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Cancer risk in socially marginalised women: An exploratory study

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ABSTRACT

Background: Cancer is a leading cause of premature death in women worldwide, and is associated with socio-economic disadvantage. Yet many interventions designed to reduce risk and improve health fail to reach the most marginalised with the greatest needs. Our study focused on socially marginalised women at two women's centres that provide support and training to women in the judicial system or who have experienced domestic abuse.

Methods: This qualitative study was framed within a sociological rather than behavioural perspective involving thirty participants in individual interviews and focus groups. It sought to understand perceptions of, and vulnerability to, cancer; decision making (including screening); cancer symptom awareness and views on health promoting activities within the context of the women's social circumstances.

Findings: Women's experiences of social adversity profoundly shaped their practices, aspirations and attitudes towards risk, health and healthcare. We found that behaviours, such as unhealthy eating and smoking need to be understood in the context of inherently risky lives. They were a coping mechanism whilst living in extreme adverse circumstances, navigating complex everyday lives and structural failings. Long term experiences of neglect, harm and violence, often by people they should be able to trust, led to low self-esteem and influenced their perceptions of risk and self-care. This was reinforced by negative experiences of navigating state services and a lack of control and agency over their own lives.

Conclusion: Women in this study were at high risk of cancer, but it would be better to understand these risk factors as markers of distress and duress. Without appreciating the wider determinants of health and systemic disadvantage of marginalised groups, and addressing these with a structural rather than an individual response, we risk increasing cancer inequities by failing those who are in the greatest need.

1. Background

Cancer is a leading cause of premature death and disability worldwide, especially in women (Soerjomataram et al., 2012; Vos et al., 2015). Worldwide, more than 2 million women are diagnosed with breast or cervical cancer every year, but where a woman lives and, equally important, how she lives will influence whether or not she develops one of these cancers (Ginsburg et al., 2017).

Preventable cancers linked to behaviours such as smoking and physical inactivity, often termed 'lifestyle diseases', are estimated to cause 42% of UK cases (Cancer Research UK, 2013). However, many interventions which are designed to improve health, for example screening or smoking cessation, fail to reach the most disadvantaged and marginalised. Smoking rates, for example, are four times higher

among the most disadvantaged in the United Kingdom (Hiscock et al., 2012) and the age-standardised mortality rate for all cancers is higher in more socio-economically deprived groups (Cancer Research UK, 2013). There are also substantial socio-economic variations in cancer screening attendance. People with higher levels of education are more likely to participate in screening for cervical, breast and colorectal cancer (Willems and Bracke, 2017). One reason for this may be limited health literacy, which has been suggested as a barrier to England's national colorectal cancer screening programme, which is available at no cost (Kobayashi et al., 2014). In England, whilst there has been an improvement in screening inequalities for breast screening, low uptake of cervical screening continues to be resistant to change in poorer areas (Douglas et al., 2016). It is possible that this is because information and access are not socially equitable, rather than as a consequence of

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informed choice (Douglas et al., 2016). Additionally, delays in symptomatic presentation are associated with greater socio-economic deprivation suggesting a need for tailored approaches to promote the importance of cancer symptom awareness and early presentation for people of the lowest socio-economic status (Forbes et al., 2014; Simon et al., 2010). Cancer risk perceptions are a key predictor of risk-reduction practices (Klein and Stefanek, 2007). However, a recent scoping review found a lack of research on how those considered vulnerable perceive their vulnerability (Grabovschi et al., 2013).

Women in refuges, victims of domestic abuse and female offenders are examples of socially marginalised people at high risk of cancer through multiple risk factors such as socio-economic disadvantage, personal circumstance, substance abuse and low screening uptake (Cadman et al., 2012; Collier and Quinlivan, 2014; Douglas et al., 2016; Levinson et al., 2016; McNutt et al., 2002). Specifically, more needs to be understood about the social circumstances and structural violence women experience (Winter et al., 2001), which may profoundly shape women's vulnerability to cancer and its risk factors. There is a close link between domestic abuse and offending. Fifty-seven per cent of women in prison report having been victims of domestic violence (and likely to be subject to under-reporting) and more than half (53%) report having experienced emotional, physical or sexual abuse as a child (Prison Reform Trust, 2017). Women in the judicial system are frequently underserved by health services and negative experiences with professionals make it harder for them to seek help, hence women's multiple needs are often overlooked (Prison Reform Trust, 2016). Such women are likely to come from socially marginalised backgrounds where persistent health inequity remains (Marmot, 2015). Importantly, these groups are also under-represented in research. This study therefore sought to listen to the experiences of socially marginalised women and understand risk from their perspective within their particular social context reflecting the wider determinants of health (Dahlgren and Whitehead, 1991; Marmot et al., 2010).

