

# “Quality Care is Like a Carton of Eggs”

## Using a Gender-Based Diversity Analysis to Assess Quality of Health Care

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*Cet article assure que les recherches qualitatives ne rendent pas justice à l'expérience des femmes comme aidantes, patientes, coordonnatrices des soins et si on adoptait une analyse des soins basée sur la diversité des genres, on serait en mesure d'évaluer et de mieux décrire ce que veut dire la qualité des soins.*

In the 1990s, extensive restructuring in the Canadian health care system occurred as most provincial governments launched health care “reforms” such as: increased use of day surgery, delayed admission, and early release; de-listing of insured services and restrictions on entitlement to insured services; bed closures; and reductions in health care personnel (notably, nurses and other allied health care workers) (Armstrong *et al.*). While changes such as these have been implemented largely to control costs, governments and other payers need to demonstrate that quality is maintained and even enhanced by restructuring so that they are seen as meeting their responsibilities to taxpayers, “clients” and stockholders (Baker *et al.*; Brook, McGlynn and Cleary; Chassin; McGlynn). Governments, health care organizations and insurance companies have turned to quality assessments to provide this evidence.

In this paper, we argue that current health care quality assessments lack mechanisms to represent and respond to: 1) important structural features of the health care system (e.g. heterosexism) and 2) women’s diverse experiences of care, including what the health system “costs” the women who use it. First, conventional quality assessments examine only limited dimensions of the “structure” of the health care system, conceptualizing structure in terms of the material and human resources, and organizational arrangements of health care settings. This approach fails to recognize and measure important structural relations of power that constitute and shape the health care experience. Second, health quality assessments are largely concerned with “cost,” defined in economic terms. Yet research into women’s experiences of health care suggests

that a broader conceptualization of “cost” would be useful in understanding health care quality. We discuss these missing elements in health quality assessments, illustrating them with material drawn from focus group discussions with lesbian/bisexual/queer women undertaken as part of a larger investigation of women’s understanding of quality of health care in Canada. Our findings suggest that health care researchers, policy makers, workers, and recipients must critically examine what counts as evidence in quality reports and recognize the limitations arising from current conceptualizations and measurement practices. Because current quality assessments rely ultimately on individual-level, decontextualized data, their analysis of quality emerges from simple aggregation of discrete individuals and events. They miss the complex social production of health care structures, processes, and outcomes. Consequently, they do not fully capture women’s experiences of health care (as patients, providers, and coordinators of care). Moreover, they envision change as emerging primarily from individual action and local institutional adjustments rather than systemic reorganization. Health-quality assessments informed by a gender-based diversity analysis would produce an explicit systemic analysis to more fully account for what creates quality health care for women.

Health-quality assessments that are informed by a gender-based diversity analysis would consider the possible implications for conceptualizing and measuring health quality from the perspectives of women and men in diverse social, economic, geographic and political locations (Health Canada). A gender-based diversity analysis recognizes not only that there are differences between women and men, but that women do not constitute a homogeneous group and that significant differences may exist *among* women. Gender-based diversity analysis rests on an understanding of intersectionality (Weber and Parra-Medina), which considers the multiple, intertwined and mutually constructed social processes underlying

social experiences. For example, intersectionality recognizes that gender, race, sexuality, and social class, among other things, are not simply characteristics of individuals; rather, they are products of social systems and are continuously constructed through the actions of social actors. Accordingly, in this view, change emanates not only from individuals; it also requires systemic adjustments.

### Current Measurement Practices

Quality assessments in health care tend to adopt either

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a universalist approach or a localized approach. The universalist approach, most evident in purchaser assessments of quality, standardizes health care experiences and thereby strips them of their context. In contrast, the localized approach, apparent in provider (e.g., doctors, nurses) and patient accounts of quality, focuses on particular (i.e., “local”) experiences of key participants in the health care system but generally does not account for the structural conditions in which those participants are situated. Consequently, these accounts are localized but decontextualized. The discussion that follows focuses on the universalist approach, as it figures prominently in current large-scale health care reforms (the localized approach is discussed elsewhere; see Jackson 2004).

