HARMS AND BENEFITS: COLLECTING ETHNICITY DATA IN A CLINICAL CONTEXT


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“...if morality is too much a matter of what is, and who has the power to make it so, then those without, or with less power, are left without moral appeal” (Walker, 2001, p. 4)

In the interests of monitoring what groups were accessing services, and potentially reducing access inequities and making services more culturally relevant, a local health authority wanted to initiate collection of ethnicity data at clinical points of contact – that is, they wanted to begin to ask each patient about his or her ‘ethnicity’ when presenting for care. Prior to implementing the data collection process, the health authority joined with researchers to examine what might be the best questions and approaches to asking about ethnicity. Thus, together we undertook a study which included a) focus groups with policy decision makers and leaders in health care, b) community leaders representing range of ethnocultural groups, c) individual in-depth interviews with over 60 patients regarding their responses to the idea of being asked about their ethnicity, and d) observations of people’s reactions to being asked about their ethnicity in health care settings.

As one aspect of our analysis, we used an ethical lens to explicitly consider both the potential harms and benefits of collecting ethnicity data in a clinical context. Analysis of interview and observational data showed that policy makers/leaders and patients saw potential for both enhancing and undermining care. Policy makers and leaders primarily saw the benefits as being related to having group data – that is, knowing which groups of people (as identified by ethnicity) are accessing care. Patients primarily saw the benefits as being related to individuals – in particular, to knowing about an individual’s genetic make-up. However, both policy makers/leaders and patients expressed considerable concern over the potential harms that might ensue, both through the processes of collecting data and through the subsequent uses of such data. Patients wondered why such data might be collected, and imagined various uses, ranging from helping health care professionals to identifying particular genetic problems, to providing a basis for discrimination and denial of care. Patients linked their own ethnic identities and experiences related to those identities to the benefits and harms they anticipated.

This analysis illustrates that the very act of collecting ethnicity data may engender harm. The analysis further considers the balance between the benefits that may be derived from having ethnicity data to illustrate inequities, and the harm that may be done in the collection process and the categorization that ensues. The analysis demonstrates that the advantages and disadvantages of having and collecting ethnicity data need to be considered within the wider global context of widening health disparities, intensified racial profiling, and an increasing preoccupation with difference as a source of threat.

Background to the Study

Over the past two decades researchers have made compelling calls to examine variables such as ethnicity, race, and socio-economic status that are believed to underlie persistent inequities (Bhopal, 2001; Krieger, 1999; New Zealand Ministry of Health, 2004; Sheth et al., 1997; Smedley, Stith, & Nelson, 2002; Williams, 2002; Wu & Schimmele, 2005). Within a research context, these and other authors argue that progress or setbacks in addressing racial and ethnic inequalities in health cannot be monitored without racial and ethnic data (Krieger, 2000). Although some take this position while cautioning that collecting race and ethnicity data is a
“double edged sword” (Krieger, 2004), others argue for elimination of racial and ethnic categories in data collection, suggesting that classifying people by race and ethnicity may tacitly reinforce racial and ethnic divisions in society (Kaplan & Bennett, 2003; Bhopal R. 1998).

Beyond the research context, there has also been a trend toward collecting ethnicity data within health care organizations. For example, the Institute of Medicine (IOM), Physicians for Human Rights, and The Commonwealth Fund emphasize the collection of standardized data on race, ethnicity, and primary language of patients within health care organizations (Hasnain-Wynia & Baker, 2006; Hasnain-Wynia, Pierce, & Pittman, 2004; Hasnain-Wynia & Pierce, 2005; Perot & Youdelman, 2001; Physicians for Human Rights, 2003; Smedley et al., 2002). This has been suggested primarily a) to identify and mitigate existing health disparities by facilitating the provision of culturally and linguistically appropriate health care, and b) to promote quality health care for all population groups by contributing to better information databases (New Zealand Ministry of Health, 2004; Sheth et al., 1997; Smedley et al., 2002; Stanger, 2001). For example, according to the IOM, standardized data collection on race and ethnicity and primary language of patients “is critical to understanding and eliminating racial and ethnic disparities in health care” (Hasnain-Wynia et al, 2004, p. v). This report argues further that “A critical barrier to eliminating disparities and improving the quality of patient care is the frequent lack of even the most basic data on race, ethnicity or primary language of patients within health care organizations” (p. v). There is an assumption that providing equitable, quality care requires race and ethnicity data, but to date the connections among the availability of such data, the identification of barriers, and the improvement of care have not been documented. Further, to date the effect of collecting such data in a clinical context has not been examined.

