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Analyzing Qualitative Data: Health Care Experiences of Women with Gynecological Cancer

MILICA MARKOVIC
Monash University

This article describes the process of writing up qualitative research and developing and testing a grounded theory. The article is based on data collected from in-depth interviews conducted in Australia with women with gynecological cancer. Thematic analysis of the data identified issues pertinent to women’s experiences. The article describes the discovery of themes in women’s stories and develops a grounded theory on women’s health care experiences on the basis of interview data.

Keywords: qualitative data analysis; in-depth interviews; Australia; immigrants

In this article, I describe how I used the constant comparative method to derive themes in a grounded-theory project on why women in Australia delay seeing a physician for symptoms of gynecological (cervical, ovarian, uterine, and endometrial) cancer. My goal is to show that the search for themes in qualitative research—the “discovery of grounded theory,” in the phrase used by Glaser and Strauss (1967) in the title of their book on the subject—may be as much a deductive effort as it is inductive.

Cervical cancer is the second most common cancer among women worldwide, with almost half a million new cases each year (WHO 2002). The age-standardized incidence rates for cervical cancer are higher in less developed than in more developed countries; availability of cervical cancer screening accounts for these differences. In contrast, uterine and ovarian cancers are more prevalent in the developing countries (see Table 1), although the etiology of these cancers is largely unknown.

I gratefully acknowledge the University of Melbourne, the William Buckland Foundation, the Royal Women’s Hospital in Melbourne, and the National Health and Medical Research Council that funded the study on women’s experiences of gynecological cancer. Professor Lenore Manderson provided invaluable academic support throughout this project, and Professor Michael Quinn facilitated access to patients. Thanks to the editor of Field Methods and anonymous reviewers for their helpful comments.

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Gynecological cancers are among the top ten most frequently diagnosed new cancers as well as causes of death in Australian women (AIHW 2001). Medical anthropological and sociological research, however, has focused mainly on breast cancer (Chavez et al. 1995; Adler 1999; Crouch and McKenzie 2000; Mathews 2000; Hart 2003; Winefield et al. 2003), ranked first by incidence and mortality in industrialized countries (Ferlay, Parkin, and Pisani 2001). The availability and effectiveness of the Australian national cervical cancer screening program, which detects precancerous cervical abnormalities, limited that research mainly to understanding social and personal circumstances that facilitate or impede Australian-born or immigrant women’s compliance with screening recommendations (Fernbach 2002; Siahpush and Singh 2002; Taylor et al. 2003). The study that is the basis for this article investigated Australian-born and immigrant women’s personal experiences of gynecological cancer.

Elsewhere (Markovic, Manderson, and Quinn 2004, 2006; Markovic et al. 2004, 2006; Manderson, Markovic, and Quinn 2005), I have discussed patient-provider communication before diagnosis, women’s understandings of the causes of their illness, and women’s response to their illness, including the use of complementary and alternative treatments. Here, I am concerned with methodological issues in developing a grounded theory of Australian women’s experiences with cancer.

<table>
<thead>
<tr>
<th>Country/Region</th>
<th>Cervical</th>
<th>Uterine</th>
<th>Ovarian</th>
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<tbody>
<tr>
<td>More developed countries</td>
<td>10.3</td>
<td>13.6</td>
<td>10.2</td>
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<tr>
<td>Less developed countries</td>
<td>19.1</td>
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<tr>
<td>Australia/New Zealand</td>
<td>7.4</td>
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<td>Canada</td>
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<td>France</td>
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<td>United States</td>
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IMMIGRANT WOMEN AND HEALTH CARE

It is well established that immigrant women experience many barriers to accessing health care services in modern industrial societies (Bollini and Siem 1995; Stephenson 1995; Rice 1999). This ultimately may compromise their health status. Indeed, in Australia, for example, the health of immigrants deteriorates, irrespective of aging, the longer their residence in the country (ABS 1989). Barriers include low education and lower socioeconomic status, resulting in low language proficiency and poor literacy skills, both of which make patient-provider communication difficult (Newbold and Danforth 2003; Stewart and Do 2003). Lay beliefs about sexual health also may impede women’s access to health care services (Dawson and Gifford 2003). Marginalized Australian-born women, such as indigenous Australians and those living in rural areas, are also disadvantaged in relation to access to health services (Reath and Usherwood 1998; Wain et al. 2001; Coory et al. 2002).

