Health Quality Ontario

The provincial advisor on the quality of health care in Ontario

Ontario Health Technology Assessment Series

Women's Experiences of Inaccurate Breast Cancer Screening Results: A Systematic Review and Qualitative Meta-synthesis

KEY MESSAGES

Breast cancer screening is the process of checking healthy women for signs of breast cancer, so it can be found, assessed, and treated early. No test is perfect, however, and more testing can lead to higher numbers of false-positive results—that is, women are told they may have cancer when they do not. Health Quality Ontario commissioned this review of research on how women feel when they get inaccurate results from breast cancer screening. It was part of a larger review of research into using ultrasound (a procedure that uses sound waves to image the breast) in addition to mammography (a low-dose x-ray), the usual method of breast cancer screening.

Women who have experienced a false-positive result felt anxious and worried. First, they were worried when they were told they needed to have more tests done. Then, even when the additional tests showed they did not have breast cancer, they felt anxious every time they were asked to be screened again.

Women with a high risk of developing breast cancer described even greater worry and fear. While waiting for more tests, they often thought about family members who had experienced or died from breast cancer. They feared they were also going to die.

Despite their anxiety, most women who had received a false-positive result were still willing to participate in breast cancer screening in the future. In fact, the experience made them want more screening.

On the other hand, women who had received a false-negative result—that is, they were told they did not have breast cancer when they really did—lost trust in mammography. Sometimes they met other women whose breast cancer had been found using mammography, so they believed that mammography screening could be beneficial for some women in the population, even though it did not find their cancer.

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ABSTRACT

Background

Adjunct screening with ultrasound has the potential to detect breast cancers that may not be visible on screening mammography. The use of adjunct ultrasonography is thought to be a safe and inexpensive approach to improving the sensitivity of screening with mammography alone, but potentially at the expense of increasing the rate of false-positive findings.

The objective of this review was to examine women's experiences of inaccurate breast cancer screening results and how they affect perceptions of breast cancer screening technologies.

Methods

This report synthesizes 16 primary qualitative studies, which together involved 690 participating women, to examine women's experiences of inaccurate breast cancer screening results. Qualitative meta-synthesis was used to integrate findings across primary research studies.

Results

The experience of a false-positive result caused short-term anxiety until the negative result was confirmed. It also led to reoccurring anxiety during future screening. The anxiety experienced in the face of a false-positive result was magnified in high-risk women, who often reflected on the previous breast cancer experiences of family members while awaiting further results.

Despite this increased anxiety, women who had experienced a false-positive result were generally not deterred from future screening. Rather, the experiences heightened their awareness of breast cancer and led to a desire for more examinations and more technologies.

Women who had experienced false-negative results struggled to restore trust in screening but recognized that some breast cancers were identified through mammography. They were willing to see themselves as exceptions to an otherwise beneficial service.

Conclusions

Qualitative studies provide some insight into how breast cancer screening inaccuracy affects women, including their faith in the screening technology. Although women suffered marked anxiety from experiencing false-positive mammography tests and loss of confidence from false-negative results, these feelings generally did not diminish women's belief in the value of mammography screening. In many cases, the experiences reinforced the importance of risk reduction as well as screening.

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BACKGROUND

Objective

The objective of this analysis was to examine women's experiences of inaccurate breast cancer screening results and how they affect perceptions of breast cancer screening technologies.

Breast Cancer Screening

Breast cancer screening is the regular examination of healthy, asymptomatic women's breasts to look for signs of breast cancer. The intent of breast screening programs is to identify tumours early in the diagnostic pathway to allow for timely and effective treatment. To be successful, a screening program should not only improve mortality (reduce deaths); it should also have a low rate of false-positive tests (results suggesting there may be cancer present when there is not), which can lead to unnecessary biopsies, treatment, and increased patient anxiety.

The primary method used for breast cancer screening is mammography, which involves the use of low-dose x-rays to image the breast. Mammography is currently the only screening tool for breast cancer that has been shown to reduce deaths related to breast cancer through early detection among average-risk women aged 50 to 74 years.¹

Adjunct (supplementary) screening with ultrasound has the potential to detect breast cancers that may not be visible on a mammogram. The use of adjunct ultrasound is thought to be a safe and inexpensive approach to improving the sensitivity of screening with mammography alone (i.e., the rate of true-positives), but potentially at the expense of increasing the rate of false-positive findings.

