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ARTICLE

"Knowing that I had HPV, I literally just shut down": A qualitative exploration of the psychosocial impact of human papillomavirus (HPV) in women living with mental health conditions

Nicola O'Donnell[1] | Jo Waller[2] | Laura Marlow[2] | Niall C. Anderson[3] | Emily McBride[4]

[1]Department of Health Sciences, University of York, London, UK

[2]School of Cancer and Pharmaceutical Sciences, King's College London (KCL), London, UK

[3]Psychology, NHS Education for Scotland (NES), Edinburgh, UK

[4]Institute of Psychology, Psychiatry and Neuroscience (IoPPN), King's College London (KCL), London, UK

Correspondence
Emily McBride, Institute of Psychology, Psychiatry and Neuroscience (IoPPN), King's College London (KCL), London, UK.
Email: emily.mcbride@kcl.ac.uk

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Abstract

Objective: Psychological distress after testing positive for human papillomavirus (HPV) at cervical cancer screening is well documented in the general population. However, little is known about the impact of an HPV-positive result on those with pre-existing mental health conditions, who may be at higher risk of experiencing clinically significant distress. This study explored the psychosocial impact of HPV in women with co-morbid mental health conditions, as well as their experience of cervical screening during the COVID-19 pandemic.

Methods: Semi-structured telephone interviews were conducted with 22 women aged 27–54 who had tested positive for HPV at routine cervical screening in England, and who reported having at least one mental health condition. Data were analysed using thematic analysis.

Results: Being informed of an HPV-positive result increased distress and heightened pre-existing psychological challenges. Psychosocial response and duration of HPV-related distress appeared to be influenced by the ability to regulate emotions, number of consecutive HPV-positive results, interactions with health care professionals, and other life stressors. The experience added further complexity to many women's perceptions of self and self-esteem. Women who had received psychological treatment for their mental health condition were best able to self-manage HPV-related distress by applying learned coping skills.

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Conclusions: Receiving an HPV-positive result at cervical screening appears to be a distressing experience for women with co-morbid mental health conditions. Future hypothesis-driven research is needed to confirm findings and develop effective interventions to reduce psychosocial burden.

KEYWORDS

cancer, cervical screening, COVID-19, Human Papillomavirus, mental health, Oncology, Psycho-Oncology, Psychological Distress, Psychology, Qualitative

Statement of Contribution

What is already known on this subject?

- HPV diagnosis is linked to adverse psychological effects in the general population
- Individuals with mental health conditions are more likely to experience stigma and challenges around help-seeking, for example attending follow-up cervical screening
- UK cervical screening attendance is suboptimal and had worsened due to the COVID-19 pandemic causing delayed or cancelled appointments

What does this study add?

- Novel research on the impact of an HPV diagnosis in women with a mental health condition during COVID-19
- Application of theory novel to the HPV context
- Suggestions for practical application of findings to inform evidence-based resources

INTRODUCTION

Human Papillomavirus (HPV) is a common sexually transmitted infection responsible for over 99% of cervical cancers (Morgan et al., 2020; Wierzbicka et al., 2021). In England, HPV primary screening is used for cervical cancer screening (Maver & Poljak, 2020; Public Health England, 2019) meaning that all women who attend are tested for HPV. Approximately 270,000 women receive a result of HPV-positive with normal cytology in England annually (Rebolj et al., 2019). These women are at increased, yet still very low, absolute risk (~1.7%) of developing cervical cancer (Ritu et al., 2019; Thomsen et al., 2014). They are monitored at 12-month intervals, before referral to colposcopy after three consecutive HPV-positive screenings or if abnormal cells are identified (Dodd et al., 2014). For most women, HPV will spontaneously clear within 24 months (Huber et al., 2021; Muñoz et al., 2004; Woodman et al., 2001).

Receiving an HPV-positive result is associated with heightened anxiety and psychological distress, which for most people is short-lived and improves over time (McBride et al., 2020). Some women, however, experience prolonged or clinically significant anxiety and distress, which may be more prevalent in those with pre-existing mental health conditions (McBride, Tatar, et al., 2021). Many women are unfamiliar with HPV, lack understanding about how it relates to cancer, and experience shame regarding its sexual transmission. The notion of being diagnosed with a virus, especially one that is sexually transmitted, can lead to stigma and psychosexual distress (Foster et al., 2021; Shepherd & Gerend, 2014). Wider psychosocial literature suggests that adverse psychological responses (fear, embarrassment, perceived stigma, self-blame and anxiety) can reduce and/or influence help-seeking and future attendance

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at cancer screening (Nick et al., 2021). This may be enhanced in women who have or are vulnerable to developing mental health difficulties (Foster et al., 2021; McBride et al., 2020).

Furthermore, the COVID-19 pandemic caused unprecedented disruption to health systems, including to the NHS Cervical Screening Programme (NHSCSP) in England (CRUK, 2020; Eve Appeal, 2020). For women who have both HPV and a mental health condition(s), the pandemic may have exacerbated pre-existing HPV-related distress. For example, the World Health Organization (WHO) expressed concern over the impact of social distancing measures on those already experiencing anxiety, depression or suicidality (World Health Organisation, 2020). For these women, the pandemic may have triggered additional emotional responses to, and/or avoidance of, cervical screening and related health services.