Thus our study worked with a women's group that supports women who have been subject to domestic abuse or who are on probation or at risk of offending. It is run by one of England's largest providers of housing and support for people in need. Housing Associations provide low-cost social housing on a non-profit-making basis. They house more than 5 million people in England and support the more socio-economically marginalised, such as those with experience of domestic violence or mental ill-health (Buck et al., 2016). Moreover, they have a long-standing tradition of providing support in prevention and self-help to disadvantaged groups, and are increasingly commissioned as National Health Service (NHS) partners (Chevin, 2014). The aim of the study was to explore women's perceived vulnerabilities to cancer within the social context of their lives, and to better understand how this contributes to increased cancer risk. The longer term aim was to explore the feasibility of developing a personalised cancer prevention strategy in this underserved high cancer risk population.

This study was framed within a social practice perspective, focusing on women's actions and active negotiations rather than treating them as passive in their experiences of health and social care. A social practice approach recognises the importance of social context and practices shared with others that are learned over the life-course (Blue et al., 2014). As such it moves beyond the presumption that individuals are capable of making 'better choices' based on information they receive (Blue et al., 2014) and recognises that the context and conditions of people's lives needs greater consideration to reduce disease beyond 'lifestyle choices', individual motivation and behaviour change (Blue et al., 2014; Cohn, 2014). From this perspective health behaviours, such as smoking, need to be understood as a shared social practice, existing beyond the individual self, related to other practices, people and life-long experience (Blue et al., 2014). Importantly, this socially situated way of viewing health recognises that health or social care information can be overwhelming, ineffective or simply inappropriate in people's complex everyday lives (Horrocks and Johnson, 2014) and may help to

explain why changing health-related behaviour is so difficult (Kelly and Barker, 2016).

2. Methods

2.1. Research design

The focus of this qualitative research was to understand cancer risk, decision making and opportunities for improving access to health care for women who are socially marginalised and subject to inequities in health, framed by a social theoretical, rather than a psychological, attitudinal approach. We used semi-structured interviews to obtain qualitative data, as the focus of interest was the perspective of the women and the staff who support them (Mason, 2002). Face-to-face interviews also provide an opportunity to create rapport and to enable a comfortable interaction, encouraging engaging and honest dialogue (Tracy, 2012) about sensitive health and lifestyle information (Ezzy, 2013). This was considered particularly important in our population. In addition to individual interviews, a focus group was run with two women's groups that were run in different locations. The participants in each group were well known to each other due to training programmes they were attending together. The focus group was used to capture the exchanging of anecdotes, collective experience and why people think the way they do (Kitzinger, 1994, 1995).

The study followed the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007). Ethical approval was given by the ethics committee at [removed for peer review] in February 2017 and in June 2017 for the additional use of focus groups to collect group data.

2.2. Participants and recruitment

The study was conducted with women who attend two women's centres for support, based in [removed for peer review]. This takes the form of informal 'drop-in' coffee mornings that are supported by a peer volunteer, training programmes that the women choose to attend and courses run by women as a mandatory element of their probation conditions. The centre is a 'secure base' for the women where they have built positive and trusting relationships with staff. The primary author (SH) visited the women's centre to propose the research and joined one of the training sessions to discuss acceptability and feasibility. She is a white, middle-class, post-doctoral researcher with a career in health and has worked in a men's prison in an education capacity. The women gave their support to the research and the type of questions likely to be posed was discussed and agreed with them. The research was promoted on the women's social media page (their suggestion, and content not seen by the researcher) and with posters in the centre. Women were given the option to attend interviews or focus groups. In total fourteen women and seven members of staff were interviewed, and the two focus groups had seven participants (which included three women who had been interviewed but also expressed interest in the group discussion) and five participants respectively. One woman declined to be interviewed and one did not attend. In total 23 women were involved and seven staff. The interviews and focus groups were conducted by SH. The interviews and focus groups appeared to give a wide range of differing views. However, when we started to see recurring themes and ideas we made a pragmatic decision that we had collected sufficient data to be representative of the women's experiences and ceased data collection.

2.3. Data collection and analysis

Questions for the interviews with clients included experience and perceived vulnerability to chronic disease and cancer; experience of the UK national screening programme for cervical, breast and bowel cancer, lifestyle questions and views on health in general. The interviews also included validated quantitative questions. For physical

activity we used the single item question (Milton et al., 2010); for smoking we adapted the WHO tobacco use survey to establish current, past and quit attempts (Global Adult Tobacco Survey Collaboration Group, 2011), for alcohol, we used AUDIT-C (Bradley et al., 2007), wellbeing we used the WHO-5 Wellbeing index (Topp et al., 2015) and for self-rated health the UK Census questions (Office for National Statistics, 2013). These quantitative results have not been fully reported in this paper as they were intended to assess feasibility and appropriacy for a potential national survey. For this study, aggregate results were used as an interview prompt to guide the questions around health and to give insight and context into individual circumstances. Questions for the staff covered their experiences of health promoting activities for the women, their views on the women's needs and barriers and facilitators for support for the women. Staff were front-line support workers as well as managers – all of whom had experience in working with women who were marginalised by their social conditions. Questions for the focus groups included a warm-up activity using pictures to debate and rate well known determinants of cancer (e.g. eating healthy food, cancer screening), their experience of accessing health information and support, and knowledge of symptoms that might cause concern about cancer. Personal questions, such as questions about their own health, were not asked in the focus groups. The interview and focus group topic guides can be found in the supplementary file. Data from the focus groups was combined with data from the interviews to give both individual insight into their health practices and also shared experiences of health services (such as cancer screening) that was gained through group conversations.