Research Questions

- What are women's experiences of inaccurate breast cancer screening results?
- What is the effect of a false-positive or false-negative result on women's perceptions of breast cancer screening technologies?

METHODS

Literature Search

Search Strategy

We performed literature searches for studies published from January 1, 2000, to June 30, 2015, on July 15, 2015, using Ovid MEDLINE, EBSCO Cumulative Index to Nursing and Allied Health Literature, and ISI Web of Science Social Sciences Citation Index. To identify qualitative research, we developed a qualitative hybrid filter by combining existing published qualitative filters.²⁻⁴ The filters were compared, and redundant search terms were deleted. We added exclusionary terms to the search filter that would be likely to identify quantitative research and reduce the number of irrelevant articles. We then applied the qualitative hybrid filter to the clinical search provided by Health Quality Ontario. Two authors reviewed titles and abstracts to determine eligibility. We obtained full-text articles when a review of titles and abstracts failed to yield enough information to determine eligibility.

Details of the literature search strategy are presented in the Appendix.

Inclusion Criteria

- English-language full reports
- Studies published online between January 1, 2000, and June 30, 2015
- Primary qualitative empirical research (using any descriptive or interpretive qualitative methodology, including the qualitative component of mixed-methods studies) and secondary syntheses of primary qualitative empirical research
- Studies involving adult women (> 18 years of age) with experience with breast cancer screening technologies (articles that included participants with and without experience were included)
- Published research work (no theses)
- Studies addressing the experience of receiving inaccurate breast cancer screening results

Exclusion Criteria

- Studies addressing topics other than breast cancer screening
- Studies that did not include women who had experience with breast cancer screening
- Studies labelled "qualitative" but that did not use a qualitative descriptive or interpretive methodology (e.g., case studies, experiments, or observational analyses using qualitative categorical variables)
- Quantitative research (i.e., using statistical hypothesis testing, using primarily quantitative data or analyses, or expressing results in quantitative or statistical terms)
- Studies that did not pose an empirical research objective or question or did not involve primary or secondary analysis of empirical data

Qualitative Analysis

We analyzed published qualitative research using techniques of integrative qualitative metasynthesis, ⁵⁻⁷ also known as qualitative research integration. Qualitative meta-synthesis summarizes research over a number of studies with the intent of combining findings from multiple articles. The objective of qualitative meta-synthesis is twofold: first, the aggregate of a result reflects the range of findings while retaining the original meaning; second, by comparing and contrasting findings across studies, a new integrative interpretation is produced.

A predefined topic and research question about the experience of receiving inaccurate breast cancer screening results guided the research collection, data extraction, and analysis. We defined topics in stages as relevant literature was identified, and corresponding evidence-based analyses proceeded. First, all qualitative research relevant to the condition under analysis was retrieved. Next, a specific research question regarding the experience of receiving inaccurate breast cancer screening results was chosen, and a final search was performed to retrieve articles relevant to this question. The analysis in this report includes articles that addressed the issue of how women experience breast cancer screening inaccuracies.

Data extraction focused on, and was limited to, findings that were relevant to this research topic. Qualitative findings are the "data-driven and integrated discoveries, judgments, and/or pronouncements researchers offer about the phenomena, events, or cases under investigation." In addition to the researchers' findings, we also extracted original data excerpts (participant quotes, stories, or incidents) to illustrate or communicate specific findings.

Using a staged coding process similar to that of grounded theory, ^{8,9} findings were broken into their component parts (key themes, categories, concepts) and then regrouped across studies and related to each other thematically. This allowed us to organize and reflect on the full range of interpretative insights across the body of research.^{6,10} We used a "constant comparative" and iterative approach, in which preliminary categories were repeatedly compared with the research findings, raw data excerpts, and co-investigators' interpretations of the studies.