To our knowledge, to date, there has been no research assessing the impact of HPV in women living with comorbid mental health conditions, who may be more prone to clinically significant reactions and/or changes to help-seeking behaviour. This qualitative study aimed to explore psychosocial responses to testing HPV-positive following routine cervical screening in England in those who reported a mental health condition, as well as their experiences of cervical screening during COVID-19. We sought to highlight relevant information for informing future practice, improving service provision and intervention development.

METHODS

Participants

In-depth, semi-structured interviews were conducted by telephone between 11 March and 7 June 2021. Twenty-two women took part who were aged 27–54 and had tested HPV-positive with normal cytology for the first, second, or third consecutive time at routine cervical screening. They had previously taken part in a cross-sectional psychological survey study (which will be referred to as the primary study) conducted at two NHSCSP HPV primary screening sites in England in 2019–2020 (McBride et al., 2022). In their survey, participants opted into being contacted to take part in a future interview study. Purposive sampling was used to ensure the sample represented a range of sociodemographic backgrounds, where possible (e.g., ethnicity, age, deprivation score, education, religion and mental health status).

Materials and procedure

Eligible participants who had opted in were contacted by phone to confirm interest in interview participation. Those who agreed completed a study information sheet, demographic questionnaire and consent form providing written informed consent. Data from the primary study were used to assess demographics, cervical screening test results and mental health conditions. All recruited participants had self-reported having at least one current clinical diagnosis of anxiety, depression and/or other mental health disorder(s) in the primary study. We also cross-referenced self-reported mental health status via the demographic questionnaire used in this current study. See Files S1 and S2 for the questionnaire used in the primary cross-sectional and current study, respectively.

Data collection and analysis

Interviews followed a topic guide informed by evidence and theory, devised iteratively from previous HPV literature (McBride, Marlow, et al., 2021) and emerging COVID-19 research (Castanon et al., 2022; Ivanuš et al., 2021). We drew upon the Affect and Behaviour Framework

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(Williams & Evans, 2014) to consider affective responses pre-and post-cervical screening in both the short-and long-term. See File S3 for the full topic guide. Interviews were audio recorded and transcribed verbatim, then uploaded to NVivo (QSR International Pty Ltd., 2020) where deductive six-step thematic analysis was utilized (Braun et al., 2023; Braun & Clarke, 2006, 2021). First-level semantic coding was initiated by two researchers (NOD and EM) to identify key topics. NOD coded all transcripts and EM independently coded ~20% of the transcripts ($n = 4$). This indicated good inter-rater reliability ($\kappa = .81$). A framework matrix was then devised to summarize codes compared by mental health condition. This approach was chosen due to its structured yet flexible approach in allowing immersion in the collected data, increasing understanding of key participant themes (Gale et al., 2013). The consolidated criteria for reporting qualitative research was cross-referenced throughout to ensure data was appropriately collected and reported in a trustworthy manner (Tong et al., 2007).

Data governance and ethical guidelines were followed, with initial approvals received from the Health Research Authority on 9 January 2019, and amendments approved on 24 November 2020 (Research Ethics Committee reference: 18/EM/0227 and Confidentiality Advisory Group reference: 18/CAG/0118). Cervical Screening Research Advisory Committee approval was granted on 15 March 2019 (ODR1819_005; McBride et al., 2022).

RESULTS

Twenty-two women completed interviews, lasting between 20 and 71 min. In line with the International Classification of Diseases 10 mental health categories (WHO, 1992), four reported depressive disorders; six had anxiety disorders; eight co-morbid anxiety and depressive disorders; and four other conditions (psychosis, anorexia nervosa, bulimia nervosa and post-traumatic stress disorder; Table 1).

Summary of themes

Women's responses covered five themes: (1) Psychological response to test result; (2) Impact of pre-existing mental health conditions; (3) Health behaviours and information seeking; (4) Virus beliefs and (5) Impact of COVID-19 on health care provision. Quotes are reported with participant number (P) and mental health status (depression as D, anxiety as A, both depression and anxiety as DA and other as O).

Psychological response to test result

When initially testing positive for HPV, women described feeling "worried" (P5, A), "frustrated" (P22, DA), "upset" (P9, A), "panicked" (P3, O) and "shocked" (P20, O):

> I was absolutely distraught when I got that result… the embarrassment of it and being devastated.
>
> (P5, A)

The impact of receiving a repeat HPV-positive result (at follow-up screen) appeared to evoke similar emotions, but these varied in intensity and over time. Although less of a shock when HPV was detected for a consecutive time, some women were increasingly fearful that this signified worse outcomes. Those with an anxiety disorder experienced particularly high levels of worry between follow-up screens:

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TABLE 1 Demographic and clinical characteristics ($n = 22$).

