








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# Holistic sexuality post gynaecological cancer treatment: A review of recent literature



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**Background:** Sexual difficulties post gynaecological cancer treatment are commonplace and can impact multiple aspects of a woman's life. Yet, health care practitioners remain reluctant to discuss sexuality from a holistic perspective with their patients.

**Aim:** This article reviewed the literature on sexuality post gynaecological cancer treatment from the last 10 years. The aim was to understand research trends as well as identify gaps in the field.

**Methods:** The review was framed using the neo-theoretical framework of sexuality. A comprehensive literature search, using the electronic databases EBSCOHost, Ovid, Clinical Key and PubMed, was conducted for articles concentrating on sexuality after gynaecological cancer treatment, published from 2007 to 2017 in English.

**Results:** The results showed that the majority of the literature still approaches sexuality post treatment from a biomedical perspective with a focus on physical sexual functioning. However, there has been a slight shift towards understanding sexuality from a comprehensive standpoint, although there is a dearth of research relating to the psychological and relational aspects of sexuality.

**Conclusion:** Comprehensive sexuality post treatment should be given further consideration in South Africa, and our unique socio-cultural context ought to be taken into consideration. Additionally, interventions at multiple levels should be explored, such as broadening sexual health training within the medical curriculum, considering the development of holistic cancer clinics and widening the scope of research relating to gynaecological cancer care.

## Introduction

Sexual well-being is an important quality of life factor,<sup>1</sup> and women who have active and satisfying sexual relationships report higher levels of happiness and relationship fulfilment.<sup>2</sup> Sexuality post gynaecological cancer treatment is important to consider as 40% – 100% of gynaecological cancer patients will experience sexual complaints after treatment.<sup>3</sup> These alterations vary in duration but may remain with a woman for life and thus can have a profound impact on well-being.<sup>4</sup> Yet, health care professionals are often reluctant to discuss sexuality issues with their patients.<sup>5</sup> When sexuality post gynaecological cancer treatment is discussed, it is often done so from a biomedical perspective that narrowly defines sexuality as the ability to have sexual intercourse and focuses predominantly on sexual dysfunction.<sup>6</sup> Given South Africa's high rates of sexual violence and HIV and AIDS – problems that have interpersonal and psychological impact – it is imperative to think of sexuality beyond physical acts. This article aims to review the literature on women's sexuality post gynaecological cancer treatment in order to understand it from a holistic perspective. It also outlines issues requiring further research and provides critical commentary. Improved understandings and conceptualisations of women's experiences of sexuality post treatment are imperative to improving patient-centred care and developing support programmes in South Africa.

This article utilised Cleary and Hegarty's neo-theoretical framework of sexuality<sup>7</sup> to frame the review. This framework is based on Woods's<sup>8</sup> inclusive understanding of sexuality and was elaborated on by incorporating theoretical and empirical literature. The neo-theoretical framework of sexuality consists of three interconnected elements: (1) sexual functioning, (2) sexual self-concept and (3) sexual relationships.

Within this framework, sexual functioning is defined according to the sexual response cycle: desire, arousal and orgasm. Sexual desire is multifaceted but can be broadly conceptualised as a

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motivational state in which people seek out sexual partners or experiences.<sup>9</sup> Sexual arousal is outlined as physiological and psychological responses in anticipation of, or during, sexual activity. In women, this is signified by vasocongestion in the nipples, vulva, vagina and clitoris, as well as increased vaginal lubrication. Experiences of orgasm are highly subjective but are generally understood as the height of sexual pleasure during which pelvic contractions occur.

Sexual self-concept refers to psychological and cognitive constructs relating to how one experiences and understands one's sexual identity. It incorporates the sub-categories of sexual self-schema, body image and sexual esteem. Sexual self-schemas are ideas about one's sexuality that originate from past experiences and influence current sexual behaviour and information processing.<sup>10</sup> They are understood as being either 'positive' or 'negative'.<sup>10</sup> A positive sexual self-schema refers to viewing oneself as passionate and romantic and as a person who is open to new sexual experiences and is not limited by self-consciousness, embarrassment or negative feelings. Conversely, in a negative sexual self-schema, a person sees himself or herself as inhibited, conservative, self-conscious and embarrassed about his or her sexuality with limited passionate or romantic abilities. 'Body image' relates to how one mentally perceives and subjectively experiences his or her body.<sup>7</sup> Feeling feminine is important for some women's body image, although how a woman interprets her femininity is dependent on socio-culturally produced ideas about gender and sexuality. For example, in numerous cultures, female reproductive organs are representative of femininity, motherhood and female sexuality.<sup>11</sup> Lastly, sexual esteem is a type of self-esteem relating to one's sense of self-worth in terms of sexual behaviour and identity.<sup>7</sup> It also refers to how one evaluates his or her sexual self.