Quality of Evidence

For valid epistemological reasons, the field of qualitative research lacks consensus on the importance of, and methods/standards for, critical appraisal of research quality. ¹¹ Qualitative health researchers conventionally under-report procedural details, and the quality of findings tends to rest more on the conceptual prowess of the researchers than on methodological processes. ^{7,11} Theoretically sophisticated findings are promoted as a marker of study quality because they make valuable theoretical contributions to social science academic disciplines. ¹² However, theoretical sophistication is not necessary to contribute potentially valuable information to a synthesis of multiple studies, or to inform questions posed by the interdisciplinary and interprofessional field of health technology assessment. Qualitative metasynthesis researchers typically do not exclude qualitative research on the basis of independently appraised "quality." This approach is common to multiple types of interpretive qualitative synthesis. ^{5,6,12-15}

For this review, we presumed the academic peer review and publication processes eliminated scientifically unsound studies, according to current standards. Beyond this, we included all topically relevant, accessible, and published research using any qualitative interpretive or descriptive methodology. We appraised the value of the research findings solely in terms of their

relevance to the research question and illustrative data excerpts that supported the authors' findings.

Results of Literature Search

The bibliographic database search yielded 5,875 citations published between January 1, 2000, and June 30, 2015 (with duplicates removed). Articles were excluded based on information in the title and abstract; two reviewers reviewed all titles and abstracts to confine the database to primary qualitative research articles eligible according to the criteria listed above. Figure 1 shows the breakdown of when and for what reason citations were excluded from the analysis.

Sixteen studies met the inclusion criteria. Studies were conducted in Australia and New Zealand (n = 4), Europe (n = 6), the United States (n = 4), and Canada (n = 2). Methodologies varied, with a significant number of studies using unspecified methods beyond a generic description of thematic analysis (n = 12). The 16 included studies incorporated data from 690 women, including 218 with experience with breast cancer screening, 443 women with varying levels of participation in screening, and 29 women identified by the study authors as high-risk. Women were identified as being at high risk for developing breast cancer if they had a family history of breast cancer 16,17 or had individual genetic susceptibilities. 17

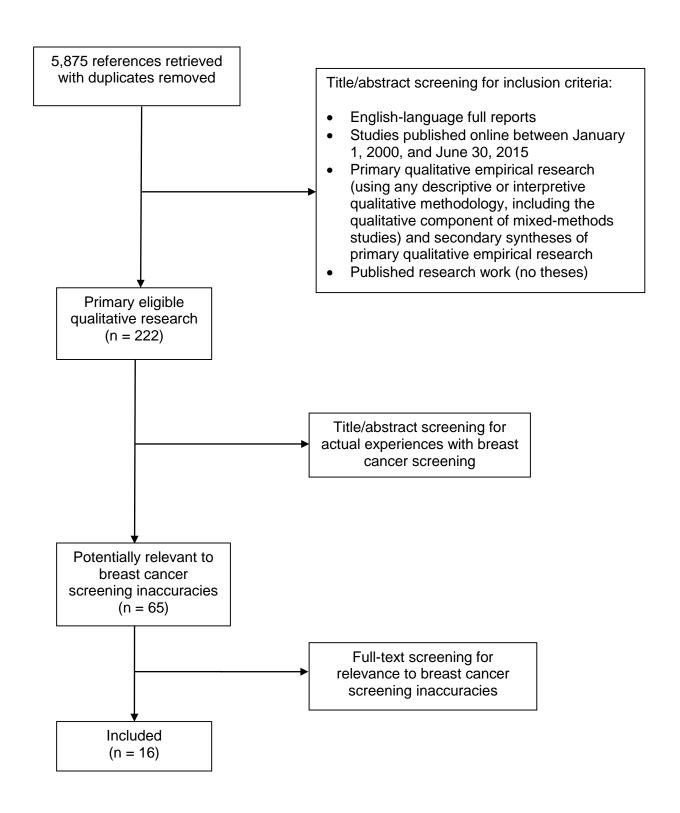


Figure 1: Citation Flow Chart

For each included study, we identified the study design, location, and the type and number of participants. This information is summarized in Tables 1, 2, and 3.