Outcome	
Self-reported mental health condition (*N*)	
Depressive dsisorder[a]	4
Anxiety disorder[b]	6
Anxiety and depressive disorders	8
Other mental health condition[c]	4
Mean age in years [SD] (range)	33.4 [9.5] (26–54)
Marital status (*N*)	
Single	15
Married	3
Cohabiting	4
Employment status (*N*)	
Full-time	14
Part-time	5
Not working[d]	3
Highest level of education (*N*)	
Below degree level	12
Degree level and above	10
Religion (*N*)	
None	16
Christian	5
Jewish	1
Ethnicity (*N*)	
White	18
Black	1
Mixed/multiple	3
Last cervical screening date (*N*)	
0–6 months ago	8
6–12 months ago	10
>12 months ago	4
HPV with normal cytology found[e] (*N*)	
1st result	8
2nd result	10
3rd result	4
IMD decile[f] (*N*)	
Most deprived (deciles 1–5)	14
Least deprived (deciles 6–10)	8

Abbreviations: HPV, human papillomavirus; *N*, number; SD, standard deviation.

[a]Depressive disorders included recurrent depressive disorder (F33) ($n = 2$) and persistent mood (affective) disorder (F34) ($n = 2$).

[b]Neurotic, stress-related and somatoform disorders included Generalized Anxiety Disorder (F41.1) ($n = 4$), Panic Disorder ($n = 1$) and Intrusive Thought Disorder (F42) ($n = 1$).

[c]Other mental health conditions comprised of Anorexia Nervosa (F50.0) ($n = 1$), Psychosis (F23) ($n = 1$), Bulimia Nervosa (F50.2) ($n = 1$) and Post Traumatic Stress Disorder (PTSD) (F43.1) ($n = 1$) (WHO, 1992).

[d]Not working comprised of women who were Unemployed ($n = 1$), Student ($n = 1$) and Homemaker ($n = 1$).

[e]Women had tested HPV positive with normal cytology for a first, second or third consecutive time at their 12-month recall at HPV primary screening.

[f]Index of multiple deprivation (IMD) is a multidimensional marker of the level of deprivation of a geographical location, based on current residential postcode.

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> The next time…in my mind, to me, it had gotten worse. It maybe hadn't, but in my head and my understanding, if it hasn't gone then it's gotten worse and it could keep getting worse and I could end up with cervical cancer.
>
> (P5, A)

For many women, heightened emotions remained over time, with some describing continued distress 2 years after their first HPV-positive result:

> I still get very shocked, and I can't understand…. It's just a really scary, very difficult situation, I don't wish it on anybody else.
>
> (P11, DA)

For others, emotional response subsided over time, and they were able to "put it to the back of my mind" (P18, DA); especially those who had tested negative for HPV at a consecutive screen.

Regardless of whether women had received a consecutive HPV-positive or -negative result, feelings of shame, blame and humiliation pre-occupied many. Several described themselves as "dirty" (P12, A) and held self-blaming beliefs. This seemed particularly apparent for women with depression and conditions that influence the perception of self, such as Anorexia Nervosa:

> …it reflects really badly on me. I just worry that people would think bad things about me, I tend to take things quite badly… people are gonna judge you for it in some way.
>
> (P19, O)

Many women spoke at length about fear of cancer and HPV being out of their control, contributing to longer-term distress. The uncertainty was difficult for many to tolerate, especially given the 12-month interval between initial and follow-up screen, as well as having to accept that there is no recommended treatment during this period:

> It's very scary to know that cells are staying inside of you and you can literally do nothing to stop them… it's out of our control.
>
> (P11, DA)

Several spoke about the desire to know what is going on inside their body, and how the feeling of 'not knowing' (P11, DA) was difficult to endure, particularly those reporting high anxiety:

> When you suffer with anxiety or anything like that, I think if you're told about something quite worrying, you tend to fixate on it a bit more, that's what I did.
>
> (P3, O)

Several women, especially those with depression, described feeling to blame regarding the impact of HPV on their relationships. A few reported concerns around their partner's fidelity, but most described internalized and negative self-beliefs:

> I felt like I was being punished for something, but that's probably my mind-set… I was thinking to myself "What's wrong with me? What is wrong with my body to create this HPV?
>
> (P13, D)

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Impact of pre-existing mental health conditions

Many women reported insight into the interaction between their mental health difficulties and their HPV result, openly discussing how pre-existing difficulties can shape their cognitions and subsequent behaviour. Many described a relationship between their mental health and HPV status, with HPV worsening their psychological state alongside pre-existing difficulties making life "horrendous" (P3, DA) and like "I can't process this, I can't talk about this" (P11, DA):

> If you have a mental health condition you might process information differently to someone that doesn't because it just brings up questions and panic.
>
> (P22, DA)

For one woman with a history of psychosis, being informed of her HPV-positive status had a particularly detrimental impact and reportedly led to her being sectioned under the Mental Health Act (Mental Health Act, 2007). Although this is an isolated response, it demonstrates the extreme levels of distress that an HPV-positive result can have on women who live with more severe mental health difficulties:

> I panicked but I wasn't altogether right in the head at that point. When I actually had the psychotic episode, I thought I had cancer… I just saw the word HPV, and I thought I was going into hospital to die.
>
> (P17, O)

Others were able to use their mental health challenges as a strength. Many drew upon skills that they had learnt through previous mental health interventions, such as Cognitive Behavioural Therapy (CBT) to cope with their HPV result and the wait for subsequent follow-up screening:

> I went to CBT so you can kind of register the thoughts that you know are heading down before it starts to spiral into an anxiety attack.
>
> (P9, A)

Many said HPV worsened their psychological state alongside pre-existing difficulties and left them feeling unable to cope. Several women with depression withdrew from others as they felt unable to speak to anyone. One woman stated that she "didn't feel like leaving my house, I just stayed in bed" (P11, DA), whilst another said "knowing that I had HPV, I literally just shut down. I didn't want to do anything, I didn't want to go anywhere" (P13, D).

