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COVER IMAGE

Yemen, 2011. Ambulances take huge risks during armed conflicts to reach and transport the wounded and can fall victim to stray bullets.

Catalina Martin-Chico, winner of the first International Committee of the Red Cross Humanitarian Visa d'or photojournalism award. (23rd "Visa pour l'Image" International Photojournalism Festival – September 2011 – Perpignan, France).

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From the Editor-in-Chief

I am delighted to pen my first editorial as Editor-in-Chief of *World Health & Population* (*WHP*). Global health and health policy have been central to my interests for decades. *WHP* is a great instrument to make sure that new knowledge is disseminated and exchanged among policy makers, decision makers, scientists and practitioners alike in the broad field of health.

Our health and that of our communities and nations depends on many factors. While the healthcare system makes a contribution, larger factors that determine our health are nested in many others. This issue introduces you to one of those topics – the situation of healthcare in conflict zones where there is armed conflict and civil unrest. "Protection of Health Workers, Patients and Facilities in Times of Violence" (see page 43) is the report from a conference held in Bellagio, Italy, in November 2013. We will dedicate a special issue to this important topic later in 2014.

Our current issue also presents articles from Lydia Kapriri et al., Michael Costello et al. and Catherine Holtz et al. that raise fundamental issues we grapple with across the globe at all levels of economic development: high-, middle- and low-income countries. They examine the ongoing tension between cultural norms and values; scientific evidence and associated practice and policy recommendations; and financial, funding and income levels and their impact on the decisions of individuals, communities and policy makers. Far too often this complexity is either ignored or misunderstood by professionals, decision makers and funders. Evidence-based policies, which are grounded on available, and accurate, data – a challenge on its own as discussed in this issue by Pushpanjali Swain et al. – are essential but insufficient to guarantee uptake by various individuals, groups, communities and populations. All these factors have to be well thought through in order to work toward outcome-based systems where the health and well-being of our population is our goal. I greatly look forward to *WHP's* publishing papers that examine these complex and inter-connected factors in my tenure as Editor-in-Chief.

As a final note in my first editorial, I'd like to acknowledge the enormous contribution of outgoing Editor-in-Chief John E. Paul. With your strong commitment and network of authors and editors, *WHP* has thrived over the last nine years. I'd also like to welcome Farah Farahati as an associate editor; we look forward to working with you and benefitting from your wide knowledge and experience.

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End-of-Life Decisions – Some International Comparisons

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Abstract

Healthcare professionals often confront difficult issues in end-of-life care. Caregivers who question futile care and treatment can find themselves at odds with patients, family members and surrogates who stress patient autonomy. Many developed nations recognize hospital ethics committees as appropriate venues for discussion of end-of-life care, and palliative care initiatives in many hospitals play important roles in patient care at the end of life. As health systems worldwide confront diminishing resources and endless questioning on expenditures, the concept of medical futility has taken on increasing prominence. Medical professionals know intuitively that certain interventions near the end of life can neither extend life nor improve the quality of life remaining. In addition to medical futility, concerns about international economic pressures and enhanced recognition of patient autonomy lead to questions as to the appropriateness of withdrawing life-sustaining treatment, assisted suicide and euthanasia. While some appellate courts seem willing to entertain questions on the legal rights of patients to access certain end-of-life measures, legislative bodies appear reluctant to legalize assisted suicide and euthanasia.

Introduction

Some of the most difficult ethical and legal questions arising in healthcare result from end-of-life issues. Physicians, nurses and social workers can find themselves confronted with problematic situations involving patient and family wishes for end-of-life care as well as professional concerns about continuing to provide medically futile treatment for patients. Palliative care and hospice programs have been instituted in many hospitals worldwide and provide valuable resources for providing end-of-life care (see Figure 1).

The use of hospital ethics committees, ethics consultants and legal counsel can all help to focus specific case discussions in an attempt to provide appropriate resolutions, but the use of these resources is mostly advisory in nature. Final decisions in institutions remain the responsibility of the hospital's management and attending medical staff, meaning that healthcare executives and medical staff members must develop appreciation for the appropriateness of specific medical interventions at the end of life, even if the patient has executed an advance directive.

Figure 1. International legal status on end-of-life care

	Law allows for institutional ethics committees	Law allows for advance directives	Law allows for assisted suicide and/or euthanasia
Great Britain	Yes (McLean 2007)	Yes (Toller and Budge 2006)	No
Canada	Yes (Gaudine et al. 2011)	Yes (Browne and Sullivan 2006)	No
US	Yes (McGee et al. 2002)	Yes (Lehmann 2008)	Assisted suicide only in five of 50 states
Netherlands	Yes (der Kloot Meijburg and ter Muelen, 2001)	Yes (Rurup 2008)	Both assisted suicide and euthanasia
Slovakia	Yes (Glasa et al. 2000)	No (Glasova 2008)	No
Japan	Yes (Akabayashi et al. 2008)	Yes (Takezako 2012)	No

VOIP = voice over Internet protocol.

Medical care interventions at the end of life have been a rich source of controversy and debate in several Western nations. Withdrawing or withholding life-sustaining treatment (sometimes referred to as passive euthanasia), assisted suicide and euthanasia have drawn increased public attention as both proponents and opponents seek legislative and judicial remedies to more formally establish their positions, both for and against.

Three major themes seem to dominate early twenty-first century discussions of end-of-life care. The concept of medical futility, increased pressure worldwide to constrain the growth of healthcare spending and growing emphasis on the notion of patient autonomy have all served to raise the level of public discourse on end-of-life care.

Medical Futility

The concept of medical futility incorporates questions of resource consumption and economics (Darr 2005). When medical treatment might result in an anticipated effect, but yet not be beneficial to the patient, the concept of medical futility would indicate that healthcare providers are not obligated to initiate or continue the treatment. Thus the resources that would ordinarily be expended in the futile treatment are conserved and theoretically would be available for treatment of another patient who might benefit.

The application of the concept often places healthcare professionals in conflict with patients and surrogates who wish certain treatment to be initiated and continued in their belief that the treatment might improve the patient's situation. The conflict usually arises between the professional's knowledge of the likely futility of the intervention and the patient or surrogate's hope for improvement or cure.

Institutional policies and procedures have been developed to navigate complex futility questions in ethics committees. In the United States and the United Kingdom there is open public debate about age as a criterion for healthcare rationing, while in Sweden age prioritization is less visible (Werntoft et al. 2007). Nevertheless, without regulatory guidance, economic pressures will force healthcare providers to closely examine the meaning of life and value of life under the umbrella of medical futility.

As medical futility discussions intensify in the United States and Europe, efforts to legislate end-of-life care will also intensify and legislative actions will reflect public sentiment both for, and in opposition to, end-of-life measures.

… without regulatory guidance, economic pressures will force healthcare providers to closely examine the meaning of life and value of life under the umbrella of medical futility.

Economic Pressure

World economic pressures and human rights concerns impact healthcare systems globally. Governments seek to balance access and quality of care against financing considerations, without violating social norms and creating ethical dilemmas. Healthcare reforms generate concerns for consumers, political parties, religious leaders, insurance companies, regulatory bodies and advocacy groups. Always present in reform discussions are end-of-life considerations and attempts to reduce the use of non-beneficial care.

Without clear national policy and understanding on non-beneficial care, managing and delivering care will be challenged in areas of informed consent, equity, prioritization and quality of life. Providing inappropriate care will be heavily scrutinized in cost-conscious economies, and issues of medical futility will require careful ethical analysis by physicians, administrators, groups and politicians. The right to refuse treatment and the right to die have drawn attention in Europe and in the United States. The circumstances under which

medical futility might be argued and the concepts of patient autonomy versus physician autonomy will generate debate on human rights, equity and transparency.

Patient Autonomy

Arguments surrounding end-of-life issues are somewhat similar to those encountered in discussions of population health: the interests of the individual may differ from the interests of the larger society.

Patient autonomy has been recognized as a first principle of bioethics. This principle holds that patients should be capable of determining their course of medical treatment to include having the ability to refuse unwanted treatment such as ventilator support. If the patient is incapable of communicating his or her wishes to caregivers, a legally recognized surrogate may be empowered to make decisions on the patient's behalf.

The US Supreme Court addressed patient autonomy in end-of-life decision making when it issued its ruling in Cruzan v. Director, Missouri Department of Health (1990). The parents of a young woman rendered incompetent as the result of severe injuries from an automobile accident had sought permission from a Missouri state court to remove their daughter's artificial hydration and nutrition equipment when it became apparent that the daughter had virtually no chance of recovering her cognitive abilities. In the majority opinion authored by Chief Justice William Rehnquist, the court ruled that "The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions" (Cruzan v. Director, Missouri Department of Health 1990).

Advance directives, to include living wills and durable powers of attorney for healthcare, may give direction in effecting the patient's course of treatment. By making a living will, the patient specifies in advance the care that he or she wishes to have rendered in the event that the patient is unable to cogently express his or her wishes. Until a patient reaches the point of being unable to express his or her wishes, the patient may change his or her mind and countermand the intentions expressed in a previously prepared living will.

A durable power of attorney, prepared at the direction of the patient, designates a specific individual to make healthcare decisions on behalf of the patient when he or she is unable to do so. In the United States, holders of durable powers of attorney for healthcare are generally expected to use "substituted judgment" in making decisions for the patient who made the durable power of attorney, meaning that they are supposed to make decisions as they believe the patient would have made the decision himself or herself if they had been able to communicate their desires.

If the patient or surrogate reasonably believes that initiating or continuing certain forms of care or treatment is medically futile in that it will not improve the patient's condition beyond the then-current state, such treatment generally may be refused or terminated. Some observers have argued that if the refusal results in the patient's death, the patient has been the victim of passive euthanasia. The more frequently argued position is that a death resulting from foregoing or withdrawing life-sustaining treatment is an example of "double effect reasoning" as noted below (Munson 2012). Withdrawing or withholding life-sustaining treatment when such care is deemed medically futile has generally been accepted as appropriate in the United States, Canada and Europe.

Traditionally, legal authority would seem to favour the patient or surrogate's decision to initiate or continue treatment over the professional's wish to deny or discontinue the treatment. Courts in the United States and Europe have seemed to give greater weight to the ethical principle of patient autonomy and the right of self-determination in treatment decisions. But as state legislative action in Texas demonstrates, The Texas Advance Directives Act (1999) specified a protocol for

resolving medical futility cases in hospitals. The Texas protocol, which follows American Medical Association recommendations for a due process approach, specifies that if a physician refuses to comply with a patient or surrogate's request for treatment, the matter must be referred to "a hospital appointed medical or ethics committee in which the attending physician does not participate" (Truog 2007). The family is given 48 hours' notice and is invited to participate in the consultation process. The committee then issues a written report that becomes part of the medical record. If the consultation process fails to resolve the dispute, the hospital and family must make reasonable efforts to transfer the patient to another facility willing to provide the requested treatment. If, after ten days, no such provider can be found, the hospital and physician may unilaterally withhold or withdraw the allegedly futile therapy. The patient or surrogate may seek a court ordered extension, which the law says should only be granted if the judge believes there is a reasonable likelihood of finding another provider willing to offer the treatment in question. If the family does not seek an extension, or the judge fails to grant one, the futile treatment may be unilaterally withdrawn and the treatment team is immune from civil and criminal prosecution (Truog 2007).

Withdrawing or withholding sustaining treatment when such care is deemed medically futile has been generally accepted as appropriate in the United States, Canada and Europe. The natural law ethical principle of double effect holds that if an action will have both bad and good effects, the action may be performed only if the good effect is intended and the bad effect will be an "unintended or indirect consequence" (Munson 2012: 887). Munson states that four conditions must be met:

> The action itself must be morally indifferent or morally good.
> The bad effect must not be the means by which the good effect is achieved.
> The motive must be the achievement of the good effect only.
> The good effect must be at least equally important to the bad effect (Munson 2012).

Assisted suicide involves a patient taking his or her own life with the assistance of one or more persons. Physician-assisted suicide means that a physician caregiver provides the assistance to the patient who is seeking to end his or her own life. The assistance would usually consist of providing lethal doses of medication that the patient would self-administer at the time of his or her choosing.

Although terminology varies somewhat in different nations, unlike assisted suicide, euthanasia involves another person taking direct action to terminate a patient's life as opposed to the patient taking his or her own life. Euthanasia can further be categorized as voluntary, involuntary or non-voluntary depending on whether the patient has requested or consented to having someone else cause his or her death (Munson 2012). If the patient or surrogate is not actively involved in making the decision to end the patient's life, the act is considered involuntary euthanasia.

Some might argue that the administration of terminal sedation is euthanasia…

Some might argue that the administration of terminal sedation is euthanasia, but critics of the latter would argue that the very term "terminal sedation" is a misnomer and that the administration of pain medication is intended to comfort the patient and relieve the accompanying suffering. Although continued administration of pain medication may ultimately result in the death of the patient, adherents to the double effect principle would argue that the intent of administering the sedation is not to cause the death of the patient.

Ethical Theory and Principles

Advocates of assisted suicide and euthanasia advance a number of arguments for their positions. Materstvedt and colleagues (2003) cited a lack of palliative care in certain regions of Europe as a possible explanation for support of assisted suicide and euthanasia. From the ethical principle perspective, supporters of assisted suicide and euthanasia can argue that the principles of autonomy and beneficence support the idea that patients should be allowed to "choose the circumstances" of their death (Doyal 2001) and that if patients wish to die under those circumstances, that is in the best interests of the patients and should be legally permitted.