Sexual relationships are characterised as any relation within which a person shares his or her sexuality with another or others.<sup>8</sup> A fulfilling sex life is important to many couples as it is an opportunity for bonding, intimacy and quality time. Sexual difficulties post gynaecological cancer can therefore be stressful for couples as it can feel like a core part of the relationship has disappeared. These problems generally manifest in disparate intimacy needs and poor communication.<sup>12</sup> The relationships category is thus delineated accordingly. Although intimacy and communication are the foundation of any relationship, in this article, they are spoken about in relation to sexual activities.

This article seeks to approach sexuality post treatment from a holistic perspective. However, it is necessary to outline the physical or physiological side effects to contextualise the other changes experienced. Physical side effects depend on the type of treatments received. Surgery to the genital area may not only be cosmetically disfiguring, but if it is followed by radiotherapy, additional physical changes may ensue, predominantly, loss of tissue elasticity. Radiotherapy for cervical cancer involves the application of both external radiation to the entire pelvic area and internal brachytherapy to boost doses to the cervix. Hence, possible anatomical

changes include vaginal shortening, reduced vaginal elasticity, vaginal stenosis, genital swelling, pelvic nerve damage, clitoral fibrosis (or removal) and genital hypersensitivity.<sup>13</sup> Vaginal bleeding after intercourse may occur from vaginal adhesions or atrophy after radiotherapy treatment,<sup>14</sup> and, at the extreme end of this spectrum, vaginal necrosis with fistula formation may develop. Other physical or functional changes include dyspareunia, decreased vaginal lubrication,<sup>13</sup> chronic pelvic pain, temporary or permanent colostomy, and premature menopause.<sup>15</sup> Premature menopause involves symptoms that impact on sexual functioning – such as decreased libido and vaginal dryness – as well as loss of fertility<sup>16</sup> which may have an emotional and socio-cultural impact. In addition, there are long-term consequences such as increased risk of osteoporosis, dementia and cardiovascular disease. Other related physical effects of pelvic therapy include acute and/or chronic diarrhoea, or radiation cystitis.<sup>17</sup> Occasionally, the placement of an urostomy or colostomy is required. Fatigue is common and is often multifactorial in causation.<sup>14</sup>

## Methods

A comprehensive literature search was conducted by accessing the online electronic database platforms: EBSCOHost, Ovid, Clinical Key and PubMed. Search terms included variations of the type of cancer, the geographical area of interest, the type of treatment and terms relating to sexuality (Table 1). The time frame was limited to literature published within the last 10 years to obtain an overview of the most recent research trends. Articles were included if they were full-text articles from peer-reviewed journals, published in English and focused on some aspect of female sexuality post gynaecological cancer treatment. However, given the small scope of the published literature in this area in South Africa, relevant grey literature from South Africa was also included. Exclusion criteria consisted of literature reviews or articles from non-peer-reviewed journals, studies not published in English and research that did not focus on female sexuality post gynaecological cancer treatment.

## Results

The search yielded a total of 38 articles (Table 2). The majority of the articles emanated from Europe ( $n = 20$ )<sup>18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37</sup> with the rest spread between North America ( $n = 7$ ),<sup>38,29,40,41,42,43,44</sup> Australia ( $n = 4$ )<sup>45,46,47,48</sup> and Asia ( $n = 2$ ).<sup>49,50</sup> Five of the articles were from South Africa,<sup>51,52,53,54,55</sup>

