Restrictive Measures in an Influenza Pandemic: A Qualitative Study of Public Perspectives

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ABSTRACT

Objectives: Recent experiences have demonstrated that restrictive measures remain a useful public health tool during infectious disease outbreaks. However, the use of restrictive measures is not without controversy, as there is no agreed-upon threshold for when and how to invoke restrictive measures. The objectives of this study are to solicit perspectives from Canadians on the ethical considerations of using restrictive measures in response to influenza pandemics, and in turn, to use public views to contribute to a better understanding of what is considered to be the justifiable use of restrictive measures.

Methods: A series of town hall focus groups with Canadian residents from June 2008 to May 2009, in three Canadian regions, in order to achieve broad public engagement (n=3 focus groups with a total of 17 participants).

Results: Two key themes emerged from all town hall focus groups: 1) create an environment for compliance through communication rather than enforcement, and 2) establish the delineation between individual rights, community values, and the greater good.

Conclusion: While there is a need for a decision-making authority and even a mechanism for enforcement, our data suggest that a more tractable approach to restrictive measures is one that enables individuals to voluntarily comply by creating an environment to compel compliance based on communication. This approach requires restrictive measures to be a) proportional to the threat, b) implemented along with reciprocal arrangements provided to those affected, and c) accompanied by open and transparent communication throughout all stages so that citizens can both understand and participate in decision-making.

Key words: Public health; influenza; pandemics; bioethics; qualitative research; quarantine

La traduction du résumé se trouve à la fin de l'article.

Can J Public Health 2012;103(5):e348-e352.

The use of restrictive measures to curb the spread of influenza during a pandemic raises difficult questions about how to achieve public health goals in today's democratic societies. More than any other public health intervention, it highlights the inherent tension between the collective good and individual rights. Despite this tension, however, recent experiences have demonstrated that restrictive measures remain a valid public health tool.[1-3] Still, the use of restrictive measures is not without controversy; there is no agreed-upon threshold for when and how to invoke restrictive measures during a public health emergency, such as a pandemic.[4,5]

Much of the academic and policy discourse on restrictive measures is concerned with its effectiveness, such as whether particular measures delay or reduce transmission,[3,6-8] how measures ought to be evaluated,[8] and what constitutes an effective intervention.[2,9] Some scholars have challenged the centrality of the effectiveness claim, arguing that justifications for the use of restrictive measures ought to transcend scientific and utilitarian claims, which have proven to be insufficient, and instead should be grounded in deliberations on the use of restrictive measures. In so doing, they sought to expand the scope of moral argumentation to justify the legitimate use of coercive public health measures during communicable disease outbreaks.[10]

As part of its research platform, the Canadian Program of Research on Ethics in a Pandemic (CanPREP) conducted three town hall meetings across Canada in order to elicit citizens' views about ethical issues related to pandemic influenza, including the use of restrictive measures. A related goal was to enhance the legitimacy of the values proposed in the University of Toronto Joint Centre for Bioethics seminal report on the ethical considerations for planning and decision-making during a pandemic, which had been developed without public input.[11] In this paper, we present CanPREP's findings from the town hall discussions on restrictive measures with the view of further bolstering our empirical understanding of the justifiability of using restrictive measures to achieve public health goals.

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Acknowledgements: This project was financially supported by the Canadian Institutes of Health Research Pandemic Planning Strategic Research Initiative. Mr. Smith is supported by a CIHR Frederick Banting and Charles Best Canada Graduate Scholarship. Dr. Upshur is supported by the Canada Research Chair in Primary Care Research. The authors thank the participants of the Vancouver, Winnipeg, and Saint John town hall meetings, as well as those who collaborated with, and who are team members of, the Canadian Program of Research on Ethics in Pandemic (CanPREP).

Conflict of Interest: None to declare.

METHODS

Participants and settings

The team conducted three town halls in three major Canadian urban settings (Vancouver, BC; Winnipeg, MB; Saint John, NB) between June 2008 and May 2009. Canadian residents aged 18 and over who spoke fluent English and who had no relationship with study investigators were recruited from the general public using local newspaper advertisements and social networking websites. In addition, study collaborators (i.e., local contacts who assisted in organizing town halls) used snowball sampling to recruit participants in their local areas. A total of 17 participants attended: 5 in Vancouver, 6 in Winnipeg, and 6 in Saint John.

Data collection and analysis

Data were collected through day-long facilitated discussions using case scenarios and focus group guides (Appendix A), which were developed collaboratively by the research team. At each town hall meeting, participants were randomly divided into groups of five to eight people and asked to deliberate on the ethical issues concerning an assigned scenario (see Appendix), in this case restrictive measures. Groups met in the morning and afternoon (for a total of approximately eight hours) and were both given new details on the case and asked a new set of questions as deliberations progressed. At the end of the day, the four scenario groups met to debrief and share the key issues raised and discussed in their small groups. This paper reports only the results from the restrictive measures group. Group discussions were facilitated by a member of the team while another member took notes. Town halls were audio recorded, transcribed verbatim, and verified by team members.