Opponents of assisted suicide and euthanasia would seem to base their arguments on the ethical principle of nonmaleficence, which Munson (2012: 892) categorizes as "perhaps the most famous and most quoted of all moral maxims in medicine." The argument under this principle is that any action taken to intentionally end the life of the patient is morally wrong. The theoretical arguments in favour of assisted suicide and euthanasia might be categorized as utilitarian or teleological in that the morality of the act is to be judged by the outcome: the patient's death is the desired result that validates the act of assisted suicide or euthanasia. Correspondingly, the opponents would argue from a deontological or perhaps Kantian perspective that the acts of assisted suicide and euthanasia are inherently immoral and should therefore be prohibited.

United States Perspectives

A patient or surrogate's legal right to forego unwanted care and treatment, or to have life-sustaining treatment withdrawn if considered futile, has been generally accepted as permissible, and the US courts have upheld the rights of both patients and surrogates to forego life-sustaining treatment or to have it withdrawn, a distinction that some US courts have rejected (Menikoff 2001).

Elizabeth Bouvia was a 28-year-old patient in a California public hospital who petitioned the state court to have a nasogastric tube removed, which had been inserted and monitored without her consent to keep her alive through involuntary forced feeding (Bouvia v. Superior Court 1986). The California Court of Appeals ruled in her case that "a patient has the right to refuse any medical treatment or medical service.… This right exists even if its exercise creates a life threatening condition." Despite the fact that Bouvia won her case, she decided not to end her life (Bouvia v. Superior Court 1986). Although the Bouvia decision is not legally binding in other states, its reasoning has been cited in other jurisdictions in support of a patient's right to self-determination.

The right of a surrogate to have a patient's life-sustaining treatment withdrawn was decided ten years earlier in a New Jersey appellate court case (In Re Quinlan 1976). The father of a 22-year-old female patient requested the withdrawal of life-support mechanisms from his daughter, who was diagnosed as being in a persistent vegetative state, but his request was opposed by her physicians, hospital and state law enforcement authorities. In a well-publicized and frequently cited decision, the New Jersey Supreme Court relied upon "the constitutional right of privacy" in ruling in the father's favour.

Assisted suicide is legally permitted in five states. Oregon, Washington and Vermont have enacted statutes that allow for assisted suicide (ProCon.org 2013). In 2009, the Montana Supreme Court ruled that although physician-assisted suicide was not constitutionally protected, state law did not make it a crime for a physician to assist in a suicide (Baxter et al. v. Montana 1999). Two years later, a bill to legalize physician-assisted suicide in Montana failed in the state legislature, leading the bill's sponsor to admit "…there's nothing to protect the doctor from prosecution" (Williams 2011). In January 2014, a New Mexico state judge ruled that state law permitted physician assisted suicide (Mungin 2014).

From a federal constitution perspective, the US Supreme Court issued two significant decisions on assisted suicide in 1997. When asked to decide if New York State's prohibition on assisting suicide violated the Equal Protection Clause of the US Constitution's Fourteenth Amendment, since withdrawing life-sustaining treatment was permitted in New York, the Supreme Court ruled that the state's position did not violate the amendment since there is a clear distinction between the two practices:

> The distinction comports with fundamental legal principles of causation and intent. First, when a patient refuses life sustaining medical treatment, he dies from an underlying fatal disease or pathology, but if a patient ingests lethal medication prescribed by a physician, he is killed by the medication (Vacco v. Quill 1997).

Prior to the state of Washington legalizing assisted suicide in 2009, the state had a law that specifically prohibited the practice. Opponents of the state's ban filed suit in federal court arguing that the state's prohibition violated the Fourteenth Amendment to the US Constitution. The US Supreme Court ruled that the prohibition was permissible since "…our decisions lead us to conclude that the asserted 'right' to assistance in committing suicide is not a fundamental liberty interest protected by the Due Process Clause [of the Fourteenth Amendment]" (Washington v. Glucksberg 1997).

Euthanasia differs from assisted suicide in that someone other than the patient takes the action that causes the patient's death. Euthanasia is not legally permitted in any of the United States.

Since 1991, ballot initiatives in five states have been introduced to legalize euthanasia and assisted suicide. Voters approved measures in Oregon, Washington and Vermont, but other initiatives were defeated in California, Michigan and Maine (Patient Rights Council 2012). A first such initiative in Washington state had been defeated in 1991. A total of 109 legislative proposals have been introduced in 24 states since 1994, but none have been passed by those states' legislative bodies (Patient Rights Council 2012). Thirty-nine states statutorily prohibit assisted suicide and three additional states prohibit assisted suicide by common law. Four other states are unclear on the legality of assisted suicide (ProCon.org 2013).

European Perspectives

A consideration of European national policies on medical futility and end-of-life care reveals some interesting differences to the US perspective. While there is not a legal consensus among European countries on the issue of assisted suicide and euthanasia, the practices within individual nations demonstrate some variability (Spooner 2009).

Definitional differences among European nations further complicate the effort to compare European practices to those of the United States. Gadd (2004: 147) notes that "Although terms such as 'euthanasia,' 'active euthanasia' and 'passive euthanasia' were generally recognized, such terms were not necessarily found in national legislation." She further noted of the terms that:

> …their scope varied widely, for example from the Russian Federation which legally defines euthanasia as 'complying with the request of a patient to hasten his (her) death with some action or means including discontinuing of life sustaining treatment' to the Netherlands which defines it as 'termination of life by a doctor at the voluntary and carefully considered request of a patient.' (Gadd 2004:147)

As of August 2012, Belgium, the Netherlands and Luxemburg permitted voluntary euthanasia and assisted suicide.

Switzerland permits assisted suicide but not voluntary euthanasia (Burki 2009). All other European nations ban both voluntary euthanasia and assisted suicide.

As of August 2012, Belgium, the Netherlands and Luxemburg permitted voluntary euthanasia and assisted suicide.

Great Britain has never permitted assisted suicide or euthanasia. While the Suicide Act of 1961 decriminalized suicide, the act prohibited assisting suicide. In its final ruling in 2009 before being replaced by the United Kingdom's new Supreme Court, the Appellate Committee of the House of Lords ruled that the Director of Public Prosecution must issue an "offense-specific" policy identifying the facts and circumstances under which he would prosecute assistance in suicide under the provisions of the 1961 Act (Keown 2012). The appeal grew out of a petition in which a multiple sclerosis patient asked for a determination as to whether her husband would be prosecuted for helping her travel to Switzerland, where assisted suicide is legal, to end her life there.

Legislative efforts in other European nations have failed to legalize either assisted suicide or euthanasia. Schadenberg (2011) reported that in recent years Scotland, Israel and France all rejected attempts to legalize the practices in those nations.

Puppinck (2012) cited the adoption of a resolution against euthanasia by the Parliamentary Assembly of the Council of Europe as the first time, in recent decades, that a European political institution so clearly rejected euthanasia. The resolution came one year after the European Court "asserted that there is no right to euthanasia or assisted suicide under the European Convention" (Puppinck 2012). The Parliamentary Assembly developed a list of principles to govern the preparation of advance directives in the 47 states of the Council of Europe, stating that such documents are often a "back door" for introducing euthanasia or assisted suicide into legislation (Puppinck 2012). Based in large part on this resolution, the European Court of Human Rights issued a ruling on July 19, 2012, upholding Germany's ban on assisted suicide (Koch v. Germany 2012).

Several anonymous surveys of European physicians have indicated their willingness to engage in a range of end-of-life practices, especially if requested by a patient. However, the accuracy of such surveys might be called into question based upon physician respondents' fear of prosecution. As Burki (2009: 447) has written: "… it is a mistake to assume that euthanasia and assisted suicide do not occur under prohibition."

Canadian Perspective

Assisted suicide has long been prohibited under Canadian law. The Criminal Code of Canada outlaws assisted suicide and provides for incarceration of anyone assisting in a suicide (CBC.ca 2012). Attempted suicide was decriminalized in 1972.

In 1992, a woman from Victoria petitioned the Canadian Parliament, asking the legislators to change the country's law banning assisted suicide (CBC.ca 2012). The Supreme Court of Canada ultimately ruled against her.

However, a June 2012 ruling of the Supreme Court of British Columbia brought the issue of assisted suicide to the forefront of Canadian public policy. In the case of Carter v. Canada (Attorney General), the court granted a constitutional exemption permitting a Canadian citizen to obtain "physician-assisted death" under a number of conditions (Supreme Court of British Columbia 2012), ruling that the challenged provisions of the Criminal Code, when analyzed in light of the Canadian Charter of Rights, "unjustly infringe [on] the equality rights … and the rights to life, liberty and security of the person…" (Supreme Court of British Columbia 2012).

Interestingly, the court suspended the operation of the invalid provisions for one year, most likely to give parliament time to modify the law in conformity with the opinion. The British Columbia Court subsequently reversed the Supreme Court, fully upholding Canada's laws against "doctor-prescribed death."

Conclusion

Withholding and withdrawing life-sustaining treatment would seem to be ethically accepted practices in the United States, Canada and the nations of Europe. Although sometimes referred to as "passive euthanasia," such practices are rationalized as recognition of medical futility, not as intending the death of the patient. As a similar manifestation of "double effect," the administration of medication for pain or symptom relief is generally considered accepted even though it may have the unintended consequence of ending the patient's life.

While institutional ethics committees and legally sanctioned patient advance directives might have been expected to facilitate discussion and debate on end-of-life issues, those measures do not seem to have increased public acceptance of assisted suicide and euthanasia. As Figure 1 indicates, while many advanced nations do have ethics committees and advance directives in place, the vast majority still do not legally allow for either assisted suicide or euthanasia.

Assisted suicide is legally permitted in four European nations and in five of the United States. In all, most jurisdictions that recognize the practice have detailed regulations that prescribe the involvement of the "assistants," the documentation of the patient's request and the required reporting to legal authorities.

Euthanasia is not legally permitted in any of the United States, but it does have legal recognition in three European nations: Belgium, the Netherlands and Luxemburg. Switzerland permits assisted suicide but not euthanasia.

While appellate courts have demonstrated some willingness to hear constitutional challenges to laws prohibiting the practices, legislative efforts in the United States, Canada and Europe have generally failed to advance the course of legalizing assisted suicide and euthanasia. Legislative bodies have more than likely reflected what they believe to be the will of the majority of their citizenry in refusing to legalize assisted suicide and euthanasia.

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The Experiences of Making Infant Feeding Choices by African, Caribbean and Black HIV-Positive Mothers in Ontario, Canada

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Abstract

Mothers in HIV-endemic countries are advised to exclusively breastfeed their babies until six months because of lack of resources and better chances for child survival, while in developed countries, replacement feeding is advised. What are the experiences of HIV-positive women who migrate from HIV-endemic countries to developed countries, when making infant feeding choices?

Methods: In-depth interviews and focus group discussions with a total of 25 women living with HIV in Toronto and Hamilton, Ontario.

Results: Free infant formula alleviates the practical constraints in making infant feeding choices. However, cultural beliefs and social expectations constrain HIV-positive mothers' decision not to breastfeed. This is further complicated by the different policies. Service providers should understand the psychological and emotional experiences of the mothers in order to provide the appropriate support. Peers could be potential sources of support. The differences in policies are issues of global justice that need to be addressed.

Background

Breastfeeding has been considered a normal and optimal infant feeding practice globally. While the World Health Organization (WHO) recommended that infants be exclusively breastfed for a minimum of six months (Kramer et al. 2001), the discovery that breastfeeding significantly increases the risk of mother-to-child transmission of HIV changed this policy. Children born to HIV-positive mothers have a 5% to 20% risk of contracting HIV through breastfeeding in the absence of any intervention (WHO et al. 2007). The risk is lowered with exclusive breastfeeding, breastfeeding for a short time, reduced viral load (e.g., mother receiving antiretroviral treatment [ART]) and with prompt treatment of mastitis (Burge et al. 2003).

Given the risk of vertical transmission, the WHO made the following recommendations, which were adopted globally: (i) When replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), mothers are advised to use replacement feeding exclusively; (ii) When replacement feeding is not AFASS, mothers are advised to breastfeed exclusively until the baby is six months old, then stop and use replacement feeding exclusively (WHO et al., 2007). These recommendations were revised in 2010 (see Table 1) (WHO et al. 2010).

While there is a new push to encourage breastfeeding in Canada (Ontario Ministry of Health and Long-Term Care 2013), Health Canada's strategies for preventing vertical transmission of HIV/AIDS include exclusive replacement feeding. According to this policy, "breastfeeding should be avoided irrespective of antiretroviral therapy, as this practice is contraindicated for HIV-infected mothers..." (Burge et al. 2003: 1673). Since mothers are provided with free infant milk, one would assume that their decision not to breastfeed, within the Canadian context, is relatively easier (Palda et al. 2004). However, the situation is different in low income countries (LICs).

Breastfeeding is perceived as a cultural norm in many Afro–Caribbean and black communities and most of the low income countries, and adoption of formula feeding is not widespread. Furthermore, unhygienic conditions, lack of supplementary food and lack of safe water make alternative feeding unsafe (Nogueira 2002). Moreover, mixed feeding in the earlier months has been found to increase the risk of HIV transmission

Table 1. Summary of WHO principles and recommendations on HIV and infant feeding of relevance to this paper

Principle	Explanation	
Setting national recommendations for infant feeding in the context of HIV	Mothers should be counselled and support to either: (i) Breastfeed and receive ARV intervention OR (ii) Avoid all breastfeeding	Basis of decisions: • Mother's socio-economic and cultural context • Availability and quality of health services • Prevalence of HIV among pregnant women • Main causes of infant mortality and malnutrition
Informing HIV-positive mothers about infant feeding alternatives	Mothers should be informed about: (i) The national recommendations (ii) Availability of alternatives they could adopt	
Providing support services for mothers to appropriately feed their infants	Skilled counselling and support in appropriate infant feeding practices and ARV treatment to reduce PMTCT should be available to all mothers	

ARV = antiretroviral; PMTCT = preventing mother-to-child transmission. Source: WHO 2010

compared to exclusive breastfeeding (Lauer et al. 2004). Given the socio-economic and cultural context for women in low income countries, the 2010 WHO principles on HIV and infant feeding recommend that HIV-positive mothers on ART should exclusively breastfeed for the first six months, then introduce supplementary feeding and continue breastfeeding until the baby is 12 months old (WHO 2010). When such women migrate to Canada where different standards and policies prevail, what are their experiences in making infant feeding choices? Understanding these experiences is critical, since this population represents the highest rates of HIV-exposed infants (48.3%) (Health Canada 2011). Women may face cultural and social problems, especially if they have not disclosed their HIV status to the people they live with. In some cases, women may be forced to breastfeed and face the various repercussions this may have for the mother and baby.