### Who Measures Quality?

Universalist health care quality assessments, embodied in such reports as those issuing from the Standing Senate Committee on the State of the Health Care System in Canada (Kirby) and the Royal Commission on the Future of Health Care in Canada (Romanow), foreground the voices of insurers, regulators, and large-scale purchasers.<sup>1</sup> In such documents, quality may be *defined* broadly, including patients’, providers’ and population-level perspectives, but it is frequently *measured* in much narrower terms. For example, the Romanow Commission recommends that the proposed Health Council of Canada “establish a national framework for measuring and assessing the quality of Canada’s health care system, comparing the outcomes with other OECD countries” (Romanow 150).

However, the Organization for Economic Co-operation and Development (OECD) measurement strategies emphasize narrow outcome measures such as morbidity

and mortality rates. They do so in part because international comparison is very difficult when not all participating countries collect the same kinds of information or have the resources to do so. Morbidity and mortality statistics tell us little about the social conditions of health, illness, or care and they tell us nothing about the gendered experience of well-being or caregiving. Comparison with other OECD countries, therefore, is no standard to set for quality measurement if it does not inspire us to generate more nuanced and systemic analyses of the performance of our health care system.

### What is Measured?

Conventional quality assessments typically measure three elements of health care: structure, process, and outcome (Donabedian; also see Campbell, Roland, and Buetow; Hogston). “Structure” frequently refers to “attributes of the settings in which care occurs”—this *could* be understood quite broadly to include, for example, social determinants of health such as racism or heterosexism, but universalist quality assessments primarily operationalize “structure” as material resources, human resources, and organizational arrangements. “Process” refers to what is actually done in giving and receiving care. This may include both practitioners’ and patients’ activities, and may measure both technical aspects of care (i.e., the appropriate and skilful application medical interventions) and interpersonal aspects of care (i.e., humane and compassionate treatment) (Donabedian). “Outcome” refers to the effects of care on the health status of patients and populations. Here, “health” is defined in predominantly biomedical terms, excluding other, non-medical aspects of well-being. Universalist quality assessments typically focus on narrowly defined “structure” and “outcome” measures.

What is *not* measured? When “structure” is understood simply as material and human resources and organizational arrangements in institutional settings, the social and political conditions in which health care takes place are not accounted for. But even this limited view of structure is not judged to be terribly important to health care quality: structural characteristics are viewed as “a rather blunt instrument in quality assessment” (Donabedian 1746). Minimizing the importance of structural components undermines the impact they have on more vulnerable participants in the health care system, including workers and patients, most of whom are women (Adams and Bond), and undermines the extent to which quality assessment will effect systemic change rather than sustain the status quo.

### How is Evidence on Quality Produced?

In the universalist approach to quality assessment, quality is typically defined in terms of cost containment

and economic efficiency (Baker *et al.*; Brook, McGlynn and Cleary; Chassin; McGlynn). For example, while “accessibility” of health care is a key concern in the Kirby and Romanow reports, this concern is situated in a discourse of sustainability—and the sustainability of the health care system is in turn framed exclusively in financial terms. In this framework, quality is transformed into a resource to be managed, like monetary, capital or human resources, and efficiency is understood in fiscal terms and measured accordingly. Universalist quality assessments frequently rest on statistical data gleaned from administrative and billing records which reflect managerial concerns of cost efficiency; they tend to lack clinical details, information about structural conditions in which individuals provide and receive care, and information about interpersonal processes of care. Where interpersonal aspects of care *are* measured, those measurements tend to rely on standardized clinical guidelines. Such guidelines usually represent the perspectives and language of health care professionals, not patients, so while they do provide some information about clinical practice, they are poor sources of information about women’s diverse experiences of receiving care. Clinical outcomes are frequently the sole outcome measures used, but these tend not to include patients’ evaluations of care. And when patient satisfaction surveys are employed, they suffer from serious limitations (Hall and Dornan 1; van Teijlingen *et al.*), are rarely developed with gender issues in mind, do not contain questions specific to women’s health care, are not systematically analyzed for gender differences, and are not reported separately for women and men (Weisman 19).