In Canada, information on ethnicity is generally not collected in health care contexts in Canada (Rummens, 2003). In Canada, there is no Federal, Provincial, or governmental mandate that requires health care institutions or agencies to collect data on ethnicity. Therefore, most Canadian research on ethnicity and health uses large national-level population surveys, such as the Canadian Community Health Survey, the National Population Health Survey, and the Canada census (via Statistics Canada) as their sources of ethnicity data on Canadians. Statistics Canada acknowledges that ethnicity¹ is an ambiguous concept because it can encompass multiple different aspects such as race², origin or ancestry, identity, language and religion (Statistics Canada, 2006), often changing from context to context as a result of new immigration flows and the development of new identifies (Statistics Canada, 2003).

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¹ For the purposes of this paper, we conceptualized ethnicity as a socially, politically, and historically constructed concept used to categorize populations based on any number of the following characteristics: nationality, culture, language, identity, origin, religion, ancestry, race, geographic location, traditions, and lived experience. Ethnicity is typically self-defined, and may change with time, location, or context.
² In this paper we define Race as a socially constructed category used to classify humankind according to common ancestry and reliant on differentiation by such physical characteristics such as colour of skin, hair texture, stature and facial characteristics. The concept of race has no basis in biological reality and, as such has no meaning independent of its social definitions. But as a social construction, race significantly affects the lives of people of colour. (Henry, Tator, with Mattis, & Rees, 2006, p. 351)
Currently, some Health Authorities in Western Canada are considering the merits of inserting an ethnicity variable as part of patient information collected at the point of care – meaning when people come for health care at community health clinics, emergency departments, hospital settings, and physician’s offices. However, the effects of collecting ethnicity data in the clinical setting are not known.

Collecting ethnicity data in a clinical context, particularly in a Canadian context where such data has not previously been collected, has different features than collecting data in the context of a national survey or in other research contexts. In health care contexts, ethnicity tends to be conceptualized very narrowly, and is often used as synonymous with “race” (Anderson & Kirkham, 1999; Bhopal, 2001; Doane & Varcoe, 2005; Gerrish, 2000). Further, there is mounting evidence of ethnic and racial discrimination and structural racism in health care (e.g. Anderson & Kirkham, 1998; Berdes & Eckert, 2001; Bourassa, McKay-McNabb, & Hampton, 2004; Eliason, 1999; Henry, Tator, with Mattis, & Rees, 2006; Shaha, 1998; Whaley, 1998). For example, our programs of research have demonstrated some of the dynamics of such discrimination against Aboriginal women (Browne, 2007; Browne & Smye, 2002), and the effects of such discrimination on dealing with violence against women in health care (Varcoe, 2001, in press). It is not known what the effects may be of collecting ethnicity data within such contexts.

The study we discuss in this paper was designed to extend understanding of the issues and challenges related to collecting ethnicity data at the point of care in health care settings. Research team members included people from within local Health Authorities, health care decision-makers, and university researchers with research and policy expertise in the area of culture and health. The specific purpose of this paper is to use an ethical lens to examine the potential benefits and harms associated with collecting ethnicity data in a clinical context.

**Research Methods**

We employed an ethnographic design, and collected data in four modes: (a) in-depth interviews with 10 decision-makers and policy makers who were affiliated with several health authorities and policy research units; (b) three focus groups that included community leaders (n = 18) who served on committees struck by the local health authority to represent patients’ perspectives concerning healthcare planning decisions; (c) 60 open-ended interviews with patients who were seeking health services in either a sub-acute clinic of a large urban Emergency Dept, or a community health centre located in a large Western Canadian city; and (d) interviews with 16 direct care providers who were involved in either administering a version of an ethnic identity question in specific health care agencies, or whose agencies were considering instituting an ethnic identity variable as part of intake data. A total of 104 participants were involved in this study.

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3 Health Authorities are the regional governing bodies responsible for health care planning and delivery in defined geographic areas of Canada’s provinces and territories.