**TABLE 1:** Search strategy.

Field	Search terms
Type of cancer	'gynecological cancer' OR 'gynaecological cancer', 'cervical cancer', 'vulva cancer', 'vulval cancer', 'vulvar cancer', 'vaginal cancer', 'uterine cancer', 'endometrial cancer', 'ovarian cancer' and 'fallopian cancer'
Geographical area of interest	'South Africa'
Type of treatment	'treatment', 'post-treatment', 'after treatment' 'radiotherapy', 'radiation', 'chemotherapy', 'surgery'
Sexuality	'sexuality', 'sexual function*' OR 'sexual dysfunction*', 'sexual complications', 'sexual well-being', 'sexual health', 'sexual pleasure', 'sexual relationships', 'intimacy', 'sexual self-concept', 'communication'

**TABLE 2:** Summary of results.

Variable	n
<b>Geographical area of origin</b>	
Europe	20
North America	7
Australia	4
Asia	2
South Africa	5
<b>Methodology used</b>	
Quantitative	22
Qualitative	13
Mixed methods	3
<b>Articles published per year</b>	
2007	5
2008	4
2009	5
2010	3
2011	5
2012	1
2013	5
2014	3
2015	1
2016	4
2017	2
<b>Type of gynaecological cancer</b>	
Mixed	14
Cervical	12
Ovarian	4
Vulvar	1
Endometrial	4
Not specified	3
<b>Focus of research</b>	
Sexual functioning	25
Sexual functioning plus another aspect of sexuality	15
Sexual self-concept and sexual relationships	5
Holistic sexuality	6
Other aspects of the treatment process	2

although two of these were grey literature.<sup>52,54</sup> Most of the studies incorporated a variety of gynaecological cancers ( $n = 14$ ) (e.g. endometrial, ovarian, cervical and vulvar) with almost as many focusing exclusively on cervical cancer ( $n = 12$ ). In terms of content, sexual functioning was maintained as a focal point in the majority of studies ( $n = 25$ ); however, many of these also investigated another aspect of sexuality post treatment ( $n = 15$ ). Some studies did approach sexuality from a holistic perspective ( $n = 6$ ), with one of them making use of the neo-theoretical framework of sexuality.<sup>26</sup> The remaining articles looked at sexual relationships and aspects of sexual self-concept after treatment ( $n = 5$ ). This variety in content marks a departure from previous literature trends that focused on biomedical aspects of sexual dysfunction. The results of the review are structured according to the different aspects of the neo-theoretical framework of sexuality.

## Sexual functioning

In keeping with findings from previous decades, the majority of the studies in this review underscored how gynaecological cancer treatments can negatively affect

one or more aspects of sexual functioning. Common problems include decreased desire; low frequency of sexual activity, sexual pleasure and satisfaction; high levels of discomfort; loss of vaginal elasticity; deep dyspareunia; vaginal dryness and shortening; and difficulty reaching orgasm.<sup>18,20,21,22,23,24,27,29,30,32,34,35,38,39,40,42,43,49,50</sup> Side effects that manifest in other areas of the body – such as urinary or bowel dysfunction, and fatigue – also hinder sexual activity.<sup>18,21,22,48</sup> These symptoms of sexual dysfunction persist for many years into survivorship.<sup>18,24</sup>

Articles included in this review continue the debate concerning which treatments have the greatest negative impact.<sup>7</sup> Some studies suggest that radiotherapy leads to higher levels of sexual dysfunction than surgery or chemotherapy.<sup>22,24,27,38,47</sup> Additionally, radiotherapy patients also score lower on global quality of life measures than women treated with surgery or adjuvant chemotherapy.<sup>23,47</sup> However, other studies found no significant difference in sexual functioning between groups treated with radiotherapy and those not.<sup>34,36,37,44</sup> For example, endometrial cancer survivors ( $n = 246$ ) who received adjuvant external beam radiotherapy showed no difference in sexual difficulties to those who did not undergo adjuvant treatment.<sup>37</sup> Interestingly, while Greimel et al.<sup>23</sup> found poorer quality of life scores among radiotherapy patients, there was no significant difference between sexual pleasure and sexual discomfort between the surgery, surgery/CT group and surgery/RT groups. One other study reported lower levels of sexual functioning post treatment in patients who had received surgery and adjuvant chemotherapy, or chemotherapy alone, compared to the surgery only group.<sup>20</sup> None of the South African studies compared sexuality outcomes across treatment modalities, and most of the participants in these studies had been treated for cervical cancer with external beam radiation and brachytherapy.<sup>51,52,53,54,55</sup> However, the studies did make reference to the unique socio-demographic context in which such treatment occurs. Patients typically present in advanced stages where definitive radiotherapy is the treatment of choice. The higher doses received, compared with adjuvant radiotherapy doses as discussed in the studies above, may likely result in higher levels of sexual dysfunction. These patients are also typically younger, and thus the impact on fertility can be more distressing than for older women who have already completed their families.