Both interviews and focus groups were digitally recorded and transcribed verbatim by an experienced member of faculty staff. The transcripts were then coded – initially deductively following the topic guides – and then analysed thematically (Braun and Clarke, 2006). The initial codes were categorised and explored more inductively by SH and CG, in particular women's rich contextualisation of our questions in the descriptions of their social lives.

3. Findings

The following themes were found, and are presented with supporting illustrative quotes from either the interviewed women (W), staff (S), or the women participating in the focus groups (FG). The themes are summarised in Table 1.

3.1. Risk factors in the context of the women's daily lives

Women's narratives of risk factors were strongly situated in the circumstances of their very difficult daily lives. For example, material poverty, the use of food banks, living in a hostel and the mental distress of children being removed and prison sentences. Our findings suggest that these circumstances represent the conditions and lack of control over their lives that are the sources of their risk, rather than single behaviours.

3.1.1. Physical activity for pragmatic reasons or as a coping strategy

Women shared a variety of different narratives relating to questions of physical activity as a health behaviour, or of physical inactivity as a risk factor. Whilst there were high levels of walking amongst about half of the women, they did not speak about this as a desired or pleasurable experience, or an activity chosen for health. Instead, women walked because they did not have access to a car, or could not afford a car – 'I've got no option but to walk. I walk miles and miles and miles to appointments' (W8) – and also, 'because I lost my [driving] licence so now I do walk more' (W7).

Walking was therefore often not a positive experience but at best a functional one and at worst a distressing one. Walking was also associated with anxiety, and here perhaps acted as a coping mechanism rather than merely a form of transport:

'If I'm really anxious I don't do anything I just pace about ... I count that as active but I count that as being extremely anxious ... I walk about anywhere, even like over the woods if it's late at night ... I've been so anxious I've walked over the road without even looking ... it's like a fight or flight'. (W5)

For others, poor mental health led to sedentary behaviour. For example, 'I suppose I'm mentally exhausted so I'd just rather sit down and it's probably not helping me and I understand that but again I'm not mentally ready to do anything about it' (W9) and 'If I didn't have somewhere like this place [support group] to come to I would be indoors most of the time' (W10).

However, some women talked about being physically active as a positive and deliberate experience, although this was also in the context of adverse experiences and ill-health. One participant expressed walking as an enjoyable experience for its own sake, although she had also suffered with an eating disorder for twenty years and had a structured fitness regime as part of her weight control.

'Walking's a very good stress reliever ... I do speed walking, I can do 5 miles in an hour if I put my mind to it ... I'll always make time to go out for a walk. I can walk for hours without even realising, by the time I get back it's been 2 hours gone, that's 2 hours' worth of my time that I haven't sat there just smoking cannabis or having a cigarette ... I love walking'. (W12)

For one woman, physical activity was viewed as a positive influence on her mental health.

I don't know if I've still got a bit of PTSD. Certain things can trigger it off so I do meditation which I find really helpful, very calming and I usually do yoga as well, every week. (W2)

For another woman, living in a hostel, walking occupied her time but she didn't view it as exercise although she walked for several hours each day.

'I just walk around all day to be honest. I didn't know that was exercise. I enjoy it. I live in a hostel and I get bored so I walk for hours all day. I walk one end of the town to the other and I do it again after dinner and then I do it again but I don't like exercise. If I'm at home, that's all I do just sit about ... I'm surprised that I'm that active [after being told that she met the Government guidelines for moderate physical activity], I'm a

Table 1
Themes.

Higher order themes	Sub-themes
Risk factors in the context of the women's daily lives	Physical activity for pragmatic reasons or as a coping strategy Eating in the context of mental distress and material deprivation Alcohol and smoking in the context of substance abuse
Risk perception shaped by social circumstances	Self-neglect, self-harm, fatalism and mental ill health Social isolation and social support
Navigating health systems	Structural issues Trust in the system and people Health screening and reporting symptoms

lazy person to be honest. I wouldn't have even called that exercise ... But I do smoke a lot. Yeh, I smoke as I walk along. (FG 2)

Issues of poor sleep also featured, with sleep failing to give rest and a respite from the stressors from the day.

So I'd say it's been years, I can't remember when I last had what I'd call a restful sleep. (W5)

Terrible. Because it drains you. Last night I didn't get a lot of sleep at all, I probably got an hour, 2 hours because my brain, sometimes I'm physically tired but emotionally I'm not. Try to go to bed, read a book, make my eyes tired, shut my brain down, as soon as everything's shut off "tick tick tick" it's just a nightmare. (W12)

For another participant, sleep was an enjoyable part of her life, 'I do like my sleep. I can stay in bed and can sleep all weekend'. (W13).

