Cancer screening behaviours among South Asian immigrants in the UK, US and Canada: a scoping study

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ABSTRACT

South Asian (SA) immigrants settled in the United Kingdom (UK) and North America [United States (US) and Canada] have low screening rates for breast, cervical and colorectal cancers. Incidence rates of these cancers increase among SA immigrants after migration, becoming similar to rates in non-Asian native populations. However, there are disparities in cancer screening, with low cancer screening uptake in this population. We conducted a scoping study using Arksey & O'Malley's framework to examine cancer screening literature on SA immigrants residing in the UK, US and Canada. Eight electronic databases, key journals and reference lists were searched for English language studies and reports. Of 1465 identified references, 70 studies from 1994 to November 2014 were included: 63% on breast or cervical cancer screening or both; 10% examined colorectal cancer screening only; 16% explored health promotion/service provision; 8% studied breast, cervical and colorectal cancer screening; and 3% examined breast and colorectal cancer screening. A thematic analysis uncovered four dominant themes: (i) beliefs and attitudes towards cancer and screening included centrality of family, holistic healthcare, fatalism, screening as unnecessary and emotion-laden perceptions; (ii) lack of knowledge of cancer and screening related to not having heard about cancer and its causes, or lack of awareness of screening, its rationale and/or how to access services; (iii) barriers to access including individual and structural barriers; and (iv) gender differences in screening uptake and their associated factors. Findings offer insights that can be used to develop culturally sensitive interventions to minimise barriers and increase cancer screening uptake in these communities, while recognising the diversity within the SA culture. Further research is required to address the gap in colorectal cancer screening literature to more fully understand SA immigrants' perspectives, as well as research to better understand gender-specific factors that influence screening uptake.

Key words: access to healthcare, cancer prevention and control, ethnic minorities, ethnicity and health, screening, South Asian

Bullets Section

What is known about this topic?

- Over time, South Asian immigrants who settle in western countries have similar rates of cancer incidence for breast, cervical and colorectal cancers as native-born populations. Population-based breast, cervical and colorectal cancer screening is recommended for early detection. Yet, disparities in screening uptake among South Asian immigrants persist.

- An understanding of the sociocultural context influencing cancer screening uptake is needed to develop effective programmes to improve cancer screening rates among South Asian immigrants.

What this paper adds?

- An examination of the sociocultural context of South Asian immigrants' beliefs and attitudes towards cancer screening elucidated the need to consider family and holistic beliefs in the development of health-promoting messages; to increase knowledge about risk factors and cancer screening benefits; and to address health system barriers to increase screening uptake.

- Public health and cancer care practitioners should involve South Asian immigrants in the development of community-based programming to address local needs with the aim of increasing screening uptake.

- There is limited evidence about factors influencing uptake of (or participation in) colorectal cancer screening including gender-specific factors among South Asian immigrants.

Introduction

Access to health services has been the focus of almost four decades of research, policy and practice (Aday & Andersen 1974, Andersen 1995, Gulliford *et al.* 2002, Bierman & Dunn 2006, Gulliford 2009). Canada's

universal healthcare coverage removes financial barriers to access; yet, some Canadian studies have shown different patterns of utilisation between men and women (Kazanjian *et al.* 2004, Drapeau *et al.* 2009, Reid *et al.* 2009, Bierman *et al.* 2010, Nie *et al.* 2010). Furthermore, utilisation may differ among men and women of different ages, socioeconomic backgrounds and rural/urban residency (Bergeron & Senn 2003, Reid *et al.* 2009, Bierman *et al.* 2010, Marshall *et al.* 2010). Evidently, in the process of seeking care from the same health services, people may encounter different problems; however, as many studies focus on utilisation of services, they cannot identify the mechanisms and work involved in gaining access (Sanmartin & Ross 2006, Mooney 2009).

Access has been more recently conceptualised in terms of the freedom to use health services within dimensions of availability, affordability and acceptability (Thiede 2005, Thiede & McIntyre 2008). This approach emphasises the degree of fit between the services on offer (supply) and the needs of consumers (demand), and it places emphasis on relations of access, based on socially structured interactions between healthcare services and consumers (McIntyre *et al.* 2009). Furthermore, this relational view maps on to realist theories that emphasise the interplay between individual agency and social structures (Archer 2003). In the realist view, situated barriers, constraints and resources are activated in the formulation of an intention to pursue a goal (such as seeking healthcare), and these barriers, constraints and resources are embedded within sociopolitical contexts (Archer 2003). Thus, social structural factors do not directly determine the health of individuals, but create the conditions that constrain or facilitate health-seeking activities. This means that the tactics devised by individuals to overcome or reconsider obstacles to access are of great interest to researchers (Angus *et al.* 2006, Clark *et al.* 2008).

In Canada, the publicly funded healthcare system is composed of ten provincial and three territorial health insurance plans. All of the plans are based on the principle of universal coverage for medically necessary hospital and physician services, to be provided on the basis of need, rather than the ability to pay. However, the provinces have different definitions of 'medically necessary services' and different proportions of public funds are allocated to healthcare expenditures (Deber 2003). Recently, fiscal pressures on some provincial budgets resulted in cost-restructuring 'reforms' that have changed opportunities for access to certain health services (Armstrong & Armstrong 2010). For example, over the past decade in Ontario, two cost-containment strategies involved changing the

location of service delivery from hospital settings to the community and reducing the list of insured services, such as physiotherapy and routine eye examinations (Landry *et al.* 2006, Paul *et al.* 2008). Community-based home health services were subject to 'managed competition', tendering of contracts to lowest bidders and tightening of eligibility requirements for public funding (Baranek *et al.* 1999, Daly 2007). These changes have had direct health consequences for those who lack additional private insurance or have low incomes (Paul *et al.* 2008, Armstrong & Armstrong 2010).