Universalist quality assessments standardize experience. “Standardized population health” status is often used as a crude outcome measure of quality, but tremendous diversity is smoothed over in the practice of aggregation (Grant; Jackson 2003; Kaufert). In population-level analysis aggregated data are presented as if they are applicable to “everyone” (Hayes 1994), obscuring particularity and creating the impression that the participants in the health care system, and the services they provide or receive, are interchangeable. But a standardized patient does not represent “everyone.” The standard or “universal” patient (or provider) is removed from any historical and political context. For example, it is widely acknowledged that existing indicators for population health do not adequately reflect women’s biological and social differences from men.<sup>2</sup> Despite these limitations, there remains an overwhelming urge to standardize health care experiences in quality assessments.

There are serious gaps between these universalist approaches to quality assessment and the experiences and expectations of women working in and receiving health care. To illustrate some of these gaps, we now turn to the health care experiences and expectations of lesbian/bisexual/queer women in two major Canadian cities.<sup>3</sup>

## Structure and Cost: What Quality Means to Lesbian/Bisexual/Queer women

According to a focus group participant from a drop-in for lesbian/bisexual/transgendered young women:

*Quality care is like a carton of eggs—if there is like one egg missing, it isn’t a full carton, right? And then quality care is like—if you don’t have—like, you have to have the trust, and respect, confidentiality, et ceteras, right? or you don’t have the whole package.... You know, like you*

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*went to go buy a dozen eggs, you know, but you don’t get it. It’s kind of like quality care, you want the whole package but you can’t have it and you just kind of feel like blah. You can’t, like make your cake or something.<sup>4</sup>*

This account of quality in health care suggests a gap between lesbian/bisexual/queer women’s experiences of care and how quality of care is frequently conceptualized and measured in current health care quality assessment frameworks. The elements of “trust, respect, [and] confidentiality” clearly point to interpersonal aspects of care, which are less frequently measured in universalist quality assessments than technical aspects or outcomes of care. These elements also point to structural conditions such as heterosexism, classism, racism, ableism, and other social relations of power that shape the interpersonal contexts in which women deliver and receive care. The accounts of lesbian/bisexual/queer participants in our study illustrate how heterosexism is a structural feature of the health care system, that is, a consistent element of the health care encounter that organizes and shapes the interactions between health care providers and those seeking their care. These participants also described how issues of sexual disclosure and psychological safety “cost” them in their encounters with health care providers. They challenged traditional notions of “cost” in economic terms with nuanced descriptions of the invisible emotional and interpersonal work generated by heterosexist assumptions in the health care system and among health care providers.

As we have noted above, “structure” is inadequately conceptualized and addressed in conventional quality assessments, neglecting the socio-political structures that shape health care. Heterosexism, which interacts with other systemic relations of power, is an important structural element that profoundly affects health care quality.

Heterosexism “assumes that all people are heterosexual and incorporates mainstream attitudes that value heterosexuality more highly than other types of sexuality” (McNair). Research suggests that heterosexism limits lesbian and bisexual women’s willingness to disclose their sexuality and other potentially important life issues to practitioners, possibly compromising the quality of the care they receive and their experiences of safety and trust. It can also lead to them avoiding care or being denied care (Coalition for Lesbian and Gay Rights in Ontario; McNair). One participant in our study described visiting

*to identify the bio, the biology of every single person that I mentioned, and it was just so incredibly frustrating and it just, it got us nowhere because from there on she knew that some of my friends couldn’t fit into her perceptions.... And at one point I was just like “Okay, I’m sorry. No more. I’m going. Bye.” Because it was just causing more problems than it was worth.*

As this example demonstrates, for many women heterosexism combines with other systemic barriers to make access to appropriate, adequate health care particu-

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an emergency room after she had been injured during sexual play with her partner, the result of which was significant vaginal bleeding:

*We go to the hospital, they tried to tell me I’m pregnant. I said “That’s not possible.” They’re convinced I’ve miscarried and maybe I’ve even tried an abortion. I had to, with haemorrhaging, go and find my doctor and get a note saying I was in a lesbian relationship, I am not pregnant, in order to access the facilities—and be accompanied by my gynaecologist who at that point met me at the hospital—and have to listen to everybody in the hallway going “Which one is fem? Which one is butch?” “I don’t know.” For hours. Now if that isn’t affecting my health care....*

