholder confidence in the policymakers’ and healthcare providers’ trustworthiness. In part, the value of trust is respected and promoted by following the outlined ethical process.

their stigmatized patients, and replace it with a willing delivery of care. The value of privacy prevents healthcare providers and their institutions from exposing these patients to public scrutiny through a non-disclosing approach in their attitude and method of care delivery. Relating to the value of reciprocity, policymakers should ease the burden of healthcare providers and community agencies. One example is to provide required financial, emotional, and educational support for healthcare workers and community agencies dealing with pregnant women with substance-related disorder. A well-informed public conversant with the values of this ethical framework, and aware of the emerging programs and societal and individual outcomes resulting from optimal healthcare delivery to families with such a mother, would come to see the importance of the trust and transparency values in this process.

One cannot underestimate the role of the necessary institutions for a successful implementation of an ethical framework into the conduct of individuals and institutions. Hence, the sponsorship of the framework by the Ministry of Health, the Ministry of Child and Family Development, and the Ministry of Social Development cannot be underestimated. Vetting of the framework by healthcare providers and representatives/advocates of pregnant women with a substance-related disorder; and a decision review/re-evaluation process are all needed.^{1,2,12}

Conclusion

Within our society there are important ethical perspectives on the health of stigmatized populations in general, and pregnant women afflicted with addictive substance use in particular. This ethical framework can guide policymakers, healthcare professionals, and care providers in providing optimal care to populations of stigmatized patients in accordance with the above ethical values and against the background values of the general society.

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