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Abstract: This paper, drawn from a larger phenomenological study, critiques the effects of "waiting" for women when they have an abnormal Pap test result. The hurt and injury incurred by women who perceive they have no choice but to become patient waiters in a health system that seemingly values the time of the health care provider over the health care recipient is discussed. These iatrogenic, unintended, harmful consequences are referred to as the nocebo effect. The participants provide the principal voices and their stories are dialogued to a lesser degree with the literature and the discourse of critical theorists who question power relationships in health professional practice. The purpose of this paper is served when the women's stories strip away some of the taken-for-granted, invisible aspects of the health professional's power.

The Nocebo Effect for Women in Waiting

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Abstract

This paper, drawn from a larger phenomenological study, critiques the effects of “waiting” for women when they have an abnormal Pap test result. The hurt and injury incurred by women who perceive they have no choice but to become patient waiters in a health system that seemingly values the time of the health care provider over the health care recipient is discussed. These iatrogenic, unintended, harmful consequences are referred to as the nocebo effect. The participants provide the principal voices and their stories are dialogued to a lesser degree with the literature and the discourse of critical theorists who question power relationships in health professional practice. The purpose of this paper is served when the women’s stories strip away some of the taken-for-granted, invisible aspects of the health professional’s power.

Key words: cervical screening, nocebo effect, power relationships, waiting, women’s health

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Introduction

[Critique functions as] *a process of self-enlightenment of socialised individuals about what they could want if they knew what they could want*
(Habermas, 1971a)

Waiting is inevitable, taken-for-granted and often perceived as no more than an inconvenience by all, except those waiting! The message received by women waiting is that their time and by implication, they themselves are of less value than health professionals, as the following participant responses indicate:

But I suppose they're busy, and you're only a patient ... You're just a number, aren't you really? (Joyce)

[We're] *valueless in terms of who we are as human beings.* (Marie)

One more cervix in a long line of cervixes. (Ann)

Causing another person to wait is rarely a deliberate ploy by any individual health professional. Waiting is however, the byproduct of an Australian health system which aims at increased productivity and efficiency through microeconomic reforms (Willis, 2004). Personal experience indicates that clinician awareness of women's waiting increases anxiety and decreases professional satisfaction. Of greater significance than job satisfaction for the health professional, this paper argues that waiting adds to the harm done to women by the health system, known as the nocebo effect (Illich, 1976a), in this instance when women have a cervical screening detected abnormality. Odent (1994) refers to the nocebo effect as a harmful effect in direct contrast to the principles of the placebo effect. Placebo, derived from the Latin word, *to please* implies that no harm is caused by

the action and indeed, positive changes can occur after a given treatment (*Mosby's Dictionary*, 2006). In the context of menopause, O'Brien Cousins and Edwards (2002, p. 326) define the nocebo effect as "unintended harm, created when a generally healthy group of women experience socially constructed dis-ease and turn to medicine to manage their currently healthy bodies". The nocebo effect, for the purposes of this paper is an umbrella term and includes direct iatrogenic concepts and other, more hidden influences such as the effects of inadequate communication and systematic power imbalances between women and health professionals. Foucault (1980), Illich (1976a, 1976b) and Habermas (1971b) all implied that as long as practitioners remain the dominant players in the patient-health professional relationship, the nocebo effect is inevitable.

Waiting will be critiqued in this paper as an example where participants perceived that the health system valued itself above the people who it was meant to serve. There were many ways women waited – waiting to get an appointment, multitudes of women waiting in the waiting room, waiting to see the health professional, and then waiting for results. Waiting is such an established component of health care that it is seen as inevitable and accepted without question. Waiting to see a health professional is a taken-for-granted process and the "waiting room" an essential component in any health facility. Inequality of status between health care provider and recipient is reinforced by the need to wait. Frankenberg (1992) argued that the health professional has become the principal actor in the performance (consultation). The professionals, though scarce, have a symbolic value above and beyond their scarcity value that is reinforced by the subordinate member of the dyad, the client, always waiting for the clinician. The purpose of sharing the participants' stories in this paper is to make women's waiting visible to nurses and in so doing, strip away some of what Cheek, Shoebridge, Willis and Zadoroznyj (1996) described as the taken-for-granted, invisible aspects of the health professional's power.