4 Such clinics located in emergency departments (often named “First Aid”, “Fast Track”, “Subacute”) are designed to respond to the health concerns of patients triaged as stable and non-urgent, and who generally “walk-in” (versus acutely ill patients).
The decision-makers and policy leaders included those with responsibility for patient information systems, Aboriginal health and “diversity” portfolios in the Health Authorities, and those associated with policy research units that deal with issues related to health disparities. The focus group participants included: one group of community members who self-identified as “visible minorities” (more specifically, primarily as East Indian and Chinese people), and two groups of community members who self-identified as Aboriginal: either status, non-status, or Métis people. The individual patients we interviewed included 22 people who identified themselves as Aboriginal, 17 people who identified English-speaking Euro-Canadians, and 21 people who self-identified as members of various other ethnocultural groups. These included people who would be defined by the Canadian federal government as “visible minorities” such as people who immigrated or were descendants from those who immigrated from India, Taiwan, South America, Turkey, and people who would not be so defined who were recent immigrants to Canada from countries such as Eastern Europe, Russia and so on.

A thematic analysis of the data is currently in progress. We are using a qualitative software package (NVivo) to manage the interview data and assist in organizing preliminary coding. The findings presented in this paper represent our preliminary analysis using an ethical lens as our theoretical perspective.

An Ethical Lens
Ethics are concerned with values and morality. From a feminist perspective, however, ethics “is fundamentally, a discourse about morality and power” (Walker, 2001, p. 4). A feminist ethical lens is useful to the analysis of the questions posed in this research. Inherent in the quest to understand what might be the best questions and approaches to asking about ethnicity is the desire to identify how such questions should be asked, an approach that will optimize the benefits and avoid harm. Such questions are ethical questions. Further, however, the question addresses contexts of power—patients are to be asked particular questions within social structures and organizational systems in which power differentials operate with particular effects. Patients coming for health care generally are made more vulnerable due to illness, disability and position within the health care system. Thus, an ethical lens that considers power is required. Finally, the questions that are being asked are questions of considerable moral concern—because they concern ethnicity, they must consider discrimination on the basis of ethnicity. While it is controversial as to whether discrimination is always bad, as Lippert-Rasmussen argues “discrimination is bad, when it is, because it harms people” [emphasis added] (2006, p. 167). Thus, a feminist ethical analysis of the approaches to asking about ethnicity must address the extent to which the practices involved (which may include various approaches, including not collecting such data) harm people.

5 In Canada, the federal government defines visible minorities as “persons who are identified...as being non-Caucasian in race or non-white in Colour...Aboriginal persons are not considered to be members of visible minority groups” (Statistics Canada, 2003)
6 The term “Aboriginal peoples” is used to refer generally to the indigenous inhabitants of Canada including First Nations, Métis and Inuit peoples (Royal Commission on Aboriginal Peoples, 1996, p. xii)
7 Although the term “White” is the more common colloquial term used in Canada to distinguish non-Aboriginal people from Aboriginal people and other people of color, Furniss (1999) suggests that Euro-Canadian is often used as the accepted term in formal academic discourses to refer to the majority of Canada’s population who are of European ancestry.
The concept of harm is central to ethics. However, what is meant by harm is varied. Within biomedical ethics the caveat “First, do no harm”, for example as articulated within the mid-range principles proposed Beauchamp and Childress (2001), is interpreted primarily to mean that one should not cause harm to others in the course of delivering health care. The emphasis is on physical harm incurred by providers in the process of giving care (Pauly, in press). This places a focus upon individual care providers in interaction with individual clients. However, as Pauly points out, within bioethics, preventing harm is rarely seen as a priority. Because the principle of autonomy is given more weight, individual liberty is promoted rather than focusing upon reducing harm to individuals.

From a broader theoretical perspective, harm can be understood as the end or consequence of a wider range of circumstances or actions, that is, beyond the actions of particular individuals. The emphasis remains focused upon reducing negative consequences for individuals, but is widened to consider harms emanating from a wider range of sources. More recently, feminist philosophers such as Iris Marion Young (Young, 1990) draw attention to the harms associated with belonging to certain groups and experiencing certain conditions. As the question being posed is how best to approach questions of ethnicity, an ethical analysis of the harms associated with belonging, being assigned or not assigned to, and being seen or not seen as belonging to particular ethnic groups is required. Thus, for the purposes of this study, we understood harm to refer to damage that might ensue from a wide range of social structures and practices, while focusing on practices related to collecting ethnicity data.

