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## ORIGINAL ARTICLE

# ‘Sometimes I can't look in the mirror’: Recognising the importance of the sociocultural context in patient experiences of sexuality, relationships and body image after ovarian cancer

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## Abstract

**Objective:** Ovarian cancer (OC) can significantly change the way women feel about their body. However, personal accounts regarding these changes are lacking in the literature. Therefore, the aim of this study was to gain an understanding of the ways in which OC can affect relationships, sexuality, womanhood and body image.

**Methods:** Ninety-eight Australian women aged 18 and over diagnosed with OC completed an online survey that invited narrative responses to open-ended questions about relationships, sexuality, body image and womanhood following OC treatment. Responses were analysed thematically while applying a sociocultural lens.

**Results:** Three themes and two subthemes were identified: *Failure and Loss of Femininity and Womanhood*, *Internalising Public Perception of Body and Illness* and *Altered Relationships* which comprised two subthemes, *Loss of the Sexual Self* and *Relationship Burden*. These themes suggest women view themselves and their relationships in comparison with sociocultural understandings of body normalcy. Women often questioned their self-worth, their relationships and place within society due to changes in fertility, sexuality and bodily functioning.

**Conclusion:** These results highlight a need for health care professionals to open dialogue with women about sexuality and ensure information and support is given to reduce stigma and positively influence self-perception and increase body acceptance.

## KEYWORDS

body image, emotional, ovarian cancer, psychological, quality of life, social

## 1 | INTRODUCTION

In 2021, an estimated 1720 Australians will be diagnosed with ovarian cancer (OC), a disease with a 5-year survival rate of 48% (Cancer Australia, 2021). Lower survival rates are linked to diagnoses occurring at advanced stages due to asymptomatic or nonspecific

symptoms (Boban et al., 2021). While the physical sequelae of OC are well researched, less is known about psychosocial and emotional well-being following diagnosis and treatment (Kim et al., 2015).

One of the major impacts OC can have is a change to sexual functioning and sexuality which has been proven to be an integral contributor to well-being and overall quality of life (QoL) (Roussin

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et al., 2021; Whicker et al., 2017). Kim et al. (2015) suggest that sexuality is a multidimensional construct which involves social, physical and psychological aspects. Despite the importance and impact of sexual functioning in QoL, the related side effects from cancer treatments are rarely discussed by healthcare professionals. This can lead to inconsistencies in psychosexual support which can reduce emotional intimacy and feelings of sexual normalcy within relationships (Kim et al., 2015; Perndorfer et al., 2019; Pitcher et al., 2020).

Gynaecological cancer treatment outcomes can also result in changes to body image (Bajpai & Shylasree, 2018; Teo et al., 2018) as well as femininity and womanhood (Dryden et al., 2014; Jayde et al., 2013; Parton et al., 2017) all of which are associated with increased feelings of isolation, depression, anxiety, poor body image and diminished emotional intimacy within relationships (Boban et al., 2021; Perndorfer et al., 2019; Pitcher et al., 2020; Teo et al., 2018; Tetteh, 2017).

The changes that occur due to treatments and the way women interpret these changes may also be influenced by sociocultural norms. Sociocultural norms tend to be based on idealised Western standards of beauty whereby women are influenced by peers, family and media which places pressure on women to look a certain way (Glauert et al., 2009; Weaver & Byers, 2013), as well as individual conceptions of what constitutes a 'normal', healthy functioning body. Interpretations may result in feelings of being incomplete, worthless, inadequate and fearful of rejection from partners both present and future (Dryden et al., 2014; Ussher et al., 2014), thereby significantly reducing QoL. Yet, accounts of lived experience through personal narrative are missing from the literature, especially in OC. Perceptions of bodily changes often occur through medicalised perspectives, like sexual dysfunction viewed as the inability to engage in penetrative sex and the cause of subsequent psychological distress (Ussher et al., 2013) rather than considering sociocultural norms as influencing emotional and psychological well-being. Previous OC research has also generally employed quantitative methodology or used qualitative methods with small sample sizes, focusing on specific OC stages, age ranges and treatment time points. Missing from the literature is large scale, qualitative research which captures a diverse range of experiences and outcomes and highlights the impact OC can have on psychological well-being among women of all ages at different stages of disease, treatment and recovery.