Levels of sexual activity among gynaecological cancer survivors varied greatly, with studies reporting between 9% and 60% of participants being sexually active post treatment. These variations can be attributed to differences in age and treatment modality; however, non-cancer women were more sexually active than cancer survivors.<sup>39,50</sup> Sexual activity decreases with age,<sup>56</sup> and thus, studies with a higher mean age are more likely to report lower levels of sexual activity.<sup>34</sup> Type of treatment can also impact level of sexual activity because, as outlined above, some forms of treatment are argued to have more severe sexual side effects than others.

## Sexual self-concept

There was only one study that explicitly stated investigating 'sexual self-concept' and that also included every aspect of the construct.<sup>26</sup> In this study, mean scores on the measures relating to self-concept showed that the participants generally experienced a positive sexual self-schema, body image and sexual esteem post treatment. However, it was items on the body image measure that showed the most negative effects. A few other articles did explore one or more of the constructs under the sexual self-concept umbrella.

## Sexual self-schema

It is theorised that differences in sexual functioning post treatment are related to a women's sexual self-schema,<sup>10,57</sup> namely that women with a positive sexual self-schema pre-treatment are more likely to report higher levels of functioning post treatment, whereas women with a negative sexual self-schema are more likely to report decreased functioning. One study in this review explored this correlation.<sup>41</sup> In regression analyses that controlled for patients' physical symptoms or signs, health status, socio-demographic variables, health status and level of partner's sexual difficulties, sexual self-schemas accounted for significant variance in current sexual functioning. It was also found that sexual self-schemas acted as a moderator between sexual satisfaction and psychological outcomes. This suggests that women with a positive sexual self-schema might be 'protected' from depressive symptoms even while experiencing low sexual satisfaction. However, having low sexual satisfaction combined with a negative sexual self-schema could increase a woman's likelihood for developing mental health issues. This suggests that sexual self-schemas can thus be a useful predictor for the possibility of sexual difficulties post treatment. However, no other studies have explicitly investigated this relationship, although women with lower levels of mental health concerns before and after treatment also report higher levels of sexual well-being post treatment.<sup>32</sup>

## Body image

Of all the sexual self-concept constructs, body image after gynaecological cancer treatment has received the most attention in the literature. Interestingly, most of the studies were qualitative or mixed methods. The articles reviewed show that changes in body image post gynaecological cancer treatment are commonplace<sup>18,20,24,25,26,30,31,32,35,43</sup> and relate to physical side effects and their corresponding perceived alterations in femininity. Physical changes to the body can be both external and internal.<sup>31</sup> Visible, external changes include scarring, alopecia, weight changes and symptoms of premature menopause<sup>18,25,29,30,31,32,35</sup> and negatively affect feelings of attractiveness, desirability and self-esteem.<sup>18,26,31,32,43</sup> A discourse analysis of interviews with women post gynaecological cancer treatment found that women's experiences of bodily changes intersected with culturally dominant constructs of feminine beauty.<sup>31</sup> The ability to conform to such ideals is seen as reflecting a women's desirability, sexual performance and