Findings

The findings of this study surface the tensions between the desire to do good by collecting and using ethnicity data, and the harms that may be incurred through the process of collecting and using data. Overall the benefits envisioned by all three groups of participants were benefits related to better serving groups of people. In contrast, the harms envisioned by the focus group and patient participants in particular, pertained primarily to the effects on individuals. When participants anticipated benefits, they generally were perceived as benefits contingent upon action being taken to identify and ameliorate inequities. The harms anticipated were primarily identified by the patient and focus group participants, and were to a great extent based on personal experiences of observing or being subject to discrimination.

Possible Benefits and Good Intentions

*I’m assuming they would use that information for good purposes (Patient #44)*

A range of possible benefits of ethnicity data were imagined by many participants. Policy makers and leaders in health care generally were more positive than community leaders and patients, and focused upon the potential uses of having ethnicity data to better understand patterns among groups. The advantages they identified related to groups fell into three overlapping areas that participants appeared to see as being causally linked: a) the advantage of being able to map the ethnicity of the patient populations (who is accessing care), b) the possibility of identifying barriers to care based on ethnicity, and c) the opportunity to make care better and more equitable, primarily by better tailoring services to meet the needs of diverse ethnocultural groups. For
example, this was a repeated justification for collecting ethnicity data from the perspective of health care decision makers who were working within health care authorities:

“The main reason for collecting ethnicity data or any kind of ethnic coding is to identify and therefore be able to develop strategies to address health disparities”

Health Care Decision-maker #10

“If we can’t measure disparities in either their health status, access to services, types of treatment prescribed, health outcomes, it is an invisible problem”

Health Care Decision-maker #6

Albeit to a lesser extent, some community leaders and some patients identified similar potential benefits for groups of people. For example, one patient (#36) specified that “you don’t need to turn the system upside down for a single patient, however... if you heard [any particular] concern more than once or five times, then you need to find out...what does it really mean, and how to fix it...”

Patients supposed that ethnicity data might be used to ameliorate health disparities and racism and made similar assumptions that data collection would lead to action. For example, Patient #1 thought the collection of such data could hypothetically convey to people in health care “that racism is being watched and monitored, and they will be held accountable for any wrongful action...” Other patients expressed a sense of faith in health care as an essentially equitable system, and therefore saw the collection of ethnicity data in a fairly innocuous part of patient information questions:

Well, because we live in Canada and we’re such a mixed culture....everybody is kind of equal so I don’t think anyone specifically is being targeted for anything [in health care].

Patient # 44

Although patients identified some benefits of having group data, they tended to focus on the effect on the particular individual being asked. They generally associated the advantages they envisioned with knowing a person’s country of origin, primary language, or genetic makeup, and connected that knowledge with some anticipated benefit in terms of better care for that particular person. For example, Patient #2 said “if you come from a poorer country... you hear people from Africa, their water supply is pretty bad over there, so...it could have an effect on health, so...I think the doctor needs to know... for better treatment, right?

Another common perception among the patients and the decision-makers who participated in this study stemmed from their assumption that knowing about one’s ethnicity would provide useful information about a person’s genetic predispositions, thus reflecting the genetic and racial basis of the notion of ethnicity. Consider for example the following quotes:

“There are certain groups in the population that might be prone to certain diseases based on your ethnicity, so I guess it goes back to genetics”

Patient #1

“the only need for that information would be genetic, and you know, derivatives of perhaps your genotype that would be susceptible...”

Patient #18
“your roots, like they could look back into your family history and get you the proper health care”

Patient #20

Further, patients often expressed implicit trust that data would be used for a good purpose, and that if it was being requested, it must be necessary. As patient #31 expressed: “I mean, if they have a panel of all different ethnics [referring to people in health care who would be using the ethnicity information], sure, let them [use the data].”

Some participants proposed advantages related to behaviours that they presumed are associated with particular groups. For example, one participant thought that knowing ethnicity might explain why people have trouble taking their prescribed drugs; many thought knowing ethnicity might help identify what people eat. Several thought that there would be advantages to collecting ethnicity data if the person did not speak English, reflecting a commonplace confusion in Canada between ethnicity and facility in Canada’s our two official languages.

