How Women Define the Quality of Health Care: A Canadian Study

Pat Armstrong, Madeline Boscoe, Barbara Clow, Karen Grant, Nancy Guberman, Margaret Haworth-Brockman, Beth Jackson, Ann Pederson, Morgan Seely, Kay Willson

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Introduction

What does the "quality of health care" mean to women?

Women interact with the health care system and experience the quality of care in a number of ways. Women are the majority of paid and unpaid health care providers. Women use health services more frequently than men. Women are often responsible for overseeing the health care of children and other family members. These multiple roles give women several vantage points from which to view the health care system. Women's experiences of health care are also influenced by their social, cultural, economic and geographic locations, as well as their age, abilities, and sexual orientation. The diversity of women's experiences and their multiple roles within the health care system offer important 'ways of seeing' the quality of care.

Over the past decade, there have been provincial and national studies of the Canadian health care system which have called for better information on the quality of care (Romanow, 2002; Saskatchewan Commission on Medicare, 2001). There have been new initiatives to assess and monitor the quality of care including major national studies on patient safety (Baker *et al.* 2004; Health Council of Canada, 2006). Few, if any, of these initiatives have specifically examined women's perspectives on the quality of care. Most have emphasized the collection of quantitative data and the development of measurable indicators which can be used to track changes in quality performance over time. As a result, the information available on the quality of care tends to be gender-blind and to consider only those dimensions of quality which can be easily counted. In addition, conventional quality assessments fail to examine the structure of power relations within the health care system and how these power relations can influence the quality of care (Jackson *et al*. 2006).

Quality of care is sometimes measured in terms of the availability of health services and providers, e.g., how many doctors or hospital beds are available to serve the population? It is sometimes measured in terms of patient safety, e.g., how frequently are patients harmed by errors in medications or clinical procedures? Quality is sometimes measured in terms of wait times, e.g., how long does a person have to wait for an appointment with a specialist, a diagnostic test or a surgical procedure? It is sometimes measured in terms of adherence to clinical practice guidelines, e.g., how regularly do physicians offer the recommended treatments or diagnostic tests for specific conditions? All of these approaches can offer useful information, but all have acknowledged limitations. Some measures tell us more about the quantity of services used than the effectiveness of the care provided. Some measures emphasize the technical aspects of treatment and tend to overlook other important dimensions of care. Most of these measures have been developed by health researchers, health care administrators, policy makers, and physicians, whose definitions of quality may differ in significant ways from those of patients and other health care workers.

In recent years, many health organizations have used patient satisfaction surveys to measure how patients rate the quality of care they have received. Patient satisfaction surveys have been found to produce generally positive assessments of quality that may not correspond to other quality measures. In other words, high patient satisfaction scores are not reliable indicators of high quality care. According to Sitzia & Wood (1997, 1840), "A positive response in a satisfaction survey should not be interpreted as indicating that the care was 'good' but simply that nothing 'extremely bad' occurred." Some studies raise serious questions about the validity of using patient satisfaction responses as indicators of quality of care. In one study of patients' care after acute myocardial infarction, the patient satisfaction responses were not associated with either quality of care or with survival (Lee *et al*, 2008). Furthermore, despite the fact that Canada has made a commitment to gender-based analysis of health policies, patient satisfaction surveys often pay little attention to gender issues. According to Weisman *et al*. (2000, 657), "The standard outpatient satisfaction instruments have not been developed with gender issues in mind and have not been analyzed for gender differences." Listening to patients is important, but we need better tools than patient satisfaction surveys to gather patients' perspectives on the quality of care.

Methods

In 2003, we initiated a national study on women's perspectives on the quality of health care in Canada. We began with the assumption that women, in their multiple roles and diverse social locations, have important knowledge of the health care system and the quality of care.

Our central research questions were: What does the quality of care mean to women? What contributes to or detracts from the quality of care? What changes are needed to improve the quality of care?

Since our research team included members across Canada, many of whom were affiliated with the Centres of Excellence for Women's Health, we were able to organize 25 focus groups of women in seven provinces: British Columbia, Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia, and Prince Edward Island. The focus groups offered an opportunity for women to reflect upon their own experiences of health care and to describe, in their own words, what the quality of care meant to them. The focus groups were held in 2003-2004 and each focus group lasted approximately 1½ -2 hours.

Focus groups offered two clear advantages over the use of individual interviews. By using focus groups, we were able to gather input from a larger number of women. Individual interviews would have been much more costly and time-consuming. More importantly, the interactive nature of the group discussions enabled the participants to build upon or otherwise respond to each other's comments. This provided an opportunity for identifying shared experiences as well as a reality check on the diversity of women's perspectives. Direct quotations from the focus group participants are italicized in the remainder of this report.

In each group, a facilitator used a semi-structured interview guide to focus the discussion and ensure that important topics were covered. Open-ended questions were used to encourage the participants to reflect upon their own experiences of health care as patients and as care providers. Participants were asked to describe what good quality health care meant to them. In each focus group, women shared their health care experiences, both good and bad. They talked about the kind of health care they would like to have, not just for themselves, but for others. As a way of summing up the discussions, the participants were asked what changes they would recommend to improve the quality of health care.

Each focus group discussion was recorded on audiotape and the audiotapes were transcribed verbatim. The transcripts were analyzed to identify an initial set of codes for categorizing the data. All the transcripts were then reread and coded, using N6 qualitative data analysis software. By rereading, sorting and analyzing the data across all 25 focus groups, we were able to identify several important and recurrent themes. By analyzing specific group transcripts we were able to analyze the input of women from particular social and geographic locations.

Although the participants in this study are not a representative sample in the statistical sense, we took steps to ensure that our focus groups reflected some of the regional, economic, and cultural diversity of women in Canada. The focus groups included young, middle-aged, and senior women residing in seven different provinces. The participants included women from several major cities, as well as women living in smaller communities and rural and northern areas. While most of the focus groups were conducted in English, a few were conducted in French. Four focus groups were held to gather input from Aboriginal women, including women from both First Nations and Métis communities. Two focus groups were organized for immigrant women and two groups were held for women from Asian-Canadian communities. Two focus groups were organized with lesbian/bisexual/queer women. One focus group was held specifically with a group of health care providers, though other groups also included women working in the health care system. One group was organized for women of size with chronic health conditions, one group for women with disabilities, and one group for women injured in the workplace. Focus groups were held with groups of middle class women and economically marginalized women, university students and young women living on the street. All participants had experience as users of health care services; many were also providing care or overseeing the care of children, partners, parents or friends. Several participants were directly involved in the provision of health services. Overall, 145 women participated in focus group discussions on the quality of care.