Therefore, the aim of the current study is to investigate the psychological and emotional impact of OC on sexuality, relationships, body image and womanhood by analysing qualitative accounts of personal experiences through a sociocultural lens. The findings will shed light on the realities of living with OC and how this influences the way women see and think about themselves. We refer to participants in this study as women as the significant majority of participants self-identified this way; however, it is acknowledged that individuals who do not identify as female can also be diagnosed with OC.

## 2 | METHOD

Women affected by OC were recruited from across Australia and invited to complete an anonymous online survey. Data presented here

are part of a larger study which was approved by the Research Ethics Committee at The Royal Women's Hospital (#19/22).

### 2.1 | Recruitment and eligibility

Eligibility criteria were a previous or current OC diagnosis, regardless of stage of treatment or recovery. Participants had to be 18 years or older with sufficient English proficiency to consent and complete the survey. Recruitment occurred from October 2019 to February 2020 via social media, print and radio advertising and the Ovarian Cancer Australia (OCA) membership database. Potential participants were directed to a website containing consent information and the study questionnaire. Consenting participants then completed a 30-min online survey.

### 2.2 | Measures

Participants were asked about their demographic details as well as OC type, stage, treatment and any recurrences. Prospective participants were told that the researchers were conducting a study to advance our knowledge of the impact of OC on women's sexuality, self-image and self-esteem during diagnosis, treatment and in survivorship; that the research would assist in shaping support services in the future; and that participation was via a confidential, anonymous online survey. The larger study included completion of validated self-report measures of sexuality, body image, sexual flexibility, psychological morbidity and QoL in women with OC. In addition to a number of quantitative psychometric measures (not reported on here), participants were invited to answer four open-ended questions about the impact of OC on womanhood, body image, sexuality and partnered relationships. Specifically, these questions asked (i) *How has your OC diagnosis and/or treatment affected the way you feel about yourself as a woman?* (ii) *How has your diagnosis and/or treatment affected your body image (the way you view your body)?* (iii) *How has your diagnosis and/or treatment affected your sexuality (the way you see yourself as a sexual being, your sexual activity, functioning, etc)?* (iv) *How has your diagnosis/and or treatment affected all aspects of your relationship with your partner?*

### 2.3 | Data analysis

Data were thematically analysed in NVivo (QRS International, 2021) following Braun and Clarke's (2006) method. The sociocultural lens was applied to analysis, while inductive and deductive modes of analyses were incorporated through the analytic process to allow clarity of surface meaning, but also allowing for deeper analytic meaning. This entailed immersion of the data through reading and re-reading responses and noting obvious patterns at the semantic level, using descriptive coding to organise data. One fifth of transcripts were coded by a second researcher whereby consensus of coding was reached. Examples of initial codes were 'negative body image' or 'impact on intimacy'. Following generation of these descriptive codes, the sociocultural

lens and a more deductive approach to analyses was applied. The focus of the sociocultural lens allowed for deep analysis regarding the way in which social expectations and influences impact the way women view themselves through comparison with others, and through the socially constructed ideas around what normal bodies should look like and how they should function (Glauert et al., 2009; Ussher et al., 2013; Weaver & Byers, 2013). By incorporating this lens, the way women view their bodies and relationships can be analysed through this Westernised ideal. Data were then re-read to identify patterns and moved into themes. Initial themes were descriptive and reflected codes, such as 'understanding womanhood' and 'perceptions of womanhood and femininity' which were then further refined into the current themes. Themes were generated through constant consultation with the researchers and named to reflect their content. Due to the large sample size, data saturation was easily achieved.

### 3 | RESULTS

A total of 98 OC survivors completed the survey. The average age of participants was 52.8 years (range = 22–81) and average time since diagnosis was 5.5 years (range = 4 months to 30 years). The majority of participants identified as female, were partnered, had children, were tertiary educated and lived with another person. Epithelial OC was the most common OC type identified and nearly a quarter of participants were currently receiving treatment. Characteristics of the participants are described in Table 1.