3.1.2. Eating in the context of mental distress and material deprivation

Another key risk factor for many cancers is unhealthy nutrition. Our findings on eating were presented by participants in the context of their everyday lives where their food options where largely dictated by their circumstances which included poverty, food bank use and prison diets. For example relying on food banks or 'food is provided [in the hostel], breakfast, dinner and lunch'. (FG2) Thus healthy eating is problematic at a structural level and the notion of balanced nutrition is rendered unrealistic.

When I went in prison I was just over 7 stone, I was just skin on bones, I was that bad. I was drinking, not eating that was my lifestyle ... when I went into prison, obviously they had mostly potatoes and pasta with everything so when I came out 6 months later I weighed 11 stone. (W11)

The thing is with a food bank, I find you can't really make a meal out of what they give you. You can't put that together to make a meal. Tins of soup are ok for lunch but can't do meat, potatoes and vegetables ... it's ok if you want pasta on toast. (FG2).

Also, when asked about their eating, it was the issue of weight and (largely negative) body image that predominated, rather than health reasons guiding their food and eating choices.

You're made to feel ashamed, so you internalise that and make that your body shape and it builds up and it's just like a snowball effect, it just builds and builds and builds and with your easy food like the rubbish foods like the chocolate and the crisps and that, because that's easy and cheap it's easy just to keep doing that. (FG1)

This woman's account described a distressing experience of shame and little self-worth beyond notions of being over-weight risky for one's health. Even starker were accounts of women who placed their answers about healthy eating in the context of very concerning attitudes – here a woman explicitly not wishing for a long life – and the context of experiences such as prison diet.

I did try to start being healthy, sort of pasta salads and stuff like that but I just can't be arsed with it, I don't see the point. It's not as if I want to live to be like 70–80 years old. I want to be gone well before that. (W10)

3.1.3. Alcohol and smoking in the context of substance abuse

Finally, excessive alcohol consumption and smoking are important risk factors for cancer. As with physical activity and diet, women's narratives went beyond discussion of healthy levels of drinking and included starker accounts of alcohol abuse, which featured in most of the women's lives, alongside other substance abuse.

Yeah I'm sober. With a lot hard work and a lot of peer support and I actually stopped drinking. I had to stop. I nearly died. I nearly killed myself for it, I was falling into cars ... I was just going round in this vicious circle so in the end something had to go and that was the alcohol. (W3)

I took an overdose after drinking and the twice when I've tried to take my life and self-harmed has always been when I've drunk. (W7)

I felt completely isolated and I started to use alcohol more and more and then in the mornings that would be just a couple just to straighten me out for the day. Before I knew it I was an alcoholic. (w11)

The majority of the women were also smokers or ex-smokers. For some this was expressed as an enjoyable and sociable activity. Cancer prevention was not seen as a reason to quit, but other health reasons were given:

I have thought about it [quitting] but not for that reason [cancer prevention], just for my asthma more than anything. No I just get so tight at times and my breathing feels funny. I don't care if I go I just don't want to suffer. (W10)

Women's smoking was also narrated in relation to experiences of mental health problems, distress or deprivation.

I get anxious a lot so, I don't like being round people and I just wanna be on my own so. I have a fag just to make me relax more. (W14).

I smoke. I enjoy smoking. I've had four kids. I think well I'm on my own now, I enjoy a cigarette and that's the only thing, I work but I'm not well off and that's one thing that I enjoy so I'm not gonna give that up and then be grumpy all the time. That's my enjoyment. And that's the only thing I have for myself. (FG1)

The interviews with the women also included specific questions about their health and perceptions of health and wellbeing to enable us to contextualise the extent of their poor health. This demographic and health information was only asked of the 14 women who were individually interviewed. The average age was 46 and ranged from 34 to 67 years of age. All were white British. Twelve were smokers, one an ex-smoker and one was a non-smoker. Thirteen reported that they struggled with excessive alcohol consumption, six of whom had gone through at least one recovery programme. Women were asked to rate their health using the UK Census self-rated questions ([Office for National Statistics, 2013](#)) which is a five point tool rated from very good to very bad health. The women rated their health from good to very bad. There were divergent reasons for the answers given; for example, one woman who had Hepatitis C and was in a recovery programme rated herself as having good health. Self-rating of fair or bad health was explained by eating issues, smoking, alcohol consumption, stress and sleep difficulties. Participants explained that their positive views of health would be having more energy, being able to breathe properly, feeling lighter, 'getting out and about' and being able to eat one meal a day. Twelve women also completed the WHO 5 wellbeing questionnaire which assesses subjective wellbeing ([Topp et al., 2015](#)). A percentage score of zero represents worst possible and 100% represents best possible subjective wellbeing. The average score was 40% and ranged from 9 to 68%. All twelve reported mental health problems including anxiety, depression, functional disorder, eating disorders and bi-polar disorder and eleven reported receiving medication for their mental health. Two did not complete the questionnaire fully and therefore these were unable to be analysed.