Results

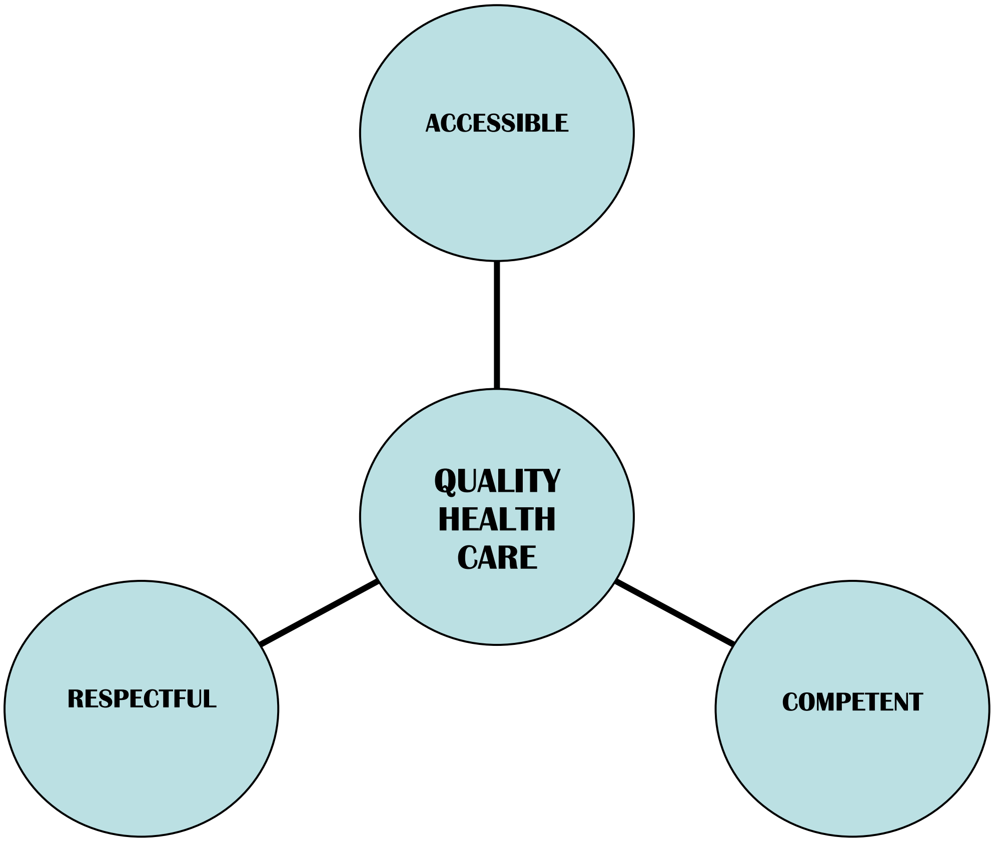
Three major themes emerged from the focus group discussions.

1. **Quality health care is accessible**. Women want the basic resources for health and comprehensive health care services to be accessible to all. They want timely access to services located close to their homes. They want the health care system to remove multiple barriers which prevent people from seeking or receiving the care they need.

2. **Quality health care is respectful**. Women want health care providers to treat them with respect, to respond to their concerns and to provide care that is culturally-sensitive and non-discriminatory. They want relationships with health care providers who know them as people and who welcome their participation in decisions about care.

3. **Quality health care is competent**. Women want competent care provided by skilled health care providers. They want accurate diagnosis and safe, effective treatment, but they also want care that addresses their physical, mental and emotional needs and care that responds to the contexts of their lives.

Dimensions of Quality Health Care



Quality Health Care Is Accessible

Access to the Basic Resources for Health

Quality of health care is sometimes defined as "the right services at the right time, in the right place." On the face of it, this sounds like a good start. However, women define health care more broadly than the delivery of services. They see basic necessities – like food, shelter, transportation, personal safety, and supportive relationships as fundamental to their own health and their ability to provide care for others. For women, good quality health care begins long before they reach the doctor's office or the hospital door. It begins with the conditions of their lives. As one woman said, *"At least have the basics. Good food, good housing, good water."*

The women we spoke to recognized that their ability to care for their own or others' health is affected by their income, their work, their access to decent housing and nutritional food, their relationships with other people, the safety of their neighborhoods, their opportunities for exercise and recreation, and their access to health information.

Young homeless women in Toronto told us how their health was threatened by the hazards of living on the street, their only 'bathroom' a back alley shared with strangers. A worker in a women's shelter told us that *"poverty is common to every single person that comes through our doors. They are the poorest of the poor. They are people who are homeless, people who are struggling, who don't have resources, haven't eaten; don't have access to a good quality lifestyle in general. People don't see them as health issues but they are probably the gravest health issues that we deal with... [They need] a place where they are safe and off the street. They can get fed. They can have a bath. They can have clean clothes."*

Many women talked about the need for reliable information so they could manage their own care more effectively. *"It's not easy being a woman nowadays,"* one woman said. *"Take hormones for years. Don't take them. You might take them. No, don't take them. Mammograms, are they good for you? Some say yes, others say no ... So whom do you believe?"*

More than one woman talked about "time poverty," how the pressures of juggling paid jobs, long travel times to work, and family responsibilities left them little time to take care of themselves. Women talked about the care provided by family members and friends, and what happens when people are cut off from those sources of support.

For many women, access to health care includes access to the material resources, information and social supports one needs to live a healthy life.

Access to Comprehensive Health Care Services

Women told us that quality health care means having access to a wide range of community services and health professionals. This includes mental health, as well as physical health and the women include prevention and health promotion, as well as treatment. One woman explained that *"we need services for mental health, physical, and in general, just to have good well-being* *and to have good healthy lifestyles. And we have to have a very wide range of health services and we need it to be acceptable to all people. We need it affordable or people won't be healthy. Like we can't wait until the end when people are sick. We have to do something before they're sick."*

Services that women defined as contributing to health care include care provided by family doctors, nurses, medical specialists, hospitals, nursing homes, pharmacists, nutritionists, dentists, physiotherapists, ambulance services, diagnostic services, alternative health practitioners, health information services, education and prevention programs, counseling, mental health services, addictions treatment, harm reduction programs, immunization programs, home care, public health, family support programs, safe shelters, and more. Some women called for new services such as safe injection sites for drug users, or expanded services to meet unmet needs, such as better care for the frail elderly, most of whom are women.

Access to health care services was seen as crucial for women as patients, but also as family members who were often expected to fill the gaps in care.

"I guess if you asked me about what does health care mean to me, it means accessibility. Accessibility to doctors, to nurses, to services, to hospitals, to medical centres, and to medication. And what I see happening is that more and more of this type of stuff is being pushed into the home. It's being pushed on the backs of the family members. You're expected to go into the hospital and care for your family member because there's not sufficient nurses to take care of you or they're overworked or their case loads are too many. And you're expected as a family member if you want your family member to be cared for properly, to have what I call quality care, you're almost obliged to do it yourself."

Even when a broad range of health services are available, access can be limited by the way those services are organized. Women commented on the basic necessity of knowing whom to call and where to go for a referral, how to get the information and connections to find the particular services they need. Women valued health facilities that offered easy access to multiple, connected services and they appreciated health care providers who referred them to other types of practitioners, support groups, and sources of health information. However, many women described their frustrations in trying to navigate through a maze of fragmented, uncoordinated services searching for the help they needed. An uncoordinated system requires navigation skills and time that many women lack. *"You almost need a road map in order to be able to get in, to figure that out."*

On the other hand, one woman described the value of integrated services: *"A lot of us go to the community clinic and, you know, I certainly go there because it's a group practice with other services there. I mean, I think that's a good model…where you have a group of physicians practicing together, so they have the benefit of having colleagues, of sharing calls. They have diagnostic services in the same location and services like physiotherapy and occupational therapy and counseling."*

Access Based on Need, Not Ability to Pay

Canadians have a strong commitment to the principle of universal access to health care based on need, rather than the ability to pay. This commitment was reflected in the focus group discussions.