Table 1: Body of Evidence Examined According to Study Design

Study Design	Number of Eligible Studies
Grounded theory or constant comparative analysis	2
Other (framework analysis, hermeneutic approach)	2
Qualitative (otherwise unspecified)/thematic analysis	12
Total	16

Table 2: Body of Evidence Examined According to Study Location

Study Location	Number of Eligible Studies
Australia/New Zealand	4
Canada (not Ontario)	1
Europe	6
Ontario	1
United States	4
Total	16

Table 3: Body of Evidence Examined According to Type and Number of Participants

Type of Participant	Number of Participants
Women with high risk for breast cancer	29
Women with varying levels of participation in screening	443
Women with experience in screening	218
Total	690

RESULTS

The Effect of a False-Positive Screening Result

Anxiety: Short-Term and Long-Term

Patients in many studies described heightened feelings of anxiety and worry in the face of a false-positive breast cancer screening result. First, there was immediate anxiety in the interval before the positive result was deemed to be false. Women described feelings of anxiety, concern, fear, and shock when they learned that there was an abnormal finding in their screening test. 16,17,19-21 Time seemed to pass slowly as they waited for further testing, and the anxiety increased when there was a delay in receiving test results. One study noted that women used coping mechanisms to control the uncertainty they felt while waiting, such as disclosing the information to close friends, choosing not to inform their children, or using the time to organize their affairs.

In addition to the relatively short-term anxiety experienced in the wake of a false-positive test result, women described lasting uncertainty that was particularly triggered by future screening rounds. 19,22

In high-risk women, these feelings of anxiety are magnified. ^{16,17,19} Women with family members who had experienced breast cancer faced being recalled for further testing with negative expectations about the outcome. ^{19,24} They perceived the recall letter as a "death sentence." ¹⁹ During the wait for further testing, they reflected on family members' experiences with breast cancer ^{16,17,19} and had thoughts about cancer deaths in their families and their own possible deaths. ¹⁹

Lasting Effects of the False-Positive Experience

One study noted the changes in women's perceptions of life, their health, and breast cancer in the aftermath of a false-positive experience. Women viewed the outcome of further tests establishing that the initial result was false as an "acquittal," and they perceived mammography as a "saviour." Interestingly, they did not comment on the paradox that rather than freeing them from anxiety, screening technology had introduced the anxiety into their lives. 19

Some women felt that the anxiety caused by the false-positive experience had made them more appreciative of life.¹⁹ In addition, the experience increased their awareness of the possibility of developing breast cancer.^{19,22} They paid more attention to information about healthy lifestyles and increased their breast self-examinations.^{19,22}

Trust in Technology After a False-Positive Experience

Most women who had experienced a false-positive result were not deterred from future screening. Instead, the uncertainty following a false-positive experience seemed to create a desire and need for more screening. Women felt that the screening gave them a sense of safety and reassurance, despite the fact that they had experienced a false-positive result that in some cases had led to invasive diagnostic procedures. Many women described false-positives as an acceptable risk of the screening technology. However, a small number of women noted that the experience of a false-positive result did deter them from future screening.

The Effect of a False-Negative Screening Result

Trust in Technology After a False-Negative Experience

One study described the experiences of women who had received a false-negative result—indicating they did not have cancer when in fact they did—and its relation to mammography screening. Women who had experienced a false-negative screening result lost trust in the technology and felt that it had failed them. Some women were surprised that their breast cancer had not been detected by mammography screening; they expected that mammography would find all breast cancer. The distrust they described was not extended to all screening technologies; indeed, rather than avoiding breast cancer screening technologies, they looked for solutions through more examinations and more technology. Ultrasound was perceived as safer and more trustworthy than mammography, and some women suggested that it should be offered to all women undergoing breast cancer screening.

Some women suggested that experts might show too much trust in mammographic images and neglect women's own interpretations of their symptoms.²³

Losing trust in the benefits of mammography screening for themselves did not necessarily imply that they had lost trust in mammography screening at the population level. Some women had met others, for example through support groups, whose cancer had been discovered through mammography.²³ In addition to such personal encounters, women in the study were aware of the statistics indicating that mammography improved survival rates from breast cancer. Therefore, despite feeling that the technology had failed them, they acknowledged that it might be beneficial at the population level.²³

Interestingly, all women who had experienced a false-negative test result indicated that they would continue to participate in mammography screening when they were transferred back to the screening program after 10 years of follow-up.²³ However, some said that they would have a more guarded attitude towards it.²³

Limitations

Qualitative research provides theoretical and contextual insights into the experiences of limited numbers of people in specific settings. Qualitative research findings are not intended to generalize directly to populations, although meta-synthesis across a number of qualitative studies builds an increasingly robust understanding that is more likely to be transferable. While qualitative insights are robust and often enlightening for understanding experiences and planning services in other settings, the findings of the studies reviewed here—and of this synthesis—do not strictly generalize to the Ontario (or any specific) population. This evidence must be interpreted and applied carefully, in light of expertise and the experiences of the relevant community.