Another participant who identifies as gender-queer and who works as a drag king spoke about how heterosexism and transphobia in mental health care made it difficult to get the help she needed:

*[O]nce you’re in there, uh, a lot of it are misconceptions about queer or whichever identified women can be very frustrating. It almost feels like it’s not worth going in at all.... a lot of my friends are transsexuals or gender queer or just relatively open to that kind of thing. And so when [my therapist and I] were discussing incidents that had happened that upset me or I was having trouble dealing with ... she would make me, she’d be like, “okay, so when you say ‘he,’ that he is actually a woman?” And I’d be like, “No, no, no. That ‘he’ was born as a woman but is a man.” ... I’m like okay, “So John and I were doing this.” “So you mean John, the girl?” I’m like, “No, John the boy. So him and I did this.” “But you mean she though? That’s the she?” And you know, she’d force me*

larly difficult. In the case that follows, heterosexism and combines with the complex experience of immigration and the acute lack of supportive resources for new Canadians to create substantial obstacles to appropriate health care. Consider the account of Jody and her partner Jean, who recently immigrated to Canada from China:

*We haven’t found a suitable family doctor. We tried two or three.... We tried to pick up some like Chinese, like ethnic, who can speak Chinese or Mandarin. Then, because doctor, we have to talk to them about a lot of private issues and a lot of, like in details. We hope, like, solve the language problem may be the primary issue. But then we tried a couple of them, not really that good. Well because, sexuality, we don’t want the Chinese community to know too much about, you know, well because this is also close community sometimes. So and then we tried to find Caucasian. But then we couldn’t find anybody.*

Systemic heterosexism is responsible for creating substantial “invisible work” for lesbian/bisexual/queer women as they try to get health care for themselves and their families. Conventional assessments of health care system efficiency focus exclusively on expenditures related to machines, human resources and buildings and do not take into account other elements of “cost.” But lesbian/bisexual/queer women must work hard to manage social interactions with health care workers and to negotiate the health care system, work that represents a significant cost to them and that must ultimately be calculated in the cost of care. For example, one participant talked about her neighbours, an elderly lesbian couple for whom she does occasional, unpaid care. The couple has been together for about 40 years; they are both housebound and require

occasional hospitalization. She spoke about the work they all do to balance the need to feel safe, connected and informed in the context of a heterosexist system that does not readily acknowledge lesbian family relations:

*And now when one of them goes into the hospital, the other one . . . can't go to the hospital and visit or anything like that. So with respect to being a lesbian, they encounter the system I think in a very biased sense where no one would—they're listed as friends instead of being acknowledged as partners.... I've actually presented myself as the niece to one of them, um, which has worked very well because I can gain entry. And I thought to myself "Who's to say I'm not a niece?" You know, there are lots of people who are other people's aunts and there's no biological relationship. So she's my aunt. And this other woman's partner has said on the phone that she's the niece to get information about her partner. Do you know what I mean? So she's pretended to be me in order to gain access.*

Invisible work to accommodate heterosexist assumptions is required in a variety of health care settings (not just hospitals and clinics). A participant who has a partner with schizophrenia talked about her experience of attending a support group for family members affected by the disease:

*... [W]hen I got in I kind of assessed what was going on and I just felt like, hmm, no, this is not going to be a safe environment for me. I just don't, I'm not going to be caring and sharing at this point.... They were very welcoming, but you know, just like anyone else. They made assumptions about who I was there for. And I just wasn't comfortable. Cause it just seemed like an extra layer of something that wasn't relevant, you know what I mean? It wasn't something that I needed to spend energy working on explaining.*

Being able to build a relationship with a trusted health care provider can alleviate some of the invisible work created by uncertainty about how lesbian/bisexual/queer women's sexuality and family connections may/may not be understood or acknowledged. But finding and building a relationship with a health care provider is difficult in an environment of health care reform where efficiency (measured by money and time) is seen as the ultimate goal.