While Medicare provides coverage for hospital care and physicians' services, many aspects of health care require private payment. Although there are a variety of public programs which cover additional services for some, these programs vary across different jurisdictions. One woman described how she'd had to purchase equipment to care for her frail elderly father in one province, and she expressed appreciation that her home province had public programs to lend the same kind of equipment to families as needed.

Access to dental care, prescription drugs, transportation to and from hospital, home care, midwifery, physiotherapy, eye care, counseling, and other services is often limited to those with private health insurance or the financial resources to pay directly out-of-pocket. Many women in the focus groups identified financial barriers which limited access to care.

"It's easy to make the presumption that (those who) work have benefits and can afford all these kinds of things but I couldn't afford a pair of glasses and like I had to save up for months..."

"You know, some of us have a health plan, and we don't think about it, but others, who don't, have to pay for it."

Women are less likely than men to have health insurance benefits connected to their paid jobs, and women have less income to pay for care when they don't have employee benefits. It is important for women to have services provided through a public system (Jenkins 2007). Many advocated bringing more services under the umbrella of Medicare.

"Medicare, like having universal access to services. And I think we haven't talked about it too much, because we tend to take it for granted. We've had it here for so long. But I think it's really important that we don't let that get eroded and that it should be expanded ... to the gaps that we have, that we talked about, in terms of mental health services and home care too and dental care too. People are having a lot of problems who don't have access to insurance. And I think it should include eye care."

Timely Access to Care

Accessible care is also timely care. Women frequently described waiting for care, waiting to see doctors, waiting for surgery, waiting for diagnostic tests, waiting in emergency rooms.

"It seems my experience with the health care system is time waiting, all the time waiting for babies, waiting with old people, waiting for myself."

Women described the stress and worry that resulted from waiting for diagnostic tests, then waiting to hear the test results, then waiting yet again for access to treatment. Women also recounted instances where patients had died or suffered serious setbacks while waiting for surgery.

One woman described how her mother had an ovarian cyst that wasn't treated for months because her doctor assumed it wasn't urgent. *"She waited from February until May, and in that time, the cyst popped and it was cancerous. So because a doctor does a kind of best guess and says this doesn't look cancerous to me, she's not an emergency. Mom waited for her surgery too long and it had already popped. So, you know, this is not unusual. This is a very, very common problem. People waiting for surgery."*

As one woman said, *"Good quality care to me would be available when you need it or within a very reasonable time."*

Most paid and unpaid health care work is provided by women. Not surprisingly, the women in our study see access to good quality care as linked to the time that health care providers spend with patients. Timely access is not simply about reducing waiting times; it is about ensuring that health care providers have the time to care (Armstrong et al 2006). Women repeatedly told us about situations where patients did not receive good quality care because their health care providers did not have enough time.

"What's very clear when you're in the hospital is that the doctors are essentially not around and the day-to-day care is provided by the aides and the nurses. And what you really want when you're in the hospital is some of that person's time. And when you have that person's attention, you need that person to be able to listen to you for awhile. And the nurses now, in my experience, they all wear running shoes because that's all they do all day is they run. And they feel terrible with the quality of care they're giving because they literally can't spend time with anybody. So I think it's in the patients' and those health care professionals', those health care workers' interest for things to be changed, so that it's more focused on improving quality of care, allowing those people to spend more time with patients."

Women described hospital staff rushing to provide care, *"in a frenzy themselves 'cause they're burned out."* They spoke about hospital patients without friends and relatives to provide care *"who didn't have that support, they just didn't get it, you know, because the health care workers didn't have the time to give it."* They spoke about how health care reforms have left women in long-term care without bath time because the providers *"are overworked. They didn't have the time."* One woman nicely summed up what many said in various forms: *"All these processes take time. That's the big factor in providing quality."*

Care Close to Home

Women in the focus groups told us that it is important to have health care services close to where they live. Women living far away from urban centres told us about the time and distance which separated them from many health services. They told us about people who had to leave their home communities and their families in order to get the health care they needed. A woman from Northern Saskatchewan told us, *"We need specialists to come here instead of always having to travel."* Another woman described the use of telehealth technology to connect specialists with patients and local care providers in distant communities.

Several women spoke about the distance they had to travel, the need for transportation to get to health services, and the importance of having health services close to home. *"Greater distance equals fewer visits equals less care."* Whether taking family and friends to care or visiting those in care, women make more trips for health. However, women are less likely than men to own a car, so affordable and convenient public transit is especially important for women's access to care. As one woman said, *"Good health and good transportation systems are intertwined."*

Community-based services were important to women, particularly those with chronic conditions who required frequent contact with health care providers. Specialist visits to rural and remote areas were seen as one way to significantly improve access as would other strategies for *"moving health care providers to the patient."* As women are frequently in touch with schools through their children, women want public health nurses available in schools and running local well-baby clinics. *"A feeling [of] community close at hand"* defines important aspects of access for them.

Responding to the Needs of a Diverse Population

While navigating the health care system can be complex and difficult for many women, some women face additional barriers. Sometimes health services are organized in ways to reduce those barriers to care. One woman described prenatal and parenting programs that helped women by providing transportation and child care so that low income mothers could more easily keep their appointments with health care providers.

Homeless women have limited access to health services. Without a home address it is difficult to get a provincial health card. Without a home, it is impossible to receive home care.

Women with disabilities face both physical and communications barriers in gaining access to the right services. Women with disabilities told us that health care providers need to adapt their facilities and their communications strategies to make them accessible and appropriate for people with a wide range of needs and abilities. As one woman explained, *"just because it has a button on the front door does not make the location physically accessible."*