Most significant in the interviews with patients and focus group participants was the extent to which participants tended to draw upon their own identities, social locations, and experiences when responding to the interview questions. For example, Patient #31 had a positive health care experience that she associated with the doctor knowing about her ethnicity.

“I had a couple of doctors that did know native background and he asked me where I was from and automatically he knew what kind of [pause] he asked me these questions, like there’s heart disease and arthritis, and there’s a kind of blood type we get in this area... and I have one of them. And he seemed to understand more...and right away I got the help I needed instead of doing all the run around of people”

Patient #31

Repeatedly, patients, focus group, and decision-maker participants identified benefits that might accrue in clinical care if providers drew upon links they perceived between the biological or genetic basis of disease and ethnicity. Reflecting popularized “geneticization” discourses (Poudrier, 2007), patients and decision-makers repeatedly reiterated that the primary benefit was in ensuring that clinical care would take into account risk factors that could arise from specific ethnicities.

Our preliminary analysis showed that perceptions of benefits (and harms) were related to the participants’ social and historical locations. For example, individuals who self-identified as ‘white’, Euro-Canadian or Caucasian, tended to see no benefit for themselves. Patient #36 said that there was no benefit to reporting his/her ethnicity “because I am part of the main stream”. Patient #44 said “For me specifically it probably won’t benefit me that much because I was born and raised in Canada, and so I am quite fluent in English...” If they imagined benefits, then the benefits they identified were associated with people who have immigrated to Canada, are not fluent in English or who could be classified as ethnic minorities. Similarly, the potential harms they identified did not tend to apply to themselves. For example, Patient #35 said, “I am a Canadian white guy, so it doesn’t bother me at all”.

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8 Geneticization refers to the conditions under which cultures (and assumed “races”) of individuals and groups become defined by genetic categories in scientific, health, and popularized discourses (Poudrier, 2007).
Harms and Concerns

“What do you mean, what am I? I’m here to get treatment, is what I am, right?”

Patient #21

At the same time as suggestions were offered regarding the potential benefits, primarily of having ethnicity data and serving groups better, the overwhelming response to the idea of the process of asking about ethnicity was deep concern. Concerns were related to both collecting data in health care settings at the point of care, and in other contexts.

Because we conducted patient interviews in an Emergency unit and in a community health care center, patients were ideally positioned to think about what such data collection would be like in a clinical context. That is, in contrast to asking about the experience more theoretically in a survey context (for example, as was recently done in Ontario), patients sitting in waiting rooms were able to reflect more directly on what the experiences would be like.

Across the focus group and patient participants, the harms they anticipated in relation to asking about ethnicity were associated with being judged on the basis of assumptions related to their ethnicity, subjected to assumptions, and stereotyped, and were related to the possibility of receiving poorer care based on such judgements, assumptions and stereotypes. While, as previously described, benefits were anticipated in terms of groups, participants anticipated harmful effects primarily at the level of the individual being asked. Many participants extended their concerns to members of groups that they thought would be likely to experience the effects of racialization.

As noted earlier, patients and focus group participants’ most often constructed their responses in relation to their own identities, experiences, and social positioning. For example, Patient #31, who was quoted earlier as having had a positive experience when her physician knew “native background”, expressed concern about being asked to identify her ethnicity in a health care setting:

“If they just want to know if I’m Aboriginal, that would bother me...sometimes they look at natives as if we’re only in here for the drugs and we’re in here to get the attention or whatever”

The idea that “Aboriginality” could itself represent a risk factor for health or social problems was identified by several participants – and echoed the concerns of Janet Smylie (2005) about risks of pathologizing Aboriginal peoples in health care contexts. Indeed, a number of the participants who identified as Aboriginal described the effects of discrimination on their health. Patient #31 described how the stereotypical idea that Aboriginal people sell their medications not only can create problems for pain management, but may create or exacerbate the problem of street sale of prescription drugs.

“A lot of us have arthritis, and... are being put down from Tylenol 3’s to Tylenol 2’s, then to regular Tylenol because [the doctors] don’t want to hand it out, they think we are selling them. In other words we have to go out and buy our medications off the street sometimes.”
Many participants who self-identified as ‘white’, Euro-Canadian or Caucasian expressed concern, not for themselves, but for those that they saw might be targets of negative judgement. For example, Patient #36 said

“just imagine if you had a physician or a nurse that didn’t like Aboriginal people or didn’t like Indo Canadians or didn’t like new immigrants...I worked a lot with Aboriginal people, so the issue for them is, can the data be used against them.”