Although not related to their mental health condition directly, other cancer and gynaecological factors influenced women's distress, for example, a family history of cancer or close bereavement. This speaks to the level of information and understanding that women have about the likelihood of HPV becoming cancer:

> I was quite worried because we've got quite a lot of cancer in our family. I was really, really worried when they were saying how I had abnormalities.
>
> (participant 3, O)

It was not uncommon for some women in the sample to report multiple gynaecological issues, with HPV adding to a list of diagnoses affecting their self-esteem. Although unrelated to HPV, this seemed to bring up complex feelings about self-image and confidence, potentially linking to ideas around femininity and something being 'wrong' gynaecologically:

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> Obviously because of my endometriosis I don't really have confidence with everything down there anyway, so having HPV on top just made me feel extra disgusted.
>
> (P2, DA)

Health behaviours and information seeking

Many women explained how their HPV diagnosis and subsequent cognitions had impacted upon their behaviours, positively and negatively. Some made positive changes to their health behaviours through trying to "be even more healthy" (P1, DA); such as using vitamin supplements and reducing alcohol consumption and smoking. Some women described that they aimed to "boost my immune system" (P15, DA), explaining that their belief was that having a strong immune system would rid HPV from their system more quickly.

Sexual intimacy was commonly discussed, with women who were single stating that HPV had influenced their consideration of sexual partners "it made me think about who I sleep with" (P16, A). Women in relationships stated that they experienced changes to how they perceived their sex lives. Many women felt that having HPV made them less likely to want to have sex and then worried about the impact that this may have on their relationship and partner:

> the fact that I'm struggling to be intimate with my other half does cause concern…it's like "Well, if I can't make him happy, is he going to go and find somebody else?
>
> (P13, D)

In terms of information seeking behaviours, most women reported limited understanding of HPV, citing that they doubted themselves. Many spoke of having to "do my own research" (P9, A), turning to the internet for information, as "learning about something makes you feel better…settles the doubt in your brain" (P9, A) and re-gain perceived control. Many women with an anxiety disorder acknowledged that their independent research led to increased worry:

> Anxiety definitely made me do the research. If I didn't have anxious thoughts, I probably wouldn't have gone so deep into reading about it and thinking about it.
>
> (P9, A)

> When you read up on them kind of things, it can go one of two ways. It can either scare you or, or you can gain knowledge from it and be okay.
>
> (P3, O)

Some women reported that health care professionals (HCP) lacked knowledge of HPV which deepened fears, suggesting that wider training may be needed, both in terms of HPV and its' emotional impact:

> I went and spoke to my doctor who actually had no idea and had to research HPV as well.
>
> (P6, DA)

Despite this, all women stated that they were reassured by the information given by their HCP, explaining that their distress declined after they sought out professional guidance. This suggests that HCPs play a crucial role in alleviating HPV-related distress:

> I wanted her to magic it away and she wasn't able to do that. I left feeling more reassured, more educated… she did, kind of, put my mind at ease.
>
> (P5, A)

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Virus beliefs

Given that interviews took place during the COVID-19 pandemic when public fear and stigma related to viruses were prominent, women were asked about their views on viruses to explore whether this perpetuated negative associations with HPV. Nearly all stated that they did not consciously connect the viral components of HPV and COVID-19, with many describing COVID-19 as "so extreme" (P10, A) that it is incomparable to any other virus, such as HPV:

> I think it's because Covid's a new virus, it's wreaking havoc on the whole world and it makes you realise how different they [viruses] can all be in strengths and what they're capable of. So, I think for some people hearing the word 'virus' could really, really affect some people. But in terms of the smear [cervical screen] and the HPV, I don't think Covid's affected my mentality so much on it.
>
> (P14, DA)

Thoughts about bodily invasion from viruses were common, with any virus making women feel "uncomfortable" (P10, A) because it "isn't supposed to be there" (P7, D). One woman said that HPV was intrinsically linked with a sense of lower self-worth and stigma, in contrast with COVID-19 which was a 'general illness' that 'isn't anyone's fault' (P8, DA).