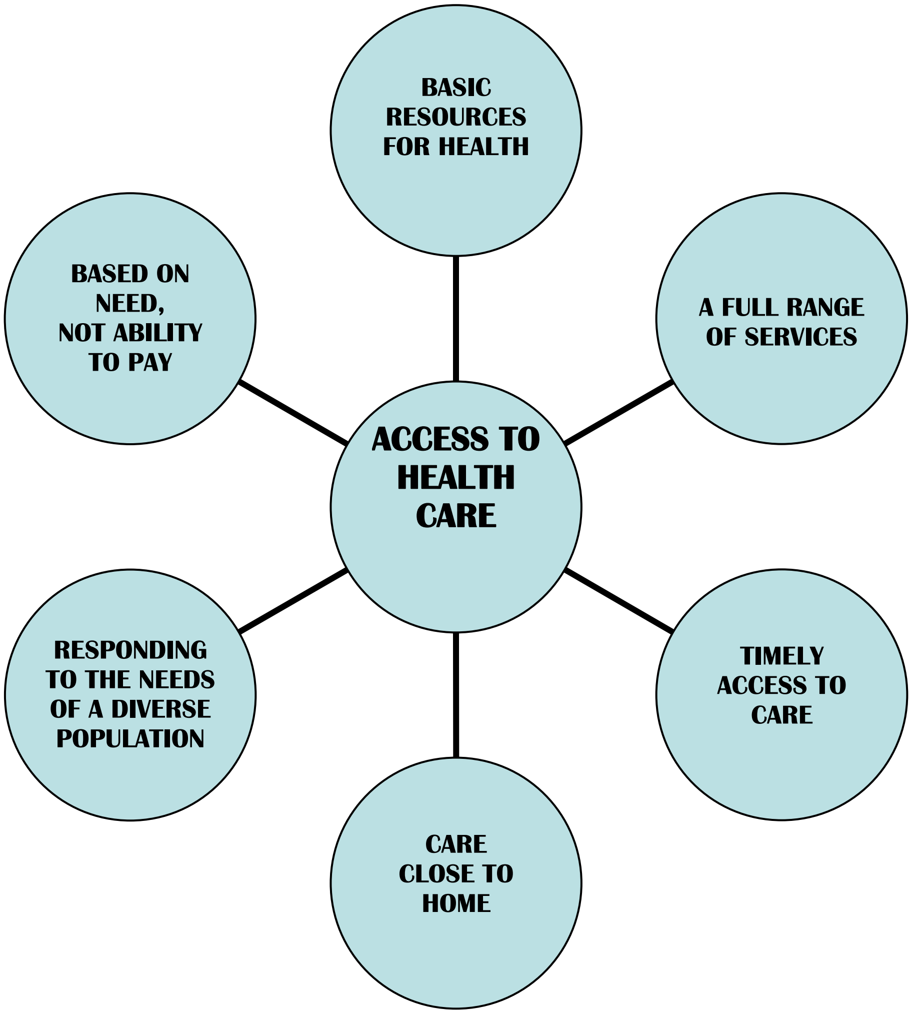
Navigating the health care system is particularly difficult for those who are not fluent in the language of their health care providers. A woman in Quebec described an encounter with a doctor who *"treated me as an imbecile because of my bad French."* (Translated from French)

Without access to health care providers or interpreters who can communicate in their own language, it is difficult for patients to discuss health issues and understand what's going on.

An Aboriginal woman described her aunt's experience in the hospital: *"Because she didn't understand proper English, the nurses just totally dismissed her health and didn't explain* *anything about what was happening. They just took part of her leg off. They just amputated her leg, without any questions asked or anything … She could only understand Cree. They should have people explaining this in their language."*

Canadian women are culturally and economically diverse, they speak different languages, live in diverse relationships, and have different abilities. Many women find that the health care system does not reflect or respond to that diversity. As a result, many women are unable to find the kind of care they need. For example, a lesbian couple from an Asian-Canadian community told us that they were unable to find a health care provider who was able to speak their language and responsive to their needs, *"We haven't found a suitable family doctor… We couldn't find anybody."*

Dimensions of Accessible Care



For the women in this study, accessible care includes access to the basic resources for health. It means easy access to a full range of health services. It means care that is universally available based on need, rather than the ability to pay. It means timely access to care, close to where women live and work, linked to public transportation systems. It means valuing and responding to diversity in cultures, languages, sexual orientations and (dis)abilities. And it means structural arrangements and pro-active policies to counter inequities and eliminate barriers to care.

Quality Health Care is Respectful

"Treat me with respect." All across the country, women told us that respectful treatment by health care providers is essential to quality care. "*Respect is the key.*"

Being Listened To and Taken Seriously

When it came to their own care or care of their loved ones, women insisted that good outcomes and quality care could only be achieved when health care providers took the time to listen to them. When women talked about quality care, they described health care providers who listened to what patients had to say and who took their health concerns seriously. One woman explained, *"I've had lots of really good experiences with the health care system, and a lot of it was when I really felt like people were responding to me and listening to what I said, and just understanding what I needed."*

Other women in our study described frustrating encounters with health care providers who dismissed their concerns. Some women were told their problems were *'just in your head'* while others were told that *'nothing is wrong'*. This sometimes led to serious delays in diagnosis and treatment.

A young mother told us, *"I took [my son] to the hospital because he was throwing up and I knew that there was something wrong with him. He was three months old. He was dehydrated and they kept sending me home. 'There's nothing wrong. There's nothing wrong.' …The doctor kept saying there was nothing wrong with him. For a year and a half, I fought with them, but now he's fine. It's unreal. It turns out his large intestine wasn't working properly and they had to take it out."*

Failure to take women's concerns seriously is belittling and causes unnecessary pain. Women want health care providers to respect their knowledge of their own bodies and their knowledge of the health of others in their care.

An Aboriginal woman said, "*The first thing on my mind would be getting medical personnel to believe the people. Like they go and they say they have a toothache. Yes. They have a toothache or whatever. The second, having respect for these people. You know. Don't treat them as if they are stupid and they don't know what they are feeling."*

What are women seeking when they talk about being treated with respect? They want to be listened to. They want to be believed. They want to be recognized as having valid information about their own bodies and the health of other family members. They want timely diagnosis and treatment in response to their health problems. They do not want to be sent home and told that there is nothing wrong with them.

Being 'Known' and Treated as a Human Being

Women told us they want to be known and treated as human beings. Being known by their doctors was very important to many women, and they valued the relationships that developed from seeing the same provider over time. An Ontario woman commented that she felt her family doctor, a woman, was *"part of my social support and my friends."*

When a woman has a relationship with a health care provider who sees her as a unique person, it becomes possible to share difficult information about oneself. As a young homeless woman from Ontario reported, *"I'm not gonna spill my guts out to someone I don't know … Even if they're a doctor, you know?"*

Women want their health care providers to see them as whole people, not as isolated body parts.

"I think that some of the doctors, and I've heard my mom say this too, is that you can only go and you can only deal with one thing at a time. I've heard my partner say it too. And it's completely ridiculous .…You don't separate mind and body so how would you even be okay with asking me about my kidneys and ignoring my heart? How can you talk about one system in isolation? It's completely ludicrous. So I mean I feel very obviously passionate about that, that we're treated as a whole person and not rushed out the door."

Some women described health care encounters that led to feelings of objectification and dehumanization. Women spoke about being treated in a routine, assembly-line fashion, and of physical facilities that prevented intimate experiences from being private.

"I'm my health card number, not my name. That is almost offensive – when you walk in, they want your health card number so they know who you are instead of just asking you what your name is."

"There have been a couple of times in my earlier life, in my teens and in my childhood, where it was like, there was a lot of objectification. Because I was an 'interesting case.' And the last time I went to my orthopedic surgeon, … it was like the weirdest thing because my doctor, who was a lovely guy, had a herd of residents with him and he said, 'Drop your trousers and walk for me.' I said, 'No.' I said, 'I will walk for you. I will do whatever you want, but I will not drop my trousers. You have seen me walk hundreds of times before and I will not drop my trousers.' And it was just so degrading."

The women in our study stressed that quality care was done best when there is a respectful relationship between the patient and the care provider. Being ‘known’ was central to women’s experience of quality care. They want to be treated as persons, not as an objects, body parts, or diseases. They want to have relationships with their providers so that they are known and their particular life circumstances are recognized and understood.