youthfulness, and thus, any violation of these ideals because of treatment side effects results in a perceived decrease in social value. In South Africa, women reported excessive bleeding, smelly discharge and incontinence which led to feelings of humiliation and social stigmatisation.<sup>55</sup> However, in another study, despite these drastic changes to their body, some women expressed gratitude for still being alive<sup>32</sup> and others experienced a change in body image but did not feel 'mutilated'.<sup>20</sup> Another predominant theme within the studies related to the impact of internal, 'invisible' changes because of the loss of reproductive organs through surgery, for example, hysterectomy.<sup>25,29,30,31,32,35</sup> The studies reviewed show that women experience varying reactions to the removal of their uterus. For some women, especially those who have completed their family or are beyond child-bearing age, having their uterus removed was preferable to having a breast removed because there was minimal impact on their feelings of external feminine expression.<sup>25</sup> Others were also relieved to be free from unpleasant symptoms.<sup>25,32</sup> However, many experienced a sense of loss, in terms of having physically lost a part of their body, as well as a part of their sexual identity that was symbolised by their uterus.<sup>29,30,31,32,35</sup> The latter concern appears to be linked with gender role functioning because of the fact that reproductive organs – particularly the uterus – are often cultural signifiers of femininity, fertility and motherhood.<sup>25,26,29,35</sup> The loss of the uterus can therefore feel like the loss of one's ability to be feminine and a mother.<sup>35</sup>

## Sexual esteem

There is a dearth of research that directly examines gynaecological cancer and sexual esteem as only two studies could be located. One study, as part of a holistic assessment of sexuality post treatment, measured sexual esteem using the Sexual Esteem Scale.<sup>26</sup> The mean score indicated medium to low levels of sexual esteem. The other, a qualitative study, tenuously looked at sexual esteem in women with gynaecological cancer, although this was also used to refer to 'self-esteem'.<sup>19</sup> This study aimed to better understand how ovarian cancer affects women's sexuality through semi-structured, individual interviews. One of the key themes that emerged was how the treatment affected women's evaluation of their sexual identity. It is evident that this aspect of sexuality necessitates further research in the context of gynaecological cancer.

## Sexual relationships

Studies that focused solely on sexual relationships post-gynaecological cancer treatment were rare; however, they were often incorporated as part of broader areas of investigation.

## Intimacy and communication

The articles reviewed, highlighted how diminished sexual intimacy can be a result of decreased frequency of intercourse,<sup>26</sup> worries about being unattractive to partner or

partners,<sup>31</sup> fears of recurring disease,<sup>29</sup> feelings of distance,<sup>43</sup> unenjoyable intercourse<sup>48,51,53</sup> and attachment anxiety.<sup>50</sup> Women were also concerned that the lack of sexual intimacy would encourage partners to seek fulfilment elsewhere<sup>32,51,53</sup> and thus reported that they often had intercourse even if they were in pain or felt no desire.<sup>29,51</sup> These anxieties also emerge from wider, heteronormative assumptions around sex which construct penetrative vaginal intercourse as the only 'legitimate' way of signifying intimacy.<sup>58</sup> Conversely, high levels of social support – particularly from a significant other – have been correlated with a higher quality of sex life among gynaecological cancer survivors<sup>28</sup> and some women have reported loving support from partners post treatment.<sup>20,26</sup> Furthermore, although sexual intimacy might decrease after treatment, the desire for other forms of intimacy such as being held, stroked or touched increases for some women, and thus, intimacy within relationships is not limited to sexual intercourse.<sup>26</sup>

Only one study was found that explored communication in intimate relationships post treatment.<sup>26</sup> Findings from this study show that communication changes post treatment are not always negative, as 33% ( $n = 25$ ) of the participants found more time for quiet conversation with their partner since their cancer diagnosis and 49% ( $n = 37$ ) said that time for communication remained unchanged. Additionally, 55% ( $n = 41$ ) indicated that their comfort in discussing sexual matters with their partners remained unchanged.

## Discussion

### The complexity of sexuality

The above review has highlighted the multifaceted and complex ways that gynaecological cancer treatment affects female sexuality. Although the recent literature reflects a shift to more comprehensive understandings of sexuality, difficulties in sexual functioning remain the predominant focus, with aspects of sexual identity and relationships being secondary considerations. It is important to study all aspects of sexuality equally, as it is possible that women can be experiencing difficulties in one area, while satisfaction and pleasure in another. For example, Sekse et al.<sup>34</sup> found that although the majority of their participants were sexually active, half of them expressed minimal satisfaction with this activity. Conversely, Moodley<sup>52</sup> found that most of their participants (61%) were also no longer sexually active post treatment; however, the majority reported a 'sense of satisfaction' on the sexual functioning measure, thereby highlighting that frequent sexual activity does not equate with pleasure or sexual satisfaction. In terms of frequency of intercourse, Greimel et al.<sup>23</sup> found that even though 43.3% of their participants had not been sexually active in the last month, the reasons were not explicitly related to treatment side effects. Rather, the main reasons included not having a partner or not being in an intimate relationship and having a general lack of interest in sex. Some women also reported that they could not have sex because of their partner's health problems. Thus, sexual inactivity cannot exclusively be attributed to treatment side effects. It is imperative to be able

