Experiences of Recurrent Vulvovaginal Thrush in Primary Care: A Qualitative Study of Patient and Healthcare Professional Perspectives

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Abstract

Vulvovaginal candidiasis, also known as thrush, is a common genital infection that causes itching, burning, and changes in vaginal discharge. While most cases are acute, transient, and easily resolved with over-the-counter medication, a subset of people experience thrush on a repeated basis. This condition is known as recurrent vulvovaginal candidiasis (or recurrent thrush). An estimated 1.2 million women in the UK annually experience recurrent thrush, with this number anticipated to rise.

This thesis takes a qualitative and feminist lens to analyse experiences of recurrent thrush and its management. I conducted interviews with 34 people with recurrent thrush and 25 healthcare professionals working in primary care and/or sexual health.

This study identified key challenges of living with recurrent thrush, navigating healthcare systems, and understanding diagnosis – all while negotiating multiple identities and health contexts. Findings from this study suggest that recurrent thrush is not merely a series of acute episodes, but a distinct experience requiring specific attention in research and practice.

To address a need for clear, sensitive, and practical information, I developed and published an online resource for the HEXI (Health Experience Insights) platform, incorporating patient narratives to support individuals living with recurrent thrush and their healthcare providers.

This thesis demonstrates the importance of recognising recurrent thrush as a complex, multidimensional health issue. By amplifying the voices of patients and healthcare workers, it provides a foundation for improved resources, practices, and understanding that can transform experiences of care and management.

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Introduction

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1.1 Recurrent thrush as a multifaceted health experience

> *If I had [thrush] once or twice in my life, it would be uncomfortable, but when you get it recurrently, every month, it's a completely different condition, they should be treated completely separately and not related.* – Harry (Patient interview)

> *The gap is the transition between seeing thrush as a self-limiting one-off condition, and having it often or all the time. For our health systems, making the jump between those is difficult.* – GP Dr A (Healthcare professional interview)

> *My doctor turns to me and asks: 'You're doing your PhD on this topic, what do you think is going on?' In that moment, I don't know how to articulate that no amount of knowledge stops my body from being in pain* – Tori (Research reflexive journal*)*

These three quotes represent the different voices on which this thesis draws: people with recurrent thrush, health care professionals and my own reflexive account. These perspectives underscore the complexity of recurrent thrush as both a medical problem and a lived experience intertwined with emotional, embodied, social, and systemic dimensions. This qualitative thesis is rooted in these multiple layers, seeking solutions that are as comprehensive as the problem itself.

1.2 The problem of recurrent thrush

1.2.1 Defining recurrent thrush

Vulvovaginal candidiasis, known colloquially as thrush or a yeast infection, is an overgrowth of yeast in the vaginal microbiome. Symptoms include genital itching, burning, redness, swelling, pain, and abnormal vaginal discharge (often described as thick, white, and clumpy). Most cases present as acute, one-off and transient. However, some people experience thrush on a repeated, cyclical, or persistent basis. These cases are known as recurrent thrush, which is clinically defined as four or more thrush episodes within a 12-month period (BASHH 2019, NICE 2023).

Recurrent thrush can vary in presentation. Some people experience discrete episodes with symptom relief in-between episodes and after treatment, while others have ongoing, continuous or persistent discomfort. Clinical guidelines recognise these variations (BASHH 2019, NICE 2023). Some scholars propose that vulvovaginal thrush exists along a spectrum of acute, recurrent, and chronic subtypes, and have been calling for more research into these experiences (Donders et al. 2010).

In this thesis, I use the term "recurrent thrush" to capture both subtypes (recurrent, chronic) and include the full range of experience, whether intermittent or continuous. I chose to use this colloquial term instead of more clinical language such as 'recurrent vulvovaginal candidiasis' to mirror the language used by patient groups and participants and to increase accessibility of this research.

Certain health conditions that affect the immune system can increase the likelihood of recurrent thrush. These include diabetes, HIV, and other autoimmune health conditions such as Sjogren's syndrome (an autoimmune condition that affects parts of the body that produce fluids), and mannose-binding lectin deficiency (BASHH 2019).

Anyone with a vagina can experience this condition (including women, transgender men, and non-binary people assigned female at birth). However, existing research overwhelmingly presents findings from samples of cisgender women, with data not available for trans and non-binary individuals. The following descriptions of the literature refer to the study population of women as described in those studies, but have implications for all those affected by recurrent vulvovaginal thrush.