Lesbian/bisexual/queer women in our focus groups regarded "efficiency" as a synonym for "cutbacks" and argued that it leads to decreased access to health care providers, shorter visits, and a lack of continuity of care. In these conditions lesbian/bisexual/queer women do not have the opportunity to develop relations of trust with health care providers, which are crucial for them to feel safe to disclose their sexual orientation and related health care concerns (Solarz and Committee on Lesbian Health Research Priorities; Duncan *et al.*; Dobinson *et al.*; Coa-

lition for Lesbian and Gay Rights in Ontario). For example, street-involved women talked about how it is important "to be known," and how being known is most likely when you have the same health care provider over time:

*It's better if you have your doctor, your family doctor that you see every week that knows you, that knows what your problems, that knows how you are, what you like and what you don't like, and respects you. Cause you never know, you're gonna get a doctor that treats you like shit next time or who is not going to want to fucking deal with you or is not going to be too nice, you know what I mean?*

*And you've got to explain to a new doctor every time. I hate that.*

*Oh yeah, I hate that. You need to be able to trust your doctor...*

*Exactly.*

*... and you can't do that unless you know them, and you see them all the time.*

Where it is possible to build a relationship with a trusted provider, the benefits are obvious. In one case, a participant's partner (Abby) and her partner's daughter (Kate) had a long history with a family physician:

*[On a few occasions I had] to take Kate to the doctor and I keep saying there's sadly lacking a word if you're not the biological mother but you're a parent. There's no, like it's really easy for Abby to say "I'm Kate's mom." And I'd say "I'm her... I'm her, I made up some really crazy word. But so I always have to say "I'm one of Abby's parents." So I just said it that way.... The clinic, like I said, she had a history already with the clinic and it wasn't an issue. So we were actually quite fortunate.*

The history and continuity of this relationship reduced the "cost" of negotiating the health care system for this participant, and in many ways made her encounter with the system "efficient" for all concerned.

### **Summary: "Quality is Like a Carton of Eggs"**

We have illustrated two ways in which the women in our focus groups challenged the discourse of conventional universalist quality assessments. What is missing in most quality assessments and the tools that are used to generate them are mechanisms to represent and systematically address women's diverse experiences, including how structural features of the health care system such as heterosexism reduce the quality of the health care experience, and what the health care system "costs" the women who use its

services. Too often, the accounts of marginalized women are reduced to “preferences” or dismissed as the griping of “interest groups” rather than recognized as responses mediated by intersecting, persistent social systems such as class, race, gender, and sexuality. Given the limitations of the universalist approach to quality assessment, what might provide better evidence of quality?

We urge that quality assessments adopt a gender-based diversity approach (Jackson 2004). Quality must be understood both in the local context of women’s diverse everyday experiences (as both users and providers in the health care system), and in the context of the systemic social relations of power in which those experiences are situated. Unlike a universalized approach to quality assessment, a gender-based diversity approach puts social relations of power at the centre of its analysis by measuring contextualized experiences, situated within the systemic social relations of heterosexism, racism, poverty, ableism, sexism, etc. Moreover, unlike a localized approach to health quality assessment, a gender-based diversity analysis offers such a systemic analysis and locates particular experiences of the health care system in a socio-historical and political context. These measurements give us an account of social relations in process, that is, how complex systems intersect and interact to create conditions in which quality is enhanced or compromised. Accordingly, they produce what feminist philosopher Lorraine Code calls “responsible knowledge” which is inclusive, situated, and has community/local accountability. A full, responsible account of quality in health care needs to acknowledge and address the “whole carton” of experiences, needs, and diversity, nested in complex, persistent social relations of power.