Following thematic analysis, three themes and two subthemes were identified: *Failure and Loss of Femininity and Womanhood*, *Internalising Public Perception of Body and Illness* and *Altered Relationships* which comprised two subthemes, *Loss of the Sexual Self* and *Relationship Burden*. Due to large sample size and anonymity of participants, numbers were allocated to participants rather than pseudonyms. This is reflected in referring to participants according to their survey response number, for example, participant 42 = P42.

#### 3.1 | Failure and loss of femininity and womanhood

One of the primary consequences of OC was the way in which womanhood and femininity had been altered, questioned and, for some, erased. Women experienced these changes in the form of loss of reproductive organs and hormones and impact on fertility. For many, these factors played a part in how they viewed themselves, their bodies and their role as a woman: 'I felt as though I had failed as a woman because I could not do the one thing I was meant to be able to do, i.e. have a child naturally' (P51) and 'I have no ovaries, so I feel like I am less of a woman' (P77). Feeling 'less than' was also described by women who retained some reproductive organs: 'Sometimes I get worried as I have lost an ovary and if I'm worth less as I may not be able to have children' (P14). Loss of fertility was also repeatedly mentioned in terms of how isolated women felt from their peers:

**TABLE 1** Characteristics of participants (N = 98)

	N	%
Gender		
Female	97	99%
Prefer not to say	1	1%
First language English (yes)	94	95.9%
Has a partner (yes)	67	68.4%
Children (yes)	63	64.3%
Lives alone (yes)	21	21.4%
Annual income (\$AU)		
Prefer not to say	18	18.4%
≤AU \$69,999	35	35.7%
≥AU \$70,000	45	45.9%
Tertiary education (yes)	69	70.4%
Working (yes)	54	55.1%
Menopausal status at diagnosis		
Premenopausal	45	45.9%
Perimenopausal	15	15.3%
Postmenopausal	38	38.8%
Ovarian cancer type		
Epithelial	46	46.9%
Germ cell	7	7.10%
Stromal cell	3	3.10%
Other/unsure	42	42.86%
Stage at diagnosis		
I or II	43	43.88%
III or IV	51	52.04%
Unsure	4	4.08%
Recurrence (yes)	27	27.60%
One recurrence	11	11.20%
Two recurrences	6	6.10%
Three + recurrences	10	10.20%
Currently receiving OC treatment (yes)	23	23.50%
Previously received OC treatment (yes)	96	98.00%
Treatment		
Surgery	85	86.70%
Chemotherapy	77	81.10%
Radiotherapy	7	7.10%
Other (e.g., targeted therapies)	16	16.30%

I was diagnosed in my early 30s. I had not yet had kids and desperately wanted to be a mother. I watched as women in my networks had kids. I just felt like all my body had done was grow a lump of death. It was a very hard time. I became withdrawn and isolated (P9).

While womanhood was mainly connected to reproduction and hormonal changes, participants sometimes used the term

interchangeably with femininity. However, the latter centred more around external feminine attributes such the desire to dress well, wear make-up and 'make an effort' with appearance. Women mentioned these aspects when discussing wanting to appear feminine, attractive and more like their pre-cancer selves: 'I still try to feel feminine for myself e.g. by ensuring I do not shop in track pants, trying to do something with my hair and wearing perfume and earrings at home' (P86). For many women, though, there was a complete loss of femininity, or they had given up on perceived feminine activities: 'I do not feel feminine in the least and do not wear makeup anymore or care about my appearance as much as I used to' (P67) or 'I do not have any sense of femininity left. I cannot even wear high heels as now my toes are numb, and I have balance problems' (P69).

### 3.2 | Internalising public perceptions of the self

Intertwined with womanhood, femininity and fertility are experiences of body image. For many, body image had shifted and been influenced by experiences of weight gain, changes to body shape, scarring and hair loss. Responses seemed to be informed by personal ideologies of body image and assumptions of negative public perception. The way participants described the negative influence of personal and public discourse demonstrated an interconnectedness between emotional distress and physical changes: 'My body image was severely impacted by my treatment. Steroids made me bloated, and I hate the way I looked. My scar looked raw and frightening' (P31). For some, this negative perception of their body meant '... sometimes I cannot look in the mirror' (P94).