There is a paucity of literature on the experiences of immigrant mothers with making infant feeding choices in Canada. This paper fills the gap.

Objectives

The objectives of this paper are:

- To describe the cultural beliefs and practices surrounding infant feeding among HIV-positive Afro–Caribbean and black immigrant women in Ontario;
- To describe these women's experiences with making infant feeding choices;
- To discuss the factors that influence the women's experiences and their implications for policy and practice.

Methods

Approach and Population

This was a qualitative study involving a total of 25 adult (21–56 years) immigrant women living with HIV. Seven were from Hamilton and 18 from Toronto in Ontario, Canada. Five were of non-African origin and two had no children. Participants were recruited through posters and snowball sampling. Interested participants contacted us. Interviewed participants gave our contact information to their friends.

Data Collection

Seventeen in-depth interviews and three group discussions were conducted by the principle investigator and a trained research assistant. Both interviews and group discussions involved themes about (i) cultural beliefs and practices about infant feeding, (ii) infant feeding choices when one has HIV and, (iii) how those choices are made and the respondents' experiences with making these choices. The interview guide was pilot-tested on two women living with HIV to ensure clarity and appropriateness of the questions. The interviews were audio-recorded with permission from the respondents. Each interview lasted for about 45minutes.

Analysis

The audio-recorded interviews were transcribed and analyzed using Nvivo10 (QSR International, Victoria, Australia). The analysis involved reading through whole transcripts while identifying key ideas and giving them code names. At the abstract level, related codes were linked together, then grouped under categories. Related categories were then grouped under emerging themes, which we present in the Results section.

The study was reviewed by the McMaster University Research ethics board, and written consent was obtained from all respondents.

Results

The results section is organized according to the themes that emerged from the interviews: (i) cultural beliefs, (ii) knowledge of dangers, (iii) making tough decisions, and (iv) contextualizing women's experiences. Illustrative quotes are provided in the text and in Table 2. Respondents are identified by age and region of origin: (A: Africa; C: Caribbean; O: Other).

Cultural Beliefs

Most of our respondents believed that breast milk was the best for the baby because it is healthy, safe, fresh, natural, easier to digest, cheap, convenient, provides immunity and makes the baby more intelligent. The act of breastfeeding was also thought to strengthen the bond between mother and baby. Because of these benefits, women in their culture are expected, and are pushed by healthcare providers and family members, to breastfeed since "... it is what mothers do...." In view of these social and cultural expectations, we asked about how women who do not breastfeed are perceived.

Not Breastfeeding: "... What Kind of Mother Are You ...?"

Not breastfeeding is perceived unfavourably in these communities. The mother would be the subject of gossip or face continual questions from friends and community members about why she is not breastfeeding. Mothers who do not breastfeed are perceived as cruel and unloving toward their baby; some group discussants reported that these mothers could be treated like a criminal. One said,

> It is [a] must to breastfeed ... if you don't breastfeed ... they think that you don't love your child ... that's why everyone will have to breastfeed ... because there is no way to escape...." (R13, 37 years, A)

Strong cultural beliefs about breastfeeding and the negative perception of people who do not breastfeed in these cultures introduce pressure and constrain how HIV-positive women make infant feeding choices. However, before examining this issue further, we explored the women's knowledge about the implications of breastfeeding if one had HIV.

Knowing Does Not Reduce the Complexity of Decision Making

All respondents knew the potential dangers of breastfeeding with HIV. Some likened it to "... giving a stone to your child ..." (R3, 45 years, O), and "... giving poison; how can you give poison to your baby?" (FGD 1).

They also knew that while in their home countries they may have been able to breastfeed their babies, in Canada, it is "not an option." They spoke of a complex responsibility, a special natural instinct and a duty to protect their babies from contracting HIV.

> ... if you infect that baby ... you are gonna live with that for the rest of your life ... that's your kid ... you are supposed to protect them ... you have to love them and you have to make the decision not to breastfeed and not to infect the baby. (R2, 45 years, C)

One would expect that respondents' knowledge of the dangers of breastfeeding and their commitment to protect their babies would make their decision not to breastfeed easier. However, their cultural beliefs about infant feeding made the decision a challenge.

Making the Tough Decision

Almost all our respondents expressed the difficulties of deciding not to breastfeed within their cultural and social contexts. Not breastfeeding could lead to alienation, unwanted disclosure and the related consequences; it also causes emotional and psychological pain. We discuss these in detail.

Table 2. Summary of themes with corresponding quotes

Theme	Quotes
Cultural beliefs	
Perceptions of people who do not breastfeed	"... the people treat you like a criminal you are a criminal because breast milk is like a food for the baby ... and so they think you are criminal and you want to kill that baby ..." (FGD2)
Tough decisions	
Unwanted disclosure: the external pressures	"I didn't breastfeed and my mother went ballistic ... it doesn't matter if you are almost dead ... you are supposed to breastfeed ... so ... it's an issue ... my Japanese grandmother still didn't talk to me till the day she died because I didn't breastfeed her granddaughter ... but I'm ok with that ... it's her issue not mine...." (FGD2) "... some breastfeed their kid even if they are HIV positive ... due to the stigma associated with not breastfeeding because if you don't breastfeed automatically (people assume) you have HIV...." (FGD3) "... The problem I think I am going to have maybe is when people come to visit me ... I am sure everyone will have questions like why ... are you not breastfeeding? ... and that maybe is going to make them start saying ... maybe she has it (HIV) ... coz we all know that you have to breastfeed a new born baby.... I am gonna have to deal with that ... it will be very hard.... (R10, 33 years, A) "... I am not going to breastfeed my baby ... even though I want but I wish there would be another way ... so far I am already protecting my baby with taking medication ... so I don't think after all these months of protecting the baby then I breastfeed ... that is kind of useless for me. I will make sure that I don't infect my baby, so I just told myself that it's going to hurt if people ask why are you not breastfeeding but ... I will not care what people will say coz this is me this how I live my life so nobody should come and judge me. (R4, 32 years, A)
Inherent pressures	"... it is very hard it's not easy to overcome ... knowing I am HIV positive and I have a child and I can't breastfeed ... [sigh] ... I don't know if something can be done to stop that because like I said it's a big loss...." (R9, 41 years, A) "... when the baby looks at the mother's eyes when breastfeeding ... the first contact that you'll be my mother ... and they recognize you everywhere you go ... no matter what can make you apart but that first sight of both parties through breastfeeding is very important. (R7, 47 years, A) "... if you are not breastfeeding, that bond will be gone ... so it will be hard coz that bond helps with their growing stage...." (RI, 49 years, C)
Contextualizing the decisions	"... I don't think it (not breastfeeding) will be an issue ... a lot of people choose to do that anyways whether or not they are HIV positive so I don't think there is any problem with it ... everybody is very accepting of formula here...." (R8, 41 years, A) "... I know my doctor will support me ... because they don't want me to infect my baby and they want the baby to be healthy...." (R11, 33 years, A)

Unwanted Disclosure: A New Culture, a New Location

Since breastfeeding is a cultural expectation, the decision not to breastfeed was perceived as acquiring a "new culture." With this new culture, the women no longer fit within their ethnic groups and have to seek new communities. The new communities are either people living with HIV (where community service organizations play a big role), or, in some cases, a new geographical location where no one would question their new culture. One respondent reported,

> First off, if a person is living with HIV ... she runs away from the people in her community ... she avoids all contact with them because she doesn't want to show people she is not breastfeeding. (R14, 32 years, A)

The physical relocation is an effort to avoid disclosing the mothers' HIV status. Within their communities, not breastfeeding automatically raises questions. People would guess their HIV status, which, in many communities is followed with stigmatization and alienation. A discussion group participant reported,

> ... at that point you are forced to tell them that it's because I'm not well I cannot breastfeed this child ... and then as you tell them you've just opened a flood gate ... no one is coming to visit you ... no one will ever carry that child; that child will never visit anyone's house ... so that is the dilemma of this breastfeeding issue. (FGD2)

The emphasis on breastfeeding in the community, in health units and on public advertisements further increases the women's sense of guilt and complicates their ability to make the decision not to breastfeed. They are chastised for not fulfilling their maternal functions and stigmatized by their families and community members. Respondents feared that the continuous external pressure and fear of discrimination and abandonment could force some of those mothers to breastfeed, at least in front of others, to hide their HIV status. In the words of one respondent,

> They know they are positive but they want to feed the baby to show their families [that they are ok], because if they don't feed their baby the husband can ask, why you don't feed my baby? So she breastfeeds the baby, yet she knows she has HIV. (R3, 45 years, O)

It is clear that the socio-cultural expectations and cultural beliefs negatively impact the women's decision not to breastfeed to the extent that it is a source of worry and distress long before the baby is born. This was expressed by some respondents who were pregnant at the time of the interview. One such respondent reported,

> I think this is going to be a tough decision not to breastfeed. [However,] at the end of day, I don't want to pass it [HIV] on to my child ... so what I will do, I am just going to do mostly what my doctor says." (R10, 33 years, A)

The stressors were not only external. Some respondents reported that they face inherent pressures entrenched in their socialization as mothers.

Inherent Pressures: "What Kind of Mother Am I?"

Another source of psychological and emotional pressure related to how these women are socialized. Not breastfeeding makes them question their ability to be good mothers since they "fail" to provide the "best food" for their babies. Furthermore, since breastfeeding was perceived as what "real" mothers do, there were feelings of guilt and loss, of missing out on the real maternal experiences of a "mature" woman. In the words of one respondent,

> "Now if somebody can ask me, why don't you breastfeed, I would have this guilt[y] conscience. I really want to breastfeed ... now I think I am a real mum ... mature, and I know what breastfeeding is ... I really want it, this pregnancy. I really wish I could breastfeed. (R4, 32 years, A)

Another internal factor that made the decision not to breastfeed emotionally painful was the loss of the chance to bond early with the baby through the physical and emotional experience of breastfeeding. This was affirmed by respondents with older children who, comparing their children who had not breastfed to those who had, believed they had a weaker and more difficult relationship with the former. One respondent said,

> If I am in bed, my son will climb in bed with me ... my youngest daughter will do that too. My other daughter, the one I didn't breastfeed, she'll sit on the bed, and I keep thinking this is because I didn't breastfeed her. It's stuck in my head because we don't have that bond. Not having that bonding makes me feel really guilty for not breastfeeding. (FGD1)

While the majority of respondents narrated the conflict of reconciling their duty to protect their babies as mothers with what they have learned about being a good mother in their cultures, a few respondents contextualized these experiences.

Contextualizing the Decision Making

Five respondents thought that the pressure to breastfeed was less in Canada, where not breastfeeding is less stigmatized than in their home countries. Furthermore, these respondents thought that the free medical care, social services and infant feeding formula in Canada would contribute to making the decision not to breastfeed easier. One respondent reported,

> You know in Canada they make sure that you really don't get tempted; they help in that way ... there's no way that you can infect your baby. (R4, 32 years, A)

It is important to note that of the five respondents with these perceptions, only one was pregnant at the time of the interview; the rest had older children.

Discussion

We have explored a sample of HIV-positive women's beliefs about infant feeding and how they impact infant feeding choices. The findings should be interpreted with caution because of the study limitations. Ours was a qualitative study; the results are not generalizable and might have been biased in sampling, interviewing and analysis. Despite these limitations, however, we maintain that the results contribute to the current knowledge and practices.

The findings that women still upheld their cultural beliefs about infant feeding, despite having moved from their home countries, was interesting. This would have been good if they were able to breastfeed. However, because their HIV-positive status prohibits them from breastfeeding, they face many challenges in making infant feeding choices, in addition to living with their diagnosis. It is of great concern that some find it necessary to relocate to avoid these challenges, more so given the difficulties they face in accessing affordable housing. Physical relocation may result in further marginalizing of an already marginalized population (Greene et al. 2013).

Moreover, since some of the pressures are from their immediate families, relocation may not solve these women's external pressures permanently. Other viable options are needed, such as education and sensitization of communities about HIV to demystify the disease and reduce stigma. Also, providing these mothers with ways to navigate these pressures would be a useful strategy in preventing them from caving in.

One suggestion from respondents was using peers to support the new HIV-positive mothers. Peers have provided social support successfully in several African countries (The Aids Support Organization 2013). The Ontario HIV Treatment Network is already training peers for research, including a module on peer support and the challenging issues faced by mothers living with HIV, would be a viable intervention.

The health and social support workers supporting these mothers have a very important role to play in mitigating the emotional and psychological difficulties that the women face. First, promotion of breastfeeding in clinics where HIV-positive mothers go may add to their guilt of not breastfeeding. In such clinics, these materials could be removed. Second, since the women struggle with questioning their motherhood, the workers could re-affirm them as good mothers who are trying to protect their children. Third, the workers can provide alternative ways for promoting mother–baby bonding without breastfeeding, for example, opportunities for skin-to-skin contact. And health workers should continue being their patients' advocates and sources of sustained support.

Since both external and internal pressures that women face are entrenched in their cultural beliefs and practices, interventions should be sensitive and culturally relevant to this community to be effective. They should also take into account the cultural underpinnings of different perceptions and practices. The need for cultural sensitivity in provision of care and design of health interventions cannot be overemphasized.