Timely diagnosis of cancers results from a combination of prompt health-seeking behavior by patients and good clinical skills of health providers. Research in Europe, Canada, and the United States indicates that patients and health professionals both contribute to delays in diagnosing gynecological cancers. For example, in the early stage of ovarian cancer, women experience nonspecific, vague symptoms such as back pain, bloating, weight gain, indigestion, and changes in bowel function (Wikborn, Pettersson, and Moberg 1996; LoBuono 2000; Fitch et al. 2002). Other, more direct symptoms such as intermittent vaginal bleeding may be interpreted as signs of the onset of menopause rather than as indicators of an underlying pathology such as endometrial cancer (Cochran, Hacker, and Berek 1986). It is well known that early diagnosis affects the probability of surviving many cancers including ovarian, endometrial, and uterine cancer (Menczer et al. 1995; Holschneider and Berek 2000).

STUDY DESIGN

The study involved immigrant (N = 17) and Australian (N = 13) women newly diagnosed with gynecological cancer and receiving care at a tertiary hospital in Melbourne, Australia. None of the women in the study had any prior history of a malignancy. The women were approached during their visits to the outpatients department or while they were receiving treatment as inpatients, given a participant-information statement about the study, and asked to participate. All interviews took place at the woman’s home. Of the
immigrant women, twelve were interviewed in English, four in Serbo-Croatian, and one in Turkish, either by a trained bilingual assistant or by me. The interviews lasted, on average, about 90 minutes.

In these open-ended interviews, women were invited to tell their story. We rarely interrupted the storytelling and sought clarifications or additional information only after a woman concluded her story. The idea was to encourage informants to speak about the issues that were pertinent to their experience of illness and to introduce ideas with which we were not already familiar. The recorded interviews were transcribed verbatim and analyzed for themes, using Atlas/ti to manage the data.

THEMATIC ANALYSIS

Many researchers refer to their use of the constant comparative method in identifying themes in a corpus of narrative data as well as their use of their personal experiences and themes taken from prior literature (Strauss and Corbin 1990; Dey 1995; Sandelowski and Barroso 2002; Ryan and Bernard 2003). I concentrate here on the details of how constant comparison actually was done: how I conducted the thematic analysis, developed and refined assumptions, and developed a grounded theory to explain why some women delay consulting a physician about signs of gynecological cancer. I use excerpts to illustrate the process. The names of the women in the excerpts are pseudonyms chosen by the women themselves.

The empirical realities of people’s lives are complex, but in theorizing about health care decisions, I start with the assumptions that (1) we can identify patterns in those decisions by focusing on the most common experiences (Strauss and Corbin 1990; Gibson 1997) and that (2) social contexts (i.e., a woman’s social status, her access to health care, and her lay health beliefs) are important components of these experiences. This second assumption became apparent from my reading on the sociology of health care, of women, and of Australian immigration, which produced a set of preconceived themes that I applied in my analysis of the transcripts. These themes were enriched by others identified along the way. The following sections explain this in greater detail.

DISCOVERY OF THEMES IN WOMEN’S STORIES

One of the most common methods for identifying themes is identifying repetitions within and across narratives (Ryan and Bernard 2003). As I
identified a theme in one transcript, I checked for its presence in others and noted the similarities and dissimilarities in the way women expressed each theme. One recurrent theme across the narratives was women’s path to being diagnosed with gynecological cancer: symptoms that they noticed, their beliefs about the cause of each symptom and their responses to the symptoms based on those beliefs, responses of health professionals to women’s complaints, and investigative procedures that led to a definitive diagnosis of gynecological cancer.

Tipani, a 59-year-old woman from the Asia-Pacific region (who lived in an English-speaking country before settling in Australia), was the first woman I interviewed. She offered the following account:

I’ve been bleeding for about 3 months actually, when I finally had to go in. I am now nearly 59 and my period had already stopped, I think when I was about 54–55. It did sort of come as a surprise, when I started to bleed again, and I thought, oh, no, this is just one of those things, it’s all bad blood coming out, anyway so, really, didn’t really worry me to the extent that I even wanted to go to the doctor, and tell the doctor about it, no, I just thought it was one of those things. The other women I had spoken about it, a couple of other women 60 years old, and one of them said, oh, yes, I’ve had blood now and again, and the other one said, no, mine had stopped completely. And I thought, I am in that group that do have some sort of period, you know, it really didn’t really bother me, I mean, not really, but when I went to my doctor because I am on high blood pressure tablets, and I said to her, oh, I’ve been bleeding for about, at that stage for about 2 months, and she was stunned, she said, “What?” so I repeated, and she said, “Well, you shouldn’t be bleeding at your age, it must be something wrong, I want you to come back and get your smear test done. Five days, let your period stop, and then 5 days after that you come back, and have your smear.” Well, that didn’t happen, because it never got stopped.... Two months, I bled really heavily... one night, I was standing like in a pool of blood.... I had to go to the emergency [in the study hospital]... they said to me that there is definitely something wrong, so they examined me and the doctor said I had to have a curette the next day... a week later, it was explained to me that they found some traces of cancer. (Tipani)

I identified several themes (in italics above) that Tipani raised: physical symptoms (“bleeding”), duration and severity of symptoms (“bleeding heavily for 2 months”), lay understanding of these symptoms (“surprise,” “bad blood coming out”), informal health-advice seeking (“a couple of other women 60 years old”), reasons for initially seeking advice from a health provider (“blood pressure tablets”), the health professional’s advice (“something wrong... come back for a smear”), reasons for subsequent presentation to a health professional (“standing in a pool of blood”), and the medical diagnostic test that she had undergone to find the underlying cause of her health problem (“curette”). I arrived at these themes inductively,
although some themes, such as women’s lack of understanding of their symptoms as a reason for postponing going to a health professional, were not unexpected.

However, in discovering the theme of physical symptoms, I identified a metaphor not revealed in other research on women’s cancer. In saying that her intermittent bleeding was a positive sign, that bad blood was coming out, Tipani applied a concept she was familiar with (menstruation and menopause) to interpret a new event with which she was unfamiliar. This metaphor was an example of women’s lay understanding of health problems (Chirawatkul and Manderson 1994; Rice 1995; Lock 1998).

Themes from the first interview produced the following hypothesis, which I would check in subsequent interviews: In the presence of an unusual symptom, women (more specifically, immigrant women) seek advice from their peers. If they (or those whom they ask for advice) interpret their symptoms in light of their previous life experiences and normalize the severity of the symptoms, women wait until their next regular appointment for an ongoing health problem before reporting their cancer symptoms to a health professional. On the other hand, if women experience disruptions to their everyday life (that is, symptoms that cannot be normalized easily), this influences their decision to report the symptoms to a health professional earlier.

With these hypotheses in mind, I analyzed the second interview with Betty, a European-born woman who immigrated to Australia as a teenager and who had been diagnosed with endometrial cancer:

I had difficulties for a few months . . . my urine was burning . . . because of the urine, I had to put pads, just as if I had my period, and I was watching not to drink the full glass of water, but rather half, so I don’t have liquid in my stomach—I know every toilet in the shopping center. . . . And when I went to see my GP [regular Pap smear appointment], I say to him, my water works does not seem to be working properly, and he says, “I can see it.” He [my GP] did the first test [Pap smear] . . . [after the first test, he said] that something was not quite right, and to wait for a few weeks and then come again after Christmas, it was about few weeks [before Christmas]. . . . I see that something is wrong, but I think it’s just women’s things, there is always something. . . . I came there [for the second Pap smear] . . . and [later] the doctor ordered I go for a hysteroscopy [in the hospital]. . . . After that, they told me to come for a curette . . . my GP rang the hospital to arrange it . . . [afterward] they said that nothing was all right, and that I should go for the main operation [scheduled about a few weeks later because of a hospital waiting list]. . . . I was always putting up with things, I wasn’t thinking about me a lot, I was thinking more about my husband [diabetic, amputated leg]. I thought, it’s only a cold, I didn’t think that something big could happen. From a small cold, it turned out to be a bit more. (Betty)
In Betty’s story, similar themes emerged as in Tipani’s: physical symptoms (different from those that Tipani experienced) that are disruptive to everyday functioning (frequent urination, causing difficulties when in public space) and that persist for a long time before being shown to a health professional as part of a regular checkup. New themes emerged, including gender roles (“I was thinking more about my husband”), which prevented Betty from prioritizing her health, and barriers to accessing diagnostic tests. A new metaphor appeared (“it’s just women’s things”), which I interpreted as part of a theme I labeled *lay understandings of a health problem* and as an indicator of the recurrent theme “finding reasons for normalizing symptoms.” Seeking health advice from a woman’s social network was absent from Betty’s account, but other assumptions about women’s health-seeking behavior remained the same as those found in Tipani’s.