Literature Review

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The balance of professional literature on cervical screening and pathology is heavily slanted towards the microbiological perspective. Research articles in the psychological literature are skewed towards “victim blaming”. Many argue that women predisposed to cervical dysplasia are more likely to be pessimistic, passive, compliant, inhibited, depressed and anxious (see Antoni, & Goodkin, 1989; Eysenck, & Grossarth-Maticek, 1991; Pereira, Antoni, Danielson, Simon, Efantis-Poter, & O’Sullivan, 2004 as examples). Feminist literature seeks to redress this imbalance through sociological analysis that explores the effects of medical dominance on women and examines the reason why a woman may demonstrate a given attribute (see Fisher, 1986; Posner, 1991 as seminal examples). The focus on biomedical research precludes many sociological implications, including the effects of waiting, from being fully explored.

The woman’s experience has been largely ignored in mainstream medical research and this ignorance has led to a tendency for women with an abnormal Pap test result to be blamed and to blame themselves for putting themselves at risk (Clarke, Hatcher, McKeown-Eyssen, & Lickrish, 1985; Forss, Tishelman, Widmark, & Sachs, 2004; McKie, 1995; Pereira et al., 2004; Taylor, Keller, & Egan, 1997). While there are multiple risk factors for having an abnormal Pap test result reported, the factors that have captured the most professional attention, media and public fascination are those that relate to the woman’s sexual history. Consequently, many women with an abnormal Pap result fear that they will be judged and this may be justified when statements are made in the literature such as: “the disease could, to a large extent, be prevented altogether through healthful behaviour and sexual practices” (Sevin, 1999, p. 759). This suggests to a woman that she has an abnormal Pap result because she has chosen either unhealthy behavioural or sexual practices (Quilliam, 1990; Teale, Moffitt, Mann, & Luesley, 2000). The literature that feeds health professional bias, attitudes, values and worldviews therefore exacerbates the harm done to women, who already feel vulnerable and powerless when they have an abnormal Pap test result.

Norwegian research revealed ambivalence in women when they discuss Pap tests because of the intimate relationship between sex, power and medical knowledge in the cervical screening process (Larsen, Oldeide, & Malterud, 1997). Unrealistic beliefs in the diagnostic validity of this examination and a misplaced trust in medical knowledge, common for the women in both the Norwegian research and this study, means that informed consent is not necessarily given and the imbalance of power is consequently even more serious. Women have long waits and short visits when attending for cervical screening (Kapsalis, 1997) and, because of the power differential between clinicians and themselves, may feel unable to take the time of the “busy” professional to ask questions that may help to alleviate their confusion and fear (Kavanagh, & Broom, 1997). They are highly unlikely to formally complain about protracted waiting times.

Information related to the effects of waiting on women with an abnormal Pap test has not previously been published. Therefore findings from outside the gynaecological/cervical screening literature needed to be sourced. Education and general medical literature report that waiting results in negative behavioural sequelae, including an increase in anxiety and a decrease in compliance with recommended treatments/instructions (see Antrop, Buyssem, Roeyers, & Oost, 2005; Connor-Spady, Sanmugasunderam, Courtright, McGurran, & Noseworth et al., 2004; Leung, Castan-Comeo, McGhee, Wong, & Johnston, 2003; Oudhoff, Timmermans, Bijen, & van der Wal, 2004 as examples). In Europe, health professionals as well as those waiting for services are becoming increasingly dissatisfied with waiting times which, in spite of good intentions, continue to increase (Robinson, Bell, Moller, & Basnett, 2003). Authors, including Oudhoff et al. (2004) draw attention to the paucity of information on the impact of waiting for health services, demonstrating the need for the present study.

The Study

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Aims of the Study

This paper is drawn from a larger phenomenological study that explored women's experience of having an abnormal Pap test result (Dietsch, 2003). The research acknowledges both the inevitability and the worth of subjectivity and values holism, accepting that every original intuition is a legitimate source of knowledge (Benner, 1994; Kockelmans, 1967; Parse, Coyne, & Smith, 1985). First person account stories of experience provide access to a kind of knowledge not ordinarily regarded as appropriate for epistemological consideration (MacPherson, 1983; Omery, 1983). The project actively sought the stories of women from groups whose voices have previously gone unheard and unpublished. The participants' subjectivity, objectivity and intuitiveness, all evident from their experiential stories, are valued.