Shared Decision-Making

Women stressed the importance of having health care providers who respect a woman’s right to make decisions about her own care. One Saskatchewan woman defined quality care as “*care that involves me as a full partner and recognizes that I have the ultimate say in what’s going to happen to me, even if the health practitioner… maybe, would recommend something else. That it’s my ultimate decision and if they’re respectful of that.”*

While women insisted on the need for skilled, knowledgeable health care professionals, they also saw themselves as having expertise about their own health and bodies, expertise that was often ignored or belittled. One Manitoba woman concluded, *“We are not trusted. We are not trusted to know our own bodies, or to know what we want.”*

Another woman explained the difference between good and poor quality care by comparing her treatment by two different physicians – one who refused to perform a tubal ligation for her and one who respected her right to make that decision.

“I was asking the doctor for a tubal ligation. [He says] ‘You’re not old enough to make that decision.’ I said, ‘I’m alone. I’ve got my kids. That’s all the kids I want. I’ve known this for a long time. That’s what I want.’ [He says] ‘No, you better not. You better come back in a year’s time.’ … To not be respected and given that voice. It’s just a horrible feeling to have somebody telling you ‘No, you’re not old enough.’ It’s very patronizing to tell me what I need in my life, as opposed to the next doctor who says ‘I have a consult with you and you know your mind and you know your body and I respect you for that decision.’ That makes the difference for me. That if I am listened to and respected and treated like I am an adult instead of a kid that doesn’t know anything.”

Equitable Treatment for All

Women appreciated it when health care providers treated everyone with respect. One woman described how her local pharmacist was respectful of people seeking treating for addictions. *“If I go to fill out a prescription ... around nine o’clock in the morning, I’m in the methadone line, so I’m waiting behind like five or six people and what I’m very impressed with is how respectful the pharmacist is towards the people and how, what a pleasant kind of interaction it is between the clients and the pharmacists. You get a real sense of people appreciating a service that’s offered to them in a very simple and respectful manner.”*

However, many women described discriminatory, patronizing and disrespectful treatment by physicians and other care providers. They described health care providers who overtly stereotyped and judged them on the basis of gender, race, ethnicity, age, sexuality, ability, economic class, language, and other social locations. Taken together, their stories reveal multiple forms of discrimination within the health care system.

Many women felt that health care providers were more likely to talk down to female patients or dismiss their concerns while accepting the reports of male patients. A woman from Manitoba said: *"When you're accessing health care and you're a woman with disabilities, you're well, first of all you're a woman and you still fit that stereotype, 'You're a woman—women complain a lot'."*

One woman described an encounter with a group of medical students who made assumptions that women in poverty were *"addicted and obese and in and out of jail and ... not responsible parents."* Another woman told us, *"When you're homeless, they don't care about you like they care about people who've got money. They don't treat you the same."*

A black woman from Nova Scotia described the racial stereotyping she faced when she went for a physical. *"The nurse practitioner yelled across the hallway, that other patients could hear too, to the physician, 'Oh, I've got an STD here.' Which I did not have. Even if I had, that would have been inappropriate. But I didn't ... But the immediate assumption is 'Oh, she's black, she must be a whore'."*

Another woman told us *"All patients need to get respect from the nurses and doctors. And they shouldn't be treated with dumbness just because they are different skinned. After all, it's their body. They are the ones that are experiencing the symptoms of their disease."*

Another woman described how she and her mother find it difficult to receive appropriate care for their health problems because of weight discrimination: *"My doctor's response to everything is 'You've got to lose weight.' Like everything. She says that to my mum all the time ... She doesn't treat her the same way as if she was a smaller woman."*

A lesbian woman described a frustrating experience where her doctor insisted on a pregnancy test, ignoring the woman's own account of her life and circumstances:

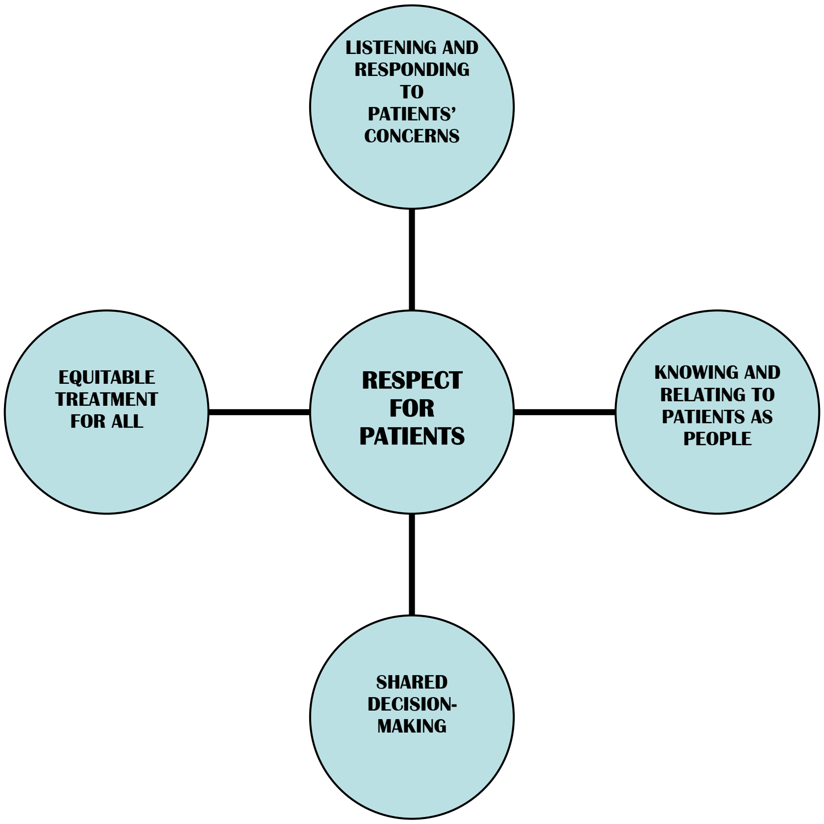
"I had been complaining about new pains, you know, and [the doctor said] 'Well, we should get you a pregnancy test.' And I said, 'No. I don't think so. Like, I'm in a monogamous lesbian relationship. I have a daughter …' [She said] 'I know you say that, but I really think I want to rule this out.' And she was insisting. It took two or three times where I was looking so frustrated because I thought 'What?' You know, it was insulting. It was insulting. I'm 40 years old and you're telling me that I can't be trusted to tell you that I'm not pregnant."

One woman reported that as a result of homophobia *"members of the queer community have been injured by health professionals."* More positively, some women discussed respectful relationships with care providers who resist making judgments, and are accepting of differences among women. A lesbian woman from Ontario described how doctors and hospital staff made her feel welcome.

"I brought my partner with me and yes she can come in, she can stay with me. It's a whole turn around. And that's of course, you work at it. And I find I'm up front with them. They know. And they've been very accepting of it. They're very gay positive there, and everybody is welcome, and that's how it should be."

Stereotypes and discrimination by health care providers may directly jeopardize a woman's health and well-being by increasing her feelings of anxiety and alienation. Negative experiences hinder the development of trust and good communication between patient and provider. Poor relationships make it more difficult for women to make appropriate use of the health care system, to discuss their concerns with health care providers, and to ask questions about treatment plans. Errors in diagnosis and inequitable treatment may be more likely when stereotypes cloud clinical judgment. Discrimination also reduces the efficiency of the health care system. Women who are treated with respect are more likely to feel that their accounts of their health needs are treated as credible. On the other hand, women may switch physicians as a result of negative encounters, or go to multiple health care providers before receiving the necessary and desired care.