The third interview was with Tulip, a recent immigrant from Europe who had been diagnosed with ovarian cancer. Her experience was somewhat different. Unlike the other two immigrant women, she did not delay her appointment with a health professional:

> One day I didn’t feel well, not pain, just uncomfortable... just uncomfortable in my abdomen, like a 9-month-pregnant woman, and my breasts hurt a little bit when I walk. I had a problem with my breathing when walking and that’s all, no pain... and I went to my GP and she sent me to have a blood test and (ultra)sound examination. After that, when she got results, she sent me to a doctor, gastroenterologist, and they did the examination, and the doctor told me, “You’re not my patient,” and he sent me to another doctor. He [the gynecologist] examined me in the morning and sent me to... [the cancer hospital]. They found I had fluids in my abdomen, my lungs, and the cause of that was tumor, tumor of ovaries. (Tulip)

Guided by Strauss and Corbin (1990:144), I aimed to identify “the evolving nature of events by noting why and how action/interaction—in the form of events, doings, or happenings—changes, stays the same, or regresses; why there is progression of events or what enables continuity of a line of action/interaction, in the face of changing conditions, and with what consequences.”

In this study, the “doings” were women’s health practices. In comparing Betty’s and Tipani’s accounts with Tulip’s, I saw that lay understanding of the symptoms differentiated these narratives. Tulip could not make sense of the physical symptoms that she had. The nature of the symptom and her personal life cycle did not allow for any cultural interpretations as was the case with the other two women. At the age of 63, Tulip knew she could not be pregnant, and she sought professional advice about her suddenly enlarged abdomen.
This also explains why Tulip did not wait for a regular appointment with her general practitioner, in contrast to the other two women. Hence, lay interpretations of the symptoms, still present as a theme, led to a different health behavior. As in Betty’s case, Tulip did not seek informal health advice. A new theme in Tulip’s account was initial referral to a specialist other than a gynecologist. These themes led to modifying the hypothesis about women’s health care practices: Unusual symptoms that cannot be interpreted as normal, given the woman’s individual life circumstances, influence her prompt seeking of advice from a health professional. A health professional, however, may provide referral for diagnostic tests and to a specialist other than a gynecologist, which can lead to diagnostic delays.

In presenting the story of Barbara, an Australian-born woman, I illustrate how in subsequent interviews, I continued to search for repetitions of themes and identified the emergence of new themes:

When I turned 50, my period stopped and then when I got my period again, I thought something is definitely wrong here. Because mum having bowel cancer, I thought, no way I am going to stop at this. I’ve got to do, to find out. . . . So the doctor did a few ultrasounds . . . and they said to me, we are sorry to tell you, but you’ve got cancer . . . [Before that bleeding, did you notice anything happening?] Yes, I was feeling, I call myself an active person, I was always on the go. And then I just started to be a bit lethargic, not wanting to do this and not wanting to do that, just sitting around and doing my knitting. I’d cry for the least small thing, watch TV shows, I’d get emotional, and anyone who’d say anything to me, or there would be an argument, I’d start crying. . . . I just felt terrible. I just sat around, and my daughter would say to me, mum, what’s wrong with you? And I’d say, I don’t feel well, and I kept telling I don’t feel well, and I am sick and tired of telling you. Well, go to the doctor’s if you don’t feel well. So I’d go the doctor; I tell him, I feel sick in the stomach, or something like that. The doctor would send me for an ultrasound or a blood test, and then the ultrasound . . . it would come back negative. And I’d think, but there is something wrong with me. How come I feel so bad, anyhow it just went on and on and on. And one time, I went and the doctor told me I had an enlarged liver. And he said, all that alcohol that you drink. And I said, listen here, if the pubs had to depend on me buying alcohol, they’d go broke. Then another time I had something wrong with my chest and he’d say, you’d have to stop smoking. And I said, I smoke two smokes a day if that. When I buy a packet of smokes, it lasts me a month. He turned around and he said, “I don’t know, I don’t know then what’s wrong with you then.” And I said to him, “Aren’t you getting sick and tired of sending me for all these ultrasounds and everything?” So he said, “Look, I’ll refer you to [a woman’s hospital] to see what they say.” (Barbara)

In comparing the emerging themes from interviews with immigrant women with those of Barbara, I identified several similarities and differences.
Her illness experience commenced with feeling unwell and having pain in the abdomen; the former was a repetitive theme. In contrast to Tipani’s experience, the source and the type of the informal network’s advice were different. Her lay interpretation was similar to that of Tulip’s (i.e., she could not understand why this was suddenly happening to her given her personal life cycle). She perceived the symptoms to be disruptive, affecting her social functioning, and like Betty, she decided to make an appointment with a health professional.