By approaching each participant interview with only two predetermined prompts: "Please tell me about yourself as a woman" and "Please tell me about your experience when you had an abnormal Pap test result", this study sought to obtain the contextualised and personally most significant aspects of the woman's experience. Information related to waiting was never sought, but always spontaneously shared by the participants.

Ethical Considerations

It was ethical considerations that determined that phenomenology should be the methodology of choice for this study. The data produced from memory would not be collected with the intention of generalising to a larger population but rather to add to nurses' understanding of how it is for women when they experience an abnormal Pap test result. Women were invited to share their stories of having an abnormal Pap test and any other issue they considered relevant. Approval was obtained from both the Charles Sturt University and the then Greater Murray Area Health Service institutional ethics committees. More importantly, every woman who participated in this study

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requested that their stories be shared as widely as possible so that others might learn from them.

This paper responds to their request.

Selection of Participants

The participants chose their own pseudonyms and were clients from women's health nurse clinics. The women were purposively invited because they identified as being from groups at greatest risk of developing cervical pathology. The voices of women from these groups have been largely silenced in the professional journals. Literature describing the possible effects of an abnormal Pap test result on lesbians and bisexual women is extremely limited. Furthermore, there is no previous literature describing the experience of an abnormal Pap test result, from the woman's perspective, for women who have a disability, or are obese, identify as Aboriginal, from a non-English speaking background, socio-economically and/or geographically disadvantaged or aged at either end of the recommended cervical screening spectrum (18–70 years). These are the same groups of women identified as being at greatest risk of cervical intraepithelial neoplasia (CIN) and given priority of access to cervical screening attended by women's health nurses (Dietsch, 1999).

Women with an abnormal Pap test result who had had contact with a woman's health nurse in what was then the Greater Murray Area Health Service and who identified as being from one of the population groups listed above were given information about the study. If they chose to participate they contacted the principal researcher and were forwarded detailed information about the study and an informed consent form to sign. On receipt of this signed form, women were contacted to arrange a mutually convenient time and place for the interview(s).

Sixteen women contacted the principal researcher and were invited to participate but three women declined. Of the thirteen who participated, the youngest woman was eighteen and the oldest seventy years old. Eight were socio-economically disadvantaged and in receipt of social security payments.

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One had been homeless for eighteen months and two lived in caravan parks. Three women had a disability – one was deaf and communicated by lip reading, one had had paraplegia since childhood and another was mildly developmentally delayed. Three of the women were distressed by their obesity. One woman identified as Aboriginal and spoke Wiradjuri as a second language. Two of the women were from non-English speaking backgrounds. One woman was a refugee and one woman identified as lesbian. Three professional women self-selected and were accepted as participants (Dietsch, 2003).

The length of time between when the women had an abnormal Pap test result and their data collection interview was extremely varied and ranged from a few weeks to many years. This variable time lapse was not considered significant because, as Crotty (1996) explains, the emphasis in selecting participants must be on the participants' strong desire to share their stories and their ability to reflect, focus, intuit and describe, as the phenomenological method requires.

Data collection and analysis

Data were gathered during indepth interviewing, using only prompts that were broad, open-ended and designed to avoid influencing the informants' responses in any way (Baker, Wuest, & Stern, 1992). The stories the women chose to tell in response to those prompts were listened to intently, as far as possible without interruption, except for conversational acknowledgments. A recursive model was utilised where the participant guided the pace and direction of the interview (Minichiello, Aroni, Timewell, & Alexander, 1996). Each participant chose the time, length and venue for her interview. Between two and four formal interviews were attended with each participant. The preliminary interviews were audiotaped, transcribed verbatim and then thematically analysed. Individual transcripts were offered to the women to read and discuss before and after interpretative analysis. All but one participant elected to participate in this process. Transcript verifications and

the interpretation processes were therefore in keeping with the recommendations of Colaizzi (1978) who advocated that the phenomenological researcher return to the informants to validate the findings and reflect on their perceptions of the experience. Four major thematic interpretations emerged from the transcript analysis of the larger study (Dietsch, 2003). From the third nocebo effect theme, six sub themes were identified, one of which was waiting (months for an appointment, hours to see the clinician, weeks for the results). The nocebo effect of waiting is the focus of this paper.