Women's access to healthcare was one focus of The Project for an Ontario Women's Health Evidence-Based Report (POWER) (Bierman *et al.* 2010). The POWER study, which used data from 2002 to 2008, drew on a comprehensive set of quantitative evidence-based indicators to evaluate gender and socio-economic differences in utilisation of primary care, care for chronic disease and specialised services and home care, as well as barriers to access. The indicators used were selected after an extensive review of existing databases, as well as input and agreement from experts in the field. However, community consultants encouraged the team to also study women's life *contexts* and the *activities* of obtaining healthcare. As qualitative research can help explore how individual people must act to circumvent challenges to health services access, the POWER study of access indicators was combined with a qualitative meta-synthesis to better understand the phenomenon of women's access to healthcare in Ontario. The meta-synthesis encompassed literature from the same 2002–2008 period of the larger POWER study.

Two main questions guided the meta-synthesis:

1 How do the reviewed studies describe the conditions under which women engage with the healthcare system in Ontario?
2 How do these studies describe women's agency in engaging with the healthcare system in Ontario?

In answer to the first question, the meta-synthesis indicated that women's access to healthcare is shaped by four major, sometimes opposing forces or mechanisms: (i) contextual conditions; (ii) constraints; (iii) barriers; and (iv) deterrents (Angus *et al.* 2013). In effect, these forces combined to push, pull, obstruct and/or even repel women's efforts as they sought to access health services. Furthermore, the synthesised studies also indicated that some women encountered combinations of two or more of these forces when seeking care for health needs.

This paper focuses on the second question guiding the meta-synthesis. We found that, despite the reported challenges to accessing care, there was

considerable evidence that women expended some effort and devised strategies to access healthcare. We conclude with suggestions about the implications of these findings for policy development for health and social care.

Methods and materials

Systematic search strategy

With input from a health services librarian specialist, MEDLINE, CINAHL, PsycInfo, Social Sciences Abstracts, Web of Science, Scopus, Gender Studies and LGBT Life databases were searched for qualitative studies published from 2002 to 2008, which align with the timing of the POWER study. To update the review, the same search was later repeated for the years 2008 to 2010. The keywords and terms represented broad topics related to access (e.g. 'health services accessibility,' 'health services for the indigent,' 'healthcare delivery,' 'health services misuse' and 'access'), groups of women (e.g. 'marginalized,' 'disadvantaged,' 'aged,' 'homeless,' 'youth,' 'lesbian' and 'immigrant') and regions of Ontario (e.g. 'rural health,' 'urban health,' 'medically underserved area' and 'remote'). Terms to capture qualitative enquiry were also used (e.g. 'qualitative research,' 'focus groups,' 'ethnographic,' 'grounded theory' and 'interviews'). Additional studies were located by crosschecking with reference lists of relevant articles and through suggestions from POWER study stakeholders and colleagues.

Inclusion/exclusion criteria

In the first search, a total of 194 abstracts were retrieved, 38 of which were duplicates. In the second search, 104 abstracts were retrieved, 36 of which were duplicates. In both searches, the abstracts were screened against the following inclusion criteria: (i) use of qualitative design; (ii) published in peer-reviewed journals between January 2002 and December 2010; (iii) sample recruited at least partially in Ontario; (iv) women participants; (v) English language studies; (vi) studies approved by ethical review boards. Mixed-method studies with detailed discussion of a qualitative component were eligible for inclusion. The second and third authors screened any abstracts that were in question. Seventy-one abstracts met the inclusion criteria, and the articles were retrieved and appraised.

Appraisal of included articles

Across both searches, 89 research reports were removed from the set after the initial screening process

because they (i) reported on mixed-method studies and included insufficient detail about the qualitative methods and findings; (ii) included both men and women, but pooled findings and hence gender differences were not analysed; or (iii) did not include any people from Ontario. Articles that included substantial sections on access to healthcare, but had a central focus on another topic, were also included in the set.

In the first search, the remaining 37 articles were read, reviewed and scored independently by two of three reviewers, the second, third and fourth authors, using the Critical Appraisal Skills Program tool for qualitative research (National Health Service 2006). Although the form was not designed to assign numeric scores to research articles, we initially adapted it by assigning points to each section to make a total of ten.

The two scores from the reviewer pairs were then compared and they were consistent between reviewer pairs. Following Malpass *et al.* (2009), we ultimately chose to score all relevant articles into three groups: key articles (KA) rigorous research that offered substantial depth to the synthesis; satisfactory articles (SA) rigorous research that contributed to the synthesis; or as unsatisfactory articles (US) that did not offer sufficient detail to assess rigour (see Figure 1 for
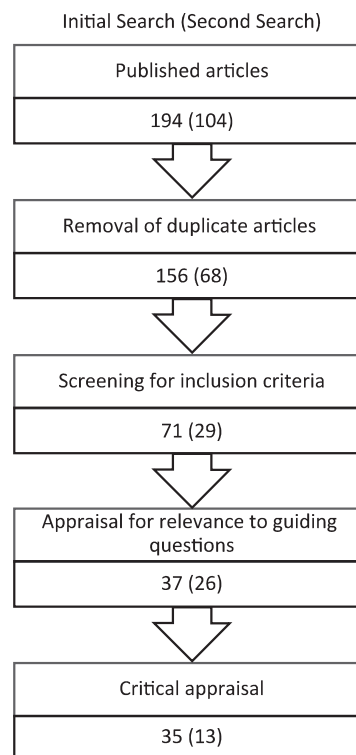
Figure 1 Systematic search strategy.

summary of article selection). In the second search, the first, second and fourth authors reviewed the remaining 13 articles for eligibility and scored them as KA, SA or US following the criteria used in the first search.