In contrast to Tulip, who only saw one other specialist before being referred to a gynecologist, Barbara had undergone several diagnostic tests, none of which, according to Barbara, showed any abnormality. These results did not change her belief that she was indeed sick, and she persisted in consulting health care professionals. This was the new emerging theme, and so was the attitude of the health professionals whom Barbara perceived as both having dismissed her concerns and having wrongly attributed her health problems to her risky personal health behaviors (drinking and smoking).

Also, because of her family history (her mother’s bowel cancer), Barbara interpreted her vaginal bleeding as something wrong that definitely needed attention rather than as something that might be normal among women her age, as Tipani had done. It was, according to Barbara, only with her reporting of this new symptom (the vaginal bleeding) along with her insistence that something must be wrong that she was referred to a gynecologist and diagnosed with cancer. Based on these themes, the hypotheses about women’s health care practices were modified to accommodate the reported lack of responsiveness of health providers to women’s distress and women’s perception that the onus was being placed on them to be persistent in seeking professional health advice.

These themes re-emerged in the interview with Alba, another Australian-born woman with endometrial cancer whose path to diagnosis resembled Barbara’s experience. According to Alba, she kept visiting her local general practitioner for 2 years because of intermittent vaginal bleeding. This symptom, she says, was attributed to her premenopausal status, and she was not offered any diagnostic tests. She finally requested an ultrasound and was told that the results showed she had nonmalignant polyps; the general practitioner agreed to refer her to a gynecologist. Alba reported that on seeing the ultrasound results, the gynecologist said: “I have seen cancerous ones [polyps] and they [Alba’s] don’t look bad at all.” He offered to do a curette, and when Alba woke up following surgery, she says, the doctor confirmed that everything looked fine. Two days later, when the pathology results became available, Alba received a phone call from him and was informed that she needed to undergo a radical hysterectomy.
Incorrect diagnoses and women’s initiatives in representing to a general practitioner during a long period of time despite their concerns being dismissed were repetitive themes in these narratives. As I read through Alba’s narrative, yet another theme emerged—the gynecologist’s initial assessment about the lack of abnormality. This theme also appeared in the interview with Linda, an Asian-born woman who has lived in Australia for about 20 years. According to Linda, when she complained about abdominal pain, a hospital specialist and her gynecologist, whom Linda had been seeing regularly, argued confidently that the ultrasound results were normal. With the occurrence of the new symptom—vaginal bleeding—as in Barbara’s case, Linda went yet again to the gynecologist, who ordered another ultrasound. During the examination, Linda said the specialist did not detect any abnormality, but when Linda argued vehemently that she had abdominal pain, a senior gynecologist was called in, who diagnosed a lump; shortly afterward, Linda was diagnosed with ovarian cancer.

Continuing to compare the emerging themes in other interviews, I categorized them into three domains: women’s interpretations of symptoms, health professionals’ actions, and access to health services, all of which were common both among Australian-born and immigrant women (see Table 2).

Two less common themes also emerged: (1) women’s reporting having no symptoms that they could recall but being diagnosed with cancer as the result of regular Pap smear screening (although one woman was diagnosed with ovarian cancer rather than cervical); and (2) postmenopausal women’s reporting that they had vaginal bleeding and being promptly referred to a gynecologist, who conducted a curette.

In the following section, I explain how, based on these themes, I developed a grounded theory of health experiences and outcomes.