With regard to government policies, many still follow the older version of the WHO guidelines, which have since evolved (WHO 2007, 2010). Since formula is provided at no cost for mothers in Ontario (Teresa 2013), one would assume that opting not to breastfeed is easy. However, the cultural beliefs and divergent contextualized policy recommendations (Coutsoudis et al. 2008) may be confusing and potentially dangerous for women who risk criminalization (Global Network of People Living with Aids 2010), yet they may just be doing what they were told to do in their home countries. The contradicting policies for LICs and high-income countries raise concerns with regard to global justice and are a source of debate (Nogueira 2002; World Alliance for Breastfeeding Action 2013). Conversely, the current WHO guidelines on infant feeding seem to have changed positions in regard to not encouraging breastfeeding for HIV-positive mothers. This is partly due to the discovery that ART and a reduced viral load remarkably reduce the chances of HIV transmission through breast milk (WHO 2010).

Conclusions

Our sample of women expressed psychological and social pressure in making their infant feeding choices, especially since these vary between contexts. These findings, although exploratory, have policy implications within the Canadian context, more so since this population accounts for almost half of mother-to-child HIV transmission cases. Women are routinely strongly advised against breastfeeding in spite of their viral load. There is need for dialogue about this policy, in view of the new WHO guidelines and the study findings. Furthermore, at the service delivery level, providers need to be given clear messages to enable them to provide appropriate counselling on the risks and support for all HIV-positive mothers, whatever choice they may make with regard to infant feeding.

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Consistency and Quality Check of Survey Data in India

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Abstract

Objective: Reliability of survey responses on topics such as utilization of health facilities by mother and child has long been a subject of concern. This paper explores consistency of responses from the same individuals over time on utilization of health services involving child delivery and child care.

Methods: A sub-sample survey was carried out by an independent monitoring agency in 13 states as a part of a larger Coverage Evaluation Survey of all states of India in 2009 by UNICEF, to recheck the responses to improve data quality. Our randomly chosen sub-sample consisted of 510 questionnaires regarding mothers and 497 regarding children. Differences of responses were noted and conveyed to field agencies to rectify recurring errors. Statistical analysis was conducted to find consistency of responses.

Results: Matching between the original and rechecked responses varied. Generally, however, the overall match was greater than 90%.

Conclusion: Findings suggest that response inconsistencies and the manner in which they are resolved are shown to have important implications for the overall estimate of indicators of utilization of health facilities. The monitoring exercise has, therefore, addressed the quality and consistency issue, which needs further consideration in large-scale surveys. Otherwise, it poses a validity threat to data quality and results on which national policy is framed.

Introduction

The reliability of survey responses to questionnaires on topics such as utilization of health facilities by mother and child has long been a subject of concern. Evidence from developed countries suggests that the quality of responses appears to be as high as that found in studies of other topics. Studies on reliability of survey responses are far fewer in developing than in developed countries. Existing studies clearly indicate that poor reliability of responses is associated with poor design (Dare and Cleland 1994).

Studies on reliability of survey responses are far fewer in developing than in developed countries

In the first approach, a respondent is interviewed on two separate occasions, with the length of time between interviews ranging from a few hours to several days. The observations are evaluated for consistency of responses (e.g., contraceptive use, place of delivery, etc.) Studies of this nature have been carried out in the United States as well as in developing countries (Knodel and Piampiti 1977; Ryder 1979; Westoff et al. 1961). The clinic record approach is based on a comparison of an individual's interview response with some known program or clinic record (Stoeckel and Choudhury 1969).

While the pattern of inconsistency varies considerably from study to study, the most common discrepancy results from husbands reporting contraception use while their wives do not (Keonig et al. 1984; Coombs and Chang 1981). All these approaches are subject to inherent limitations as indicators of response validity. In spite of a large number of studies on response inconsistencies among a significant sub-sample of respondents, research on the underlying causes of inconsistencies appears lacking.

This paper deals with the reliability of information on a few aspects of reproductive health and immunization status of children aged 12 to 23 months. In the present study, we consider the reliability of data concerning pregnant mothers' antenatal care, deliveries, immunization and feeding practices for the child, as measured by the consistency between responses from the same individual by two different agencies, that is, field investigator and independent monitor. The duration between the two observations of response varied from a few hours to a few days during the survey period. We examine the level of response inconsistency and possible underlying factors, and we suggest an approach to minimize inconsistent responses. We subsequently consider the broader implications of reporting inconsistencies for both aggregate and state-level analyses of utilization of health facilities by women who delivered during the 12 months preceding the survey and mothers/caregivers of children aged 12 to 23 months.

The basic objective of UNICEF's 2009 Coverage Evaluation Survey (CES) (UNICEF 2009) was to assess routine immunization levels among children as well as maternal health services across all 28 states and seven union territories in India. Specifically, the CES assessed routine immunization and vitamin A coverage; antenatal care (ANC), delivery care and postnatal care (PNC) coverage; availability and use of iodized salt; initiation of

breastfeeding and colostrum feeding; accessibility and availability of immunization and maternal care services, and so forth.

The nationwide CES survey was carried out by a private agency appointed by UNICEF. Data collection was monitored and checked independently by a premier national-level institute, the National Institute of Health and Family Welfare (NIHFW), New Delhi, in collaboration with population research centres located in various regions of the country. UNICEF designated NIHFW as the independent monitoring agency (IMA) to monitor survey activities carried out by the private agency. Survey monitoring by independent agencies was felt to minimize errors due to non-adherence of protocols during investigator training and during data collection, thus making it easier to correct errors and compensate for them at the time of data tabulation and analysis. The idea of survey monitoring by an independent agency was to minimize non-sampling errors that could creep in for reasons such as training of investigators and supervision by field monitors, which would not be amenable for correction at the later stage of analysis and tabulation. More specifically, monitoring was designed to (i) assess whether work (training of field investigators and data collection in the field) was performed according to the methodology; (ii) assess whether the private firm was adhering to time lines; (iii) provide technical support by identifying systemic errors made by field investigators during fieldwork – any misinterpretation of questions that may lead to non-sampling errors and others that would have adverse effects on the survey and its results – and reporting them to the agency's supervisors/UNICEF; and (iv) ensure immediate reporting to the agency's supervisors/UNICEF of grave inadequacies for immediate action (such as repeating the part of the survey).

The IMA's observations provided an opportunity for onsite correction during data collection in the field and feedback to the private agency where the inadequacy was found, as well as improvement in overall field investigator performance regardless of where mistakes were detected. For the purpose of monitoring fieldwork, the NIHFW, in consultation with Ministry of Health and Family Welfare (MOHFW) and UNICEF, developed a monitoring protocol and also engaged staff from the selected population research centres (PRCs).

The IMA's observations provided an opportunity for onsite correction during data collection in the field and feedback to the private agency where the inadequacy was found.

To analyze and interpret the underlying causes of inconsistencies in responses, it was necessary to understand the process of data collection by the private agency's field investigators and the strategy adopted by the IMA to monitor data collection. The household interview was undertaken by trained field investigators engaged by the private agency, using interview questionnaires prepared by UNICEF. The IMA collected the completed questionnaires and re-interviewed randomly selected respondents, using the monitoring protocol (a checklist) prepared separately. This enabled the IMA to check the completeness and consistency of the original interview.

Methodology

A sub-sample survey was carried out by the IMA in 13 randomly selected states, broadly covering six regions – north, south, east, west, central and northeast – of the country. This survey was part of a nationwide CES conducted in all 35 states and union territories of India in 2009 by UNICEF, to monitor and improve the quality of data. Field

investigators from a private agency collected data at the field level from face-to-face interviews in selected primary sampling units (PSUs) in each state and union territory. PSUs are generally villages in rural areas and wards in urban areas. The selected 13 major states were: Uttar Pradesh, Rajasthan, Bihar, Madhya Pradesh, Chhattisgarh, Orissa, West Bengal, Maharashtra, Gujarat, Karnataka, Andhra Pradesh, Manipur and Arunachal Pradesh. Responses to two sets of questionnaires administered by private agency investigators were rechecked for (i) mothers who had delivered in the last 12 months (ii) the mother or guardian of children 12 to 23 months old.

In each of the selected states, 10% of PSUs were monitored, and in each PSU, responses from at least four households where mother had delivered in the last 12 months and four households with children 12 to 23 months old were rechecked for consistency of responses. Finally, 128 PSUs were selected for rechecking from all 13 selected states. The sub-sample survey consisted of a randomly chosen sample of 510 administered interview questionnaires of mothers and 497 such questionnaires of children by field investigators. The format developed for monitoring the survey is given in Appendix 1 (monitoring format of mothers is appended). Two monitoring strategies were adopted: (i) concurrent evaluation and (ii) back-check (the term used in this survey). Responses given by the individuals of sampled questionnaires were rechecked by monitors from the IMA. These individuals used checklists to check almost half of completed questionnaires concurrently, after the field investigators had completed the interviews. Concurrent monitoring was helpful for rectifying errors, as both monitors and field investigators were present. Similarly, monitors back-checked responses of the selected households a few days after the survey. Differences were noted and conveyed to the field agencies for rectification. Field investigators received reorientation, and instructions were passed on to senior levels of the private agency as well as to UNICEF. Whenever inconsistencies arose between field investigators and the monitoring agency, the latter prevailed because of their greater fieldwork experience. This approach resulted in improved data quality in terms of coverage, completeness and correctness. It should be noted that monitors assessed all field investigators at the beginning of the survey so that any inconsistencies in responses would be detected and minimized through the monitor's intervention. The monitoring plan was prepared by the IMA based on the field investigators' movement plan. Each monitor was assigned a group of investigators for assessment in the field of a particular state. Field teams comprised three female investigators and a supervisor. Field investigators were generally responsible for gathering information from respondents, who were generally females, to maintain sensitivity to the gender issue. Female respondents are generally comfortable with female investigators. The field supervisors' role was to oversee investigators' activities. Each field team was assessed more than once by the monitor. Statistical analysis of matching paired sub-samples was carried out to assess the level of consistency and reliability of responses.

Dependent variables in the analysis are a dichotomous measure assuming the values 1 (the responses agree) and 2 (the response disagree) between the monitor's and field investigator's response. Though we resolved some inconsistency in the field and corrected the actual data, we did not rectify the investigator error in our monitoring checklist. Therefore, the percentage of mismatch was higher in our dataset. Data analysis was done using SPSS. Tables were prepared for each matched response across the sample states by all selected sample questions. We examined the results of each question's response matching. Monitors also asked respondents about the average time field investigators took to complete the questionnaire. Differences in monitors' gender were also investigated for

possible gaps in the agreement of responses. Further analysis was done using variables such as type of residence and duration of time to complete the interview.

Results

Matching of Responses Based on Mother's Questions

Table 1 shows the matched responses of mothers regarding care during the last pregnancy, place of delivery, postnatal care, breastfeeding practices, children's illness, using facilities from government programs and intake of iodized salt. State-wise matching of responses was undertaken to further understand the level of matching (see Table 1 at www.longwoods.com/content/23793).

One set of response matching was related to the question on testing salt used by the household. Responses obtained by field investigators and monitors were compared. The level of similarity ranged from 73% in Orissa to 100% in Jharkhand, Manipur and Uttar Pradesh. Overall, 89% of responses in all sampled states were consistently matched. Barring Arunachal Pradesh (77%), Madhya Pradesh (76%) and Karnataka (78%), the rate of matching responses was about 95%. Therefore, the question on consumption of iodized salt was not perfectly matched, although it was matched to a high degree. The reason for inconsistency of responses was primarily dependent on whether field investigators treated a village or ward as a homogeneous group or not. It was observed that in a few states, investigators tested salt in just a few households. If test outcomes were similar, they skipped the test for other sampled households. However, data were reliable and valid despite this inconsistency.

The matched response for the question "did the mother receive any supplementary nutrition from the Anganwadi centre during last pregnancy?" was 96%. One hundred percent matching responses were found in Andhra Pradesh, Arunachal Pradesh, Manipur and Uttar Pradesh, whereas the lowest rates were found in Madhya Pradesh (87%) and Gujarat (89%). Remaining states performed well above 90%.

In all sampled states, the question on "place of last delivery" yielded consistent response matches in 96% of cases. Analysis of responses to the "type of delivery" question found very little difference between the original and rechecked survey data. Except for Madhya Pradesh, Karnataka and Arunachal Pradesh, the matched response rate was above 95%. The typology for place of last delivery was a long list. The response mismatch might be associated with characteristics of investigators, monitors and respondents. Moreover, validity of responses concerning government facility, private facility or home did not deviate. However, validity issues might arise with respect to exact place of delivery within government facilities, or within private facilities; where there were various categories of facilities within government or privates.

"Was the last delivery normal or cesarean or assisted?" was a straightforward question. As expected, the overall reliability of responses was about 99%. For the question "who conducted the delivery," overall, the matched response rate was 93%, ranging from 85% in Arunachal Pradesh to 100% in Jharkhand and Orissa. Matched responses to the question on postnatal checkup was comparatively low (91%) for all sampled states; lowest was Rajasthan (67%), followed by Madhya Pradesh (81%) and Karnataka (84%). Almost all responses on continuing breastfeeding were matched (99.4%), except for Rajasthan, Uttar Pradesh and Madhya Pradesh, each at 98%.

The monitoring team also matched the information on "any government assistance during pregnant women's delivery." This question was thought important for identifying funds utilized under the national rural health mission i.e., how effectively the Janani Surakya Yojana program motivated expecting mothers to deliver in the institutions (Table 1). Responses were found congruent in 97% of cases. Matched responses were lowest in

Arunachal Pradesh (85%), while exceeding 93% in other states. In response to the question "whether the Accredited Social Health Activist (ASHA) accompanied the delivering women to reach to the health facility," overall, 94% of the responses were correctly matched. However, in Jharkhand (81%) and Karnataka (84%) matching responses were lower.