Many patients and focus group participants expressed concern about creating further risks for those who might be most vulnerable to effects of inequities. Implicit in these concerns was that health care inequities are prevalent – adding this process that could exacerbate pre-existing inequities was seen as problematic.

What was perhaps of greatest concern in the set of data from patient and focus group participants was the extent and frequency with which those who identified as being from a ‘visible minority’ or who self-identified as Aboriginal expressed concern for themselves. As the following examples illustrate, in response to being asked about how they would feel if ethnicity was collected as part of routine patient information collected at the point of care, patients expressed anxiety, fear and anger:

*I feel extremely highly discriminated towards by asking such a question*

Patient #48

*I would be [offended] if this was asked of me, I think its just another means to divide*

Patient #21

*Because its, its, its not a good question, its not a good question at all, it doesn’t relate to my health, this sort of question, it makes me really angry*

Patient #41

*[I have concerns] “because of how I’m categorized, how I’m viewed, how I’m judged, right, prejudged”*

Patient #1

Some patients specifically were concerned that they would be labelled in ways with which they did not agree, and several were explicit that they would not answer a question about their ethnicity.

Importantly, patients routinely associated the harms of being judged not only with racialization, but also with classism. For example, Patient #1 explained his concerns about these intersecting issues:

... if I’m too rich people think of me as a certain type of person or they respect you more because you’re rich... they’ll like you more because you are black and good looking or because you are smart...they’ll treat you with more respect because of the fact that you’re rich or better looking, that’s why, about ethnicity, um, about your race rather, ...I would feel right away, I mean being classified as being prejudged and people would treat me accordingly.

These concerns were reiterated by patients and focus group members who were concerned about the inequities that could potentially be played out along the intersecting axes of class, culture,
“race” and ethnicity. One patient who identified as Aboriginal spoke at length regarding the contrast in her experience of accessing care depending on how she was dressed. She explained how her family carefully planned their appearance arguing that class assumptions were at least as powerful as assumptions based on her ethnicity. Similarly, a man who identified as Aboriginal described how his treatment differed when he was able to shower in contrast to when he was living on the street and unable to do so. These concerns reflect anxieties that patients have expressed in other studies about the need to transform oneself when appearing for health care in order to gain legitimacy and credibility as a medical subject (Browne & Fiske, 2001; Fiske & Browne, 2006).

Concerns identified by patients were related to their previous experiences of harmful discrimination – both within health care settings and in wider social interactions – that they had either experienced directly or witnessed. For example, Patient #1 described her daughter being treated rudely and her own experience of having her pain ignored, and associated these experiences with her ethnicity. The experiences upon which they drew included experiences of racial and class discrimination, most often as race, ethnicity and class intersected. For example, Patient #13 recounted a previous experience in Emergency watching another patient be treated in what Patient #13 saw as a discriminatory manner. These fuelled his concerns that patients would likely be treated differentially regardless of need – which in turn created concerns about how he might be “read” or treated on the basis of his socioeconomic status, ethnicity or perceived “race”.

He was bleeding all over the place and they just ignored him. You could see he needed more treatment... he was the one that needed the help the most and he was the last one they seen...he looked like a bum off the street so...they put the high class first, like, the ones that look you know, well off

Based on previous experiences, patients anticipated discrimination. Particularly for people of colour, the harms the participants anticipated related to the racializing process inherent in asking about ethnicity. For example, Patient #32, who identified as Aboriginal said

I’m just afraid that they might put a, our ethnicity more into like, or more vulnerable to diseases which I don’t think is true, right, and I’m afraid they might put more onto that and just, make it just seem like its different, different races that, that, um, it will be used against us sometime in the future...