Setting the scene

Every day, millions of healthy women have a Pap test. They choose to submit themselves to this procedure because they wish to be both reassured and insured. Reassurance comes from an objective, scientific test that they are indeed as healthy as they believe themselves to be and they feel insured against the possibility that they might develop cervical cancer.

The majority of women receive their desired reassurance and insurance. However, at least one in twenty women having a Pap test will be faced with an abnormal result and if the woman is an adolescent, an abnormal result is even more likely (Brown, et al., 2005; Insinga, Glass, & Rush, 2004; NSW Cervical Screening Program & the NSW Pap Test Register, 2005).

Imagine if you will, some of these women sitting in a living room discussing their experiences. On occasions they are joined by background voices belonging to some critical theorists but the principal voices will always be those of the women. They have invited us to listen to their stories of waiting.

Discussion

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Waiting months for an appointment

Margaret had an abnormal Pap result and was told that the “Grade 4” (adenocarcinoma in situ) result was “pretty bad” by her general practitioner (GP) in November. She was advised to see a gynaecologist as soon as possible but the earliest available appointment was in two months.

Margaret shares:

This was in about November ... and I was booked in to see the gynaecologist in January! So, I had that Christmas thinking, “I’ve got cancer! I’m going to die!” (Margaret)

Megan’s abnormal (CIN 3) Pap result also came back before Christmas. The GP informed her that he didn’t know whether she would “live or die” and booked Megan in to have the colposcopy in January. Megan contacted the colposcopist herself and managed to get an earlier appointment. Even the week she waited was a long time for Megan:

It was an awful long week ... How am I going to live ... not knowing whether I am going to live or die? ... It was a long week, yeah, not knowing anything. That’s why when I walked in there, I burst into tears. And [colposcopist] said, “What’s wrong?” And I said, “Well, I’ve got three kids, I need to know if I’m going to live or die. You know, I’ve got a life to organise here.” (Megan)

Marie believed she had cancer of the cervix. She was a young mother and midwife working night duty at the time of her abnormal Pap result. On three occasions Marie made arrangements to attend a colposcopy clinic in the city, one and a half hours’ drive away. Three times the colposcopist cancelled her appointment:

So I rearranged my night duty schedule and made sure that I had the kids in childcare for that day and the ... [afternoon before] I was at home, the telephone rang and it was the public clinic ringing to say that the clinic had been cancelled and that they had rescheduled me for a month's time. And I went, "Oh, OK, yeah fine." So I rearranged my schedule again and made sure that I was available for that appointment that they gave me for that month's time. And then the day before that next, that second appointment ... the telephone rang again and they cancelled the clinic again. And I went, "Oh, this is not good." I said, "Do you realise that my Pap test is abnormal and I'm really nervous about that." And she said, "Look I'm sorry but there is nothing I can do about it." So she rescheduled me for a third time a month later ... like three months down the track. And then lo and behold the third time, I picked up the phone, they rang me the day before and said, "Sorry but we've cancelled the clinic again – you'll have to be rescheduled." And I just lost the plot at that point in time, I was sleep deprived, I'd been working full-time night duty ... and I had to rearrange the kids' appointments again ... And I just stacked my turn, I just really let off at this receptionist on the phone and said, "Don't you realise I've got cancer in my body, and I could bloody well die and I've got two small babies and I've got a husband. And really I'm terrified out of my brain ... This is the third bloody time you've cancelled me and I could be having third grade cancer and I could be dying." She said to me, "... have you got private health insurance?" And I said, "Yeah, well what bloody good is that? ... It doesn't help me in this situation." She said, "Yes it does, you can come in tomorrow." (Marie)

Marie was in private health insurance and once that was known was able to see the colposcopist the next day. Marie's status had changed from a dependent client to a purchasing consumer. Fraser (1989), in discussing the North American social welfare system, described how women were considered either deserving or undeserving recipients of services such as health care. Women who could afford to contribute financially to their own care were seen as deserving, while women who

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relied on a public funded health system were seen as undeserving. Aspects of the American system were reflected in the stories shared by the women in this Australian study. Once it was known that Marie was contributing financially to the cost of her colposcopy, it is as if she was now deemed to deserve an appointment the following day rather than to wait for what then would have been four months. Joyce was very conscious of this two-tiered, private/public health system and expressed her concern:

But I suppose they're busy, and you're only a patient aren't you? ... you're just a number aren't you really? ... I reckon you feel like a second rate ... especially if you're not in medical schemes. (Joyce)

Joyce believed that she was considered less deserving of health care services as she was not privately insured. She had intuitively picked up on the stigmatisation and the undeserving/deserving client ideology previously described in the literature (Fraser, 1989; Oakley, 1993).

