LIVING LARGE: THE EXPERIENCES OF LARGE-BODIED WOMEN WHEN ACCESSING GENERAL PRACTICE SERVICES.

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ABSTRACT

Introduction: Numerous studies report high levels of stigma and discrimination experienced by obese/overweight women, within the health care system and society in the main. Despite general practice being the most utilised point of access for health care services, there is very little international or national exploration of the experiences of large-bodied women (LBW) accessing these services.

Aim: To explore LBWs experiences of accessing New Zealand based general practice services.

Methods: A qualitative, descriptive, feminist study. Local advertising for participants resulted in eight self-identified large-bodied women being interviewed. A post-structural feminist lens was applied to the data during thematic analysis.

Findings: The women in this study provided examples of verbal insults, inappropriate humour, negative body language, unmet health care needs and breeches of dignity at the hands of HCP's in general practice. Seven themes were identified: early experiences of body perception, confronting social stereotypes, contending with feminine beauty ideals, perceptions of health, pursuing health, respecting the whole person and feeling safe to access care.

Conclusion : Constant calls for body vigilance have, in effect, excluded the women in this study from the very locations of health that they are 'encouraged' to attend – including socialising and exercising in public, screening opportunities that require bodily exposure and accessing first point of care health services.

KEYWORDS: Obesity; large-bodied ; women; social stigma; primary health care; general practice.

WHAT GAP THIS FILLS

What is already known

Large-bodied women are highly stigmatised, and health care professionals' beliefs and opinions about large-bodied women often reflect assumptions from society in the main. There is clear international evidence that the uptake of negative stereotypes by health professionals can result in reduced engagement of large-bodied women seeking primary health care services.

What this study adds

This study confirms that international literature on obesity stigma is relevant in the New Zealand general practice context. Confronting stigmatising behaviour may offer more potential for good outcomes for large-bodied women.

INTRODUCTION

The International Association for the Study of Obesity (IASO) describes obesity/overweight as a global pandemic, placing unprecedented health, social and economic burdens on societies.[1] Similar to the global trend, in New Zealand the prevalence of obesity/overweight has almost tripled in the past thirty years, from 9% (males) and 11% (females) in 1977, to 27% (males) and 27.7% (females) in 2009.[2]

Obesity/overweight is a highly visible indicator of not adhering to Western cultural and medical norms of health and is a contentious and stigmatised human condition.[3, 4] Increased surveillance, debate and panic about causes and appropriate solutions to global and local levels of obesity/overweight have intensified the stigma and bias associated with body size, particularly so for women.[5] Weight based prejudice and discrimination towards obese/overweight women (large-bodied women/LBW) and girls has been demonstrated in employment,[3, 6-9]education,[3, 10-13] and within domains of popular culture.[14-16] Discrimination, bias and inequity of care towards LBW also exists within the health care system. Negative stereotypical labels of the overweight/obese being lazy, lacking self control, and possessing low intelligence have been revealed from physicians,[17-21] nurses,[18, 22, 23] and dieticians.[3, 18, 24] International literature suggests that one effect of this censure of LBW is that they are more likely to delay or avoid preventative health care services, including breast and cervical screening and gynaecologic examinations.[25-27]

There is thus increased attention being given to health care providers' (HCP) role in caring for obesity/overweight patients. Recommendations from the Clinical Guidelines for Weight Management in New Zealand Adults[28] encourage the establishment of a therapeutic relationship which respects and considers the lived

realities of an individual. In order to achieve this, HCPs need to bracket their own personal attitudes and cultivate an environment that reduces the burden of stigma for those living the reality of being large-bodied.

With a paucity of both local and international qualitative research to draw upon, the aim of this study was to explore LBWs experiences of accessing New Zealand based general practice services.

METHODS

Descriptive, qualitative inquiry is a generic approach within the naturalistic paradigm, and aims to provide a straight description of the studied phenomena in 'everyday' or near data terms.[29, 30] It is an emergent design that facilitates the use of various research methods,[31] and is particularly useful when wanting to explore a relatively unknown subject matter. Descriptive qualitative inquiry is often used for investigating quality and access issues for service stakeholders.[29]

The theoretical approach of this study was feminist, thus being especially aware of the role of gender in shaping experience, perception and expectation.

Self-identification of being a LBW was the fundamental criteria for inclusion in this study. Advertisements in local newspapers, a gatekeeper based at the local Primary Health Organisation and snow-ball sampling resulted in ten women volunteering for the study. Prior to being interviewed two participants withdrew consent, citing fear of identification. This was an ethical issue recognised early on in the planning phase of the study due to the small locality, a regional shortage of general practice providers and the possibility of identification compromising current relationships with HCPs. To mitigate these risks potential identifiers in the participants' medical history were

avoided. Consideration was also given to the potential of patients from the researchers practice volunteering for the study.