Data analysis

We conducted a thematic analysis of each transcript within and across town halls according to standard qualitative analysis procedures. Thematic analysis progressed via the following four steps: 1) each author coded each transcript independently, one town hall at a time; 2) a shared coding framework for each town hall meeting was developed collectively based on each individual's independent codes; 3) codes were collapsed into themes for each town hall, repeating the process for all three town halls; and 4) themes were generated across town halls.

Trustworthiness of our analysis was ensured through analyst triangulation, prolonged engagement with the data by research team members both individually and as a group, and a series of peer consultation and debriefing sessions.[12] Members of the research team met at each stage of analysis in order to discuss the interpretation of the results and consider the emerging themes. We also presented and discussed our results with the larger CanPREP research team. Finally, we kept detailed team notes at each stage of analysis as to what codes were added, removed or collapsed, in order to establish an "audit trail."[13]

Ethics

The study received ethics approval from the University of Toronto. Participants were informed of confidentiality and privacy, possible benefits and risks, and the ability to withdraw from the study. All participants provided written consent.

Appendix A. Restrictive Measures Scenario and Question Guide

The media is reporting that the World Health Organization has officially determined that an avian influenza ("bird flu") pandemic is now underway. The Public Health Agency of Canada has confirmed person-to-person spread in several Canadian cities including [town hall location city]. Some deaths have been reported, but no one knows how serious the problem may be because there is no information as yet on the extent of the outbreak. Little is known about the actual virus at this point. Vaccine development is underway; however, large-scale public vaccination programs are not expected to be available for 6 to 8 weeks.

Public health officials are strongly recommending the immediate implementation of some restrictive measures to help slow the spread of the infection. This includes the closing of community centres and the cancelling of all large public gatherings. One family whose 2 daughters, 24-yr-old Amandeep and 16-yr-old Marpareet, were killed in a car accident just as this information was released did not hear this information because it was disseminated in the English media and they do not watch TV or listen to the radio in English. Sponsored by Amandeep to come to Canada, Marpareet, her brothers, Rajinder and Darshan, and her parents had arrived from India less than a year ago and speak little English. The family holds a large memorial service for family and friends the following day. Few people do not show up because most of them, although they had heard the order by authorities, think that the cancellation of large public gatherings means cancelling social events, not a funeral, which is a sacred rite to honour the passing of a loved one. Moreover, the tragedy of this untimely loss overshadows everyone's concern about an outbreak, the actual seriousness of which no one really knows. There have been no reported deaths caused by influenza in their immediate community. Over 200 people attend the funeral.

- What are your initial thoughts and feelings about this situation?
- What do you think were the most important considerations for the family in making their decision?
- What are the features of this case that you find most compelling?

Scenario Continued (Reveal 1)

Public health authorities issue an order requiring everyone who attended the funeral to stay home for a period of 7 days, even though there is still little information about the virus or the extent of the outbreak. Rajinder wonders whether this is feasible as his family depends on his income. He decides to go to work stocking shelves at Canadian Tire, in spite of the order, while the rest of his family stays home.

- What do you think of Rajinder's decision?
- Do you think people should face consequences if they don't follow an order of quarantine? If yes, what sort of penalties do you think would be fair?
- Is there anything compelling about this development?

Scenario Continued (Reveal 2)

The [town hall location province] government has now declared a state of emergency. Three people who attended the funeral are showing symptoms of influenza and one person has died from it. Although Rajinder is aware that the outbreak has now hit home, he can't see how it would be possible for him not to go to work. After his failing to heed the order, Public Health officials detain Rajinder, meaning that the family is left with no income and stranded at home with little food.

- Have your responses to the situation changed in light of this new information?
- What do you think of public health's decision to detain Rajinder?
- Do you think society has obligations to those ordered into quarantine?
- Is there anything compelling about this development?

Final Questions

- How do you feel about the use of detention in the event of an outbreak?
- Who should make these kinds of decisions?
- How should these kinds of decisions be made?
- In the absence of consensus, how should these decisions be made?

RESULTS

Participants' responses were organized into two main themes that emerged from all three town halls: a) compliance through communication, and b) delineation between individual rights, community values, and the greater good.

Compliance through communication

The issue of compliance was a pervasive theme. Many participants categorically stated that absolute compliance with restrictive measures is not achievable, even when measures are made mandatory:

The truth of the matter is, if we're going under the assumption that we can make people do what we want them to do, that's just false.