Synthesis process

To answer the second research question, each of the selected articles was carefully read, re-read and annotated to identify concepts, phrases and metaphors that addressed women's agency. The first and second authors compared key results across studies and developed a coding scheme that iteratively evolved over the process of reviewing the entire set of articles. Codes and their definitions were developed through discussion and consensus. The fifth and sixth authors reviewed and verified the codes and definitions. Corresponding segments of text from each article were imported into NVivo and were coded using this scheme. The results of this analysis are reported in this paper.

Findings

Description of included studies

The included studies offered a diverse sample of women from urban, suburban and rural areas of Ontario. Demographics included women at various stages of the lifespan (adolescent, young adult, recent mothers, middle-aged and older), a range of economic circumstances (low-income, homeless, middle-class, self-employed) and multiple social identities (immigrant, lesbian, people with disability, racialised). Women with a number of acute health problems were represented, but many studies also examined access to care for chronic health problems, illness prevention and health promotion.

We found three major themes that highlighted women's agency in responding to issues encountered when seeking access to healthcare. These themes included (i) mobilising resources; (ii) living out shortfalls; and (iii) avoiding illness and maintaining health, as diagrammed with their respective sub-themes in Figure 2. Table S1 summarises the key themes evident in each study.

Mobilising resources
Across studies, women faced disparities by using available resources to facilitate access to healthcare. Effort was required to mobilise the following types of resources: (i) financial; (ii) social; and (iii) interpersonal.
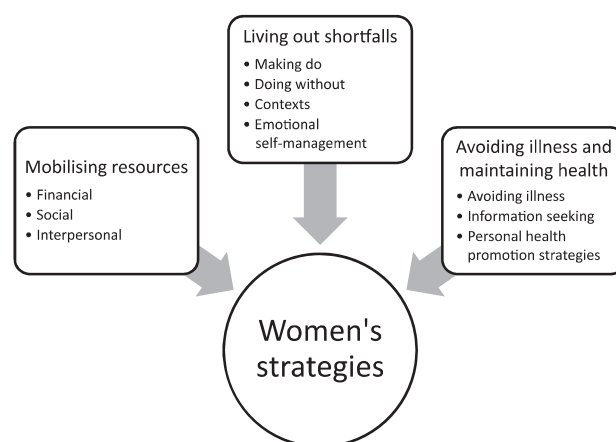
Figure 2 Key themes.

Mobilising financial resources. Women in some studies drew on financial resources to bridge gaps in their access to healthcare. The need to pay for services to bridge gaps was noted by researchers studying a number of contexts: women who relied on home-care services for which public funding was rapidly decreasing had to pay for their care needs out of pocket (Bethune-Davies *et al.* 2006); women who did not have supplementary health and dental insurance provided through an employer had to cover additional drug and dental costs (Bates 2004); and those receiving cancer care had to pay for incidental care costs – anti-nausea pills, travel and transportation, telephone calls from treatment clinics – that were not covered by Ontario's public health insurance plan (Gould 2004, Gray *et al.* 2004, Gould *et al.* 2009). Women living in rural areas experienced similar 'costs' for travelling long distances to obtain healthcare services (Leipert *et al.* 2008, Sutherns & Bourgeault 2008), as did women seeking cardiac rehabilitation services (Rolfe *et al.* 2010).

Some authors explained that women used financial resources to manage their health in other ways, such as purchasing gym equipment for home use in cardiac rehabilitation (Caldwell *et al.* 2005). In one study, immigrant women travelled back to their countries of origin to access care, such as dental work, which was too expensive and involved waiting periods in Canada (Ahmad *et al.* 2004b). Finally, in some studies, women reported paying for complementary and/or alternative forms of medicine and healthcare (Ahmad *et al.* 2004b, Wathen & Harris 2007, Leipert *et al.* 2008).

However, not all women had financial resources to cover healthcare gaps. Indeed, poverty and homelessness were identified in our previous review as a contextual condition affecting women's health as well

as a constraining force to accessing healthcare (Angus et al. 2013). Participants in several studies reported that they could not afford to pay to cover their healthcare access gaps, a discussion we return to later in the section Living out shortfalls.

Mobilising social contacts. Women's social networks helped them to manage gaps in healthcare by offering (i) health information; (ii) assistance with activities of daily life; and (iii) emotional support. First, women drew on social networks to seek and receive health information from their friends and families (Friedman & Hoffman-Goetz 2003, Ahmad et al. 2004a,b, Wathen & Harris 2007, Thomson & Hoffman-Goetz 2009); in fact, English-speaking children could become important facilitators to healthcare access for non-English-speaking mothers (Guruge et al. 2009, Thomson & Hoffman-Goetz 2009). Social contacts could also function to socialise and acculturate women, providing information about health and safety in new situations, such as childbirth (Sword 2003, Cooper-Brathwaite & Williams 2004, Sutton et al. 2007); making treatment decisions about hysterectomies (Uskul et al. 2003); or managing homelessness (Reid et al. 2005).