For women with depression, HPV appeared to impact on their identity in a way which was specific to testing HPV-positive during the COVID-19 pandemic:

> there's something wrong with me, I shut down… Almost like I would say spiraling back into the depression scenario again, having to deal with it [both COVID-19 and HPV], just feeling as though I'm worthless, like I say I'm literally like there's something wrong with me, as though like I'm not good enough.
>
> (P13, D)

Impact of COVID-19 on health care provision

When asked, all women reported that COVID-19 had not influenced their decision to attend cervical screening, with many stating that the pandemic makes them "more likely to go" (P21, D):

> No, it's not affected me, the Covid. If I've got to go (to cervical screening), I've got to go and that's it.
>
> (P17, DA)

All women, except one, reported having attended a follow-up cervical screen after their HPV-positive result. Some expressed anger at the impact of the pandemic on health provision more generally, citing the importance of cervical screening and gynaecological health:

> If I'd been one of those people that had to wait amongst the other people that have died from cancer and diagnosed with cancer, I'd have been screaming from the rooftops.
>
> (P1, DA)

Most felt that the pandemic had not impacted upon their appointments negatively, with some saying that services were more efficient:

> they have a much faster system now where they don't have people waiting around in waiting rooms. Everyone's very strict on time so it's made more spaces.
>
> (P14, DA)

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However, a minority explained that their follow-up screenings had been delayed, and that this evoked an emotional response:

> It annoyed me when I rang up in December to book in and she said "We're not doing your cervical screening because we're busy getting ready to jab the over-eighties," I thought "A healthy woman will die of cervical cancer, but it's alright because your over-eighties are alive."
>
> (P8, DA)

Some expressed concern about the impact of the pandemic on women with HPV more generally, acknowledging that even if it had not been challenging for them, it may have been for others:

> I started thinking how hard it is for people who are currently diagnosed with things like positive HPV… how they're going to cope having treatment for this illness and then having Covid around.
>
> (P11, DA)

Whilst acknowledging the challenges faced by cervical screening and cancer services, women suggested areas for improvements, notably around increasing education, refining wording of literature, and providing more in-depth information:

> things aren't always worded in the best way. It gives this idea of you being imagined to be this pathetic woman coming out of an appointment crying.
>
> (P20, O)

Several discussed how they were now familiar with COVID-19 testing and taking their own samples at home, which made them more comfortable with the idea of HPV self-sampling. Many spoke about how HPV self-sampling would improve future cervical screening provision:

> We have now take-home Covid testing so why not other testing?
>
> (P11, DA)

Whilst most were open to self-sampling and thought it would be "easier" and "more comfortable" (P14, DA) than standard screening, others expressed concern about "doing it properly" (P10, A). Nevertheless, most expressed that the pandemic had made them more "open" (P14, DA) to different health care solutions and suggested that "clear instructions" (P20, O) would ease a lot of apprehension related to self-swabbing.

DISCUSSION

This study explored the psychosocial impact of testing HPV-positive among women with a co-morbid mental health condition(s) during the COVID-19 pandemic. For most, the experience of being informed of an HPV-positive result increased distress and heightened pre-existing psychological challenges. Psychosocial response and subsequent duration of HPV-related distress appeared to be influenced by women's ability to regulate emotions, experiences of cervical screening and HCP interactions, number of consecutive HPV-positive results, and other life stressors. Interactions between HPV positivity and challenges associated with managing a mental health condition(s) added further complexity to many women's perception of self, self-esteem and intensity of distress.

Women often linked testing HPV-positive to feelings of shame and humiliation, with some internalizing blame and feeling that they deserved punishment, or that their partners deserved "better".

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This contrasts with HPV studies conducted in the general population, where sexual concerns are often externally focussed, linked to relationship infidelity or anger directed towards a partner (McBride et al., 2020; Waller et al., 2007). These differences suggest targeted post-diagnostic support or communication strategies, centred on reducing HPV-related shame and blame, may help to minimize internalization of negative self-beliefs for those with mental health conditions. Such support could draw on the existing and wider literature, for example regarding shame and help-seeking, and be specifically tailored to women with an HPV-positive result (Flynn et al., 2017; Rüsch et al., 2014).

Consistent with literature on HPV in the general population (Waller et al., 2007) women in this study reported variations in emotional response over time, with prolonged distress remaining for some. Intensity of emotional response was reported as extreme for some women, which they explicitly linked to their mental health diagnosis. Perceived sense of control, having access to knowledgeable HCPs, and being able to transfer skills from psychological therapies were reported as helpful coping strategies. Previous studies highlight the role of perceived control and its association with impaired physical and psychological health outcomes (McBride et al., 2020, 2022; Waller et al., 2007), as well as the importance of HCP interactions in modulating anxiety (McBride, Marlow, et al., 2021; McBride, Tatar, et al., 2021). Novel to our findings, many women emphasized that they felt equipped to deal with HPV-related distress due to coping strategies they had learned in psychological therapy linked to their mental health condition. Future cervical screening approaches may therefore benefit from signposting to adaptive coping strategies (e.g., talking to an HCP) or integrating therapeutic techniques into patient materials and communications, as recommended in a recent systematic review on the role of interventions to improve coping and mental health outcomes (Groth et al., 2019). This type of approach has been shown to be useful in other areas of health care, for example, the adaption of CBT techniques to aid communication between HCPs and patients (Roberts et al., 2021). Similarities in themes across mental health groups in our study suggest that resources could be generic rather than tailored to specific mental health conditions, though this would need to be confirmed in hypothesis-driven quantitative studies.