Dimensions of Respectful Health Care



Respectful care means health care providers who listen to patients and respond to their concerns. Respectful care means knowing and relating to patients as human beings, and being sensitive to their feelings as well as their physical needs. Respectful care includes respecting women's knowledge of their own bodies and their right to make their own health care decisions. Respectful care means working to overcome prejudicial attitudes and treating all people without discrimination.

Quality Health Care is Competent Care

Accurate Diagnosis

Perhaps one of the most obvious ways of measuring quality health care is by the outcomes, the success of diagnosis and treatment. A "good outcome" doesn't always mean that a patient recovers fully or regains health. Sometimes, depending on the illness and the circumstances, this kind of success is just not possible. But women told us that good outcomes start with a timely, accurate diagnosis and appropriate management of their health concerns. Quality health care is only possible when health care providers are able to correctly identify and treat illness.

Several women told us about profound failures of the health care system – illnesses misdiagnosed, treatments delayed, care denied. One young woman described how her cousin's diagnosis was delayed when her doctor kept dismissing her concerns. *"She kept going to see the doctor and he kept saying 'There is nothing wrong with you. There is nothing wrong with you.' Finally she went to see the doctor in [another community] and they told her it was her appendix. So they opened her up right away. When they opened her up, they saw that it wasn't her appendix. It turned out that she's got Crohn's disease."*

Lack of information about women's health can also contribute to misdiagnosis. One woman reported that *"The doctors in that time refused to believe that I had heart disease because I was a woman and I was so young ... Heart attack after heart attack after heart attack. It came to the point where I had to live in the hospital for a whole month. Then I went through a quadruple bypass. ... If they had diagnosed me properly before, maybe I wouldn't have had to have an operation."*

In some cases, women pointed explicitly to technical incompetence as the source of misdiagnosis. According to one mother in Atlantic Canada, *"I had a ruptured disc in my back, and lived with it for a long time, but just kept having tests: CT scan, MRI scan. Apparently the radiologist misread my test."*

Misdiagnosis can result in chronic illness or even death. An Aboriginal woman described her mother's experience: *"She was seeing this one doctor in town here. He kept telling her she had ulcers and all this time she had cancer. She finally passed away one night. By the time they found it, it was too late."*

Effective Treatment and Skilled Care

Women told us that quality of care requires trained health care professionals who can provide effective treatment and skilled care. Competent care depends upon having health care providers who *"know what they are doing."* An Ontario woman told us quality care requires health care providers who are *"informed, knowledgeable and trained."* A Manitoba woman commented on the importance of having health care providers who are skilled and experienced. She was concerned that women having PAP tests *"always say, 'I'm so glad you are female.' Not, 'I'm so glad you've done this 2,000 times and you're good at it.'*

Women want health care providers whose clinical practices meet high standards but they also want treatment decisions to be tailored to each individual's circumstances. As one Ontario woman concluded, *"It's good to have guidelines but you want to be able to adapt to the individual case. It isn't necessary to have a one-size-fits-all formula."*

Women described situations where patients did not receive effective treatment, and the serious consequences in terms of lost life. A woman from the Maritimes told us that a friend hung himself after he was released from psychiatric care without any medication or support. A woman on the prairies told us about her friend's sister who died after months of waiting for heart surgery.

Women also described instances where their health deteriorated as a consequence of inadequate care. A Manitoba woman described how she developed an infection after giving birth because *"after the delivery I wasn't cleaned properly, I wasn't looked after."* Fortunately, a nurse intervened to remedy the situation. *"Thank god, this one nurse came in after the third day and said, 'Are you still in the same gown you delivered your son in?' And I said 'yes'. And all I could remember, I can still see her flying out the door, with her white coat flying up in the air. And then things started to happen and I got better."*

Women told us that medical mistakes and inadequate treatment were neither acknowledged nor addressed by the health care system. *"I feel like there isn't any accountability now,"* concluded one woman. *"Like I don't feel they have to say anything to anyone because who's going to know if they're not doing things right?"*

Many women seemed to take the technical competence of health care providers for granted. But some women expressed a need for easy and reliable ways to get information on the skills of specific practitioners. A number of women we spoke to recommended setting up some sort of report card for health care providers or establishing an independent oversight committee to ensure competent care.

Women also raised the issue of how to ensure the competence of care provided at home when so many demands are being placed on unpaid caregivers. They felt that patients were being sent home from the hospital *"quicker and sicker,"* and that family caregivers were now expected to perform tasks that required skills that many did not have. *"All these informal caregivers. They're not on anybody's radar screen. All kinds of things are happening and no one knows about them."*

Supportive Patient-Provider Communications

Women clearly valued having access to health care providers with strong diagnostic and clinical skills, but they also considered other skills essential to competent care. They valued not only technical skills, but also social skills – the ability to communicate clearly, to show empathy and kindness, to ease patients' fears.

Many women were critical of doctors with poor communication skills, whether they were poor listeners or were unable to explain things in a language that was easily understood. One woman observed that doctors "*use all this ridiculous terminology that no lay person would ever understand and they expect you to walk out of there feeling that your needs have been met.*"

By contrast, another woman told about a doctor who took time to talk with her young daughter before performing surgery for a lump in her breast: "*It was explained very clearly to her what she was going to be experiencing, so that it dispelled her anxieties and fears to a great extent. So that part of it, I found we were treated very well.*"

Women also described how news was delivered to them, how bad news was given to them in awkward situations, with no apparent concern for its emotional impact. This lack of awareness and insensitivity is not only uncomfortable for a woman, it can mean that she misses vital information during a medical encounter because she is not given information in a way that supports her to hear it and ask necessary questions.

Women commented on the importance of having health care providers who could help and support "*people dealing with really difficult situations.*" One woman told us about the compassionate care she received following her miscarriage: "*They provided exceptional care to women who were having miscarriages…We had amazing nursing care, people checking on us all the time. And then after I lost the baby I was moved to a private room and this nurse, an LPN I think. She stayed with me for hours.*"

A woman from Ontario recounted how her family physician provided her with individual counseling over a three-year period on a regular basis. She described this as excellent, individualized care that meant that she received therapy she could not otherwise afford. She appreciated that rather than only dealing with the physical aspects of her care, this physician saw how she was feeling emotionally as part of her health.