Second, women turned to their friends and families for help with activities of daily living, such as shopping, housework and transportation (Bethune-Davies et al. 2006, Casey & Stone 2010, Greene et al. 2010). Other women described community collaboration to provide support, such as fundraising to help pay for transportation costs to urban treatment centres, or organising a nutritious food purchasing programme in a lower income apartment building (Odette et al. 2003, Leipert & George 2008).

Third, social networks provided emotional support. Women from diverse sociodemographic backgrounds and health conditions could talk, share experiences and find a safe place to disclose feelings and concerns with others in similar circumstances (Ross et al. 2003, Sword 2003, Gray et al. 2004, Reid et al. 2005, Ahmed et al. 2008). Emotional support was shown to have tangible benefits; for instance, helping to alleviate mental health issues (Ross et al. 2003, Ahmad et al. 2004b, Ahmed et al. 2008); providing a source of pride (Bethune-Davies et al. 2006); or reducing need for medication during childbirth (Cooper-Brathwaite & Williams 2004).

However, complications arose when women relied on social contacts for help in accessing healthcare. First, women's discussions of their social networks suggested that not all people had the necessary insight or expertise in certain areas. Especially valued were people with specific knowledge or experiences,

such as longer residence in Canada (Ahmad et al. 2004a); similar cultural backgrounds (Sutton et al. 2007); or experience with the same health problem (Uskul et al. 2003, Barnoff et al. 2005, Sutton et al. 2007, Wathen & Harris 2007, Ahmed et al. 2008, Rolfe et al. 2010). Informative sources had to be carefully selected.

Second, dependence on one's social network for assistance created personal risk. Many women who sought help from family and friends – mainly older women with chronic and/or disabling conditions, or those in treatment for a disease – feared becoming a burden upon their social networks (Sinding et al. 2005, Aronson 2006, Bethune-Davies et al. 2006, Casey & Stone 2010). Relying on family and friends for support could have a detrimental effect on self-worth: 'it destroys your self-esteem' (Bethune-Davies et al. 2006, p. 212). The reluctance to burden friends and family could influence treatment decisions, as in the case of older women with cancer who opted against aggressive treatment to avoid dependence on family and friends for care (Gray et al. 2004, Sinding et al. 2005). On the other hand, it appeared that social networks of women in rural settings were happy to provide support to others, 'without the expectation of recognition or acclaim' (Leipert & George 2008, p. 215). The dynamics of this issue are explored further in the Discussion section.

Reliance on social networks resulted in two further complications. Some women could lose their valued support networks; for instance, rural women connected with other women in urban treatment centres, but lost those connections when they returned home (Gray et al. 2004), and immigrant women lost important sources of social support when they left their countries of origin (Ahmad et al. 2004a). Finally, there was also potential for misinformation to be transmitted through trusted social contacts (Uskul et al. 2003, Sutton et al. 2007).

Mobilising interpersonal skills. Across a number of studies, women used interpersonal skills to accomplish three objectives: (i) 'taking charge' to respond to care they perceived as inadequate; (ii) negotiating arrangements for healthcare; and (iii) finding and forging supportive relationships with healthcare and allied health practitioners.

First, women across some studies described 'taking charge' (Sword 2003, p. 329) to improve the care they received. Women 'took charge' in a variety of ways. For instance, home-care recipients taught their workers to do chores, such as cooking a nutritious meal or laundering delicate clothing (Aronson 2003, 2006) and they also self-advocated for adaptations to

services (Aronson 2006). In other cases, women questioned the credibility of their healthcare providers, or sought other providers, when interpersonal communication or quality of care seemed unsatisfactory (Friedman & Hoffman-Goetz 2003, Sword 2003, Wathen & Harris 2007). Some women scheduled procedures (and, indeed, childbirth) during times they knew transportation, optimal care and providers would be available (Sutherns 2004, Sutherns & Bourgeault 2008). Non-English-speaking women also 'took charge' by learning English as a means to better access healthcare and to advocate on their own behalf (Guruge *et al.* 2009). Self-employed women negotiated private insurance coverage in creative ways, like bargaining with clients to be added onto their insurance plans (Bates 2004).

Second, some women reported actively negotiating decisions with their physicians, by acquiring information and enquiring about treatment options (Uskul *et al.* 2003, Wathen & Harris 2007), choosing against (or seeking alternatives to) treatments recommended by their physicians (Sinding *et al.* 2005, Sword *et al.* 2008, Gould *et al.* 2009) or insisting on referral to rehabilitation programmes (Rolfe *et al.* 2010). However, women could experience a disjuncture between wanting to be informed about their care and the responsibility for making care decisions (Sinding *et al.* 2010). Some rural women sought the help of allied health providers, such as nurses and pharmacists, to help them avoid physicians who were not well liked and to have questions answered (Wathen & Harris 2007, Leipert *et al.* 2008). An important theme in some studies was women's use of alternatives to the traditional healthcare system, such as complementary and alternative therapy (Leipert *et al.* 2008) and midwives (Parry 2008).

Some marginalised women overcame fears arising from previous negative experiences by finding and maintaining relationships with healthcare practitioners who seemed to understand their situations and whom the women saw as trustworthy. This process was seen among women who were illicit drug users (Butters & Erickson 2003), homeless (Reid *et al.* 2005), mothers of children at risk of developmental delays (Jack *et al.* 2005) as well as lesbian women who valued providers who accepted their sexual orientation (Sinding *et al.* 2004, see also Barnoff *et al.* 2005).