Thus, the question that invariably emerged was, "how do you compel compliance?" While participants explored several options ranging from voluntary compliance to enforcement, it was widely thought that creating an environment for voluntary compliance through communication, rather than employing a punitive model centered on compliance through compulsion, is both essential and desirable for the successful implementation of restrictive measures:

Allowing the public to decide whether they should do it is fair, instead of saying it has to be done as a moral or social issue.

You've got to constantly have communication between medical and public and just get as much information as you can get out there and help get people onside.

Open and transparent communication was thought to foster voluntary compliance by engaging people in understanding what and why measures were needed. Along with that, participants felt that it was preferable, indeed more appropriate, to communicate uncertainty rather than to give inconsistent estimates or assessments of the situation. That said, communicating uncertainty was not thought to preclude communicating with clarity and decisiveness. One of the most common themes identified as an element of pandemic response was the need for consistency and coherence in the messages that public health authorities and community leaders communicate to the public, both as a means to foster voluntary compliance and to engage the public in decision-making processes.

Participants suggested that, in order to create an environment for voluntary compliance, the principles of proportionality and reciprocity must be proactively operationalized.

Proportionality

The notion of proportionality served as the foundation for much of the discourse regarding planning and response efforts. Proportionality requires that restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is necessary to address the actual level of risk or critical needs of the community.[11] Participants stressed that, in order to create an environment for compliance and to justify the use of restrictive measures, measures must be proportional to the risk that is *perceived* by the public.

Furthermore, participants expressed that the *actual* risk that exists (according to experts) must be balanced with the potential impact of using restrictive measures:

I would have to weigh the amount of risk vs. the potential for panic and for there to be a backlash against the kinds of rules that are being instituted.

…there's a balance between over reacting and under reacting to a situation and I think consideration needs to be given that this kind of thing could happen.

You just want to be cognizant of the human factor of the people involved and just the emotional impact that [restrictive measures have] on individual's lives.

In sum, many participants agreed that restrictive measures must not create a disproportionate impact on those affected by such measures compared to what is strictly necessary to control an outbreak.

Reciprocity

Reciprocity, which requires that society support those who are burdened by complying with restrictive measures, was presented as both fair and integral to the implementation of restrictive measures. That is, participants were broadly supportive of using even the most restrictive measure, quarantine, provided it is applied equitably and with appropriate support mechanisms in place. Indeed, participants felt that an obligation exists to provide social and material support to persons affected by restrictive measures, including being assured that they will not be unnecessarily penalized for following orders or recommendations (e.g., not losing their job):

For me, this raises the question of interactive societal responsibility. If society deems it necessary for [someone] to stay at home to protect society from the spread of infection…then society must, in turn, be responsible to him to ensure he is well provided for and will not suffer the results of his patriotic duty.

While consequences such as fines and community service were found to be important for those who do not comply with restrictive measures, participants agreed that there ought to be no consequences in the absence of reciprocal arrangements, as in such cases individuals may be put in a position where they have no choice but to not comply with restrictive measures. Participants suggested that, without reciprocal arrangements, individuals may resort to breaking quarantine, effectively being "*forced to spread the disease*".

Although priority was given to incentivizing compliance by promoting voluntariness, participants felt overall that the context in which restrictive measures are required creates very limited options for individuals ("*you can have black or you can have black*"). That is, even though individuals may comply with restrictive measures, it does not necessarily mean that they accept the justification for implementation of the measures.

Delineation between individual rights, community values, and the greater good

The common distinction between balancing individual rights and the greater good was broadened by participants to include the notion of what is good for the community. That is, participants introduced notions of community values as being distinct from the individual or the greater good or as a different kind of greater good:

The greater good is the community or the policy, following the policy is the greatest good or is the most important thing than yeah, you'd be doing wrong but if individual autonomy is making your own decisions, that your family is the most important, your community, your immediate community is more important.

What freedom do we give communities to deliberate about the ethical sort of nature of these decisions within their own system of meaning?

In several discussions, participants expressed that there should be allowances to determine what is deemed to be an acceptable risk at the community level; for example, holding a funeral (see Appendix A), which may be detrimental for the greater good but actually beneficial for the community. Further, participants indicated that there are fundamental values that may not be within the scope of an individual's rights or the greater good (as it is conventionally viewed) that are important to, and define, a community – such as the right to assemble, obligations to one's family, and the view that religious rites trump the risk of mortality.