Technical excellence devoid of compassion is not quality health care. Empathy without proficiency is not quality health care. As one young woman from Prince Edward Island concluded, "*If I'm sick and in the hospital, I'd want someone to be compassionate and caring but I'd also want someone that I knew was doing what they knew ... Someone competent.*"

Care in the Context of Women's Lives

Many women told us that good quality health care is responsive to the context of people's lives and the circumstances that affect their needs for care. They valued health care providers who took the time to ask, *"what's going on in your life?"*

Women valued health care providers who would take the time to talk with their patients, who were interested in understanding their patients' social and economic circumstances. As one woman explained, *"Good quality care is really looking at the whole woman and her whole life and all the circumstances."*

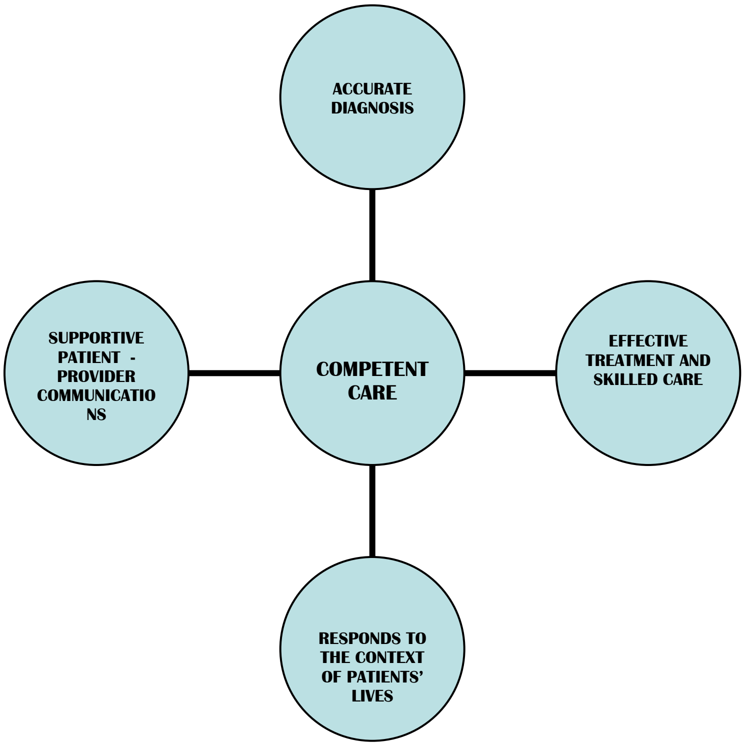
Another woman explained, *"When you go for help, they can't just look at the one thing that needs to be done. They have to see what the circumstances are … Like when I had [my first child] I had those problems, and then later when I had [my other children] I was older and I was more confident and I had more backup and I didn't need the same kind of care. I think that makes a difference too. Like who are people living with? Do they have enough money? Do they have a car to get around in?"*

One young woman from British Columbia described how her doctor paid for her prescription when she presented with a serious lung infection but was unable to pay for the medication herself. Another young woman, in Ontario, described a time when she was going through drug withdrawal and was unable to get to her physician's office but needed medical attention. She described how her doctor telephoned a prescription to a local pharmacy to facilitate the young woman's detox and to enable her to obtain her care in a convenient location.

Women with aging parents were very concerned about the quality of care available through home care programs and long term care facilities. One woman told us that the social isolation of many older women is largely ignored, that *"drugs are overprescribed"* and *"loneliness isn't dealt with."* But we were also told about home visits by medical specialists that helped seniors manage their chronic health problems, and support services like housekeeping and grocery shopping that enabled people to live in their own homes.

Health care providers are not always aware or responsive to their patients' circumstances. One woman observed that many health care providers look for biological explanations and overlook the social and economic factors affecting a woman's health. She said that health care providers tend to think that *"pregnant women are emotional because their hormones are raging"* when, in fact, a pregnant woman may actually have *"something to cry about! Maybe she's being beaten up at home. Maybe there isn't enough money. Maybe she's got a darn good reason to cry that has nothing to do with hormones."*

DIMENSIONS OF COMPETENT CARE



Competent care begins with accurate diagnosis. Competent care means that patients receive safe and effective treatment by trained health care professionals who have strong clinical skills. Competent care requires social, as well as technical, skills, particularly the ability to communicate clearly and to provide compassionate care that is sensitive to patients' emotional needs. Competent care is flexible and is attentive to the context of patients' lives.

Rethinking the Meaning of 'Quality of Care'

In this paper, we present a new gendered definition of 'quality of care', one that is grounded in women's experiences as both patients and providers of care. By developing a conceptual model that reflects the quality concerns that matter to women, we hope to encourage future quality assessments and quality improvement strategies that take women's perspectives into account.

In 2002, the Commission on the Future of Health Care in Canada reported that efforts to improve the quality of health care were widespread, but that Canada lacked "the basic and critical information needed to measure the results, assess performance, and judge the quality of the health care system" (Romanow, 2002, 151).

In recent years, the Health Council of Canada, the Canadian Patient Safety Institute, and the Canadian Institute for Health Information have all undertaken initiatives to improve the information available on the quality of care. As well, the federal, provincial, and territorial governments have collaborated on the development of comparable indicators to measure the performance of the health care system. Concerns about patient safety and timely access to care have made information about adverse events and surgical wait times high priorities.

How we define the quality of health care has consequences in the real world. Definitions of quality influence how we monitor the quality of care and what we do to improve the quality of care. Definitions of quality can influence how health care resources are allocated. If quality is defined by the number of physicians or nurses, then efforts to improve quality may focus on recruiting and retaining more health professionals. If quality is defined by access to the latest technologies, then resources may go toward purchasing new equipment. If quality is measured by surgical wait times, then reducing wait times becomes a priority.

Women in this study defined quality health care as accessible, respectful, and competent. They gave new meaning to terms used in quality assessments and they identified important dimensions of quality care that have been largely ignored or overlooked in conventional quality assessments.

A Comprehensive Concept of Health Care

Conventional quality assessments tend to focus on formal health care services. Women repeatedly told us that access to quality health care is not just about doctors and hospitals. It is about having access to the basic resources for health and a comprehensive range of services that promote health and prevent illness. It is important that quality assessments begin to reflect this broader definition of health care.

Quality Care Takes Time

In conventional quality assessments, time is frequently considered, but the emphasis has been on time spent waiting for care. Women in this study remind us that it is equally important to consider the time spent providing care, and its impact on both patients and their caregivers.

In the decade preceding this study, governments across Canada introduced several significant health reforms designed to increase efficiency and contain health care costs. These reforms often included measures to cutback permanent staff positions, reduce the number of hospital beds, shorten the length of hospital stays, and increase the use of day surgery.

Women in this study were concerned that reforms introduced to increase the ‘efficiency’ of health care services were reducing health care providers’ ‘time to care’ and shifting more care work to family members, most often women.

As both patients and as care providers, women described how the quality of care is enhanced when health care providers have the time to develop a relationship with patients, to listen to their concerns, to convey important health information, and to offer care that is sensitive to their needs and circumstances. They raised serious questions about health care 'reforms' and cost-cutting measures that have reduced the time available to patients (Armstrong et al 2006).

Unequal Power Relations and Inequities in the Quality of Care

Women repeatedly emphasized the importance of respectful treatment by healthcare providers. They recounted numerous experiences of having their concerns dismissed, their knowledge discounted, and their right to make decisions questioned. This evidence reveals how unequal power relationships are expressed in health care interactions and how this can affect the quality of care. It is important that quality assessments examine the extent to which health care encounters are disrespectful and disempowering for women, and for men. It is equally important to ask which women? which men? Quality assessments would benefit from a gender-based diversity approach that "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" (Jackson *et al*, 2006, 535).

Reporting quality assessments and patient satisfaction scores for the overall patient population tends to obscure important inequities in the health care experiences of a diverse population. By including women from diverse social and geographic locations, this study provides a more complete picture of the quality issues that arise in women's encounters with the health care system. This study reminds us that the population-wide statistics used to measure patient satisfaction or health system performance often mask important differences and inequities in health care.