Women sometimes engaged in impression management by attempting to represent themselves favourably to promote a positive relationship. For instance, women with mental health problems attempted to 'pass' as 'normal' mothers to practitioners (Jack *et al.* 2005, Montgomery *et al.* 2006), and some lesbian women reported hiding their sexual orientation (Sinding *et al.* 2004). Impression management, however, could have more practical implications, such as the need to consider oneself as 'disabled' in order to access health benefits that would otherwise be unavailable:

When the choices are limited to describe yourself … and disabled applies but it's not how I think of myself. (Crooks *et al.* 2008, p. 1844)

The benefits of good relationships with health and allied health practitioners were reported in many studies; thus, it is not surprising that some women worked to forge and maintain those relationships (Aronson 2003, Odette *et al.* 2003, Sword 2003, Tarrant & Gregory 2003, Sutherns 2004, Woolhouse *et al.* 2004, Sinding *et al.* 2005, Wathen & Harris 2007, Ahmed *et al.* 2008, Leipert *et al.* 2008, Parry 2008, Power *et al.* 2008, Sword *et al.* 2008).

These examples demonstrate how women can actively control and shape their healthcare experiences, as well as overcome access disparities. However, these strategies were not without obstacles. For instance, negotiating within and between available services was sometimes nerve-wracking (Aronson 2006), and some women expressed reticence about negotiating treatments with practitioners (Wathen & Harris 2007, Sinding *et al.* 2010). Finding and choosing new or better suited practitioners is not an option equally available to all women, especially for women living in rural settings, women with reduced mobility or women with health literacy issues.

Living out shortfalls
In this section, we illustrate how women responded to access challenges by simply 'living out' the shortfalls they experienced. Women did so by: (i) making do; (ii) doing without; and (iii) emotional self-management. We also consider in this section a number of factors that conditioned women's agency in accessing healthcare, lending to the need to 'live out' the shortfalls, rather than confront and/or overcome them.

Making do. Sometimes women had little recourse but to settle for inadequate health services and they filled in the gaps with whatever they had available to them. This situation was evident in studies about women receiving home care, whose entitlements to certain types and amounts of services were reduced in a climate of fiscal cutbacks (Aronson 2003, 2006, Odette *et al.* 2003, Bethune-Davies *et al.* 2006). To remain in their homes, these women had little choice but to accept service reductions. Indeed, some feared being institutionalised so much that they

remained grateful for what little services they did receive:

So, you see, it's [services received] far from 100 per cent, but I'm satisfied. I've got no complaints. In my position, I think I should be grateful. (Aronson 2006, p. 545)

These women also remained reluctant to turn to their families and friends for help to fill these gaps.

Women in rural settings also described accepting or continuing to rely on healthcare they perceived as substandard because of a lack of other alternatives. For instance, new mothers in rural Ontario remarked that they felt 'lucky' to have a physician, given the limited resources available in their areas (Sutherns & Bourgeault 2008, p. 869), even if the healthcare options were not ideal; as one woman remarked about the only lactation consultant available in her area, she 'wouldn't send her worst enemy to see her' (Sutherns & Bourgeault 2008, p. 871). In other cases, women simply endured negative encounters in accessing healthcare, including poor patient–provider communication (Friedman & Hoffman-Goetz 2003, Ahmad *et al.* 2004a, Woolhouse *et al.* 2004, Sinding *et al.* 2005, Mitra *et al.* 2006, Wathen & Harris 2007, Ahmed *et al.* 2008, Power *et al.* 2008), as well as discrimination and marginalisation in the healthcare system on the basis of gender, class, race, sexual orientation, mental health and physical abilities (Odette *et al.* 2003, Ross *et al.* 2003, Sword 2003, Woolhouse *et al.* 2004, Barnoff *et al.* 2005, Sinding *et al.* 2005, Montgomery *et al.* 2006, Wathen & Harris 2007).

Doing without. Women also responded by simply 'doing without' healthcare or by denying themselves of other life essentials to facilitate access to healthcare. This could result in women having to divert limited financial resources to cover additional healthcare costs (Bates 2004, Bethune-Davies *et al.* 2006, Sutherns & Bourgeault 2008, Greene *et al.* 2010). For instance, Greene *et al.* (2010) noted the 'trade-offs' HIV-positive women in their study had to make:

Choosing between paying the rent, hydro bill, buying food or buying HIV-related medications. (p. 229)

Sometimes, low income meant that women were forced to forgo healthcare. For instance, women without insurance coverage in some of the studies could not afford dental care (Odette *et al.* 2003, Bates 2004). Others were unable to afford travel or transportation to care appointments or to purchase medication (Ahmad *et al.* 2004a,b, Gould 2004, Woolhouse *et al.* 2004, Reid *et al.* 2005, Sinding *et al.* 2005, Mitra *et al.* 2006, Sutton *et al.* 2007, Leipert *et al.* 2008); one woman reported taking only half of her prescribed

medication dosage to defer the effort required for acquiring a new prescription in a rural area (Leipert *et al.* 2008). Other women could not afford incidental treatment costs not covered by insurance, such as telephone calls and anti-nausea medication (Gould 2004, Gray *et al.* 2004, Gould *et al.* 2009). As a self-employed, uninsured woman in one study put it, '… if it doesn't hurt, you don't get it looked after' (Bates 2004, p. 130). A lack of financial resources also meant that women had difficulties affording health-promoting diets or exercise (Odette *et al.* 2003).