CONCLUSIONS

The experience of a false-positive test caused short-term anxiety that began when women were notified of an abnormal result and continued until further tests established that the result was false. The distress was magnified in women at high risk of breast cancer. The anxiety experienced in the face of a false-positive result also led to reoccurring anxiety during future screening.

Despite their increased anxiety, women who had had a false-positive test were generally not deterred from future screening. Women who had experienced a false-negative test struggled to restore trust in screening, but they were generally willing to see themselves as exceptions to an otherwise beneficial service.

APPENDIX: LITERATURE SEARCH STRATEGIES

Hybrid Filter: Ovid MEDLINE

- 1. Interviews+
- 2. (theme\$ or thematic).mp.
- 3. qualitative.af.
- 4. Nursing Methodology Research/
- 5. questionnaire\$.mp.
- 6. ethnological research.mp.
- 7. ethnograph\$.mp.
- 8. ethnonursing.af.
- 9. phenomenol\$.af.
- 10. (grounded adj (theor\$ or study or studies or research or analys?s)).af.
- 11. (life stor\$ or women* stor\$).mp.
- 12. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or (data adj1 saturat\$).tw. or participant observ\$.tw.
- 13. (social construct\$ or (postmodern\$ or post- structural\$) or (post structural\$ or poststructural\$) or post modern\$ or post-modern\$ or feminis\$ or interpret\$).mp.
- 14. (action research or cooperative inquir\$ or co operative inquir\$ or co- operative inquir\$).mp.
- 15. (humanistic or existential or experiential or paradigm\$).mp.
- 16. (field adj (study or studies or research)).tw.
- 17. human science.tw.
- 18. biographical method.tw.
- 19. theoretical sampl\$.af.
- 20. ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.
- 21. (account or accounts or unstructured or open-ended or open ended or text\$ or narrative\$).mp.
- 22. (life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp
- 23. (lived or life adj experience\$.mp
- 24. cluster sampl\$.mp.
- 25. observational method\$.af.
- 26. content analysis.af.
- 27. (constant adj (comparative or comparison)).af.
- 28. ((discourse\$ or discurs\$) adj3 analys?s).tw.
- 29. narrative analys?s.af.
- 30. heidegger\$.tw.
- 31. colaizzi\$.tw.
- 32. spiegelberg\$.tw.
- 33. (van adj manen\$).tw.
- 34. (van adj kaam\$).tw.
- 35. (merleau adj ponty\$).tw
- 36. .husserl\$.tw
- 37. foucault\$.tw.
- 38. (corbin\$ adj2 strauss\$).tw
- 39. glaser\$.tw.

Hybrid Filter: EBSCO Cumulative Index to Nursing & Allied Health Literature (CINAHL)

- 1. Interviews+
- 2. MH audiorecording
- 3. MH Grounded theory
- 4. MH Qualitative Studies
- 5. MH Research, Nursing
- 6. MH Questionnaires+
- 7. MH Focus Groups (12639)
- 8. MH Discourse Analysis (1176)
- 9. MH Content Analysis (11245)
- 10. MH Ethnographic Research (2958)
- 11. MH Ethnological Research (1901)
- 12. MH Ethnonursing Research (123)
- 13. MH Constant Comparative Method (3633)
- 14. MH Qualitative Validity+ (850)
- 15. MH Purposive Sample (10730)
- 16. MH Observational Methods+ (10164)
- 17. MH Field Studies (1151)
- 18. MH theoretical sample (861)
- 19. MH Phenomenology (1561)
- 20. MH Phenomenological Research (5751)
- 21. MH Life Experiences+ (8637)
- 22. MH Cluster Sample+ (1418)
- 23. Ethnonursing (179)
- 24. ethnograph* (4630)
- 25. phenomenol* (8164)
- 26. grounded N1 theor* (6532)
- 27. grounded N1 study (601)
- 28. grounded N1 studies (22)
- 29. grounded N1 research (117)
- 30. grounded N1 analys?s (131)
- 31. life stor* (349)
- 32. women's stor* (90)
- 33. emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$ (2305)
- 34. data N1 saturat* (96)
- 35. participant observ* (3417)
- 36. social construct* or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or interpret* (25187)
- 37. action research or cooperative inquir* or co operative inquir* or co-operative inquir* (2381)
- 38. humanistic or existential or experiential or paradigm* (11017)
- 39. field N1 stud* (1269)
- 40. field N1 research (306)
- 41. human science (132)
- 42. biographical method (4)
- 43. theoretical sampl* (983)
- 44. purpos* N4 sampl* (11299)
- 45. focus N1 group* (13775)
- 46. account or accounts or unstructured or open-ended or open ended or text* or narrative* (37137)