Responding to the question on the amount of money received by delivered mothers, 490 of 510 responses matched correctly, although in Gujarat only 84% of responses matched. On the question of availability of a separate bed for delivery in the hospital/health facility, 97% of responses matched, while in Arunachal Pradesh and Manipur only 88% matched.

On the "prevalence of diarrhea in last two weeks" the lowest match was observed in Bihar, Gujarat and Rajasthan. In aggregate, nearly 97% of responses across the states matched. Similarly, for "prevalence of cough in last two weeks" consistent matching responses were only 93%, while 100% matching was attained in Andhra Pradesh, Arunachal Pradesh and Jharkhand.

For responses on the nearest place for getting the health services, the overall matching rate was 89%. Correctly matched responses varied from 76% in Madhya Pradesh to 98% in Maharashtra.

Among the 14 questions monitors posed to mothers for the re-check, responses matched in more than 95% of cases across eight questions. Whether the difference in responses was due to "type of residence" or "length of interview by field investigators to ask all questions," the analysis was conducted using chi-square tests.

Table 2 depicts the percentage of matching responses by type of residence, sex of monitor and duration of interview by investigator. Agreement of responses was lower in rural than in urban areas for all questions put to the mothers. Significant differences were found for "place of last delivery," "accompanied by accredited social health activist (ASHA)" and "had separate bed for institutional deliveries." The higher proportion of mismatches in rural areas compared to urban areas was most probably due to prevailing local languages or dialects. Field investigators may have not have been well versed in them (see Table 2 at www.longwoods.com/content/23793).

The higher proportion of mismatches in rural compared to urban areas was most probably due to prevailing local languages or dialects.

Regarding the role of gender in matching information, a higher proportion of matching was observed among female monitors in most questions on delivery-related cases, child illness and nearest facilities; this finding did not extend to "salt test" or "nutrition supplementation from AWW" questions. This higher proportion did not reach statistical significance, except for the question "What is the nearest place where you get antenatal services by skilled provider?"

During the monitoring visit, the respondent was asked, "How much time did the investigators take to ask all questions?" A higher proportion of matching responses was found where interviews lasted 30 to 45 minutes over those lasting less than 30 minutes. The highest proportion of consistent matching was found in interviews to understand the child's illness or mother's breastfeeding practices that lasted more than 45 minutes.

Matching of Responses Based on Children's Questions

In response to questions on children's health answered by the mother or guardian, a greater number of questions matched the responses collected by field investigators and those of independent monitoring agencies compared to the matched responses on the questions of mothers. Therefore, information sought for children was more accurate and

better matched than that sought for mothers, because parents and guardians must be more vigilant about their children's health than own. Nevertheless, a few questions about children were not perfectly matched (see Table 3 at www.longwoods.com/content/23793).

The response on the salt testing was matched 91% across the states, which is close to the matching response secured from mothers (89%, Table 1). On the question to confirm child's age, the match rate of investigator to independent monitor responses was 98%.

It may be noted that only 91% of responses to the question on whether the immunization card was available matched perfectly. Among the valid cases of BCG (bacillus Calmette-Guérin) vaccination, 95% of responses matched correctly. Lowest matching was observed in Karnataka (80%), followed by Gujarat (85%). Reliability of matching on the source of vaccination for children was 94%; lowest matching was observed in Karnataka (75%) and Uttar Pradesh (88%).

The question on conducting routine immunization in local areas was matched up to 90%. In Arunachal Pradesh, the rate was only 61%, and in five states – Karnataka, Madhya Pradesh, Manipur, Rajasthan, and Uttar Pradesh – the rate was below 90%. Of nine questions about child immunization, five responses were matched above 95%. The concentration of mismatch between investigators and monitoring agents was a random chance, but it clearly showed the difficulties field investigators experienced in what to ask or the way they communicated with respondents.

Discussion and Conclusion

There are many possible sources of response inconsistency in health surveys. For example, inconsistencies may be partly attributable to the survey itself, since lack of clarity of questions may contribute to erroneous responses. Response inconsistencies may also be a function of the data collection process to some extent, through factors such as errors in recording or transferring information. In this investigation, we were primarily concerned with the main source of response inconsistency – misreporting, both deliberate and unintentional, by respondents themselves.

The independent monitoring agency responsible for the UNICEF 2009 CES was concerned about the response inconsistency problem. UNICEF was concerned about data quality, and that is why the concept of using a monitoring agency arose. Indeed, all the IMA officials received the same training, along with the key trainers of the private agency. Subsequently, key trainers from the private agency trained the field investigators, and the IMA monitor observed the training. The independent monitoring officials were present during investigator training to ensure resolution of all doubts among investigators. Monitors observed mock interviews as well as interviews in the field, to ensure investigator proficiency. This process implied that data collected by field investigators and monitoring agency must be the same. Yet despite these processes, there were many discrepancies in responses collected by field investigators and independent monitoring officials. These discrepancies arose for the following reasons, observed in the field situation. Firstly, field investigators were educated up to a university graduation level, whereas monitors had a much higher level of education (post graduation and above), knowledge regarding survey work and number of years of experience. Secondly, the fieldwork itself was tedious, and investigators may have been fatigued. (Although this issue is not recorded and reflected much in the literature, it was observed during monitoring.) Thirdly, the level of field investigator motivation may have reflected the amount of remuneration they received (which was beyond the domain of the monitoring exercise).

Findings suggest that the interview context is an important factor in reporting agreement.

In other words, the same individual was interviewed twice highlighted agreement or disagreement in responses. Moreover, consistency checks could have been done without rechecking the responses again in the field but by glancing through the questionnaires filled out by the investigators, as is done in many surveys. In this process, non-sampling errors could not have been reduced much.

The main thrust of the paper is to highlight the existence of the discrepancies. It is very hard to find the solutions to this generic problem. One of the ways to resolve this lies with the field
agencies. They should limit the number of interviews undertaken by an investigator and should ensure investigators receive adequate remuneration. Therefore, it is strongly suggested that field agencies use a reward-penalty mechanism to motivate field investigators. As discussed earlier, response inconsistencies were resolved in the field during (concurrent/back-check) rechecking of responses. Since field investigator teams were monitored at PSUs and their movements tracked until the end of the survey, errors were detected early and resolved by identifying the type of errors, communicating them to the field agencies, conducting reorientation training for investigators if required, and tracking the team to ensure that similar errors would not be repeated. In this manner, mismatched responses were resolved to some extent.

How corrections and inconsistencies were treated and resolved by the field agency after we left the monitoring visits with our monitoring mechanism might be the limitation to the whole exercise. The monitoring process facilitated a sense of the reliability and to some extent quality of the data. Generally, monitoring had important implications for the overall estimate of important indicators for the utilization of health facilities in the country. The exercise addressed the fundamental issue of reliability and data quality, which needs further consideration in large-scale surveys. Otherwise, it will pose validity threats to data quality. If reliability of data is to be ensured, adoption of a separate monitoring process is desirable in such kind of surveys (given the cost consideration) and must be built in. The current survey could serve as the introduction of a mechanism to improve quality of data, so that subsequent surveys could adopt similar mechanisms. The implication of discrepancies at the aggregate level was well known at UNICEF, and therefore concurrent evaluation and back-checks by monitoring agencies were built in. Findings from this study strongly suggest the need for a strong and layered supervision of the data collection process to ensure data quality and consistency of survey data.

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Neighbourhood Variation and Inequity of Primary Health Service Use by Mothers from London–Middlesex, Ontario

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Abstract

Objective: Primary health service use (P-HSU) may be influenced by contextual characteristics and is equitable when driven by need. Contextual effects and inequity of maternal P-HSU were determined.

Methods: Participant data from a London–Middlesex, Ontario, prenatal cohort were linked by residential address to contextual characteristics. Multilevel logistic regression estimated contextual effects and tested for effect measure modification of need factors.

Results: Maternal P-HSU varied between neighbourhoods. The effect of obesity was different for rural mothers living in low- (OR = 0.26) and middle-income households (OR = 0.15) and for urban mothers living in high-income households (OR = 2.82). The effect of having a health condition was greatest in mothers with three or more children (OR = 2.41).

Discussion: Differences in maternal P-HSU exist between neighbourhoods, and enabling factors modified need factors' effects, identifying subgroups of mothers with inequitable P-HSU. Results have the potential to inform Canadian health policy with regard to contextual effects and inequity of P-HSU.

Introduction

Epidemiological studies often consider social factors as determinants, recognizing that factors other than biological ones may impact disease risk. Furthermore, literature reveals that multiple aspects of one's context, such as residential location and its corresponding social and physical structures, are associated with health outcomes (Subramanian 2004). Precedence has been placed on the role of social determinants measured at both individual and contextual levels to inform policy on social inequities of health, including those that may exist in Canada (Denny and Davidson 2012).

The importance of social and contextual determinants has been extended to health services research. Andersen's behavioural model conceptualizes predisposing, enabling and need factors measured at individual and contextual levels to influence health service use (HSU) (Andersen 2008). The study of individual characteristic influences on primary health service use (P-HSU) is well established in adult populations. It is known from health services research in Canadian adults that predisposing and enabling factors are associated with utilization in complex ways. For example, women are higher users of health services compared to their male counterparts (Asada and Kephart 2007; Blackwell et al. 2009; Nabalamba and Millar 2007; Rhodes et al. 2006; Ryan et al. 2011; Sibley and Weiner 2011). However, findings from studies of the effects of age, educational attainment, racial-ethnicity, marital status and income on P-HSU are inconsistent (Asada and Kephart 2007; Blackwell et al. 2009; Diaz-Granados et al. 2010; Dunlop et al. 2000; Fell et al. 2007; Nabalamba and Millar 2007; Rhodes et al. 2006; Ryan et al. 2011; Sibley and Weiner 2011). On the other hand, need factors have been consistently associated with P-HSU in that poorer health is generally positively associated with P-HSU in numerous populations and for various forms of primary health services (Asada and Kephart 2007; Blackwell et al. 2009; Diaz-Granados et al. 2010; Dunlop et al. 2000; Fell et al. 2007; Nabalamba and Millar 2007; Rhodes et al. 2006; Sibley and Weiner 2011). A paucity of contextual characteristics in health service research is evident (Ludwick

et al. 2009; Phillips et al. 1998; Sibley and Weiner 2011); for example: "Variation of effects across municipalities is an important area for further study and should include factors such as physician supply; travel distance required for health care; and socio-economic factors such as community income levels...." (Sibley and Weiner 2011: 28).

Further, HSU is conceptualized as equitable when driven by need factors and not the socio-economic characteristics that constitute predisposing and enabling factors (Andersen 1995). Understanding who is using health services and why, and which groups of people are disadvantaged in their use, can help effectively allocate resources and identify where changes in healthcare delivery may be required to maximize those resources.

This study explored the multilevel factors conceptualized within Andersen's behavioural model of health service utilization in a population of mothers residing in London–Middlesex, Ontario, Canada. The city of London spans 420.6 square kilometres and has an approximate population of 366,000 with about 153,000 private households, half of which are single-detached houses (Statistics Canada 2012). Middlesex County is a mostly rural region surrounding the city of London, spanning close to 3,000 square kilometres.

The first study objective was to determine whether maternal P-HSU varies between the neighbourhoods in which mothers reside and, if so, to estimate the effects of contextual characteristics on P-HSU. A variety of contextual characteristics were assessed in an exploratory manner but based on Andersen's model. Two hypotheses were tested for this objective: (1) Maternal P-HSU varies across neighbourhoods in which mothers reside; and (2) residential contextual characteristics conceptualized within the framework of Andersen's behavioural model are associated with maternal P-HSU. The second objective was to assess inequity by determining whether the effects of maternal need characteristics on P-HSU are dependent on a priori selected predisposing and enabling factors. To investigate the second objective, it was hypothesized that the effects of maternal need factors on P-HSU vary depending on subgroups of predisposing and enabling factors.

Methods

Data Sources and Sample

The study population was from the toddler/preschooler stage of the Prenatal Health Project, a cohort study that recruited pregnant women from seven ultrasound clinics in the city of London, Ontario, from 2002 to 2004. Inclusion criteria for women at recruitment were residence in the London–Middlesex region of Ontario, singleton pregnancy, maternal age of 16 years or more, gestational age 11.5 to 20.5 weeks, no known fetal abnormalities and adequate knowledge of English. Of 2,357 participants who gave birth, follow-up was conducted during the toddler/preschooler stage on 1,607 participants from 2005 to 2007 (on average 34 months postpartum). This follow-up study population was no different from the original cohort, based on known characteristics of the women. The study population had many attributes making them favourable in addressing the research objectives. Namely, the rich dataset of the Prenatal Health Project contained a multitude of maternal individual-level factors conceptualized in Andersen's behavioural model. Further, maternal residential addresses were available and linked maternal characteristic data to contextual characteristic data sourced from 2006 Census data from Statistics Canada (Statistics Canada 2006). After elimination of participants with unknown addresses or who were no longer residing in London–Middlesex during the toddler/preschooler stage, the available study population was 1,451 mothers residing in 530

unique neighbourhoods. Although data were collected from 2005 to 2007, results continue to be representative of the study population, as London–Middlesex has undergone minimal social and structural change over the past five years (Statistics Canada 2012).

Measures

P-HSU was defined as a visit to a medical doctor who provided mothers with first-line contact with the Canadian healthcare system. Mothers who reported during the toddler/preschooler stage visiting their regular care provider, a walk-in clinic and/or an emergency department in the previous two months were classified as having used a primary health service. Of the 1,451 London–Middlesex residents linked to the residential location dataset, 29 mothers had incomplete data on P-HSU, resulting in a final study population of 1,432.