HEALTH EXPERIENCES AND OUTCOMES OF WOMEN WITH GYNECOLOGICAL CANCER

In reconstructing women’s experiences, I aimed at understanding them from a public-health perspective. In my view, the theory needed to contribute to minimizing diagnostic delays (i.e., to predict under which circumstances delays are likely to occur). Sandelowski and Barroso (2002:217) argue that qualitative researchers do not make explicit how they define a pattern. They postulate that the pattern may be considered when 50% or a lesser but significant number of respondents demonstrate it or if “it is essential to an individual participant’s life.”
### TABLE 2
Recurrent Themes from Interviews with Women with Gynecological Cancers

<table>
<thead>
<tr>
<th>Themes</th>
<th>Excerpts/Metaphors: Australia-Born Women</th>
<th>Excerpts/Metaphors: Immigrant Women</th>
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<tbody>
<tr>
<td>Health services</td>
<td>The clinic where I go, there is six doctors, I had three that I used to go to regularly. I went to one, she was lovely, then she had a baby, and I didn’t see her anymore. Then there was another doctor, and she was lovely... then she left the clinic as well, then I’ve got doctor L. Now he’s in only every Wednesday.</td>
<td>I’ve made an appointment, but had to wait... you ring now, you get an appointment in 3 weeks.</td>
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<tr>
<td>Women’s interpretation of symptoms</td>
<td>I thought it [vaginal bleeding] was just a trickle... and I thought it was partly menopausal.</td>
<td>I had back pain...</td>
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<td>Poor access to health care</td>
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<td>Women’s normalization of symptoms</td>
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<tr>
<td>Personal life cycle</td>
<td>I was at my doctor, had a Pap smear, and she sent me a letter saying go see the gynaecologist... I’ve always had a reasonable flow, nothing irregular... That happened a lot and more often in that year than I remember [2 years before cancer diagnosis].</td>
<td>I had a routine Pap smear. I had no symptoms and was surprised when the doctor referred me to a specialist for a scan.</td>
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<td>Vague/absent symptoms</td>
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<td>Disruptive symptoms</td>
<td>When you haven’t had a period for 5 years... you just don’t bleed, it wasn’t just the drip, it wasn’t just a dribble, it was a full bowl, to the extent that I had bleeding for about 4 days, and it wasn’t just a little speck for those 4 days.</td>
<td>My whole abdomen was swollen, I was in great discomfort. I went to the doctor again, he could not find anything. He thought I had lazy bowels and some fluid retention. Day by day my situation got worse, I was in extreme pain. Now my whole body was swollen.</td>
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<tr>
<td>Themes</td>
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<td>Health professionals’ actions</td>
<td>They just basically said I was run down... take some time off work... I went back to work... I was starting to get really tired and certain things like lifting and stuff I was getting bad cramps. Like lower abdominal cramps.</td>
<td>I say to her that something is wrong with my ovaries [that’s where the pain was]. And she says, What would it be with them? She says she doesn’t think it’s that.</td>
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<td>Nonrecognition of vague symptoms by health professionals</td>
<td>I went to my local doctor... I sort of had spotting, bloating in the tummy, and sometimes, I would lose like bits of liver it would look like. No, they weren’t worried. No, you’re just getting ready for menopause, nothing to worry about. You’re just being silly, you’re being paranoid.</td>
<td>My GP said I had an infection [on the vulva], nothing dangerous.</td>
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<td>Health professionals’ dismissal of women’s concerns</td>
<td>It sort of started off as like a little blood blister, which burst. Then it got just like a sore and I went to the doctor and she gave me ointment for it. I suppose I was treated with the ointment for about 2 or 3 months.</td>
<td>I had abdominal pain and I spent there [in hospital] 7 days, and they told me it was hernia... second or third time [when admitted to hospital], they said we better send you to the women’s hospital.</td>
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<tr>
<td>Women’s undergoing clinically irrelevant treatment following initial consultation with a health professional</td>
<td>The doctor at the emergency said I had gastroenteritis. I swore blind no, it wasn’t gastroenteritis, because I had eaten the same things as my family, they didn’t have any signs of gastroenteritis, but I was abdominal pain, really sick, bad diarrhea, and he swore, no, you’re gastro. [On the following day I] called up the emergency and I was told to come in.</td>
<td>My stomach kept getting bigger. I looked like I was 7 months pregnant. It was awful. I said “do I have a growth?” I was really quite worried and concerned. I said “maybe I’ve got a tumor in my stomach.” I thought she was a bit rude at the time. She said “Is that all you can think about?”</td>
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</table>
I applied both of these criteria to identify a pattern among women diagnosed with gynecological cancer on the basis of four domains or themes: (1) clinical manifestation of illness, (2) women’s lay beliefs about symptoms, (3) women’s reports of their health professionals’ clinical skills, and (4) access to the health system. Applying these themes, I identified two main health outcomes for women: diagnostic delays and timely diagnosis. These exact phrases were not used by any women but were my own interpretation of the interview data. In developing the theory of these health outcomes, I explored the interrelationship of these themes and the patterns that emerged.