Women's descriptions of their health care encounters revealed multiple forms of discrimination that had a negative impact on the quality of care. Quality assessments and quality improvement strategies need to focus on identifying and reducing inequities in the quality of care by addressing the needs of underserved or poorly served groups in the population. They need to assess systemic inequities in the quality of care and track progress in reducing those inequities.

Policymakers and health care administrators need to ensure that assessments of quality are attentive to the needs of a diverse population. The multiple forms of discrimination described by women from diverse backgrounds reveal the need for all quality assessment initiatives to examine inequities in the quality of care. It is not enough to measure what percentage of the population is dissatisfied with the quality of care. Our findings show that it is important to ask how the quality of care varies by gender, race, class, language, abilities, and sexual orientation.

Competent Care Involves More than Technical Skills

In conventional quality assessments, high standards of care are often defined in terms of adherence to clinical practice guidelines. Have physicians conducted the appropriate diagnostic tests and administered the recommended treatments, according to the current level of medical knowledge? While clinical practice standards are important, the women in this study reminded us that there is more to competent care than technical skills. Competent care also requires social competence, the ability to communicate clearly and to respond with sensitivity to patients' and family members' feelings of fear, grief, distress, and anxiety which often accompany physical health problems. Quality improvement initiatives need to foster the development of social competencies so that health care providers can improve the level of compassionate and sensitive care and provide patients and their families with the support and information they need to manage their health problems.

The adherence to clinical standards could potentially lead to standardized responses to diverse situations. Women in the study reminded us of the importance of context, the need to tailor treatment to the particular needs and circumstances of individuals. Quality assessments need to provide room for flexibility in care in order to address the unique circumstances in each case.

The Value of Qualitative Research

This study demonstrates the value of using qualitative research evidence to deepen our understanding of the quality of care. Women's descriptions of their health care experiences revealed new dimensions of quality which are often overlooked in conventional quality assessments.

Most conventional quality assessments emphasize quantitative data, i.e. they monitor quality indicators which can be easily measured. While this information can be highly useful to track changes in performance over time, there is also an important contribution to be made by qualitative data. Qualitative research has been used to deepen the analysis of patient satisfaction surveys (Anderson, Barbara & Feldman, 2007). Qualitative data provides rich descriptions of the multidimensional interactions between patients and health care providers. Compared with the short, multiple choice responses that characterize patient satisfaction surveys, narrative accounts provide a fuller account of the consequences or outcomes of health care experiences.

Some of the dimensions of quality identified by the women in this study may be used to develop new quantitative quality indicators. But qualitative data is not only useful as a precursor to quantitative measures, it is also a rich source of insights and understandings which can be transferred from particular cases to other analogous situations. A rich description of quality problems encountered by one individual can sensitize health care providers and policymakers to the sometimes unintended consequences of their actions and decisions.

By providing women's descriptions of quality care in their own words, qualitative research can foster a deeper understanding of the multiple factors which influence the quality of care. Such information can be particularly useful in enabling policymakers, health care administrators, and physicians to see quality issues through women's eyes. By raising awareness of women's quality concerns, this study takes us one step closer to a health care system that is more responsive to women's needs as patients and as care providers.

Today there is a high level of concern over patient safety and the need to reduce the level of adverse events which cause harm to patients in care. Recent research has shown that hospital patients who have problems communicating with their health care providers are more likely to experience adverse events (Bartlett et al., 2008). Qualitative research which brings patients' voices to the foreground can help to identify patients' concerns and make barriers to good communication more visible. Such research could promote better communication by making health care providers more aware of patients' perspectives. And good communication is essential to patient safety.

By revealing dimensions of quality that are often overlooked, qualitative research can stimulate the development and use of better quality indicators. There appears to be some movement in this direction. For example, the U.S. National Healthcare Quality Report includes quality measures based on asking patients to assess "how often their provider listened carefully to them, explained things clearly, respected what they had to say, and spent enough time with them" (Agency for Healthcare Research and Quality, 2008, Chapter 5).

According to the 2008 Commonwealth Fund International Health Policy Survey of Sicker Adults, 86 percent of "sicker" Canadians rated the quality of care they received as good, very good or excellent, while 14 percent said that the quality of their care was either fair or poor. However, an overwhelming majority felt that the Canadian health care system needed fundamental changes (51 percent) or needed to be completely rebuilt (15 percent) (Health Council of Canada, 2009). While the overall quality rating is high, the high level of perceived need for fundamental changes suggests underlying quality concerns that need to be identified and addressed. Such results raise questions about the need for change, but do little to explain what kinds of changes patients seek.

By asking patients and care providers to explain their health care experiences, qualitative research can generate ideas for ways to improve the quality of care. Not only did women in this study identify important dimensions of quality, they also described numerous instances of poor quality care. By examining experiences of poor quality care, it is possible to gain a better understanding of the changes that are needed to improve quality.

Patient satisfaction survey results are usually reported as rates of satisfaction with the overall quality of care for the patient population as a whole. Asking for an overall assessment of quality tends to obscure important variations in the quality of care received. How can an overall satisfaction score convey the quality of care received by a woman whose concerns are initially dismissed and whose condition is misdiagnosed, but who eventually receives excellent treatment from health care providers who are respectful and attentive to her emotional as well as her physical needs? However, by asking patients and health care providers to describe the range of their experiences of quality care, it is possible to distinguish variations in the quality of care and to target areas for improvement.

Including Women in a Dialogue on Quality of Care

This research on women's perspectives on the quality of care is just one step. Hopefully, this paper will encourage other women to reflect on the quality of care they receive and to name the quality improvements they seek.

This study uncovered multiple meanings of quality of care. These suggest the need for an ongoing dialogue with diverse groups of patients, caregivers and front line health care workers in order to identify and respond to their concerns about the quality of health care. It is important that women be enabled to take a more active role in designing ways to assess and improve the quality of care.

Initiatives to improve the quality of care will benefit from a shared understanding of what quality care means to both patients and providers, and what it means to women and men.

A woman's perspective on the quality of health care is influenced by the circumstances of her life. Women living in rural and remote communities are more keenly aware of geographic barriers, while low-income women draw attention to financial barriers to care. Young women, older women, and women caring for children and elders have differing health care needs. Women who face discrimination because of their race, ethnicity, economic circumstances, language, sexuality or size encounter inequities in the quality of care. Women with disabilities face barriers to care that are often invisible to others. Women with chronic conditions, mental illness, addictions or other health problems have knowledge of the quality issues in those circumstances.

It is important to include a diversity of women's voices in discussions about health care. The aim of this paper is to share what some Canadian women have said about the quality of health care and to encourage other women to express their views to each other, to their health care providers, and to political decision-makers. By describing what the quality of care meant in their own lives, women in this study helped broaden our definition of the quality of care. They identified dimensions of quality which are often overlooked, yet which are crucial to improving the quality of care that matters to women.

While there is much to celebrate about Canada's health care system, clearly women have visions of a more accessible, comprehensive, and coordinated health care system in which health care providers have the time and skills to improve the quality of care. They also envision a health care system that is more respectful of women and more responsive to the needs of a diverse population.

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Additional Resources

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