Melanie had been contacted by the women's health nurse to say that her Pap result showed some irregularities. English was Melanie's second language and non-use of interpreters compounded the barriers. Melanie described her fear, especially when she was informed she would need to wait over a month to see the gynaecologist:

Just a little bit harder to understand in English than ... if they told me in my language ... I get a call from the nurse in the women's health clinic and she said, "Something is not normal, showing like some abnormalities." And I was very scared ... I wasn't scared for me [Melanie sobs silently], I'm not too scared to die ... I was just so scared for [son]. Where he would stay by himself and this is strange country and no friends or family and ... it was so hard ... I thought I was going to die. But I wasn't ready; I'm not ready to die. I was scared, that was my thought ... In the morning I rang Dr [gynaecologist] ... and I made appointment

and the woman, secretary she said, "The next appointment is on May the 12th." And I said, "Oh, for God's sake I'm going to die till May." (Melanie)

Having waited for up to four months from the time of the abnormal Pap result to the time of the colposcopy appointment, the informants then found they had to wait with many other women in the "waiting room" to see the colposcopist.

Waiting hours to see the clinician

Following the cone biopsy and diagnosis of adenocarcinoma in situ, Margaret needed to have regular and frequent colposcopies. This proved to be time consuming and frustrating for her:

The worst thing about them is the bloody waiting! You always have to wait! ... Always, always had to wait! ... Because you might be waiting for an hour or so ... well, two or three hours, depending on what they were doing. (Margaret)

Janette described sometimes waiting for hours to see a health professional and then waiting again for the actual procedure:

I would be undressed and just lying on the table waiting for the doctor to come, with the sheet over me. (Janette)

Janette, like most participants accepted without question that the doctor's time was so valuable, that she must be lying there waiting. Exacerbating the nocebo effect of waiting, Oakley (1986) observed that time spent talking with women during the consultation was significantly shorter when they were lying on the examination couch waiting for the clinician than when they were introduced to the practitioner while dressed and sitting in a chair. Furthermore, the woman's ability to both reason and question was reduced due to her lying horizontally rather than sitting upright. The fact that the

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woman would be more likely to ask questions of the practitioner if she were sitting in a seat was at best not considered by the clinician and at worst considered to be beneficial in an encounter where time equals money for the professional.

Faye also felt very uncomfortable and vulnerable, lying exposed on the colposcopy table, waiting for the colposcopist to arrive. She accepted that this was the way it had to be:

I mean it's just the thought of having to bare everything ... you've got nothing on from your waist down ... And I get there and I hate this part where you're laying in, so open ... He comes in and he sits down and talks to you and everything and, you sort of, just look around. And you just think, "Oh well, it's got to be done anyway" ... It's just the getting up there, and you're so open and then he walks in! ... I know all women feel the same way. It's an invasion of privacy isn't it? ... But, well, it just has to be, doesn't it? (Faye)

It was expected that clients wait, sometimes for hours to see a health professional. Marie contrasted the experience when exceptional circumstances meant that she and her family were 15 minutes late for an appointment. The emphases belong to Marie:

*We were 15 minutes late and ... the reception staff were so rude! She said to us, "You're 15 minutes late!" ... she didn't even ask us for an explanation. She just said, "You guys have to reschedule because the doctor's so busy that she can't fit you in." And I said, "Look, we're desperate, we need to see this GP, and she's been referred to us by the Mental Health Worker." "Oh, you're **that** family are you?" And by this stage the GP had come out of her office and she said, "What's going on?" And the reception staff member turned her back on us and said, "**They're late!** They're 15 minutes late for their appointment!" ... the GP looked at us and said, "Well I can't possibly fit you in now, because I'm already behind time! I'll give you ten minutes maximum! You can just sit over there and stay there until I'm*