In terms of behavioural responses, some women attempted to improve their health by reducing alcohol consumption or taking vitamin supplements. For others, the behavioural impact was negative, with detrimental effects on their sleep, sexual relationships and ability to socialize. These findings are largely consistent with the wider literature (McBride, Tatar, et al., 2021). Furthermore, nearly all women sought more information on HPV, reporting that information in their test result letter was lacking. As found in previous studies, many women incorrectly believed that an HPV-positive result was the direct precursor to cancer diagnosis (McBride et al., 2020, 2022), therefore overestimating their cancer risk. For one woman in the current study, who was experiencing a psychotic episode, the misinterpretation that HPV meant she had cancer reportedly resulted in hospitalization under the Mental Health Act (Mental Health Act, 2007). Although severe mental health conditions (such as psychosis) affect a small percentage of the general population, it is important to consider these groups through further research, and within screening policy and implementation decisions, due to risk of potential harm.

In relation to COVID-19, it is reassuring that negative connotations and fear about viruses did not appear to transfer to the viral aspect of HPV. Differences in language were used to describe the two viruses, where personal blame appeared to be attached to HPV due to its sexually transmitted nature. Furthermore, the pandemic was not reported to have influenced women's intention to attend, or attendance at, cervical screening; though in some cases screening had been unavailable or delayed, which heightened distress for most. Our findings are in line with a cross-sectional survey which indicated that most women in the UK had high intentions to attend cervical cancer screening at two timepoints during the pandemic (Wilson et al., 2020). Many women in our study, in fact, expressed that the pandemic had improved their view of cervical screening. Consistent with wider COVID-19 literature (Isautier et al., 2020; Panda et al., 2021), these women explained that appointments had become more efficient. Many hoped that some COVID-19 procedures, such as flexible appointment booking, would remain in place post-pandemic. Restructuring of health care delivery due to COVID-19 may therefore have positive implications for the future of cervical screening services.

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Strengths and limitations

To our knowledge, this is the first study to explore the impact of receiving HPV-positive results in women with co-morbid mental health conditions. Recruitment was linked to routine clinical management at HPV primary screening, ensuring a relatively diverse and well-characterized sample. The AFB was also used to inform topic guides (Williams & Evans, 2014), which is a relevant theoretical framework that has not been applied to the HPV context previously. However, the fact that this study was conducted during COVID-19 could conflate findings, as there is potential for worsened mental health due to the emotional strain of the pandemic. Use of telephone interviews meant that non-verbal communication cues may have been lost and could have impacted how women discussed intimate and sensitive topics. As participants were recruited to the original study almost 2 years prior to the interviews, recall bias related to receiving the initial test result is also a potential limitation, impacting women's recall of their affective response, cognitions and behaviour. Finally, there was minimal representation of women from ethnic minority backgrounds. This is a limitation of similar studies and could, in part, be demonstrative of cultural reluctance to disclose mental health difficulties or structural racism barriers. Due to the relatively small numbers within each of the mental health and demographic groups, we were unable to explore thematic intersections or comparisons between these variables, which may be particularly important when considering different diagnostic presentations.

Clinical implications

The psychosocial needs of those with mental health conditions, who are at higher risk of clinically significant distress, should be incorporated into future cervical screening policy and staff training. The pandemic may have offered a unique opportunity for a radical restructuring of health care services, both in the United Kingdom and abroad. This might allow for the suggestions outlined in this study to be incorporated with greater ease than previously, allowing for psychologically informed communications to be implemented and/or stratified to high-need groups and informing the development of future intervention. Furthermore, through provision of psychologically informed care in physical health settings, women with pre-existing or vulnerability to developing mental health difficulties may be less likely to require support from mental health services which are often oversubscribed.

CONCLUSION

Receiving an HPV-positive result at cervical screening result appears to be a distressing experience for women with co-morbid mental health conditions. These women expressed some unique HPV-related concerns when compared with the general population, including internalized feelings of blame and exacerbation of pre-existing symptoms related to their mental health condition. Future hypothesis-driven research is needed to confirm our findings and explore potential moderation and/or interaction effects between different mental health conditions and relevant demographics.

AUTHOR CONTRIBUTIONS

EM conceived the study and secured funding. EM and NOD designed the research question. EM, NOD, JW and LM developed the research materials. NOD conducted interviews. NOD and EM collected the data. NOD and EM analysed and interpreted the data. NOD and EM drafted the manuscript. All authors contributed to the final version of the manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors have no competing interests to report.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Nicola O'Donnell https://orcid.org/0000-0003-0661-4129
Emily McBride https://orcid.org/0000-0001-9926-429X

TWITTER

Emily McBride UCL_BSH EmilyPMcBride

REFERENCES

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2021). *Thematic analysis: A practical guide* (1st ed.). SAGE Publications Ltd.

Braun, V., Clarke, V., Braun, V., & Clarke, V. (2023). Is thematic analysis used well in health psychology? A critical review of published research, with recommendations for quality practice and reporting practice and reporting. *Health Psychology Review*, 1–24. https://doi.org/10.1080/17437199.2022.2161594

Castanon, A., Rebolj, M., Pesola, F., Pearmain, M., & Stubbs, R. (2022). COVID-19 disruption to cervical cancer screening in England. *Journal of Medical Screening*, *29*(3), 203–208.

CRUK. (2020). Cancer screening and coronavirus.