to understand these complexities properly in order to develop more nuanced and accurate understandings of female sexuality in the context of gynaecological cancer. Furthermore, when holistically oriented studies are conducted, there is little exploration of how different sexuality constructs interact with each other.

### Methodological reflections

There are a number of methodological issues that must be brought to attention within the existing literature. Firstly, in terms of operational definitions, sexual functioning is commonly defined in relation to partnered and/or penetrative sex. This limits sexual activity to certain acts and excludes those who have a sexual relationship with themselves (i.e. masturbation) or those couples who do not engage in penetrative intercourse. Secondly, the majority of the research is cross-sectional, and thus, longitudinal data are limited. It would be beneficial to collect data before, during and after treatment to be able to track changes in sexuality throughout women's cancer journeys. Lastly, most studies were conducted with samples consisting of white, middle-aged women, in long-term relationships from upper middle income countries. This is not reflective of population groups that experience the highest burden of disease with regard to gynaecological cancer.<sup>59</sup> Additionally, it should not be assumed that because a woman is not in long-term relationship, that sexual difficulties post-treatment do not affect her.

### Possibilities for interventions

The results highlight significant gaps, locally and internationally, in the ways that sexuality post gynaecological cancer is approached within research and practice. There are thus opportunities for meaningful interventions. One such option is incorporating holistic understanding of sexuality into cancer care. Recently, some Canadian cancer centres have started clinics where physical, psycho-sexual and relationship issues are taken into consideration.<sup>60,61</sup> Another possibility includes the employment of psycho-sexual therapists as part of a woman's clinical team who can work with her from diagnosis through to post treatment. Psycho-sexual support services in the form of educational booklets and group therapy have also been shown to be effective in helping women cope with the sexual side effects of treatment.<sup>62,63</sup> Additionally, comprehensive sexuality teaching should be incorporated into doctors' training. However, these suggested interventions should not be implemented in South Africa without considering the context within which they will take place. For example, creating multidisciplinary cancer clinics within South Africa's public health care system might not be realistic given the already constrained resources. Furthermore, it is necessary to investigate what type of support cancer patients feel would be most beneficial for them. Therefore, further research is needed in this area within South Africa before effective interventions can be implemented. The authors of this article are currently conducting a study which seeks to understand sexuality post gynaecological cancer treatment

from a holistic perspective and how women feel they can be better supported post treatment. It is hoped that the results of this study will contribute to greater understanding of this issue and, eventually, appropriate interventions.

## Conclusion

As this review has shown, recent literature is slowly beginning to approach sexuality post gynaecological cancer treatment from a holistic perspective. However, there is still room for greater depth of understanding – particularly with regard to how various aspects of sexuality interact with each other. Further research is also needed with more diverse populations of women and to understand what type of interventions would be most effective within the South African context. However, interventions at the levels of teaching and practice should be considered as a starting point. Additionally, research around partners' experiences of the gynaecological cancer treatment process is essential for understanding the context within which women's healing takes place. Lastly, while this article approached sexuality from a holistic perspective, it is in no way an exhaustive description of female sexuality and there is much room for expansion in our understanding of sexuality in relation to gynaecological cancer. For example, it is also necessary to consider how gender roles and stereotypes, culture, location, ability and socio-economic context influence one's sexuality. There is thus room for more work in this area, particularly with how it relates to gynaecological cancer and patient care in South Africa.

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## Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

## Authors' contributions

S.P. was the project leader and J.M. was the senior author. S.P. was responsible for the data collection and analysis. J.M. and S.P. drafted the manuscript. All authors gave critical comment throughout the writing process. All authors were responsible for the conceptualisation and design of the project. All authors approved the final version to be published.

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