The main form of data collection in this study was gathered from face-to-face interviews with participants. The interview guide for this study was based on a set of questions that had been successfully used in a similar international study (see Appendix A).[32] In addition to interview material, the researchers' field notes and journal of early analytic thought processes were included as raw data. The interview data was transcribed verbatim by a contracted transcriber, thence subjected to thematic analysis. The data corpus was searched systematically for recurrent patterns of verbal and non-verbal cues, patterns and repetitions across the participants' stories. As per agreed processes for thematic analysis, the initial broad clusters of data were thence coded and refined into a final assembly of seven themes. Interviews and initial analysis were conducted by NR. JC independently read transcripts and reviewed themes. In line with feminist reciprocity and reflexivity, participants reviewed the initial broad clusters and provided feedback on their accuracy or otherwise.

Ethical approval for the study was received from the Massey University Human Ethics committee/Southern A (reference 10/57).

FINDINGS

The women in this study were acutely aware of their inferior social positioning as LBW living in a society which cultivates slimness as both a beauty and health ideal. After interviewing the eight participants for this study, it quickly became evident that enduring effects of social stigmatisation were intrinsically related to these women's

definition of self, which ultimately influenced how they positioned and expressed themselves as health care consumers.

Early experiences of body perception

For some women, the onset of puberty and adolescence was defined as a period of weight gain and recognition that their appearance was an instant signifier for others to make judgements:

> If you're constantly told you are fat as a kid then no matter how much...cos it's so ingrained that 'You're fat, you're always going to be fat, nobody's gonna want you cause you're fat'. (Loreen)

Whilst social pressures to conform to appearance norms are experienced by both male and female youth, the pressure for slimness has a particularly salient impact on girls and women's experiences of their bodily self.[33-35] During the formative years of childhood and adolescence, a matrix of processes begins to shape and construct women's sense of femininity, health and body image. Increasing exposure to mass mediated images of feminine slim ideals set an aspirational cultural standard. All the while, reinforcement of these messages are upheld within primary group relationships with peers and parents[36] and by sanctioned 'authorities' such as medicine and media . As a result, girls enter into puberty significantly more likely than their male peers to overestimate their body size, be generally dissatisfied with their bodies and more vigilant towards self-imposed 'body work' such as dieting.[36, 37]

Confronting social stereotypes

Similar to existing literature on embodied experiences of largeness,[38-43] and despite differing backgrounds, the women in this study provided similar narratives of multiple

situations in which they perceived negative stigmatising reactions to their body size. The current social milieu strongly grounds itself in an obesity discourse based on thermodynamic theory, a simplistic and well challenged [44-50] assumption that slimness is a matter of energy in exceeding energy out.[47, 51] It is perhaps no surprise that hegemonic assumptions of overeating and indolent lifestyles are at the core of obesity stereotypes acknowledged by these women:

> ...it's that lazy thing, that you're greedy, gutsy, stupid. (Angela)

> I'm always eating cakes or lollies' – which is not true but that's an assumption people make... (Theresa)

As a consequence of enduring societal assumptions of gluttony and slothfulness, many of the women were wary of participating in social activities that involved buying food, eating or exercising in public. These acts of self-preservation from potential/actual acts of stigmatisation are both self-imposed and socially endorsed.[39] Withdrawal from even the most fundamental aspects of daily living can have significant impacts on LBWs sense of belonging and self acceptance – and ultimately their sense of health and health seeking behaviours.

Contending with feminine beauty ideals

In a society which has normalised the slim ideal and regularly ~~prolifically~~ espoused dualist frameworks of fat/ugly and slim/attractive, the visibility of a large body renders it difficult to 'blend' in and avoid becoming a target for stigmatisation.[34, 35]

> ...being overweight, people do stare and you do stand out...it's almost like being special needs. (Laura)

Perceptions of health

The Body Mass Index (BMI) and the oversimplification of weight being a proxy for health[45-47, 52, 53] was a notion that the women in this study mused upon and were able to recognise from their own everyday experiences:

> ...it's like some people who have a high cholesterol and are so flippin' skinny, and then you can get someone who is a bloody size 28 and their blood sugar is low and their cholesterol is low...and you think 'how does that work'? (Alana)

Most of the women in this study, whilst acknowledging that their bodies defy medically defined norms for health, described themselves as being healthy. Consistent with the findings of Buxton,[54] recognition of the widely reported risks associated with obesity were central to these women's definition of well being. For many, the absence of any such conditions was viewed as a sign of good health:

> I don't have any heart disease and blood pressure hasn't been a problem. Joints, well I don't think I have any problem other than the usual wear and tear as you get older...I'm pretty much healthy. I don't spend a lot of my time at the doctors'. (Selina)

Pursuing health

Corresponding with other studies,[32, 39, 54] the women described attempts to control their bodies in terms of battle. Many spoke of the fruitlessness of dieting and recognised the arduous task of losing the weight through near starvation – just to 'gain it all back again and then some':

> When I hear of kids that are going on diets I think, please don't. Cause once you start you are on the wrong road, you'll never get off it. You get your weight off and then as soon as you go stupid and have the first thing wrong, you go back and put it all back on

again...and a little bit extra. This is how you build up the weight usually. But you learn that from experience...I know that now, looking back. (Monica)

A lack of trust in the health care system to help them to negotiate the difficulties of healthy living was a common thread amongst these women's narratives. Similar to other countries,[32, 39, 54] many spoke of frustration with a lack of appropriate, effective and/or respectfully offered advice when discussing the issue of their weight with their general practitioner (GP):

They give you the fear (of weight-related health problems) but they don't give you a lot to resolve the issue if you desire. I have asked several times for assistance with my weight issue and haven't really been given the solution or tools that I need to help with that. I think they are too scared to approach it and don't know how to approach it without being negative or scaremongering. (Selina)

He/she (GP) said that the only thing I could do is lose weight. I thought 'yeah right'...between my (metabolic disorder) and the fact that I can't walk... (Laura)

Unsolicited advice by HCPs, particularly from nurses, was an occurrence frequently mentioned by the women in this study. Whilst Maggie was chaperoning a family member during an appointment with a practice nurse, the focus of weight management was quickly shifted to herself:

We were just talking. I got her weighed and we were talking there and she said, 'nana needs to lose some weight as well'. She said 'do you want to go to a dietician?' and I said, 'yeah, ok then' – I'll play your game... (Maggie)

Did she even ask what your diet was like before offering to refer you to a dietician? (Researcher)

No. She assumed, because I am big...but I didn't go. (Maggie)

Respecting the whole person

Acknowledgment that the patient is a complex and multifaceted individual who has rights to respectful, non-judgemental and appropriate care, is a fundamental principle of ethical and legal guidelines for the practice of all health care professionals.[55-57] Yet, corresponding with international findings [32, 54] many of the women in this study felt they had experiences of being treated as a pathological being rather than as a whole person with complex lives, stressors and obligations which exist outside of the health care environment:

> ...just don't see the medical part of the person, of course that's what you are there for, but you've got to see the whole person first before you see what you're trying to 'fix', because a lot of its combined I reckon, well it's all combined really. (Monica)

Similar to international studies,[32, 54] the women described their sense of frustration, anger and disappointment when their GP dismisses or belittles their presenting problems. Many felt that their body size distracts the GP's attention away from the presenting complaint and erroneously places their body size at the forefront of any diagnostic reasoning:

> It got to the point that everything about you was your weight. Whether you were sick, whether you went in for something like an infection on your leg – everything was about the weight. (Angela)

The clash of these opposing agendas, the women wanting their health concerns to be validated, and the perception that the GP was situating weight as the primary concern, meant the women often felt that they were not being listened to:

> Don't look, but <u>listen</u>. That's the thing. If you could just blindfold them all... (Monica)

> So what do you do? Stand behind a screen and just tell the doctor so he doesn't know what he is dealing with? It's the problem you are dealing with...not the fat. You've got to show you care and you have to listen. (Maggie)

Several women reported incidences when the general practitioner had walked to the door in the midst of conversation – signalling the end of the consultation:

> I still wanted to talk to him/her about something else but he/she got up and walked to the door and stood there like it was time for me to leave. He/she needed to listen to me and reassure my fears. (Selina)

Consequently, for most of the women in this study, experiences of accessing first point healthcare from general practice was fraught with battles to be heard and, as one of the participant's eloquently summarised:

> If you aren't going to listen to me, then why should I listen to you? (Angela)

Feeling unsafe threatens access to care

Several of the women spoke with a sense of resignation, suggesting that stigmatisation was part of living in a large body, but there was distinct disappointment that weight bias was also something they had to face within the confines of a consultation with a medical professional:

> It's this old judgemental thing coming in to it. They don't have the right to do that. Everybody is equal, doesn't matter what size they are, what culture, what anything...you know, stop doing that. You're a professional. You've been trained in medical school for how long to help people...a person who judges people because they are big, to me, is narrow minded and shouldn't be in the profession because that's not what they are there for. (Maggie)

Several women disclosed incidences when their general practitioner had made inappropriate 'jokes' about their size. Angela shared the following comments made to her in the course of seeking care from her previous general practitioner:

> Have you tried swimming? Cos you would definitely float!
>
> Did you think you would bounce? (post a fall with suspected fracture)
>
> You're healthy, no under nourishment there!
>
> Pheeww there is a lot of you' and 'You're a big girl

She reflected on these experiences and stated:

> The GP sort of joked about my weight like it was an 'in joke' between the two of us – but he/she was the only one laughing. (Angela)

Corresponding with previous studies,[25, 26] many of the women in this study admitted to either delaying or avoiding personal exams such as cervical smears and breast exams, fearing embarrassment and potential humiliation with body exposure. Only two women stated that they felt comfortable to approach their HCP for a personal examination:

> I choose not to go for certain things. I will avoid anything that will expose my imperfect body or go to the utmost extreme lengths...smears and all that exposing type thing unless I really have to. Probably it's due to the fact of how many bad times I've had with people that I just don't feel comfortable...you're constantly looking for responses. (Loreen)

Of those currently overdue for routine cervical screening, most had a history of experiences with a smear taker who made inappropriate comments, grunted and

sighed excessively or demonstrated facial expressions that implied the women were a nuisance, some even been told that 'it would be a lot easier if you were smaller'.

DISCUSSION

As the findings have shown, before the women in this study even enter into the domain of health care, they have been labelled as lazy, gluttonous, ugly and stupid – socially diagnosed as having a self-inflicted disability and widely prescribed as a problem needing to be 'fixed'. They entered into the general practice domain with a heightened sensitivity to stigmatisation, desperate to be acknowledged as individuals - not specimens to be pathologised and unfairly judged. The women in this study provided many examples of explicit negative weight bias experienced from their general practice team. Verbal insults, inappropriate humour, negative body language, dismissal, unmet health care needs and breeches of respect contravene expectations of a health care profession that claims to be 'committed to excellence in health care' (p.120).[58] Furthermore, professional standards of clinical competence direct registered medical professionals to:

> .. not refuse or delay treatment because you believe that a patient's actions have contributed to their condition. Nor should you unfairly discriminate against patients by allowing your personal views to negatively affect your relationship with them or the treatment you arrange or provide. Challenge colleagues if their behaviour does not comply with this guidance (p.11).[59]

In addition, the Health and Disability Commissions 'Code of Health and Disability Services Consumers' Rights Regulations, [60] clearly sets out consumer rights as well as obligations and duties of healthcare providers. Among these rights are those which assert the right of all patients' to be treated with respect, dignity, effective communication and freedom from discrimination and exploitation.

In the absence of patient-centred care, as demonstrated in this study, these women have experienced and continue to experience unmet health care needs. Several of the women have actively chosen not to pursue such procedures as pelvic exams and cervical smears because of previous humiliating experiences. This despite obesity being cited as a significant risk factor for endometrial cancer in both the pre and post-menopausal woman.[61] Many of the women also admitted to feeling disempowered within the HCP-patient relationship, selectively disclosing their health care concerns according to their perceived level of risk for dismissal of their concerns as being weight focussed. Trust for these women, was inherently based on their faith and belief that their HCP would be sensitive to their needs - not abuse/belittle/'joke' or chastise them for their body size. Those that spoke of 'good' or 'great' partnerships, said they felt their GP 'really knows' them, respects their attempts of health seeking activities and encourages them in a kind and respectful manner. They feel they are being listened to by their HCP because their needs are met in ways that do not always reduce the problem to that of their body size. In return, those women who feel respected, seek screening opportunities, disclose health concerns and feel safe to access care freely. In essence, they become engaged with the health care system and thus become partners in health.

The experience of these participants suggests that health professionals believe that body size is purely a matter of choice and willpower. Such a belief is not supported in the literature.[43-49, 53, 62-64] This study, whilst small and not generalisable, suggests that rather than stigma and exhortations to weight loss there are more constructive ways of optimising health for people living the battle of body size.

COMPETING INTERESTS

None declared.

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Appendices

Appendix A: Semi-structured interview guide

- Participants will choose a pseudonym at the beginning of the interview.

Tell me a story, one you will never forget, about going to your general practice (GP) clinic.

Can you describe to me what is it like for you to be a patient in the GP clinic?

Describe your relationship with your GP/practice nurse/clinic reception staff.

Have you ever hesitated or delayed going to your doctors' surgery because of your body size?

What sort of things would you change about your general practice experiences?

When visiting your GP, what sorts of things have contributed to a positive experience?

What sort of positive things would you like to see retained at your GP clinic?

What is it like for you, to be a woman who is large-bodied/overweight?

How would you describe yourself and your body?

What else would you like to say about your experiences with your general practice clinic?