Dodd, R. H., McCaffery, K. J., Marlow, L. A. V., Ostini, R., Zimet, G. D., & Waller, J. (2014). Knowledge of human papillomavirus (HPV) testing in the USA, the UK and Australia: An international survey. *Sexually Transmitted Infections*, *90*(3), 201–207. https://doi.org/10.1136/sextrans-2013-051402

Eve Appeal. (2020). Cervical screening and colposcopy guidance during Covid-19.

Flynn, S. M. Q., Eisenlohr-Moul, T. A., Segerstrom, S. C., Logue, C. T., & Studts, J. L. (2017). High trait shame undermines the protective effects of prevalence knowledge on state shame following HPV/CIN diagnosis in women. *Journal of Behavioral Medicine*, *40*(5), 814–820. https://doi.org/10.1007/s10865-017-9849-8

Foster, S., Carvallo, M., Lee, J., Fisher, R., & Traxler, H. (2021). An implication of impurity: The impact of feminine honor on human papillomavirus (HPV) screenings and the decision to authorize daughter's HPV vaccinations. *Stigma and Health*, *6*(2), 216–227. https://doi.org/10.1037/sah0000230

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), 117. https://doi.org/10.1186/1471-2288-13-117

Groth, N., Schnyder, N., Kaess, M., Markovic, A., Rietschel, L., Moser, S., Michel, C., Schultze-Lutter, F., & Schmidt, S. J. (2019). Coping as a mediator between locus of control, competence beliefs, and mental health: A systematic review and structural equation modelling meta-analysis. *Behaviour Research and Therapy*, *121*, 103442. https://doi.org/10.1016/j.brat.2019.103442

Huber, J., Mueller, A., Sailer, M., & Regidor, P. A. (2021). Human papillomavirus persistence or clearance after infection in reproductive age. What is the status? Review of the literature and new data of a vaginal gel containing silicate dioxide, citric acid, and selenite. *Women's Health*, *17*. https://doi.org/10.1177/17455065211020702

Isautier, J. M. J., Copp, T., Ayre, J., Cvejic, E., Meyerowitz-Katz, G., Batcup, C., Bonner, C., Dodd, R., Nickel, B., Pickles, K., Cornell, S., Dakin, T., & McCaffery, K. J. (2020). People's experiences and satisfaction with telehealth during the COVID-19 pandemic in Australia: Cross-sectional survey study. *Journal of Medical Internet Research*, *22*(12), 1–11. https://doi.org/10.2196/24531

Ivanuš, U., Jerman, T., Gašper Oblak, U., Meglič, L., Florjančič, M., Strojan Fležar, M., Premru Sršen, T., Smrkolj, Š., Pakiž, M., Primic Žakelj, M., Kloboves Prevodnik, V., Pogačnik, A., Josipović, I., Mate, T., & Gobec, M. (2021).

20448287, 2024, 1, Downloaded from https://bpspsychub.onlinelibrary.wiley.com/doi/10.1111/bjhp.12688 by University Library, Wiley Online Library on [09/10/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

The impact of the COVID-19 pandemic on organised cervical cancer screening: The first results of the Slovenian cervical screening programme and registry. *The Lancet Regional Health - Europe*, *5*, 100101. https://doi.org/10.1016/j.lanepe.2021.100101

Maver, P. J., & Poljak, M. (2020). Primary HPV-based cervical cancer screening in Europe: Implementation status, challenges, and future plans. *Clinical Microbiology and Infection*, *26*(5), 579–583. https://doi.org/10.1016/j.cmi.2019.09.006

McBride, E., Marlow, L. A. V., Bennett, K. F., Stearns, S., & Waller, J. (2021). Exploring reasons for variations in anxiety after testing positive for human papillomavirus with normal cytology: A comparative qualitative study. *Psycho-Oncology*, *30*(1), 84–92. https://doi.org/10.1002/pon.5540

McBride, E., Marlow, L. A. V., Chilcot, J., Moss-Morris, R., & Waller, J. (2022). Distinct illness representation profiles are associated with anxiety in women testing positive for human papillomavirus. *Annals of Behavioral Medicine*, *56*(1), 78–88. https://doi.org/10.1093/abm/kaab022

McBride, E., Marlow, L. A. V., Forster, A. S., Ridout, D., Kitchener, H., Patnick, J., & Waller, J. (2020). Anxiety and distress following receipt of results from routine HPV primary testing in cervical screening: The psychological impact of primary screening (PIPS) study. *International Journal of Cancer*, *146*(8), 2113–2121. https://doi.org/10.1002/ijc.32540

McBride, E., Tatar, O., Rosberger, Z., Rockliffe, L., Marlow, L. A. V., Moss-Morris, R., Kaur, N., Wade, K., & Waller, J. (2021). Emotional response to testing positive for human papillomavirus at cervical cancer screening: A mixed method systematic review with meta-analysis. *Health Psychology Review*, *15*(3), 395–429. https://doi.org/10.1080/17437199.2020.1762106

Mental Health Act 2007. (2007). *Mental Health Act 2007: Chapter 12*. 1–167.