'Doing without' was not always related to financial issues. In some cases, women had competing priorities. Family responsibilities left little time for women's own healthcare; indeed, in some cases, women chose certain treatments over others – or decided against treatment or even seeking care – to minimise the impact on their families (Gray *et al.* 2004, Sinding *et al.* 2005, Montgomery *et al.* 2006, Wathen & Harris 2007). Other women could not take time off work to attend health appointments (Bates 2004, Gray *et al.* 2004). Furthermore, immigrant women faced a 3-month period upon arrival to Ontario when they were not entitled to public healthcare coverage (Ahmad *et al.* 2004b), and certain marginalised populations of women, such as HIV-positive women, homeless women and drug-using women, had difficulties maintaining medication regimens or sustaining health coverage because of the bureaucracies of obtaining health insurance identification cards (Butters & Erickson 2003, Reid *et al.* 2005, Greene *et al.* 2010). In all of these cases, women 'did without' healthcare or other necessities of life.

Contexts of 'living out shortfalls'. The concepts of 'making do' and 'doing without' both speak of broader forces that condition women's agency in overcoming difficulties to accessing care, and subsequently, their acceptance of suboptimal care. We found a number of factors that appear to play a role in constraining women's agency in responding to these difficulties.

First, certain political–economic factors contextualised women's agency. Despite Canada's universal healthcare coverage, many needed services such as pharmaceuticals or dental care are not universally covered. Certain benefits, such as home care and physical therapy, may be limited. Some studies indicated that women without adequate financial resources lacked full access to healthcare. For women who needed home care, a pervasive 'culture of cutbacks' had a number of implications. In an extreme example, one older woman decided against chemotherapy for a cancer diagnosis because the treatment would no longer allow her to live independently

without home-care supports, which were not likely to be forthcoming (Gould et al. 2009).

This 'cutback' culture also silenced recipients' complaints about the services available. They feared repercussions such as spoiled relationships with their workers or further reductions in services – which could also result in becoming institutionalised (Aronson 2003, 2006, Bethune-Davies et al. 2006). In other cases, women were simply tired of complaining and seeing no changes; complaining became a hopeless and humiliating venture (Aronson 2003, 2006).

Second, social expectations played a role in limiting women's options for overcoming gaps in healthcare. For instance, some women feared earning a 'bad reputation' or being seen as a 'troublemaker' if they switched physicians or complained about the care they were receiving (Aronson 2003, 2006, Sutherns 2004, Wathen & Harris 2007, Sutherns & Bourgeault 2008). Women in rural settings described continuing to receive care from providers with whom they were uncomfortable (Sutherns 2004). Some did not want to fully disclose information about health and living conditions because there was little privacy in their small, tight-knit communities (Leipert & George 2008, Leipert et al. 2008, Sutherns & Bourgeault 2008).

Furthermore, non-English-speaking mothers who relied on their children to translate during health-related appointments also experienced limits to what they were willing to disclose in front of their children (Guruge et al. 2009). In a similar way, women experiencing dating violence (Ismail et al. 2007), women of colour seeking cancer support (Nelson & Agyapong 2004) and HIV-positive women (Greene et al. 2010) experienced social conditions, which kept them from seeking help. Women also refrained from complaining about care because of perceived power imbalances (Woolhouse et al. 2004) or to avoid getting home-care workers into trouble (Aronson 2006).

Finally, 'making do' and 'doing without' were also responses to the bureaucratic organisation of healthcare in Ontario, such as wait lists, coverage gaps for new immigrants and identification rules. Furthermore, systemic discriminatory aspects of the healthcare system operated at societal, institutional and interpersonal levels – both intentional (e.g. attitudinal discrimination based on sexual orientation) and unintentional (e.g. inaccessible settings and procedures) – and these curtailed women's options for exercising agency.

On the other hand, some women revealed a sense of pride in both 'making do' and 'doing without'. Women spoke of taking satisfaction in their ability to 'tough it out' without the luxuries available to women in other/better situations; this was evident in studies of rural women (Caldwell et al. 2005, Wathen & Harris 2007, Leipert & George 2008), self-employed women (Bates 2004) and older women who were chronically ill, living with physical impairments or diagnosed with cancer (Aronson 2006, Gould et al. 2009, Casey & Stone 2010).

To this end, some study participants remarked that self-care was part of a 'civic responsibility' to avoid unnecessary burden on the healthcare system (Caldwell et al. 2005, p. 62). Some rural women sought their own solutions to health issues, including self-diagnosis and self-treatment (Caldwell et al. 2005, Wathen & Harris 2007) or planning ahead and/or turning to complementary and alternative medicine to circumvent limited clinic hours and medication availability (Leipert et al. 2008):

I'd rather go to the barn and shovel cow poop than to go to emergency. (Leipert et al. 2008, p. 176)

There was a sense, then, of a rural culture of self-reliance:

When you can fill your bag of potatoes yourself, don't wait for the Lord to do it. (Caldwell et al. 2005, p. 62, Wathen & Harris 2007, see also Leipert & George 2008)

Emotional self-management. Women across the studies reported developing different affective strategies to cope with their health and their access to healthcare. Women talked about having to accept increasing physical and emotional limitations and alter their patterns of daily living (Bethune-Davies et al. 2006, Ahmed et al. 2008, Power et al. 2008); however, women could also actively reject or distance themselves from the 'disabled' label (Crooks et al. 2008).