All but three maternal characteristic variables for the study were collected by telephone interview during follow-up. Maternal nativity and education were collected prenatally, and the presence of a chronic health condition was derived from prenatal and perinatal data. Contextual characteristic variables were measured at the dissemination area level, the smallest geographical unit for which Statistics Canada provides relevant social and economic variables, and were therefore used to define neighbourhoods in this study. Descriptions of the maternal and contextual characteristics, grouped by predisposing, enabling and need factors, are shown in Table 1.

Table 1. Descriptive statistics of maternal and contextual characteristics grouped by predisposing, enabling and need factors from a population of mothers living in London–Middlesex

Variable	Categorical: frequency (%) Continuous: mean (SD)
Maternal characteristics	
Predisposing	
Age in years	33.8 (4.80)
Native to Canada	1,265/1,449 (87.30%)
Education	
High school or less	331/1,448 (22.86%)
College or trade	489/1,448 (33.77%)
University or more	628/1,448 (43.37%)
Survey season	
Winter	549/1,451 (37.84%)
Spring	404/1,451 (27.84%)
Summer	193/1,451 (13.30%)
Fall	305/1,451 (21.02%)
Enabling	
Household income	
Low (<$40,000)	168/1,335 (12.58%)
Middle ($40,000–79,999)	468/1,335 (35.06%)
High ($80,000+)	699/1,335 (52.36%)
Employment status	
Full time	647/1,446 (44.74%)
Part time	279/1,446 (19.29%)
Not working	520/1,446 (35.96%)
Marital status	
Married or common-law	1,317/1,449 (90.89%)
Single or equivalent	132/1,449 (9.11%)
Parity	
1 child	406/1,449 (28.02%)
2 children	763/1,449 (52.66%)
3 or more children	280/1,449 (19.32%)

Table 1. Continued

Variable	Categorical: frequency (%) Continuous: mean (SD)
Has a regular care provider	1,384/1,451 (95.38%)
Child has a regular care provider	1,432/1,451 (98.69%)
Need	
Health condition	662/1,451 (45.62%)
Pregnant	89/1,451 (6.13%)
BMI	
Not overweight (<25 kg/m2)	764/1,367 (55.89%)
Overweight (25–29.9 kg/m2)	395/1,367 (28.90%)
Obese (30+ kg/m2)	208/1,367 (15.22%)
Depression score (CES-D)	8.8 (8.00)
Anxiety score (STAI)	19.2 (5.25)
Contextual characteristics	
Predisposing	
Neighbourhood % immigrants	19.75 (8.241)
Neighbourhood % visible minority	11.57 (9.919)
Neighbourhood % without high school education	16.59 (7.531)
Enabling	
Neighbourhood average income	
<20th percentile	285/1,444 (19.74%)
20th–80th percentile	869/1,444 (60.18%)
>80th percentile	290/1,444 (20.08%)
Neighbourhood % unemployed	5.69 (3.868)
Neighbourhood % single parenthood	14.70 (10.357)
Neighbourhood mean # children per household	1.16 (0.253)
Residence	
Urban	1,305/1,451 (89.93%)
Rural	146/1,451 (10.07%)

CES-D = Centre for Epidemiologic Studies Depression [scale]; SD = standard deviation; STAI = State-Trait Anxiety Inventory.

Data Analysis

Analyses were performed using the statistical software package SAS®9.2 (SAS, Windows build 9.2, SAS Institute Inc., Cary, NC, USA). Descriptive analyses were performed on maternal and contextual characteristics. Univariable associations of maternal P-HSU with independent variables were investigated using logistic regression where associations with $p < 0.20$ were considered in multivariable analyses.

A multilevel model was estimated using the GLIMMIX procedure and built in three stages, using a conservative level of significance ($p < 0.20$). First, maternal characteristics were added as fixed effects to the random intercept model. Each maternal characteristic in the model was assessed for having a random effect on P-HSU by examining the Wald test statistic of the estimated random slope's variance (Hayes 2006). Contextual characteristics were then added as fixed effects. Maternal characteristics were entered into the model prior to contextual characteristics, as individual-level variables have precedence over higher-level variables (Hayes 2006). The third stage of model building tested for effect measure
modification between significant maternal need characteristics and a priori chosen covariates (i.e., maternal education level, marital status, access to a vehicle, regular care provider and residence) in the multivariable model. To achieve a final parsimonious model, variables whose effects were not significant ($p < 0.05$) were removed from the model one at a time.

Results

About half of mothers (53.4%) had used a primary health service. Descriptive statistics of the maternal and contextual characteristics, grouped by predisposing, enabling and need factors, are shown in Table 1. Univariable associations between independent variables considered in multivariable analyses and maternal P-HSU are presented in Table 2.

Table 2. Univariable associations of predisposing, enabling and need variables considered in multivariable analyses of maternal primary health service use

Variable	Odds ratio (95% CI)
Maternal characteristics	
Predisposing	
Age in years	0.96 (0.94, 0.98)[a]
Education (ref = university or more)	
High school or less	1.52 (1.16, 2.00)[a]
College or trade	1.31 (1.03, 1.66)[a]
Enabling	
Household income (ref = high)	
Low	1.24 (0.89, 1.74)
Middle	1.21 (0.96, 1.52)[b]
Parity (ref = 1 child)	
2 children	0.72 (0.56, 0.92)[a]
3 or more children	0.63 (0.46, 0.86)[a]
Has a regular care provider	1.59 (0.96, 2.62)[b]
Child has a regular care provider	2.51 (0.95, 6.65)[b]
Need	
Health condition	1.37 (1.12, 1.69)[a]
Pregnant	3.11 (1.86, 5.18)[a]
BMI (ref = not overweight)	
Overweight	1.31 (1.03, 1.67)[a]
Obese	1.93 (1.41, 2.65)[a]
Depression score (CES-D)	1.03 (1.02, 1.04)[a]
Anxiety score (STAI)	1.03 (1.01, 1.05)[a]
Contextual characteristics	
Predisposing	
Neighbourhood % immigrants	0.99 (0.98, 1.00)[b]
Enabling	
Neighbourhood mean income (ref ≥80th percentile)	
<20th percentile	1.25 (0.90, 1.74)[b]
20th–80th percentile	1.28 (0.98, 1.67)[b]
Residence (ref = rural)	0.75 (0.53, 1.07)[b]

BMI = body mass index; CES-D = Centre for Epidemiologic Studies Depression [scale]; CI = confidence interval; STAI = State-Trait Anxiety Inventory.
[a] $p < 0.05$. [b] $p < 0.20$.

The final multilevel parsimonious model is presented in Table 3. All maternal characteristics were estimated as fixed effects. The final model included four measures of maternal need, of which the effects of maternal health condition and maternal weight were modified by maternal and contextual enabling factors. The variance of the model's random intercept was statistically significant with the addition of maternal characteristics, contextual characteristics and interaction terms ($p = 0.02$), indicating that the odds of P-HSU varied depending on maternal neighbourhood residence.

Table 3. Multilevel characteristics and interaction terms retained in the parsimonious model of maternal primary health service use estimated with a random intercept

Variable	Odds ratio (95% CI)
Maternal characteristics	
Enabling	
Parity (ref = 1 child)	
2 children	0.89 (0.62, 1.28)[b]
3 or more children	0.54 (0.34, 0.86)[a,b]
Household income (ref = high)	
Low	1.13 (0.68, 1.88)[b]
Middle	1.21 (0.87, 1.68)[b]
Need	
Health condition	1.19 (0.77, 1.84)[b]
Pregnant	2.77 (1.60, 4.80)[a]
Weight (ref = not overweight)	
Overweight	1.34 (0.59, 3.03)[b]
Obese	0.48 (0.15, 1.47)[b]
Depression score (CES-D)	1.03 (1.01, 1.04)[a]
Contextual characteristics	
Enabling	
Residence (ref = rural)	0.60 (0.35, 1.03)[b]
Interactions[c]	
Health condition and parity	
Condition*3 or more children	2.04 (1.04, 4.01)[a]
BMI and household income	
Obese*low	0.31 (0.11, 0.85)[a]
BMI and residence	
Obese*urban	5.93 (1.81, 19.47)[a]

BMI = body mass index; CES-D = Centre for Epidemiologic Studies Depression [scale]; CI = confidence interval.
[a] $p < 0.05$. [b] Variable included in interaction term. Main effect odds ratios do not maintain their usual interpretation, as they are dependent on their effect measure modifier. [c] Statistical interactions between two variables are denoted by an asterisk.

No predisposing factors were retained in the final model, and the only enabling factors retained were included as effect measure modifiers of need factors. Several measures of maternal need had significant effects on P-HSU. Mothers who were pregnant during follow-up had increased odds of P-HSU compared to non-pregnant mothers. Higher depression scores were also associated with increased odds of P-HSU. The effects of maternal health condition and body mass index (BMI) on P-HSU were dependent on the presence of enabling factors, as demonstrated by the significant interaction terms in Table 3. As the interpretation of interaction term odds ratios is not straightforward, the odds ratios for the effects of maternal health condition and BMI on P-HSU in subgroups of their effect measure modifiers are presented in Table 4.

Analysis of the effect of maternal health condition on P-HSU for each subgroup of maternal parity revealed differences in magnitude and significance levels, indicative that P-HSU by mothers with a health condition was not equitable across subgroups of maternal parity. For example, in mothers with three or more children, having a health condition increased the odds of P-HSU by 2.41 (1.43, 4.05), whereas the odds ratios for having a health condition were lower in magnitude and not significant in other subgroups of parity. Therefore, mothers with a health condition were more apt to use primary health services if they had three or more children.

… mothers with a health condition were more apt to use primary health services if they had three or more children.

Table 4. Main effects of need factors in subgroups of their effect measure modifiers

Main effect	Subgroup	Odds ratio (95% CI)
Health condition	Parity of 1 child	1.19 (0.77, 1.84)
Health condition	Parity of 2 children	1.11 (0.82, 1.50)
Health condition	Parity of 3 or more children	2.41 (1.43, 4.05)[a]
BMI (ref = not overweight)	Rural and high household income	
Overweight		1.34 (0.59, 3.03)
Obese		0.48 (0.15, 1.47)
BMI (ref = not overweight)	Rural and middle household income	
Overweight		1.25 (0.54, 2.91)
Obese		0.26 (0.08, 0.89)[a]
BMI (ref = not overweight)	Rural and low household income	
Overweight		1.29 (0.56, 2.98)
Obese		0.16 (0.04, 0.56)[a]
BMI (ref = not overweight)	Urban and high household income	
Overweight		1.21 (0.84, 1.73)
Obese		2.82 (1.61, 4.94)[a]
BMI (ref = not overweight)	Urban and middle household income	
Overweight		1.11 (0.74, 1.68)
Obese		1.58 (0.94, 2.66)
BMI (ref = not overweight)	Urban and low household income	
Overweight		1.55 (0.85, 2.80)
Obese		0.94 (0.45, 1.93)

BMI = body mass index; CI = confidence interval.
[a] $p < 0.05$.

Analysis of the effect of obesity on P-HSU for each subgroup of household income and residence resulted in three significant combinations of subgroups, revealing that not all obese mothers had equitable P-HSU. First, in mothers living in rural residences and middle-income households, being obese decreased the odds of P-HSU by 0.26 (0.08, 0.89) compared to not being overweight. Similarly, in mothers living in rural residences and low-income households, the odds of P-HSU in obese mothers were 0.15 (0.04, 0.56) compared to mothers who were not overweight. Therefore, compared to non-overweight mothers, obese mothers were less likely to use primary health services when residing in rural residences and low- or middle-income households. Contrarily, being obese increased the odds of P-HSU by 2.82 (1.61, 4.94) when mothers lived in urban residences and high-income households. These results demonstrate qualitative effect measure modification in that urban and high-income household residence increased obesity's odds of P-HSU, while other subgroups of residence and household income reduced obesity's odds of P-HSU.

Discussion

This multilevel study of maternal P-HSU contributes to a gap in the health services research literature. Beyond health status, enabling factors may influence maternal P-HSU, including characteristics of the context in which mothers reside. Health services research that focuses on the role of context, defined by residential neighbourhoods, may be important to inform healthcare policy, as strategies that consider these contexts may result in place-based action (Denny and Davidson 2012). Further, changes in healthcare policy may be targeted to reduce inequities in P-HSU by identifying subpopulations whose need for P-HSU is modified by predisposing and enabling factors.

Urban/rural residence was an effect measure modifier on the effect of maternal BMI and the only contextual characteristic retained in the final model, which demonstrated significant variance in the odds of maternal P-HSU between residential neighbourhoods. The degree of urbanicity may affect the physical and social structures of geographical environments that, in turn, may contribute to patterns

of P-HSU. It has been shown that urban residence is associated with a greater degree of accessibility to primary health services, for example, higher physician density, more flexible hours of operation, transportation options and shorter travel distances (Arcury et al. 2005; Blazer et al. 1995; Goetz and Debertin 1996; Haggerty et al. 2007). The effect of urban/rural residence on P-HSU in Canada is mixed in the literature. Some suggest that living in more urban areas is associated with P-HSU (Dunlop et al. 2000; Ryan et al. 2011), while others have not reported a significant association (Diaz-Grenados et al. 2010; Nabalamba and Millar 2007; Sibley and Weiner 2011). Despite the mixed findings in the literature, residence was found to play a significant role in influencing the effect of maternal BMI on P-HSU in this study and therefore should be considered as a covariate in future health services research. Should future studies replicate these findings, then healthcare system stakeholders should be cognizant that P-HSU has the potential to vary according to the geographical environment in which patients reside and that residence may be an important contextual characteristic to consider.