With regard to the clinical manifestation of illness, although a few women \( (N = 7) \) had no or vague symptoms, the majority \( (N = 23) \) reported having symptoms that they found disruptive. In these cases, women almost always sought health care promptly (twenty out of twenty-three cases). Only four women with either type of symptom (vague or disruptive) normalized them (almost always attributing them to their personal life cycle), and hence, did not seek health care advice. Thus, from these narratives, women’s behavior contributed rarely to diagnostic delays. Based on women’s accounts, diagnostic tests (including Pap smears for regular reproductive health care) and the interpretations of their results resulted in sixteen out of thirty clinicians’ diagnosing women without delays. However, fourteen women reported that clinicians’ actions (i.e., diagnostic tests and referrals or lack of any action) led to diagnostic delays despite the women’s telling the clinicians that their symptoms were disruptive.

Seven of the thirty women reported encountering clinicians who dismissed their complaints, causing diagnostic delays. Six of these seven women were immigrants, and all but one of the six eventually were diagnosed with ovarian cancer. There were no Australian-born women with ovarian cancer. Eight of the women said that they challenged clinicians regarding their health care, but six of them reported that their complaints were dismissed.

Overall, about two-thirds (nineteen of thirty) of the women in this study reported experiencing delays in diagnosis. Australian-born and immigrant women were equally likely to report experiencing these delays. Delay in diagnosis was most common with vulvar cancer, followed by ovarian, endometrial, and cervical cancers. A few women reported having experienced difficulties accessing the health care system, which, in combination with what they say they experienced in clinical management, also resulted in diagnostic delays.

Based on the themes and patterns described, I developed the following grounded theory of these women’s health care experience.
1. If women can normalize their symptoms by placing the symptoms in the context of their life cycle or as normal signs of female physiology, they are likely to delay seeking advice from a professional, causing a delay in proper diagnosis. The likelihood of this happening in these cases is low: five out of thirty women (17%) fall in this category.

2. These women eventually visit a health professional when the symptoms become more severe. This suggests that public education about the signs of gynecological cancer is an appropriate intervention for this part of the problem.

3. Among the twenty-five women who visited doctors soon after symptoms appeared, fourteen reported that their physicians either dismissed their concerns (i.e., normalized the symptoms) or referred them to inappropriate diagnostic tests and specialists. These tests, which did not suggest any underlying pathology, caused further delays in proper diagnosis by the clinicians, according to these women.

4. Most women reported that they experienced some delay in accessing the public health care system (they were put on waiting lists), but most women would not have been on the list for longer than a couple of weeks or so.

5. The report of a prompt diagnosis (eleven of thirty cases) was accompanied by any or some combination of the following: reports of regular screening and a Pap test (which detected cervical cancer); symptoms incongruent with women’s life cycle (lump on the vulva, vaginal bleeding among younger women); accidental finding of gynecological cancer during regular health exams; and diagnostic acumen on the part of clinicians.

CONCLUSION

Women’s stories indicate that seeking advice from a health professional depends on their correct understanding of bodily functions at different times of life and on whether symptoms disrupted their lives. Public-health education, however, has not prepared the women in this study—neither Australian born nor immigrant—to recognize the symptoms of gynecological cancers. For example, the message of OvCa Australia, a nongovernment institution aiming at educating women about ovarian cancer (the so-called silent killer), “If in doubt, rule your ovaries out,” has not been effective. Lack of public-health information regarding endometrial or vulval cancer also apparently contributed to delays among women. On the other hand, if the reports by the women in this study are accurate, the failure of some clinicians to diagnose women promptly or their arguing that women’s concerns were unsubstantiated suggests gaps in the curriculum of medical professionals and indicates the power of physicians in guiding the decisions by women to seek further help.

The grounded theory offered here represents the aggregate experience of the thirty women in this study. It cannot be generalized to Australian immigrant women, much less to women elsewhere in the world. The patterns in
these data are strong, however. If they hold up on tests on larger samples of qualitative data, this would warrant population-level tests.

REFERENCES


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