3.2. Risk perception shaped by social circumstances

3.2.1. Self-neglect, self-harm, fatalism and mental ill-health

The previous theme on risk factors contextualised risk within the very difficult conditions of the women's daily lives. Additionally, our data indicates that *risk perception* was shaped by the women's social circumstances and failings at a structural level. Their narratives were framed in fatalistic, indeed from their point of view realistic, terms with a low expectation of living a long and healthy life and seemed to manifest in self-neglect and self-harm. We suggest that their fatalism

and resignation needs to be considered in the context of very real experiences of risk (of violence, drugs) and failures at a structural level. The following quote poignantly demonstrates the social circumstances of one of the women whose child had been removed by Social Services.

Because I didn't have my daughter for a couple of years so no point in cooking for myself. Cooking for her it gives me a purpose for my day. My main meal of the day is probably the only purpose I have. To go out and get it, get her from school and prepare it. (FG1)

Other women echoed these feelings of purposelessness, hopelessness or resignation.

No. If I get ill and die, I get ill and I die. I didn't think I'd make it to 40 so any more birthdays is a plus for me ... Because I didn't think I'd make it this far. So every day, I don't live it as my last, but I've done quite well to reach age 40. (W6)

No I'm not bothered about that [cancer]. Like I say, if I get it I get it so, I'm not worried about doing anything to reduce the risks. Whatever happens, I know what the risks are. (W10)

But also it's hard for people that live alone to find that motivation to cook, so when they say "Oh your lifestyle should be like this" and things like that it's like "Well how are you going to help me to achieve that?" (FG)

As the previous theme already indicated, long term mental ill-health dominated the women's conversations. Staff were also asked a question on their perception of the women's health.

I worry about dying yet I've tried to take my own life and I'm worrying about smoking compared to when I've necked loads and loads of pills and done myself some damage that way. Crazy. (W3)

Fifteen I was first diagnosed [with mental health problems]. It was weird because I couldn't explain how I was feeling. I just remember thinking in my brain 'something's wrong'. I've been on medication since I was fifteen". (W7)

This long term mental ill-health then led to poor views of self, manifested as signs of self-neglect/self-harm and poor physical health.

I know in the long term smoking isn't good for me. I know my weight fluctuating up and down, I know my sleep pattern isn't good for me, I know all these things aren't good for me but I think because the state of mind that I'm in, I don't feel mentally strong enough to actually tackle those issues and that's probably my biggest thing. (W9)

Staff in particular talked frequently about the self-neglect, poor self-esteem and self-worth that they saw amongst women. Aside from alcohol and other substance abuse, staff were concerned about frequent self-harm and eating disorders in the woman they looked after. This was related to the women's experiences not only of mental ill-health but distressing experiences of violence, losing children and deprivation.

They often have children removed so then there's even more self-neglect going on which then has an even greater impact on health and often we see women coming in here and in other services that I've worked in, really at 40, have the body of somebody much, much older than that. (S3)

Actually one woman said "Before I did this module I didn't even know what self-esteem meant" Not just have any, but actually didn't know what it was. (S7)

... that lack of self-respect is there all the time but they don't even know it's there some of the time, that sense of shame of being reliant on the state. (S7)

Yeah because you realise you're not the only person who's been in situations like that, you're not alone because most of the time when you live like that you just feel so lonely and not just lonely but alone. (W11)

And the longest days, believe it or not, are the weekends when you sit in the flat on your own and you only have your dog and cat to talk to. You find you go back to that abuser because there's no support there. (P8)

Staff provided important pastoral and practical support for the women. In terms of research they acted as vital gatekeepers. They also provided thoughtful reflections and insights into the women's circumstances which were often taken for granted by the women. For example, staff were very aware how socially isolated many of the women were, especially as they transitioned from various life events.

I've got some women that I work with who I am the only person they trust and that's quite humbling really and really sad that actually they would pick up the phone to me and not anybody else, I find that really sad but that is the way it is. (S2)

She spent a long time in prison, she's come out, she trained as a listener ... she had a cleaning job and she had the safety of the prison around her. She has struggled in the community with everything because she said "I can go a week and not speak to anyone". (S2)

Even accounts from women of their social surroundings, family and upbringing were often negative accounts and related to unhealthy practices. Several of the women reported leaving home at a young age (under 16) and the influence of parents and wider family members with mental health issues, abusive relationships and alcoholics.

I started when I was 11. I was that quiet and snappy my mother just threw a fag at me, she just went "Oh just have a fag" because I was a very naughty child, very naughty. (W8)

[addictive personality] I think it comes from my Mother's side of the family because most of them are alcoholics, smokers, whereas my Dad's side of the family suffered more with mental health. (W3)

This negative effect of others on the women's health also included practices within the state system which created problems for individual healthy behaviours.

When I went into prison they don't do vapes, they do things you can buy off the pod [shop for prison inmates] but they last about 2 days and cost about £4 each and you can't afford it so I went back to smoking and stuff. (W11)

I went into a psychiatric unit and there was nothing else to do so I got bored and everyone was smoking. That's where it was formulated [at age 26 years]. (W3)

In contrast to the above accounts of loneliness, familial and institutional neglect, there was a recognition of the support and understanding from other women who had similar experiences.