Despite the mixed findings in the literature, residence was found to play a significant role in influencing the effect of maternal BMI on P-HSU in this study …

HSU is defined as equitable when driven by need factors (Andersen 1995). This study contributes to the notion of equity by testing how need factors behave in subgroups of predisposing and enabling factors. Effect measure modification of need factors provides evidence that the effect of need on HSU differs in magnitude, direction and/or significance depending on the subgroup of the effect measure modifier, suggestive of inequitable HSU. Future health services research may consider such interactions as an analytic method to test for inequity in equity studies.

This study found that the effect of maternal health condition on P-HSU varied across subgroups of maternal parity. As an enabling factor, maternal parity may be conceptualized to facilitate P-HSU in opposing ways. First, it may be speculated that lower maternal parity enables P-HSU in that mothers responsible for fewer children have more flexibility in their ability to utilize health services. Contrarily, higher maternal parity may enable P-HSU as maternal–child HSU is highly correlated (Minkovitz et al. 2002). In this study population, the latter situation may explain the more than doubled effect size of maternal health condition in mothers with three or more children compared to mothers of lower parity; however, more research on the role of maternal parity as an effect measure modifier is warranted.

Obese mothers living in rural and either low- or middle-income households may have inequitable P-HSU compared to obese mothers living in urban and high-income households for a number of reasons. As one author suggests, people may have to invest extra time and money to seek health services that are limited in rural areas (Haggerty et al. 2007). This requires taking time off work, securing childcare and arranging for transportation, all of which have financial implications. Mothers with lower household income may also fear financial costs of healthcare resulting from P-HSU that are not covered by government plans and private insurance, such as prescriptions and treatment from other healthcare professionals. Therefore, these mothers represent a potentially vulnerable population who may not be receiving the appropriate healthcare for obesity-related health issues.

Mothers with lower household income may also fear financial costs of healthcare resulting from P-HSU that are not covered by government plans and private insurance …

While inequity of P-HSU was observed in obese mothers and mothers with a health condition, there was no evidence to suggest that the effect of depression and pregnancy varied across subgroups of predisposing and enabling factors. While this study found that pregnant mothers and mothers with higher depression scores were more likely to use primary health services, there was no evidence to suggest that any of them were disadvantaged in their P-HSU. This indicates that these mothers received healthcare from primary care providers regardless of predisposing and enabling factors.

It is important to note that P-HSU was based on maternal recall of the past two months and that this time frame may not represent poor access of P-HSU. Rather, results indicate the existence of inequities in the odds of P-HSU in subgroups of enabling factors over this time period. Future research should explore effect measure modification of need factors on P-HSU captured over a longer time frame to solidify this approach of testing for inequity. The study was limited to mothers from one region in Ontario, and therefore may not be generalizable to mothers elsewhere in Canada. Future work should broaden the geographic area of study to comparatively examine these results with other regions. However, the neighbourhoods defined by the dissemination areas in which mothers resided represented small area profiles that aid in understanding how the associations of contextual characteristics with P-HSU play out (Denny and Davidson 2012).

Medical doctors who engage with patients in private practices, walk-in clinics and emergency departments are the gatekeepers to secondary healthcare services (e.g., hospitalization, medical specialists) and have an integral role in the flow of patients through the Canadian healthcare system. It is important to understand who is using these services and why, and whether inequity of use exists. Health services research that focuses on the role of residential location may be important to inform public health policy, as strategies that consider this have the potential to affect whole groups. Examining how need factors behave in certain subgroups of predisposing and enabling factors is an analytic approach to investigate equity of HSU. The identification of subpopulations disadvantaged in their use is important, as they may benefit from targeted changes in public health policy. This research may be used as a methodological model for studying HSU in other Canadian populations. Gathering firm evidence from multilevel studies of HSU has the potential to inform Canadian public health policy with regard to inequity and the influence of place of residence on maternal primary healthcare service use.

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Protection of Health Workers, Patients and Facilities in Times of Violence – Report

A Conference Convened by the Center for Public Health and Human Rights
Johns Hopkins Bloomberg School of Public Health
Bellagio, Italy, November 2013

Introduction

Attacks on and interferences with healthcare providers, facilities and transports pose a grave threat to availability of and access to healthcare during armed conflict and civil disturbances. We have witnessed repeated and systematic violations of universal norms requiring the respect for and protection of healthcare services, committed by state military and police forces as well by armed groups. In some cases health workers, ambulances and facilities are specifically targeted; in other cases they are the result of more generalized assaults on civilian populations. Aside from violent attacks, states and armed groups engage in conduct such as occupying health facilities, obstructing travel through checkpoints and placing military posts near clinics, limiting access. Further, states fail to provide security for health workers providing treatment or preventive services, such as vaccinations.

In recent years, the humanitarian, human rights, health professional and global health communities have begun to take proactive steps to address the problem. Actions have included efforts to strengthen norms of respect for and protection of health, to broaden data collection to gain a better understanding of incidents and trends, to analyze events toward improving security and to strengthen accountability mechanisms. But knowledge gaps remain large, and the problem remains at the fringes of global health awareness. The Center for Public Health and Human Rights at the Johns Hopkins Bloomberg School of Public Health convened a diverse group of stakeholders at the Rockefeller Foundation's Bellagio Center to take stock of the current situation, to consider whether current initiatives can be better integrated or aligned, and to identify gaps in knowledge, protection, monitoring and accountability.

Conference participants were called upon to identify key actions by which the international community, including states, health ministries, United Nations (UN) agencies, non-governmental agencies (NGOs) and professional health organizations could reverse the erosion of norms for the respect for and protection of healthcare in times of armed conflict and other situations of violence, and identify potential areas for future research, in order to ensure action is grounded in a strong evidence base.

This report offers a review of the rich and varied discussions that took place during the course of the three-day conference that resulted in a Call for Action, including a global research agenda.

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The nature of the problem

Overview

A review of attacks on and interference with health workers, facilities and patients over the past three decades reveals both the global scope of the problem and the wide variety of political contexts in which it exists. Assaults on health services have often been viewed as a problem unique to armed conflict, whether international or non-international in scope. Yet we know that assaults on health also take place during times of political turmoil or civil disturbances as well as in armed conflict. They occur in fragile or weak states and in strong ones, in very poor and in middle- and high-income countries. Violations of international law are committed by formal military forces, paramilitary groups, police and armed groups. Victims include patients, doctors, nurses, ambulance drivers and attendants, and community health workers including vaccinators.

Violations against health workers and patients include harassment, beatings, torture, killings, disappearance, detention and

prosecution, as well as more insidious threats and obstructions to healthcare access. In some cases, state prosecutors have brought formal charges in courts against health workers for acting in accordance with their duty to provide impartial medical care. Facilities have been shelled, tear-gassed, looted and occupied either for military purposes or to control access to care. In some cases, medical records or other confidential information has been demanded in order to identify individuals who may be political opponents of the perpetrators. Ambulances have been fired upon and their access across checkpoints has been unreasonably delayed or prevented entirely.

Some states have enacted or stepped up enforcement of laws that either explicitly deem the impartial provision of healthcare to a person deemed to be associated with a terrorist organization to be a crime, or apply general anti-terror laws to the provision of medical care. In other states, doctors and nurses providing healthcare for victims of human rights violations are individually targeted for either speaking out or openly providing care to victims.

Aside from these direct attacks, there are many circumstances, though little documented, where states fail to live up to their responsibilities to provide protection to health workers or ensure continued access to healthcare during periods of insecurity. Passivity in the face of obligations to assure access to health services equally violates international law.

There is evidence that direct assaults, disruption in supply chains, deterioration of infrastructure and shorter working hours are profoundly disruptive to access to care. Health worker vulnerability has led to outward migration of qualified staff, high turnover of managers and diminished access to care. Less visible effects can include proliferation of agencies that seek to fill gaps in services during periods of pervasive violence, but often lack the coordination and continuity necessary to ensure quality of services is maintained. Further, understandable concerns for aid worker security have led, in some circumstances, to practices such as remote management using standardized practices without attention to context, militarization of healthcare and distancing from communities – all of which can compromise quality. These disruptions in turn can create patients' fear of and distrust in the health system. We know less about the impact of pervasive interference on health services and health outcomes, though some studies have shown increases in maternal mortality and decreases in access to anti-retroviral drugs for treatment of HIV/AIDS, as well as severe disruptions in the treatment of other chronic diseases. Far more knowledge is needed to understand these outcomes, including effects on the health status of the population. Finally, health reconstruction in the wake of conflict is more complex and expensive in circumstances where infrastructure has been damaged or destroyed and human resources have been diminished by health worker flight.

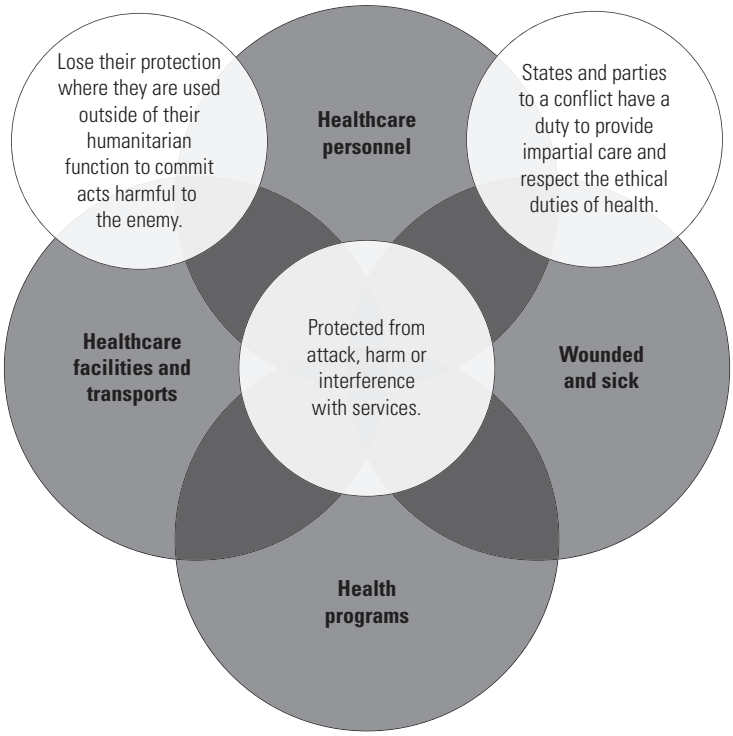
It is not entirely clear whether strong and universal norms of respect and protection for healthcare have eroded, or whether norms

2013 was a brutal year for attacks on health – and in many different contexts. In Syria, government forces assaulted health workers and facilities as a matter of systematic policy. Two thirds of hospitals have been shelled, mostly by government forces, and a third of them destroyed. Hundreds of health workers have been killed and imprisoned. Thousands of health professionals in Syria have fled. Availability of clean water and sanitation has been severely compromised. Polio has returned to the country.

In response to violent attacks on political demonstrators, doctors in Turkey provided emergency medical services. The government required physicians to report whom they treated and charged medical groups with opposing the government and is now seeking to criminalize unauthorized medical care. Physicians were required to report whom they treated and charged medical groups with opposing the government, and is now seeking to criminalize unauthorized medical care.

In Pakistan and Nigeria, 30 community health workers vaccinating children against polio have been murdered.

Figure 1.



have been insufficiently upheld over the course of history. But those norms established under international law are powerful, as illustrated in this Venn diagram:

Gaps in knowledge

Despite the severity and impacts of assaults on health services, there exist serious gaps in our knowledge about the phenomenon. These fall into three categories: routine data collection, research and awareness.

Routine data collection. In other realms of civilian protection, data collection and surveillance have profoundly informed and influenced responses at the global and national level, such as in campaigns to end the use of child soldiers and to ban anti-personnel landmines. Action to assess adherence to norms has been weak, though recent initiatives warrant development and support. The World Health Organization (WHO) and the UN Special Representative on Children in Armed Conflict are charged with developing more systematic methods for incident reporting. The WHO is required to provide global leadership in developing methods for collection and dissemination of data on attacks on health workers, facilities, ambulances and patients in complex emergencies. The Special Representative reports to the Security Council on specific incidents involving attacks on schools and hospitals, and is also authorized to require action plans and a monitoring and reporting mechanism for persistent violators. These initiatives need to be fully implemented and accompanied by others at the global, regional and national level to understand both general trends and the contextual factors that often determine the nature and impact of attacks. States, especially ministries of health, have a responsibility to develop incident reporting plans as well as to support independent monitoring from other sources including the High Commissioner for Human Rights. As we discuss later, civil society organizations also have a key role to play in the process. In reporting and monitoring, the goal should not be a single and integrated system. Rather, redundancy of effort is preferable to one integrated system, given different mandates and contexts in which violations take place.

Research. In addition to insufficiencies in incident reporting, monitoring and data collection, there is a paucity of scientific studies needed to understand motivations of perpetrators, contextual factors driving attacks, and the impacts of attacks on health-worker migration, access to services, health infrastructure, health systems and health outcomes. Strategies for protection and security are insufficiently evaluated, so we lack knowledge of the most effective strategies for the protection of patients and the health workforce, including infrastructure, supplies and services during periods of social disruption. As a result it is difficult to draw lessons from one context that may be applicable to another context, or even in the same one.

Awareness of health worker rights and responsibilities. Increasing knowledge involves more than data and research. Health workers themselves often lack awareness of their rights to practice care impartially without state or other interference, and sometimes their experiences leave them with low expectations of protection. In certain cases, health workers don't recognize violations when they occur, or if they do they lack resources to know where or how to report them. These factors lead to feelings of disempowerment, leaving health workers vulnerable to pressure from states and armed groups to act unethically.