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ready to see you!” And ... we were so stunned that we went and sat down ... I thought it was just so disgusting the way she spoke to us ... the GP would be half an hour late and we’re still expected to sit there and tolerate that, but it doesn’t work the other way around. (Marie)

The reception staff in this instance perceived that good “patients” wait for whatever length of time it takes for the health professional to be ready to see them and do so without complaining. Marie’s circumstances had inadvertently challenged the position and power of the medical practitioner. In doing so Marie brought upon herself and her family the wrath, not only of the medical practitioner but also of the workers who support the hierarchical medical structure. Fahy and Smith (1999) argued that deliberate or even accidental confrontation with the health care system is dangerous. By confronting the system, the health care recipient runs the risk of negative labelling, sanctions and even punishment for their perceived rebellion. As a consequence, women expected and accepted that they would wait, sometimes for hours to see the clinician. Having waited months for the appointment, hours to see the colposcopist, some women then described waiting for weeks to hear the results of that encounter.

Waiting weeks for the results

Terry received the bill for the colposcopy and the biopsy within days of the procedure but six weeks later had still not received the results. Annabelle described waiting for the results of a colposcopy and punch biopsy – results that took five weeks to reach her, when they were available many weeks earlier to the health professionals:

I had to wait another five weeks for the results ... the biggest five weeks of hell ... I thought what would happen if it came back positive. If ... I had to go in for other surgery, I was really worried about that ... whether it affected my ableness to have children ... A lot was going through my brain ... a whole heap of horrible thoughts. (Annabelle)

The colposcopist had communicated the results to the referring health professionals, but neither the colposcopist, general practitioner nor the women's health nurse had informed Annabelle. Accepting that "doctors are doctors" and not expecting any better service, Annabelle described how waiting five weeks for the results was the hardest part of the whole experience for her:

I believe [women's health nurse] got a letter, but I didn't! ... The most difficult part ... just the wait! That's it. The waiting to get the results, I think that was about the hardest ... It was just those five weeks that I had to wait for the results, that was about the hardest.
(Annabelle)

Annabelle was disappointed that the women's health nurse, the general practitioner and the colposcopist had not considered that contacting her about the colposcopy results might be therapeutic. Annabelle did not contemplate the possibility that she could act as an assertive consumer and contact one of the health professionals for the results. Lupton (1995) has described situations such as Annabelle's inaction as a deep-seated need to invest trust in the professional, modelled on the parent-child relationship. The inaction on the part of the health professionals was not consciously malicious, but rather an oversight or an assumption that it was the duty of one of the other professionals to contact Annabelle. The lack of malevolent intent on their behalf did not negate the nocebo effect on Annabelle and the five weeks of hell she suffered. Annabelle's needs had not been adequately met. Practitioners within the health care system had communicated between themselves; the needs of the system had been served but not the needs of the woman.

Limitations of the study and recommendations for future research

The nature of phenomenological research does not allow for generalisations to be made. Assumptions cannot be made about universal negative impacts of waiting on women with abnormal Pap test results. However, the women in this study alert nurses to the possibility that because this

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was their experience, other women with abnormal Pap results may also find that waiting exacerbates the nocebo effect for them. Future research exploring concepts related to cervical screening needs to redress the emphasis on the biomedical in favour of the sociological perspective. Women are the best source of knowledge on issues that affect them and research that listens to and publishes their stories can be used to optimise holistic nursing care.

Conclusion

Participants in this study experienced the nocebo effect which has implications for nursing practice. The women all requested that nurses be made aware that waiting is not always a mere inconvenience but that it can have serious implications for their wellbeing. The nocebo effect was not the result of any intentional act on the part of individual health professionals. Rather it was caused in part because the clinician was either unaware or felt powerless to consider and act on the effects waiting may have on a person's wellbeing. Waiting for a health service has become accepted by nurses and clients/patients alike who have been socialised through homage to the medical system to believe that waiting is both inevitable and inconsequential in non-emergency situations. However, the message received by women is of consequence. Waiting for care can be interpreted by women to mean that their time, and by implication they themselves, are of less value compared to the health professional. This can have deleterious if not devastating effects on a woman's health. The purpose of this paper has been to make women's experience of waiting visible and, in so doing help to make more equitable the taken-for-granted power differentials that exist between health professionals, including nurses and health care recipients.

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