Peer support workers have already been through the mental health system and you don't have to feel like you're explaining yourself she gets it straight away. It's more of the practical help I've found that's been really wonderful. (W5)

You're so overwhelmed with feelings you think that you're the only one that's going through it, you're the only one that's had a bad experience. You know it's not true but there are times when you are so alone and then you come here [the women's group] and you see these women and some of the things you hear and you just go "God!" You just look in their eyes and you know they've been through similar experiences. (W7)

3.2.2. Social isolation and social support

Related to women's low self-esteem were women's expressed feelings of loneliness and isolation at particular times in their lives.

3.3. Navigating health systems

3.3.1. Navigating structural complexities

In their interviews, the staff of the women's centre pointed out that all the women had experienced using and navigating mental health and wellbeing services, which was often a difficult experience, requiring resilience and perseverance.

There's still a tendency with a lot of agencies to signpost to lots of different services and I think if I was a really vulnerable woman, really difficult childhood, had lots of health issues, maybe had addiction issues ... would I speak to 7 or 8 different people? Probably not Do you know what? They didn't engage because 8 people is really overwhelming. (S3)

It's not a particularly nice process to go through because you're sitting with somebody that you don't know and they're focusing on all the things that are not very positive about your life and then you get to the end of the [mental health] assessment and they say 'we'll be in touch' and then two weeks later you get a letter saying "You didn't meet the criteria for our service" and then it's "So how would I meet the criteria?" and I just had to sit for an hour and a half telling you all this stuff and now you're just saying, can't offer you a service. (S3)

Staff emphasised that women navigated these services and complex processes while largely living in chaotic and overwhelming circumstances that required their own substantial navigation and management. Living with acute financial pressures, for example, that made women think in fortnightly or monthly cycles did not match with a longer term view in health and social care.

They think either on a fortnightly or a monthly cycle financially, that's how they operate so that then impacts on how they think about everything really. (S7)

At the moment I don't know because the picture's like, with losing my kids and things like that, everything that's happened, is happening to me at the moment so I haven't really thought that far ahead. (W14)

3.3.2. Trust in the system and people

Similarly, trust in 'the system' and also the people representing these institutions was a challenge. Both the women (and their support staff) reported vivid examples of the women being let down by the services that were meant to serve them – sometimes in extremely distressing ways such as removing children, or withholding financial or mental health services. Agencies but also health professionals were therefore often regarded with suspicion and not always trusted to provide support and help.

For me to ask for help, even from my GP [general practitioner] it takes a lot, it takes a lot for me to do that because of my past and people letting me down it's like "Ok if I open up and speak to people then I'm gonna be let down again". (FG1)

The way she was presenting herself, the ambulance didn't want to take her ... [and said] "She doesn't need to be in hospital" and this just reinforced to that particular client "Well there you go see, nobody wants to help me" because she is so chaotic. (S1)

I think you have to remember as well though that an awful lot of them have been, have a really negative view of agencies across the board, so they might have been in care or not gone into care and been failed because they've been abused so straight away there's no trust because they weren't listened to. (S2)

3.3.3. Experiences of trust, in contrast, were rare and appreciated

I'm very lucky I've got a trusting doctor and I can trust him, it's like X said, you've got to be able to trust your doctor. (FG1)

3.3.4. Health screening and reporting symptoms

Experiences of cancer screening was asked of all 14 women during their interviews. Taking the women's often negative experience with healthcare services into account, it seems unsurprising that some were reticent about health screening. All women were of an age to have had cervical screening and four were eligible for the national breast screening programme. All four were up to date with their mammograms although one only attended after having breast pain and a referral from her family doctor. None of the women participating in this study expressed it as an important feature of cancer prevention. When we asked the fourteen women about cervical screening three were opportunistically screened, for example as part of a prison sentence. Of these, two were grateful that it was done and one said she would not be screened again. Five of the fourteen women had had abnormal tests resulting in follow-up and colposcopy.

When I went into prison I hadn't had a smear test since before my youngest was born and he's 21 ... the nurse was really nice and she talked me into it and the week I was waiting for the results because I'd convinced myself that it was, ...I used to get loads of letters from the doctors saying you need your screenings. (W11)

I never had one, for years I managed to just avoid the smear test letters and something wasn't right so I had a smear test and they found out that I had HPV, had to go and have my biopsy and the worry of waiting for them test results to come back was so stressful, a week- 10 days was just horrific, just thoughts of 'Do I fight it?' 'Don't I fight it?' 'Who am I going to tell?' 'Who don't I tell?' 'If I does happen what ... ' I will encourage people now to go and do it. (W12)

We always fight for mental health services and fight to get them their medication, never crossed my mind to even ask them if they're up to date with things like that [screening] ... I never thought about it. (S2)

During the focus groups, we also asked about women's awareness and if they ever reported cancer symptoms (for bowel, breast, lung and cervical cancer). Whilst there was some general awareness of self-checking of breast lumps, women knew little about symptoms.

Symptoms? If I started coughing up blood. If I had a cough I would just brush it off until I started having other signs like coughing up blood or thick mucus or pains. (FG1)

Cervical cancer symptoms? No don't know the symptoms of that. (FG2)

A staff member pointed out that this closely links to women's difficulties in navigating the healthcare system, knowing how to seek help and perhaps trusting that help would be provided.