Toward protection and accountability

In recent years, the humanitarian community has intensively addressed means for increasing the security of their operations. The International Committee of the Red Cross's (ICRC) Healthcare in Danger project is building on these efforts to develop pragmatic means for increasing protection through a set of activities designed to engage key actors, including militaries, hospital and ambulance providers, health professional associations and armed groups. For example, in the realm of military practice, ICRC is addressing concerns such as inspection and passage practices at checkpoints, search operations in health facilities and fighting in proximity to health facilities. For facilities and ambulances, it is identifying practices that could offer greater safety, such as training and security procedures. ICRC is also convening states to consider expanding protection for healthcare services under national law.

UN agencies, including the Office for the Coordination of Humanitarian Affairs, have become more engaged, partnering with local health providers, leaders, ministries and others to advance protection through information sharing and coordinated responses. For some UN agencies the task is often complicated by tensions stemming from the need to work through national authorities whose forces may be the perpetrator. In some cases these relationships prevent agencies from providing humanitarian relief across borders, thus raising questions about fulfillment of their responsibilities. Further, in the past the need to work with member states frequently affected the willingness of the WHO, the UN Office for

There is no single pathway or means to achieve protection. Multiple human rights mechanisms and protection strategies can be reinforcing. Working independently, the ICRC, an investigatory commission of the UN Human Rights Council, Israeli and global human rights organizations, and the Special Representative on Children in Armed Conflict all contributed to major change in conduct of the Israeli Defense Forces regarding health facilities after the 2009 military operation by the Israeli Defense Forces in Gaza. Local civil society organizations demanded a transparent investigation and human rights organizations and the UN commission documented serious violations, resulting in visible public debate and pressure on the IDF to alter its conduct. Independently, the ICRC privately engaged with the Israeli military about incidents of concern and the Special Representative on Children in Armed Conflict received reports by both sides and conducted its own fact-finding, resulting in regular reports to the Security Council. These combined efforts bore fruit when, in the next episode of fighting in Gaza, there was significantly less damage to hospitals and interference with ambulances.

the Coordinator of Humanitarian Affairs (OCHA), UNICEF and other agencies to speak out publicly about harm deliberately inflicted by member states on health workers and facilities. In the past two years, however, the WHO, UNICEF and OCHA have been more outspoken in their criticism of states and armed groups that perpetrate attacks.

At the same time, the full burden of assuring respect for and protection of health should not be placed on humanitarian organizations. Humanitarian response cannot solve the political problems that underlie a humanitarian crisis. Additionally, humanitarians are often constrained in what they can report because of the need to maintain access.

Protection responsibilities need to extend in the first instance to ministries of health. All too often these ministries have either failed to come to the defense of health workers and patients or, in some cases, actively participated with state security officials in undermining professional independence. Even in circumstances in which ministries are politically free to monitor and report, they frequently lack the knowledge, mandate or will to collect data or use their influence within the government to protect health workers.

Finally, accountability in the form of costs and consequences for those who commit violations is a key but undeveloped strategy to deter violators. Accountability needs to take place at a number of levels. There is increasing recognition that diplomatic action can and should be invoked to protect health in conflict. Tools are available through both bilateral and multilateral action and can include high-level meetings and special sessions of the UN General Assembly. Any international responses need to be coordinated with advocacy and civil society groups working at the national level. The Responsibility to Protect, designed to stimulate international action to protect civilians, still holds promise but faces major challenges because of the political controversies it spawned as a result of the Iraq war and the Libya intervention.

Formal human rights mechanisms at the global level, designed to stop atrocities, have great potential but have been infrequently invoked. In the past, the problem of attacks on health was considered an issue of the law of armed conflict rather than human rights law. As evidenced by a recent report to the UN General Assembly by the UN Special Rapporteur on the Right to the Highest Attainable Standard of Health, there is increasing recognition that human rights law provides a powerful basis for protection and accountability. The law extends beyond non-interference with health services to obligations to assure continuity and access to services in volatile environments and to assure security from interference by third parties. These norms need to be reinforced at every level and at every opportunity, including in post-conflict planning.

There are, moreover, powerful linkages between diplomatic action and invocation of human rights machinery to bring pressures from other states to bear on offenders. Existing mechanisms include mandatory self-reporting by states on their own record (with possibilities for civil society shadow reports) through Universal Periodic Review, human rights treaty bodies, reports by the Special Rapporteur on the Right to Health, and field investigations by the High Commissioner for Human Rights. These can enable states and UN agencies to exert pressure on violators. The newest mechanism derives from the mandate of the Special Representative on Children in Armed Conflict. The Special Representative reports annually on 20 conflict situations and other situations of concern. Its mechanism has great potential because of its ability to name perpetrators before the UN Security Council and put monitoring and reporting into place for states and armed groups listed as persistent violators. Further, action plans for compliance are not subject to review by governments that offend.

The jurisdiction of the International Criminal Court (ICC) can and should be invoked. Under its governing statute, attacks

on health facilities are war crimes. Demands for referral to the ICC, as well as to regional human rights tribunals, can have a potentially deterrent effect and be a focal point for civil society action to demand adherence to norms.

Indeed, all these and regional and national mechanisms provide a key entry point for civil society. They can invoke available tools strategically and provide opportunities to mobilize health workers and others to demand action against impunity through influence on official reports, shadow reports and use of the media.

None of these mechanisms constitute a "silver bullet" to address the problem. Nor do the existing initiatives need to be integrated to create a single system. The multiplicity of efforts, even if overlapping to some extent, can expand opportunities to highlight the problem, promote accountability and reinforce one another. The key is to align these efforts toward the overarching goal of safe and secure health services. For example, action at high levels of the UN can strengthen the hand of ministries of health to perform key data-collection activities and demand adherence to norms by state military and security agencies. To be successful, however, there needs to be greater commitment to employ the mechanisms discussed. Political analysis is also needed to determine which UN agency or government will have the most influence in a particular situation.

Finally, protection and accountability can only improve if the broader global health community takes ownership of the problem as a fundamental feature of health and human security. It is known that fragile and conflict-affected states lag behind more stable states in achievement of the health-related Millennium Development Goals. Global campaigns to strengthen human resources for health and promote universal healthcare, however, take little account of the need to address attacks on and interference with health. Opportunities should be taken to incorporate protection of healthcare in times of crisis into global policy agendas and activities such as monitoring under the global code of conduct on health-worker migration and creation of the post-2015 development agenda. Global institutions such as the World Bank can also use their power and influence to address this issue. Principles including empowerment and engagement of multiple sectors and stakeholders can all be brought to bear on the problem.

Civil society engagement

In the past generation civil society organizations have organized toward a ban on anti-personnel landmines, use of child soldiers and other profound harms to civilians in conflict. Until recently, however, the leading proponents of protection of healthcare in conflict have been largely limited to humanitarian aid groups and a handful of human rights organizations. The leading edge of advocacy must now come from health workers, health advocacy and other civil organizations.

Civil Society Engagement Activities

- National health professional associations develop ethical standards on impartial care and protection of rights
- Incorporate training on impartial care and protection of rights in health professional training curriculum and in-service training
- Advocate for recognition of duties of impartiality and rights to protection in national laws
- Engage with governments to protect impartial care, and to monitor attacks and interference
- Liaise with UN agencies present in conflict-affected countries on monitoring, reporting and accountability
- Facilitate medical relief where needed
- Support and speak up on behalf of health workers
- Document and report violations
- Share experiences
- Raise public awareness

Global medical and nursing organizations have in recent years engaged in more robust condemnation of attacks on healthcare at the global level, partnered with the WHO and ICRC's Healthcare in Danger project and joined international coalitions such as Safeguarding Health in Conflict. There is potential for more intensive engagement through educating national associations about the rights and responsibilities of health workers in conflict situations, assuring that protection of health is included in global health agendas and addressing the role of conflict in health-worker migration.

At the national level, the challenges are greater because of lower awareness of provider rights and responsibilities, as well as limited capacity by professional associations to set standards and influence governments in conflict-affected states. In many circumstances, the key is to strengthen national-level health professional organizations, enabling them to offer training in protection and impartiality, set standards, collect data and become more engaged at the national level. This can be done through regional and global cooperation, which can provide forums for technical assistance and a means of amplifying local voices.

When they are under assault, health professional groups, like civilians generally, are severely tested. National professional organizations can experience push back or worse for speaking against the practices of government security forces. For more than 20 years the Turkish Medical Association has been subjected to harsh criticism and even arrest of its members for standing up for professionalism, service to all in need and preservation of patient confidentiality. In some circumstances, faith-based groups may have the greatest space to speak out.

In Syria, in response to the assaults on health workers, patients and facilities, civil society has been at the forefront of documentation and advocacy. Even as they treat patients in dire conditions, local medical groups have organized to transmit information on attacks on healthcare through YouTube, Twitter, Facebook and other social media. Syrian diaspora groups have organized to provide humanitarian aid, training for physicians and funding. Local NGOs document violations. All liaise with US, European and regional organizations, as well as international and local authorities.

Civil society has mobilized on the global level through the complementary Healthcare in Danger Project and the Safeguarding Health in Conflict Coalition, the latter composed of health provider, human rights, health professional and academic members and observers.

Conclusion

The problem of attacks on and interference with health workers, facilities, ambulances and persons seeking care is complex, and attention is long overdue. The problem is not insoluble and indeed there is reason for optimism. Bellagio conference participants are convinced that greater and more considered attention to the issue as a fundamental aspect of human security can bring significantly more protection and respect for health than exists now. One participant, Margaret Mungherera, President of the World Medical Association, said that beyond the substance of our recommendations, the participants wished to convey a spirit of commitment and high aspirations that the work needed can be accomplished. Vision, commitment, pragmatism, research, a full toolbox of monitoring, reporting and accountability, and political will can get the job done.

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For more information, visit: www.jhsph.edu/humanrights.

Call to action

International humanitarian and human rights law recognizes the obligation and/or the responsibility of governments and non-state actors to respect and protect health workers, facilities, medical transports and the people they serve. Violations undermine the human security and health of conflict-affected populations, disrupt health systems and undermine equitable access to healthcare, resulting in avoidable loss of life and human suffering. We, the assembled, believe urgent action is needed to address the problem and call upon the international community to advance the security of health, particularly in situations of armed conflict and internal disturbances, through the following actions:

1. *States and armed groups.* At all times, including during armed conflicts and internal disturbances, respect healthcare workers, facilities, transports and services, and persons seeking care, by not attacking, interfering with, threatening or obstructing them; refrain from punishing health workers for providing treatment to individuals in need of medical care on account of the patient's ethnic, religious, national, political or military affiliation or other non-medical considerations; and ensure availability of safe and secure access to and equitable distribution of quality healthcare.
2. *States.* Train their military, police forces and other law enforcement agents to adhere to legal standards and assure protection of health services, health workers and people seeking care; armed groups – similarly raise awareness among their forces to comply with their international obligations to respect healthcare workers, facilities, transport and services, and persons seeking care.
3. *States*, with the support of the UN. Take action to stop attacks and hold perpetrators to account in national and, where appropriate, international courts and/or special tribunals.
4. *States*. Make explicit in national law the respect for and protection of the delivery of healthcare and health workers in times of armed conflict and internal disturbances, and reaffirm and reinforce these norms through the UN General Assembly, the Security Council and the Human Rights Council.
5. *States.* Through ministries of health and other relevant agencies and UN bodies, establish, strengthen and provide resources for systematic monitoring and reporting of attacks on health workers, facilities and transports, and individuals seeking care, and support the implementation of ongoing initiatives by the UN Special Representative for Children and Armed Conflict and the WHO designed to collect and disseminate data on attacks on health services and encourage field-based reporting by the High Commissioner for Human Rights.
6. *States, through the UN*. Engage in processes such as Universal Periodic Review, treaty body review and mechanisms for the protection of civilians and children affected by conflict to promote compliance with international law and accountability for perpetrators.
7. *States, relevant UN entities, NGOs, and professional health organizations and ministries of health*. Promote, disseminate and implement recommendations

of the International Committee of the Red Cross Healthcare in Danger project to increase security of healthcare services and health workers in the field.

8. *Health professional organizations*. At the national and global level promote universally accepted standards of professional conduct among health workers in armed conflict and internal disturbances, including training health workers on human rights and medical ethics and advocating for protection and security of health services and health workers.
9. *States, the WHO and the Global Health Workforce Alliance.* As part of the UN post-2015 development agenda process incorporate strategies to address the problem of interference with healthcare and address attacks on health workers in the human resources for health agenda and related initiatives.
10. *Civil society actors*. Actively engage states and relevant international organizations to advance protection of healthcare in armed conflict and internal disturbances.
11. *States and donors*. Support civil society engagement through capacity building, technical assistance and funding.
12. *States and other research funding bodies sponsors, and researchers and practitioners*. Conduct in-depth studies on the nature of violations and the perpetrators, as well as the consequences of lack of protection of healthcare functions on the health and development of the population.

Agenda for research as foundation for protection of health workers, patients and facilities in times of violence

Understanding and acceptance of norms of respect and protection for health services in times of violence:

a. What is the level of knowledge of norms across stakeholders?
b. How do laws designed to protect state security affect norms regarding respect for health professional impartiality and autonomy?

Understanding the impact of attacks and threats on health systems:

a. What is the impact of violence in the short, medium, long term, inflicted on:
   - Health workers, including effects on retention and migration?
   - Health infrastructure, including hospitals and transportation?
   - Health delivery, including access to and availability of essential medicines?
   - Public health programming and disease prevention?
   - Health outcomes?

b. What coping mechanisms have health workers and those in need of care developed to maintain secure access to healthcare in conflict?

Understanding forms of and motivations for conflict-related violence toward healthcare:

a. What motivates attacks in varying contexts?
b. Can patterns in attacks be identified?
c. Can a taxonomy of attacks be developed?

Informing protection strategies:

a. What strategies to prevent or stop attacks, or limit their impact, have worked, in which contexts, and why?
b. How can lessons learned be best translated into practice and empower local healthcare providers working in conflict?


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