Views surrounding feeling less attractive and heightened body-consciousness extended to the assumption that others would view their bodies in the same negative way, resulting in women feeling they needed to cover up scars and bodies not only to hide physical changes, but to avoid questioning regarding their cancer experience and outcomes: '... it has made me more conscious of showing my stomach to people. I'm scared that they will ask or be disgusted [by] the scar' (P39). Fear of negative public perception and reaction to physical changes also applied to weight gain and hair loss:

I hate the way I look. Weight gain and hair-loss. It makes me sad that the world sees me this way and thinks it's the way I choose to style regrowing hair or food choices I make instead of steroids causing weight gain (P52).

However, while the majority of women reported negative changes to body image, some women reported no change in body image, and some felt respect and appreciation for what their bodies had endured: 'I look at my scars as a lifeline. The surgery saved my life, gave me more time' (P80). While this was not the norm, it highlights the complexities within body image and the variations in the way women perceive their bodies.

### 3.3 | Altered relationships

Many women reported that relationships had been altered due to stress, changes to sexual functioning and intimacy and uncertainty surrounding mortality as demonstrated by the subthemes below.

#### 3.3.1 | Loss of the sexual self

Sexual changes focused on loss of physical response, libido and arousal, as well as pain or fear of pain when engaging in sexual activities. Many noted a substantial decrease in acts of intimacy or the complete loss of all sexual activity which had significantly changed their partnered relationships. It was commonly reported that loss of libido due to hormonal changes after treatment, psychological factors, or a combination of these led to emotional distress and sadness and there was a desire to regain pre-cancer sexual functioning: 'I want to enjoy sex like I used to but it's hard to get in the mood. I feel like a failure' (P25). This alteration in sexuality also changed the way women viewed their role in sexual relationships 'I feel like sex is just a job I must perform now' (P2) and 'My libido has dropped off as well, but I try to keep our sex life going because I know how important it is to my husband' (P36).

Loss of sexual capacity was also attributed to structural genital changes and loss of hormones which resulted in pain and discomfort when engaging in not only penetrative sex, but also other forms of sexual intimacy: 'Surgical menopause gave me vaginal atrophy. The pain is so bad I cannot even wear underwear let alone want to use my vagina for pleasure' (P34). These experiences of pain left some feeling fearful and reluctant to engage in sexual activity for 'fear of being unintentionally hurt during sexual activities' (P42).

#### 3.3.2 | Relationship burden

The way in which partnered women experienced the emotional aspects of their relationships varied in relation to closeness and support. Many women reported that while the sexual aspects of their relationships had all but ceased, the emotional connection and closeness remained, or was enhanced through the cancer experience. Women discussed how their partner was a source of support and emotional stability, that they are 'much closer as partners than before the diagnosis' (P40) and 'our emotional connection, which was always wonderful, even improved. We seemed to connect and talk on a higher level' (P19). These feelings of emotional fulfilment and closeness were often coupled with expressions of guilt for being a burden, upheaval in sexual relationships and being a source of fear and worry for their partners. The sentiment of being cared for and placing emotional stress on partners was common: 'It has turned our relationship into one that is completely unbalanced. He looked after me while I was sick and now is scared of me dying, which we are told will almost definitely happen' (P22) and 'It feels strained. I feel like a burden [when] in treatment. And a ticking time bomb in between recurrences'

(P52). In this same vein, women remarked on how loss of sexual intimacy made them 'feel guilty' (P25) that their partners 'have to put up with' (P25) the loss of sexual relationships or '... sometimes I feel it would be easier if I left so he does not have to deal with it all, though he does not want that. I often feel like I'm a bit of a burden' (P34). Similar views were mentioned by un-partnered women when considering future relationships: 'I would definitely NOT enter into another relationship with a partner due to the uncertainty of the disease returning' (P57) or 'I have nothing to offer a partner' (P69).