DISCUSSION

A dominant theme that emerged from the data is that of compliance, or, more specifically, questions focusing on how to create an

environment that compels compliance. Participants strongly favoured the use of rewards – the "carrot" – or suasion – the "sermon" – rather than punishments – the "stick" – in order to create an environment for compliance. It was thought to be more acceptable to use reciprocal arrangements and effective risk communication as reinforcement tools rather than using threat of punishment to compel compliance. This finding supports results from a recent qualitative study on individuals who had been quarantined during SARS, where effective risk communication was found to help individuals understand the precursors and consequences of diseases, which was ultimately linked to participants' reported compliance.[14]

This is an interesting finding that collides with the compulsive and coercive authority that public health has traditionally used in law to justify intervention, particularly in infectious disease cases, like quarantine and border control.[15,16] Indeed, the method of compelling individuals to comply is largely based on the "stick", stemming from the theoretical and largely traditional view that infectious disease control measures must be compulsory in order to be effective.[17] Our data suggest, however, that while participants recognize a need for a decision-making authority and even a necessary mechanism for enforcement, a more tractable approach is one that enables individuals to voluntarily comply. This finding supports the conceptual and empirical claims that public health must rely on persuasion rather than force when considering the use of restrictive measures.[8,18]

Our data also go so far as to suggest how this approach can be achieved. This approach requires restrictive measures to be a) proportional to the threat, b) implemented along with reciprocal arrangements provided to those affected, and c) accompanied by open and transparent communication throughout all stages so that citizens can both understand and participate in decision-making.

With regard to the provision of reciprocal arrangements, these findings support the claim made elsewhere that reciprocity plays a vital role in establishing restrictive measures as a morally legitimate means to prevent or contain effects of infectious diseases, and ultimately helps motivate support and compliance with legitimate restrictive measures.[4]

Another important finding is that a third consideration exists when implementing restrictive measures: the community. This consideration challenges the common dichotomy made in public health between the individual and the greater good. This suggests that important substantive nuances exist between what is deemed to be the greater good and what is deemed to be a community good, which has largely been viewed as one and the same by public health. Indeed, attention must be paid to the role that community clusters play, particularly during a public health emergency, where measures such as the cancellation of social gatherings may benefit the greater good but may actually be detrimental to what participants understood to be community goods. These findings contrast, for instance, with the responsibilities outlined in the American Model State Emergency Health Powers Act, which makes explicit distinctions between the common good and individual rights, but does not consider the good of the community as described in our findings.[19]

We recognize that the views expressed by study participants may or may not be generalizable and that study participation was unevenly distributed across Canada. However, this is consistent with standards of sampling in qualitative research, which aims to evaluate the theoretical representativeness of participants by describing the range of views, rather than quantitative or demographic representativeness.

In this study, we elicited Canadians' perspectives about the use of restrictive measures during an influenza pandemic. Our analysis contributes a better understanding of public views on the acceptability of using restrictive measures as a means to stem the tide of influenza. Prior studies utilizing public engagement demonstrate that the public can make coherent and sophisticated recommendations about regulatory issues pertaining to health and can provide invaluable "local knowledge" relevant to the policy-making process.[20-22] Public engagement enhances accountability, especially in government decision-making,[23-25] and as has been argued extensively, improves the legitimacy of decisions taken.[26-30] With this in mind, what participants deemed to be the requirements for using restrictive measures, e.g., proportionality, reciprocity, and consideration of community goods, can further inform and give legitimacy to policy development efforts on pandemic planning and response.

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Received: December 14, 2011
Accepted: June 14, 2012

RÉSUMÉ

Objectifs : Des expériences récentes ont montré que les mesures restrictives demeurent un outil de santé publique efficace durant les éclosions de maladies infectieuses. Toutefois, le recours à ces mesures est controversé, car il n'y a pas de seuil communément accepté qui indique quand et comment s'en prévaloir. Les objectifs de notre étude étaient de sonder l'opinion des Canadiens sur les considérations éthiques qui sous-tendent l'emploi de mesures restrictives en réaction aux pandémies d'influenza, et en retour, d'utiliser les résultats de ce sondage pour mieux comprendre ce qui justifie le recours à des mesures restrictives aux yeux du public.

Méthode : Nous avons organisé une série de discussions publiques avec des résidents canadiens entre juin 2008 et mai 2009 dans trois régions du Canada pour obtenir une vaste mobilisation populaire (n=3 groupes de 17 participants en tout).

Résultats : Deux grands thèmes se sont dégagés des discussions publiques; il faudrait : 1) créer un climat de conformité par la communication plutôt que par des mesures coercitives et 2) délimiter les frontières entre les droits individuels, les valeurs collectives et le bien commun.

Conclusion : On aurait besoin d'un pouvoir décisionnel et même d'un mécanisme d'application, mais nos données montrent que l'on peut aborder les mesures restrictives avec plus de doigté en permettant aux gens de se conformer volontairement en créant un climat qui favorise la conformité par la communication. Une telle approche exige que les mesures restrictives soient a) proportionnelles à la menace, b) appliquées en même temps que des accords de réciprocité avec les personnes touchées et c) accompagnées par des communications ouvertes et transparentes à chaque étape pour que les citoyens puissent à la fois comprendre les décisions et participer au processus décisionnel.

Mots clés : santé publique; grippe humaine; pandémies; bioéthique; recherche qualitative; quarantaine