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*This paper is jointly authored by members of the National Coordinating Group on Health Care Reform and Women and Dr. Nancy Guberman (Université du Québec à Montréal). Primary authors are listed first, followed by Dr. Pat Armstrong (NCGHCRW Chair) and remaining co-authors. Beth Jackson is Research Coordinator for the NCGHRCW; Ann Pederson is Policy and Research Manager for the British Columbia Centre of Excellence for Women’s Health.*

*The National Coordinating Group on Health Care Reform and Women (hereafter, “the Coordinating Group”) is a collaborative working group of the Canadian Centres of Excellence for Women’s Health, the Canadian Women’s Health Network, and Health Canada’s Women’s Health Bureau. The mandate of the Coordinating Group is to illuminate the impact of health care reforms on women and to inform health policy and practice with a gender-based*

*analysis. The National Coordinating Group on Health Care Reform and Women, with Dr. Nancy Guberman (Université du Québec à Montréal), is currently conducting a study entitled “What Does Quality Health Care Mean to Women?” with support from the Social Sciences and Humanities Research Council and Health Canada, Women’s Health Bureau.*

<sup>1</sup>While these reports may give a brief nod to diverse “consumer” or patient perspectives, they devote most of their attention to the concerns of the governments and organizations that finance and deliver health care. For example, Chapter Six of the Romanow Report, entitled *Improving Access, Ensuring Quality*, “ends with a recommendation that ‘Governments, regional health authorities, and health care providers should continue their efforts to develop programs and services that recognize the different health care needs of men and women, visible minorities, people with disabilities, and new Canadians.’ In a document that spans over 350 pages, this recommendation garners only a page and a half of commentary” (National Coordinating Group on Health Care Reform and Women 41).

<sup>2</sup>In a recent Health Policy Research Program initiative to develop health indicators that reflect gender and diversity, Health Canada noted, “Women and men experience health in different ways and also differ in how they perceive health and illness, set health priorities, utilize health care services and receive treatment. We lack comprehensive indicators to track these differences in a way that takes into account the context of women’s and men’s lives. Although many health indicators are sex-disaggregated (biological), they do not adequately capture gender (social) differences that would reflect the complexity of women’s health experiences, concerns and needs and their roles as both recipients and providers of care” (Applied Research and Analysis Directorate).

<sup>3</sup>The research team for the study “What does “quality health care” mean to women?” is located in British Columbia, Saskatchewan, Manitoba, Ontario, Quebec and Nova Scotia, and has conducted a total of 22 focus groups in these five provinces. Our aim has been to gather the stories of a wide range of women; accordingly, our participants have a broad range of characteristics: young women in BC and Ontario; women who are recent immigrants (six mos. to six yrs.) from Asia, Europe, the former USSR, and Haiti; ethnic Chinese women who are not recent immigrants; middle-aged, urban women; First Nations and Metis women; women in rural and “remote” areas; low-income women and their support workers; health care workers; “women of size” with chronic health problems; women with disabilities; university students; seniors; street-involved women with addictions; lesbian, bisexual, and queer women; injured workers; mothers with children in daycare.

We attempted to capture as much diversity of social

location and experience as possible, however we acknowledge that some experiences are not represented here and that the absence of transsexual and transgender women's perspectives is a limitation in a study on gender and quality of health care. While each focus group may have attended to particular experiences and social locations of participants, these categories clearly intersect (e.g., there were health care workers and mothers and recent immigrant women in our lesbian/bisexual/queer focus groups; there were bisexual women in our street-involved focus group...). In this paper, we focus on how lesbian/bisexual/queer women define and experience "quality" health care.

<sup>4</sup>In our reporting of research participants' accounts, we have endeavoured to retain the vocabulary, syntax and cadence of their spoken words.

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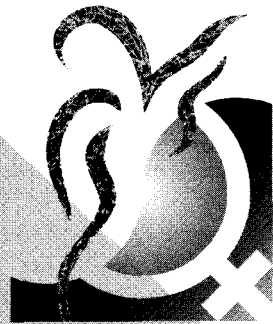
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## RENEE NORMAN

### The Canes

canes are left  
 at the top of the stairs  
 lying down  
 defeated wooden guidedogs  
 selves released  
 in nods hell.  
 we laugh at our clumsiness  
 in the water  
 the way we struggle  
 to keep our balance  
 to keep up with the exercises  
 with our bodies  
 upright flesh prisons  
 selves submerge  
 in liquid buoyancy  
 timeless  
 freedom floats  
 damage contained  
 in canes

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