As patients and focus group members discussed their ideas about declaring their ethnicity at the point of care, they frequently linked their concerns to questions about how the information might be used – and for what aims. Thus, in addition to anticipating harm to individuals, and in contrast to the explicit trust expressed by some, many participants of all identities questioned the usefulness of ethnicity data, including how and whether such data might be used in a beneficial manner. For example, Patient #24 who identified as ‘white’ said

“I’m concerned, well, yeah, curious as to why... what’s the data being used for and if its just being used for, to find out if certain groups are predisposed to preferential treatment, great, let’s get that, nip that in the bud and let’s get that clear and get the clarity out there so that people understand that that’s not the way to behave but I’m not so sure what the data is being used for”
Discussion

“It’s a stereotype, and stereotyping leads to nothing good”

(Patient #18)

The findings of this study suggest that in congruence with calls by researchers for ethnicity data, policy makers, decision-makers in health care and some patients see potential benefits in collecting ethnicity data. The benefits identified in this study by policy makers and leaders were seen as primarily beneficial to groups, and depend on ethnicity data being used to reduce health disparities and barriers to care based on ethnicity, and to develop greater cultural sensitivity in health care. However, the potential harms identified by the patients in this study suggest that the very process of asking about ethnicity data may serve as a barrier to care, and may inadvertently exacerbate concerns about inequities, particularly for those patients who are most vulnerable to the effects of such inequities.

Lippert-Rasmussen (2006) draws on Appiah, to point out that discrimination is used in relation to ethnicity, culture, and race in two senses: “racialism, which is the not necessarily objectionable view that the human race is divided into different, biologically real races, and racism, which is the objectionable view that this supposedly biologically real division involves a hierarchy of value” (Appiah, cited in Lippert-Rasmussen, p. 168). The collection of ethnicity data, presumably involves a well-intentioned implementation of racialism, that is unavoidable because of the conflation of race and ethnicity. However, the findings from this study suggest that it is not possible to enact racialism without invoking racism given the current context of health care and the inequities that are perpetuated in relation to particular groups of people.

The participants in this study were clear that both the benefits and harms that might emanate from ethnicity data are more likely to affect some people than others – that is to say, those from racialized groups (Aboriginal people and those from ‘visible minorities’ were expected to be more affected). The anger, fear and stress expressed by the patients interviewed, and the experiences they recounted, reflect concerns about an added burden of being categorized or judged in ways that could exacerbate current inequities and differential practices in health care. Thus, the current context of health care inequities served as the backdrop against which participants considered these risks. Conversely, for the smaller number of participants who expressed the sense that the health care system was inherently equitable or egalitarian, concerns about this added burden of categorization was not as prominently expressed in their interviews. Importantly, none of our decision-maker participants linked the proposed collection of ethnicity data to the possibility of addressing discrimination and racism.

Some of the decision makers we interviewed suggested that because patients had the option, ostensibly, of deciding not to answer an ethnicity question (or other questions collected as part of patient information records), the risks that may be perceived by patients could be avoided if they so chose. We argue that it is not sufficient to suggest that patients have “choice” about whether or not they answer intake questions posed at the point of care, or how they might identify themselves in response to such a question. First, many patients argued that their ethnicity was

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9 A discussion of the meaningfulness of ethnicity data is beyond the scope of this paper, however, the benefits of having ethnicity data depend first on the quality of the data. This is the subject of a subsequent paper being developed from this study (Wong et al., 2007).
visibly ‘obvious’, although some were concerned that they might be erroneously “slotted into” a particular category by the people collecting the information. Second, refusing to answer, or answering falsely, involves denial of one’s identity on some level, with differential effects on various individuals and groups depending on their histories and experiences. Because ethnicity is conflated with race, asking a person about their ethnicity requires that person to categorize themselves on the basis of race. Combining a racializing process within a context of health care which is increasingly characterized by growing inequities based on social positions, including race, exacerbates the harm of collecting ethnicity data in a clinical context. Asking patients to declare their ethnicity – conflated as it is with race, and social positioning – is also problematic because of the potential to further entrench race-based assumptions and thinking in health care. This is not to deny Krieger’s (2004) compelling arguments that, in a research-based context, not collecting data [on patients’ ethnicity or race] “reflects a time honoured tradition of removing a problem from public purview, as if to say, no data, no problem” (p. 632). However, in the context of growing concerns about inequities that shape practices in health care, and which patients will be most vulnerable to the effects of inequitable practice, more consideration must be given about the potential harms that may arise in the process of collecting such data.

Our analysis leads us to recommend that, in the current climate of health care, ethnicity not be collected at the point of care as part of routine patient intake data. The harms engendered include harms that will serve as barriers to health care access. Although benefits to groups are anticipated by many, evidence of such benefits is required. In the meanwhile the assumption that providing equitable, quality care requires race and ethnicity data might be challenged, and the business of providing such care pursued aggressively.

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