Morgan, E. L., Patterson, M. R., Ryder, E. L., Lee, S. Y., Wasson, C. W., Harper, K. L., Li, Y., Griffin, S., Blair, G. E., Whitehouse, A., & Macdonald, A. (2020). MicroRNA-18a targeting of the STK4/MST1 tumour suppressor is necessary for transformation in HPV positive cervical cancer. *PLoS Pathogens*, *16*(6), 1–27. https://doi.org/10.1371/journal.ppat.1008624

Muñoz, N., Méndez, F., Posso, H., Molano, M., van den Brule, A. J. C., Ronderos, M., Meijer, C., & Muñoz, A. (2004). Incidence, duration, and determinants of cervical human papillomavirus infection in a cohort of Colombian women with normal cytological results. *The Journal of Infectious Diseases*, *190*(12), 2077–2087. https://doi.org/10.1086/425907

Nick, N., Torabizadeh, C., & Ghahartars, M. (2021). Perceived supportive paradox after diagnosing human papillomavirus: A qualitative content analysis. *International Journal of Community Based Nursing and Midwifery*, *9*(2), 92–105. https://doi.org/10.30476/ijcbnm.2021.88802.1547

Panda, S., O'Malley, D., Barry, P., Vallejo, N., & Smith, V. (2021). Women's views and experiences of maternity care during COVID-19 in Ireland: A qualitative descriptive study. *Midwifery*, *103*, 103092. https://doi.org/10.1016/j.midw.2021.103092

Public Health England. (2019). *Cervical screening: implementation guide for primary HPV screening*.

QSR International Pty Ltd. (2020). *NVivo (version 12)*.

Rebolj, M., Rimmer, J., Denton, K., Tidy, J., Mathews, C., Ellis, K., Smith, J., Evans, C., Giles, T., Frew, V., Tyler, X., Sargent, A., Parker, J., Holbrook, M., Hunt, K., Tidbury, P., Levine, T., Smith, D., Patnick, J., … Kitchener, H. (2019). Primary cervical screening with high risk human papillomavirus testing: Observational study. *BMJ*, *364*. https://doi.org/10.1136/bmj.l240

Ritu, W., Enqi, W., Zheng, S., Wang, J., Ling, Y., & Wang, Y. (2019). Evaluation of the associations between cervical microbiota and HPV infection, clearance, and persistence in cytologically normal women. *Cancer Prevention Research*, *12*(1), 43–56. https://doi.org/10.1158/1940-6207.CAPR-18-0233

Roberts, L., White, D., David, L., Vadher, B., & Stoner, N. (2021). The development and testing of a novel cognitive Behavioural therapy (CBT)-based intervention to support medicines-related consultations for healthcare professionals. *International Journal of Pharmacy Practice*, *29*(Supplement_1), i2–i3. https://doi.org/10.1093/ijpp/riab016.002

Rüsch, N., Müller, M., Ajdacic-Gross, V., Rodgers, S., Corrigan, P. W., & Rössler, W. (2014). Shame, perceived knowledge and satisfaction associated with mental health as predictors of attitude patterns towards help-seeking. *Epidemiology and Psychiatric Sciences*, *23*(2), 177–187. https://doi.org/10.1017/S204579601300036X

Shepherd, M. A., & Gerend, M. A. (2014). The blame game: Cervical cancer, knowledge of its link to human papillomavirus and stigma. *Psychology and Health*, *29*(1), 94–109. https://doi.org/10.1080/08870446.2013.834057

Thomsen, L. T., Frederiksen, K., Munk, C., Junge, J., Castle, P. E., Iftner, T., & Kjaer, S. K. (2014). High-risk and low-risk human papillomavirus and the absolute risk of cervical intraepithelial neoplasia or cancer. *Obstetrics & Gynecology*, *123*(1), 57–64.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Waller, J., Marlow, L. A. V., & Wardle, J. (2007). The association between knowledge of HPV and feelings of stigma, shame and anxiety. *Sexually Transmitted Infections*, *83*(2), 155–159. https://doi.org/10.1136/sti.2006.023333

Wierzbicka, M., Klussmann, J. P., San Giorgi, M. R., Wuerdemann, N., & Dikkers, F. G. (2021). Oral and laryngeal HPV infection: Incidence, prevalence and risk factors, with special regard to concurrent infection in head, neck and genitals. *Vaccine*, *39*(17), 2344–2350. https://doi.org/10.1016/j.vaccine.2021.03.047

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Williams, D. M., & Evans, D. R. (2014). Current emotion research in health behavior science. *Emotion Review*, *6*(3), 277–287. https://doi.org/10.1177/1754073914523052

Wilson, R., Quinn-scoggins, H., Moriarty, Y., Hughes, J., Goddard, M., Cannings-john, R., Whitelock, V., Whitaker, K. L., Grozeva, D., Townson, J., Osborne, K., Smits, S., & Robling, M. (2020). Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information.

Woodman, C. B., Collins, S., Winter, H., Bailey, A., Ellis, J., Prior, P., Yates, M., Rollason, T. P., & Young, L. S. (2001). Natural history of cervical human papillomavirus infection in young women: A longitudinal cohort study. *Lancet*, *357*(9271), 1831–1836. https://doi.org/10.1016/S0140-6736(00)04956-4

World Health Organisation. (1992). *The ICD-10 Classification of Mental and Behavioural Disorders*.

World Health Organisation. (2020). *Mental health and COVID-19*.

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