I did have a client who was very, very unwell, hadn't engaged with anybody, she wasn't even registered with a GP and it was clear she was unwell. She ended up being diagnosed with cancer and dying about 3 or 4 months later. It was too far advanced but hers was because she was isolated and she had nobody to say to her "You're coughing and you're doing this and you're not looking well". (S1)

4. Discussion

This study sought to listen to women with complex lives and multiple vulnerabilities to non-communicable diseases, specifically cancer. Three major themes developed from the data: risk factors in the context of the women's daily lives; risk perception shaped by social circumstance and navigating health systems.

Our findings suggest that risk factors of physical inactivity, unhealthy eating, smoking and excessive alcohol consumption should not be viewed in isolation as mere modifiable behaviours or 'lifestyle choices'. Rather, viewed through a sociological lens (Blue et al., 2014), which places behaviour in relation to people's life-course and social context, we suggest that these behaviours are much better understood

when viewed as markers of distress. For example, women's accounts of physical activity included walking during the night in a distressed state, repetitive walking to pass the time when away from a hostel or as transport to get to multiple medical appointments are at worst symptoms of living in extreme adverse circumstances and at best coping mechanisms (See [Bostock \(2001\)](#) on walking and pathways of disadvantage). Similarly, accounts of unhealthy eating emerged related to material disadvantage and poverty and very real difficult social circumstances. This includes the use of food banks that provide foods which often cannot be combined to make a complete meal and are also often ultra-processed, and living in a hostel without access to cooking facilities. These experiences clearly represent wider societal, rather than individual, determinants of health.

Moreover, our participants had very limited perception of their risk of cancer, which echoes a host of similar studies in this area ([Calnan and Johnson, 1985](#); [Klein and Stefanek, 2007](#); [Thompson and Spacapan, 1991](#)). However, we explored in what way their perceptions were profoundly shaped by their experiences and circumstances of neglect and harm by others – some from a very early age - leading to self-neglect, self-harm, low self-esteem and low self-worth in later life. This was reinforced by repeated and negative (distressing) experiences with social and health care, a feeling of being let-down by such services, and a lack of control over their lives. Our study provides some insight into the resignation, hopelessness and social isolation these women experienced which rendered considerations of health risks, such as cancer a very low priority in their lives. We suggest that in such circumstances it may be a reasonable, rather than reckless, response to prioritise day-to-day basic needs such as safety, shelter and food over longer term preventive self-care.

Finally, the women's fatalistic views on health and risk should be placed in the context of lived experiences of navigating complex systems of health and social care, state benefits and referral systems, which are determined by broader forces over which a person has no control and little voice ([Brewer, 2018](#); [Thompson and Spacapan, 1991](#)). Perhaps because there are statutory systems in place and the women live in a country where access to healthcare is free at the point of delivery, their poor health might be blamed by some on 'chaotic lifestyles', but this would not acknowledge the complexity of such systems. Whilst the women were clearly overwhelmed, and often distressed, by their interaction with these services, the testimonies also pointed to their skills at navigating very complex systems for their medication requirements, psychological support, substance abuse services and for those women in the probation system, fulfilling these obligations too. Experiences of mental ill-health and signs of mental distress dominated the findings, although our questions were focused around physiological health. The women's very difficult experiences of navigating systems to try to get support for their mental health problems appeared to shape their expectations of the support they might also get for physical health issues. Viewed through this lens, screening for early detection of cancer and early reporting of symptoms becomes a marginal concern in the 'whirlwind' of everyday life, social circumstances and previous experiences. This may help to explain why delayed presentation is associated with socio-economic deprivation and represents a major challenge to improve early detection and increase survival for the most disadvantaged ([Forbes et al., 2014](#); [Simon et al., 2010](#)).

This study therefore contributes to a growing body of literature on understanding the complexities of behaviour change. Despite the contributions behavioural science has made to cancer control ([Miller et al., 2009](#)), changing health related behaviour remains very difficult, especially for those with multiple risk factors where we are seeing widening inequalities ([Buck and Frosini, 2012](#); [Kelly and Barker, 2016](#)). One of the reasons for this might be the lack of importance given to understanding the underlying psychological and sociological factors that profoundly shape people's behaviours ([Kelly and Barker, 2016](#)). Hilary Graham brought our attention to this perspective in her pivotal research with women who viewed smoking as enjoyable, indulgent and

something for themselves as a way of coping with the stressors of poverty ([Graham, 1993](#)). Graham further noted in 'Surviving by Smoking' that smoking was, "a way of keeping going when women have little going for them" ([Graham, 1994](#), p.103). It had a material and symbolic significance in marking out time away from caring responsibilities, controlling anger, relieving boredom and isolation and re-imposing order. Paradoxically smoking was identified by the women as essential to their survival ([Graham, 1994](#)).