Many women reported that the stress of treatment and physical changes were the source of relationship strain. Some women felt unsupported through treatment: 'My partner cannot deal with my illness, he is focused on himself. Makes out he's supportive but hardly comes with me to appointments, he is not present with dealing with my illness' (P13). Others disconnected from partners to navigate life post-cancer alone and focus on relationships that fulfilled them in other ways. Some women noticed their partner withdrawing: 'The emotional impact on my husband pulls him away further every time I get bad news' (P49). There were also reports of complete relationship breakdown and partner separation due to stress, tension and the intensity of change: 'My partner and I broke up after my hysterectomy and debulk (ing surgery). The stress of my illness on him was too much for him to cope with' (P50).

## 4 | DISCUSSION

This study sought to gain a deeper understanding of the ways in which OC can affect relationships, sexuality, womanhood and body image. We found that the way in which women view their body and relationships following OC treatment was influenced by sociocultural understandings of what constitutes normal functioning bodies. Our data shed light on the breadth and depth of women's experiences and the way these experiences influence how they see, understand and feel about themselves and their relationships within the framework of social normalcy.

Participants reported strong associations between feelings of being a woman and biological motherhood. Women viewed infertility as an inability to fulfil their role as a female which situated them as 'less than' or 'no longer' a woman, a view that aligns with a social norm in which motherhood and reproduction are the primary roles and identities for women (Kirkman et al., 2014; Ljungman et al., 2021; Ussher et al., 2014). These findings are consistent with previous research in breast and other cancers (Bajpai & Shylasree, 2018; Dryden et al., 2014) suggesting these norms and social identities transcend cancer type and outcomes. Our findings also emphasise how loss of reproductive organs contributed to participants' inability to connect with other women in their social world. This disconnection occurred not only through infertility, but through changes in bodily functioning due to hormonal changes and ceased menstrual cycles which led to social withdrawal, isolation and diminishment of self-worth.

Fear of social exclusion was also discussed in relation to loss of femininity following OC treatment. Women described wearing wigs

and engaging in seemingly feminine activities, such as 'dressing up', wearing jewellery and make-up to maintain or recreate their femininity (Bajpai & Shylasree, 2018; Jayde et al., 2013). This may indicate a belief that being feminine occurs only through active participation and if bodies are changed beyond the ability to 'look' feminine, femininity is then erased. For some participants, this led to 'giving up' on femininity, where women had ceased actively participating in these processes altogether. While physical limitations or personal choice were the outcome of this process, it highlights the way social ideologies of femininity can be internalised and used to determine social worth and belonging.

Women's responses showed a strong connection between womanhood, femininity and the diminishment of positive body image. As with previous research (Bajpai & Shylasree, 2018; Teo et al., 2018), perceptions of body image were substantially affected by scarring, stoma bags, weight changes and loss of hair, all of which situated women outside the realm of social 'normalcy'. The way that women viewed their changed bodies, as postulated by Boquiren et al. (2013), was altered by perceptions of the public gaze, which in turn encouraged body monitoring, surveillance and constant comparison with the normal 'other'. This suggests that women may feel untrusting of the public (Bisseling et al., 2009) to view their body positively, resulting in a need to re-align their bodies with what is considered socially acceptable and normal (Giacomoni et al., 2014). This was apparent where women discussed wanting to hide scars, hair loss and weight fluctuations. The need to conceal bodily changes was also linked to keeping cancer private to mitigate against social stigma. Women reported not wanting to be viewed as someone who had cancer for fears of negative perception and being treated differently, findings consistent with previous research (Jayde et al., 2013). This was discussed in terms of being 'outed' as a cancer patient which would require disclosure of cancer status and further position them as 'other'.

A small number of women discussed feeling proud of their bodies following treatment. This finding highlights the nuances of women's experience with OC while also demonstrating differences in how women evaluate their bodies against sociocultural standards regardless of positive or negative body image. Tetteh (2017) suggests body positivity following cancer may be due to differences in age, relationship status, experience of motherhood or interactions with social expectations and norms; however, due to the anonymity of this study, such inferences cannot be made.