Some study participants described strategies that maintained dignity; for instance, negotiating with home-care attendants for measures to maintain independence in bathing and toileting (Aronson 2003). In other cases, women attempted to more passively preserve dignity by, for instance, avoiding visitors to their homes to conceal deteriorating levels of home maintenance; by not complaining to home-care agencies to avoid humiliation; and by not burdening family and friends with requests for support or keeping health problems a secret to avoid pity (Aronson 2003, 2006, Bethune-Davies et al. 2006, Casey & Stone 2010). Unfortunately, such strategies could lead to social isolation, deteriorating living conditions and inadequate attention to women's health needs.

In some studies, participants engaged in emotional self-management by adopting a positive attitude, or cultivating spirituality, as a means of dealing with ongoing adversity (Vahabi & Gastaldo 2003, Bethune-Davies et al. 2006, Power et al. 2008). Similarly,

self-employed women without supplemental health coverage simply resigned themselves to the potential financial risks of future illness or injury (Bates 2004). In other cases, women used avoidance as a coping mechanism, learning no more than was necessary about their illnesses and/or treatment, or simply not wanting to know if they were ill (Friedman & Hoffman-Goetz 2003, Power *et al.* 2008). Thus, without the option to improve their access to needed healthcare, women could only change their cognitive and emotional coping strategies.

Avoiding illness and maintaining health
Finally, women in some studies focused on preventive behaviours to avoid illness, or to do their best to maintain their health while living with a chronic disease or condition.

Avoiding illness. Disease prevention was motivated by perceived consequences of illness, for which the women had no time or resources:

We have started to think about our health a lot more, like no, I don't want or can't get sick, because if I do.... (Ahmad *et al.* 2004b, p. 123)

Women wanted to remain healthy for the sake of their children (Ahmad *et al.* 2004a) or because there was no support network if they were to fall sick:

I don't know what we'd do if I really got sick or injured. (Bates 2004, p. 130)

Rural women used complementary and alternative medicines to circumvent the potential need for prescription medications, which could be difficult to acquire (Leipert *et al.* 2008). Women described their need to be informed to prevent disease, and/or to make decisions about treatment options (see also Wathen & Harris 2007).

Information seeking. Highlighted in many studies was disappointment in the lack of health teaching by primary and specialty care providers, prompting considerable discussion of information-seeking strategies. Health knowledge was considered a safeguard against illness for the women as well as their families, and life changes prompted new concerns. For example, recent immigrants wanted to know what different or new illnesses they might face in Canada (Ahmad *et al.* 2004a), while older women wanted to know more about diseases they could expect to encounter as they aged (Friedman & Hoffman-Goetz 2003).

Those with health problems wanted information to help prepare for next phases of conditions they already had or had been diagnosed with. Knowledge was needed to negotiate treatment plans with physicians (Uskul *et al.* 2003), cope with long waits to see oncologists (Power *et al.* 2008) or make decisions for self-treatment or self-medication (Wathen & Harris 2007, Leipert *et al.* 2008). Unfortunately, new knowledge could prove overwhelming or frightening, a downside to information seeking reported in other studies as well (Friedman & Hoffman-Goetz 2003, Wathen & Harris 2007). One study spoke of the complexities of the responsibility to be informed and participate in care decisions (Sinding *et al.* 2010).

Personal health promotion strategies. There was also evidence of women developing personal health promotion strategies to maintain their health. These strategies included eating sensibly and exercising regularly, even when disabilities made exercise difficult or low incomes limited grocery budgets (Odette *et al.* 2003, Ross *et al.* 2003, Reid *et al.* 2005, Bethune-Davies *et al.* 2006); accessing preventive care, such as mammography screening or sexually transmitted disease testing (Butters & Erickson 2003, Vahabi & Gastaldo 2003); and accessing prenatal care (Butters & Erickson 2003).

Threaded throughout was a theme of good health as 'good citizenship', reflecting a neoliberal discourse of the personal responsibility for health (Petersen & Lupton 1996). Women's frequent mentions of the need to be 'informed' and to be 'preventive' indicate a perspective of self-governance and self-regulation. For example, one woman in Butters and Erickson (2003, p. 12) stated:

I'm not really taking care of myself at all, but I have the means to do it. *It's because of my own stupidity.* [emphasis added]

In these instances, women from marginalised groups seemed to accept, either explicitly or implicitly, that lesser access to health services was congruent with their past behaviours, rather than an instance of inequitable treatment.

Discussion

This paper builds upon the earlier paper by Angus *et al.* (2013), a meta-synthesis of the same studies as discussed here (through 2008), which found that multiple forces beyond specific barriers to healthcare access condition women's access to healthcare: (i) contextual conditions; (ii) constraints; (iii) barriers; and (iv) deterrents. As a follow-up to that paper, we have explored here the ways in which women responded to these challenges and their experiences in doing so. This present meta-synthesis, encourag-

ingly, has shown that women are often resourceful and resilient in identifying strategies to overcome these obstacles. However, these findings should not be taken to mean that access to healthcare is no longer an issue for women in Ontario because we also found clear limits to women's agency and resources to address their access issues. Furthermore, the strategies available to women – and not always available equally – largely represented 'stopgap' measures that must not be seen as long-term, viable solutions to problems that would be better addressed at other levels.