- 47. life world or life-world or conversation analys?s or personal experience* or theoretical saturation (2042)
- 48. lived experience* (2170)
- 49. life experience* (6236)
- 50. cluster sampl* (1411)
- 51. theme* or thematic (25504)
- 52. observational method* (6607)
- 53. questionnaire* (126686)
- 54. content analysis (12252)
- 55. discourse* N3 analys?s (1341)
- 56. discurs* N3 analys?s (35)
- 57. constant N1 comparative (3904)
- 58. constant N1 comparison (366)
- 59. narrative analys?s (312)
- 60. Heidegger* (387)
- 61. Colaizzi* (387)
- 62. Spiegelberg* (0)
- 63. van N1 manen* (261)
- 64. van N1 kaam* (34)
- 65. merleau N1 ponty* (78)
- 66. husserl* (106)
- 67. Foucault* (253)
- 68. Corbin* N2 strauss* (50)
- 69. strauss* N2 corbin* (88)
- 70. glaser* (302)

Hybrid Filter: ISI Web of Science, Social Science Citation Index

- 1. TS=interview*
- 2. TS=(theme*)
- 3. TS=(thematic analysis)
- 4. TS=qualitative
- 5. TS=nursing research methodology
- 6. TS=questionnaire
- 7. TS=(ethnograph*)
- 8. TS= (ethnonursing)
- 9. TS=(ethnological research)
- 10. TS=(phenomenol*)
- 11. TS=(grounded theor*) OR TS=(grounded stud*) OR TS=(grounded research) OR TS=(grounded analys?s)
- 12. TS=(life stor*) OR TS=(women's stor*)
- 13. TS=(emic) OR TS=(etic) OR TS=(hermeneutic) OR TS=(heuristic) OR TS=(semiotic) OR TS=(data saturat*) OR TS=(participant observ*)
- 14. TS=(social construct*) OR TS=(postmodern*) OR TS=(post structural*) OR TS=(feminis*) OR TS=(interpret*)
- 15. TS=(action research) OR TS=(co-operative inquir*)
- 16. TS=(humanistic) OR TS=(existential) OR TS=(experiential) OR TS=(paradigm*)
- 17. TS=(field stud*) OR TS=(field research)
- 18. TS=(human science)
- 19. TS=(biographical method*)

- 20. TS=(theoretical sampl*)
- 21. TS=(purposive sampl*)
- 22. TS=(open-ended account*) OR TS=(unstructured account) OR TS=(narrative*) OR TS=(text*)
- 23. TS=(life world) OR TS=(conversation analys?s) OR TS=(theoretical saturation)
- 24. TS=(lived experience*) OR TS=(life experience*)
- 25. TS=(cluster sampl*)
- 26. TS=observational method*
- 27. TS=(content analysis)
- 28. TS=(constant comparative)
- 29. TS=(discourse analys?s) or TS =(discurs* analys?s)
- 30. TS=(narrative analys?s)
- 31. TS=(heidegger*)
- 32. TS=(colaizzi*)
- 33. TS=(spiegelberg*)
- 34. TS=(van manen*)
- 35. TS=(van kaam*)
- 36. TS=(merleau ponty*)
- 37. TS=(husserl*)
- 38. TS=(foucault*)
- 39. TS=(corbin*)
- 40. TS=(strauss*)
- 41. TS=(glaser*)

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About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians.**

Who We Are.

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

What We Do.

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voice of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

Why It Matters.

We recognize that, as a system, we have much to be proud of, but also that it often falls short of being the best it can be. Plus certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.

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About the Ontario Health Technology Advisory Committee (OHTAC)

About OHTAS

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