The implications of OC and treatment on intimate relationships were clear. The way in which women described being less able to engage in sexual activity is consistent with previous research suggesting penetrative sex is understood as 'real sex' (Ussher et al., 2014). Such a stance positions women outside 'normal' if they cannot perform this act due to pain or changes to genitalia (Parton et al., 2017; Pitcher et al., 2020; Wilmoth et al., 2011). A problematic social implication evidenced here was women feeling compelled to engage in penetrative sex, regardless of desire or experiences of pain, as recounted by participants whose feelings of guilt or obligation motivated them to engage in intercourse. This finding is consistent with the literature (Fischer et al., 2019) and suggests women may feel a

sense of unconditional personal duty to be sexually available to maintain a sexual role in partnered relationships. Ussher et al. (2013) suggests this may be due an inability to recognise the influence socio-cultural understandings have on sexual normalcy which may inhibit potential reconceptualisation of sexual intimacy following cancer. Furthermore, for some women, experiences of severe pain as a cancer symptom prior to diagnosis and following surgery and other treatment caused further psychological and emotional distress due to previous attempts at penetrative sex. This indicates that while physical aspects of pain and discomfort can impede sexual capacity, the psychological associations that result from these experiences may also play an important role in reducing sexual engagement (Bakker et al., 2017; Sears et al., 2018).

Within relationships, many women reported that even though the physical aspects of their relationships deteriorated, the emotional connection improved. Relationships thriving following cancer diagnosis in the context of being conceptualised as a 'we-disease' (Traa et al., 2015, p. 92) has been described in other tumour streams (Ussher et al., 2013). Couples who are open and honest regarding emotions and cancer outcomes feel more connected and supported (Perndorfer et al., 2019; Sekse et al., 2009). However, in our study, this closeness was often coupled with feelings of guilt and burden. Some women felt responsible for being a source of grief and worry for their partners indicating a process of 'protective buffering' where couples hide their more complex concerns from each other (Perndorfer et al., 2019). Other work has shown that hiding feelings of distress or worry or minimising cancer outcomes (such as mortality) to protect partners from further grief (Perndorfer et al., 2019; Shilling et al., 2017) may in fact inhibit bonding, reduce intimacy and increase emotional strain in both partners (Ussher et al., 2013). Carer burden may also explain feelings of reduced connection and increased tension due to higher levels of anxiety, depression and fear of recurrence in carers (Levesque et al., 2021). This may explain low levels of relationship satisfaction and, in some cases, termination of relationships for those whose protection of their partners may have caused disconnection and estrangement, or for those whose partners found the emotional burden too high. The same feelings and potential protective buffering were also mentioned by women considering future relationships. Consistent with Sacerdoti et al. (2010), some women felt the burden of OC and fear of mortality was too much for a future partner and that their body was too marred and incomplete to be accepted. This demonstrates the way in which women may not only preemptively use protective buffering but employ the social gaze to view their own bodies and worth, resulting in the denial of future companionship and further entrenching feelings of worthlessness, burden and difference. This may be important in that women denying themselves care and support following OC diagnosis may lead to unnecessary psychological distress and isolation.

The limitations of the current study include incomplete demographic data (such as sexuality or nationality) and the recruitment of participants who were likely already engaged in help-seeking behaviours through social media and OCA. Our sample may not reflect disenfranchised experiences. The strengths of this study are the

projection of women's voices by detailed accounts of their lived experiences and understanding of their bodies and relationships in their own words. This study included women with varying OC diagnoses across a range of ages, relationship status and experiences thereby adding richness and depth to the data.

As well as contributing these valuable data to the literature, our findings have clinical implications that reflect the need for health professionals to create an open dialogue with women affected by OC, as well as their partners (Stafford et al., 2022). Clinicians should have detailed and in-depth discussions about sexuality prior to the commencement of treatment and alongside ongoing treatment discussion (Fischer et al., 2019; Whicker et al., 2017) while acknowledging how sociocultural expectations may influence the way women view, see and think about themselves during and following treatment. This communication should be explicit about possible changes to a woman's body, its functioning and sexuality following treatment (Flynn et al., 2012) and overt discussion of the role that sociocultural expectations can play in emotional and psychological well-being. A deeper understanding of these issues as explained by the treating clinician, can help provide clarity, insight and, therefore, help reduce negative perceptions women may experience regarding these changes. This knowledge may also help promote body acceptance, reduce stigma and ensure adequate support is provided to those experiencing and living with these changes and those in carer roles.

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## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request, and subject to approval from the hospital's research ethics committee.

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