This review has included the relevant published literature from 2002 to 2010. While a complete synthesis of the literature published since 2010 is beyond the scope of this project, the political context of healthcare and its access remains similar (Armstrong & Armstrong 2010). In the absence of a shift in the provision of healthcare in Ontario, it is reasonable to assume that the findings of this synthesis are still applicable today.

Dixon-Woods *et al.* (2006, p. 7), in their synthesis of access to care by vulnerable groups in the United Kingdom, offered the notion of 'candidacy' for healthcare and drew attention to how such access is negotiated by individuals and the healthcare system itself:

Accomplishing access to healthcare requires considerable work on the part of users, and the amount, difficulty, and complexity of that work may operate as barriers to receipt of care.

Internationally, health systems in both the developed and developing world struggle with the challenge of ensuring access to care, particularly for vulnerable population groups (Ojanuga & Gilbert 1992, Andersen & Newman 2005, Scheil-Adlung & Kuhl 2011, Thomson *et al.* 2012). Efforts to improve access have focused primarily on identifying and addressing financial and non-financial barriers to care through policy, health systems reform, as well as local interventions.

To our knowledge, our paper is the first review to explore the dimensions of women's agency in addressing access barriers. Many of the ways in which women in our meta-synthesis were able to achieve 'candidacy', or exercise agency in the face of access difficulties involved mobilising various types of capital that are unequally distributed among women and therefore some will be unable to overcome challenges to access. We found that resources varied among women from different demographic groups, including income levels, geographical location, immigration status and ethno-racial membership, and health status (living with a chronic disease, disabilities, receiving care). Furthermore, many of the ways in which women bridged

healthcare access gaps were tenuous and relied upon fragile arrangements, which may not be sustainable. Nevertheless, women's agency has been an unrecognised resource for developing effective strategies to improve healthcare access.

In some papers, we found recurrent themes of preventing illness and maintaining health as a means of avoiding the need for the healthcare system – and, by extension, the difficulties in accessing that system. Such sentiments also speak of an underlying current of neoliberal self-governance (Petersen & Lupton 1996), wherein it is posed as the individual's responsibility to remain healthy, and those who are ill have somehow betrayed that responsibility. Thus, women discursively positioned themselves as good citizens who avoided burdening the economy and the healthcare system by taking steps to avoid illness.

This is not to suggest that women taking steps to remain healthy is a negative response or process. However, the situation may be problematic when women are distracted from confronting the broader forces, which create obstacles to their healthcare access and which may curtail their responses to those obstacles. Butters and Erickson (2003, p. 12), for instance, noted of the women crack cocaine users in their study:

The way these women may approach the healthcare system and construct their opinions about its effectiveness may be influenced by a belief that it is the individual who is responsible for their health or illness. Hence, these women were less inclined to blame the system.

Similarly, pride in rural resilience and self-sufficiency might mask the lack of healthcare resources in underserved areas. The problem is further compounded when healthcare decision and policy makers neglect to acknowledge and address these broader forces in favour of arguments for personal responsibility for health.

Thus, while it is encouraging that some women were able to find creative ways to access healthcare despite the interplay of numerous constraints, barriers and deterrents, more systemic problems are far from resolution. The findings of this review suggest a number of implications for women and the healthcare system. High-performing health systems provide equitable access to effective care. The forces impeding access to care experienced by women commonly result in suboptimal health outcomes and diminished quality of life. Our analysis shows the many ways women employ resourceful and varied approaches to overcoming these barriers, highlighting the importance of community engagement in health system redesign to facilitate access. Women's agency is a valuable resource to support these endeavours.

This meta-synthesis is significant because it is a comprehensive consideration of the ways in which women can overcome some barriers to accessing healthcare services. The findings here – with respect to both women's strategies and the broader issues those strategies highlight – are relevant to policy makers on a global scale and barriers to access to health are not an issue restricted to Ontario, Canada. This meta-synthesis was limited by the mostly moderate quality of the included studies, many of which had small samples. The search covered a specific time period and thus it is limited to a specific sociopolitical context. However, these sociopolitical trends persist and are seen in other countries (Ojanuga & Gilbert 1992, Andersen & Newman 2005, Armstrong & Armstrong 2010, Scheil-Adlung & Kuhl 2011, Thomson *et al.* 2012). Future research might focus specifically on women's responses to healthcare access gaps to provide insights into clinical and policy decision-making.

In conclusion, as providers and policy makers work to improve health system access, diverse communities of women can and should be powerful partners in designing and implementing interventions to improve access to care. Incorporating women's voices and perspectives into solutions can help increase the likelihood that these efforts will be effective. At a clinical level, providers might consider how to engage women, particularly marginalised women, as active participants in their own healthcare, and consider ways in which they may assist women in overcoming barriers to accessing healthcare or how aspects of their own practice may contribute to those barriers.

At a policy level, because many access barriers originate beyond the health system, approaches that acknowledge and address community-based barriers need to be integrated into those targeting health system factors. Better integration of community and health services, along with strategies to address the root causes of access disparities that arise from the social determinants of health, including poverty, would support efforts to reduce health inequities among women. Our findings underscore the strengths of women's agency in overcoming obstacles. This agency can be a valuable, but nonetheless somewhat tenuous, resource for innovation.

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Conflict of interest

No conflicts of interest have been declared.

Supporting Information

Additional Supporting Information may be found in the online version of this article:
Table S1. Themes identified by paper.

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