Our study aimed to contribute to the increasing focus on health risks in the context of people's lives – in our case women who are marginalised by their social circumstances ([Cohn, 2014](#)). Without this consideration, there is a risk of focusing on individuals and individual behaviours and a narrow assumption of individuals' attitudes, intentions and thus responsibility for change ([Lupton, 2003](#)) without due consideration given to their wider context. The natural progression from this stance could be that people are blamed for seemingly irresponsible or irrational choices ([Horrocks and Johnson, 2014](#)). Rather, better to recognise the meaning that individuals assign to their behaviours ([Graham, 1993](#)).

Our study particularly highlights the importance of acknowledging structural violence related to health inequalities ([Winter et al., 2001](#)). The women in this study had suffered multiple disadvantages over the life-course and indeed have suffered harm from those who should have protected them – parents, family and partners. Taking a life-course approach to risk recognises that people are subject to many positive and negative influences that shape everyday lived experiences, health practice and responses to health promotion messages ([Baum and Fisher, 2014](#), p. 215). In her work on "vulnerable populations", [Frohlich \(2008\)](#) draws us to the notion that certain social groups (with shared social characteristics) are 'at risk of risk'; that is risks generate exposure to other risks. She also raises the notion that the term vulnerable population refers to groups who, because of their position in the social strata, are commonly exposed to contextual conditions that distinguish them from the rest of the population ([Frohlich, 2008](#)). Viewed in this light, rather than being unaware of risk, it is more likely that constraints and context of the women's lives (their risk of risks) will make behaviour change particularly difficult ([Baum and Fisher, 2014](#)).

Finally, our study can speak to the growing acknowledgement that social and peer support might provide a meaningful way for service organizations to support vulnerable population groups. In our study, much support and advice (and therefore decisions) for multiple social and health issues were provided by other women, both volunteers and apprentices (many of whom are ex-clients) who are 'women like us' and in whom they trust. Such women can be viewed as 'experts by experience' ([NHS England, 2014](#)). Indeed, during our study the addition of focus groups gave an opportunity to engage in general discussions about health. Women asked questions of each other during the discussions (and gave advice) which might lend support to the case that mutual solidarity from peers can provide a social opportunity that is helpful in health improvement. It is recognised that support from peers who share similar life experiences can be a powerful tool for improving and maintaining health ([Bagnall et al., 2015](#); [Benoit et al., 2017](#); [Naylor et al., 2013](#)) and empowering people to manage their own health ([NHS England, 2014](#)). Indeed connectedness, trust and reciprocity as demonstrated in peer support can be seen as the social glue that 'binds us together' and has the potential to enhance medical services ([Rippon and Hopkins, 2015](#)). This approach aligns conceptually with social practice as a relational concept that recognises that individuals are socially situated and that behaviour cannot be reduced down to things that people do and think as if they were isolated from others ([Kelly and Barker, 2016](#)). However, it is worth considering what this means if peers, family and others in whom people should be able to trust, are unreliable and untrustworthy.

5. Strengths and limitations

This was a small qualitative study with a relatively homogenous group of white British women in an English, largely rural county with a less diverse ethnic mix than other parts of the United Kingdom. This limits our findings to one particular demographic and the findings may not be applicable to other groups of women. Moreover, more in-depth work with repeat interviews or more extensive ethnographic work might have built more trust to gain a deeper understanding of these women's everyday lives. That said, a concerted effort was made to visit the centre and build rapport with the women several months before the research started and again to establish the practicalities of the research after ethical approval was received. This effort appeared to add rapport and for women to actively seek out involvement in the research but there is always the concern that this relationship building could have led to social desirability bias. However, as the women offered personal information beyond what was asked for in the interviews and expressed enjoyment and appreciation at being asked about their experiences, it is thought that this is unlikely. A major strength of this study is thus a representation of women with multiple vulnerabilities who are under-represented in research and gaining their views from their perspective.

6. Conclusion

Our study contributes to the very limited research on socially marginalised populations' perceptions of their own vulnerability (Grabovschi et al., 2013). Our study with a population at 'risk of risk' (Frohlich, 2008) found them to have multiple risk factors increasing their vulnerabilities to cancer, chronic diseases and also psychological ill health. The women were aware that many of their behaviours and the decisions they make put them at risk of early mortality. For them, 'risky' behaviours such as unhealthy eating were intrinsically linked to, and indeed could be viewed as a reasonable and proportionate response to, the complexity and challenges that comprise their daily lives and the risks inherent in these, including domestic violence, hunger, food banks, crime and imprisonment. Low self-esteem; low self-worth and neglect of self, dominated the narratives of our participants. Exploring 'risk' as an isolated phenomena – behavioural risk factors in isolation of otherwise risky lives – inevitably limits the understanding of women's lived experiences of health, ill-health and profound adversity. Our findings have implications for those designing health promoting interventions specifically for those groups who are disadvantaged and poorly accessed. We suggest that a focus on individual determinants, behaviours or motivations without appreciating the structural disadvantage, and even violence, experienced by such population groups is highly problematic. Instead, we suggest that more research should focus on understanding the exposure of risk for such population groups at a service provider level, and ultimately addressing this problem at a structural level.

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Appendix A. Supplementary data

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