1.2.2 The vaginal microbiome

Thrush is commonly caused by an overgrowth of yeast (*Candida*) that is part of the normal vaginal microbiota, but under certain conditions, these normally harmless organisms proliferate and cause infection. The vaginal microbiome includes microorganisms, including fungi, bacteria, and viruses that reside in the vagina. Thrush is caused by a disruption to the balance of the vaginal microbiome. This disruption can be caused by a range of behaviours, such as having sex, taking antibiotics, over-washing or vaginal douching, and wearing tight, non-breathable clothing (Patel 2004).

Hormonal changes also affect the vaginal microbiome as increased endogenous or exogenous oestrogen can exacerbate thrush (including pregnancy, hormone-replacement therapy, and possibly the combined contraceptive pill) (Donders 2017). Yet, experiences linking recurrent thrush and hormonal factors remain understudied.

Candida is a genus of yeast (type of fungus), and most commonly it is *Candida Albicans* that causes vulvovaginal thrush. However, other non-albicans strains, such as *Candida glabrata*, are increasingly identified in recurrent thrush patients. Denning (2024) estimates that for 10% of cases, and 13 million women, recurrent thrush is caused by *Candida glabrata*.

1.2.3 The size of the problem

A systematic review aimed to estimate the global prevalence and lifetime incidence of recurrent vulvovaginal candidiasis (RVVC) defined RVVC as experience of four or more episodes of vulvovaginal candidiasis in a 12-month period (Denning et al. 2018). The researchers conducted a comprehensive search for population-based studies published between 1985 and 2016. They identified 489 unique articles, of which eight met the inclusion criteria, encompassing a total of 17,365 patients from 11 countries. The included studies utilised various sampling methods, primarily focusing on defined populations with either confirmed microbiological diagnoses of vulvovaginal candidiasis or self-reported cases using treatment as a proxy. The review reported that RVVC affects approximately 5-8% of women worldwide annually. The lifetime incidence was estimated at 372 million women. The highest prevalence (9%) was observed in the 25- to 34-year-old age group.

Regarding the accuracy of this estimate for the UK of 1.2 million women living with recurrent thrush, the systematic review did not specify the number of UK or European studies included. Given the limited number of studies and the variability in data sources, the applicability of the global estimate to the UK population may be limited. Denning et al. (2018) acknowledged the scarcity of comprehensive data and the need for more region-specific studies to improve the accuracy of prevalence estimates.

Since Denning's systematic review (which included papers until 2016), several studies have investigated the prevalence of recurrent thrush. A large-scale multi-country (United Kingdom, Germany, France, Italy, Spain, and the Netherlands) internet panel survey indicated a lifetime RVVC prevalence rate in women of 9% by age 50 (Blostein et al. 2017).

The true prevalence of recurrent thrush remains difficult to determine due to a limited number of population-based samples, studies relying on self-reported cases, and most studies emerging from high-income countries (Denning et al. 2018). Further, studies (including two population-based studies included in Denning et al.'s systematic review: Foxman et al. 2000, Foxman et al. 2013) have been queried as recruitment was low and the diagnostic criteria used by clinicians were not reported (Rathod 2014).

1.2.4 Impacts on patients

Recurrent thrush can significantly disrupt people's lives, causing physical, emotional, and relational impacts. People with recurrent thrush report profound effects on their mental well-being (Fukazawa 2019). An Australian interview study found that people's self-esteem and confidence were impacted by recurrent thrush due to embarrassment, shame, and the unpredictability of flare-ups (Strydom 2022). One participant in a British interview study reported that thrush made them "feel miserable, unable to work, embarrassed, or even stigmatized" (Chapple 2000). Recurrent thrush has been associated with lost work productivity and an overall decrease in quality of life, adding to the daily challenges faced by those affected (Aballéa et al. 2013).

Studies highlight the relational strain caused by recurrent thrush, with many women reporting that it adversely affected their sexual relationships and intimacy (Irving et al. 1998). Some women reported that recurrent thrush made them feel "less of a woman" (Karasz 2003, Adolfsson 2017).

Further, recurrent thrush can affect people at different ages, life stages, and for various durations. Studies have included individuals who have experienced thrush for a range of durations, often up to 10 years (Zhu et al. 2016, Chapple et al 2000, Strydrom et al. 2022). Therefore, recurrent thrush can affect people's lives across changing priorities,

perspectives, and self-perceptions. It is not limited to one age group, but instead can affect people at different points in their lives whether on a continual or fragmented basis. Speaking to people across different ages provides insight into how things have changed and how recurrent thrush has influenced them differently throughout their life. However, existing research has often overlooked the value of multi-generational perspectives and excluded the voices of older people.

1.2.5 Help-seeking and care pathways

For acute and one-off cases of thrush, self-management is possible through the pharmacy and over-the-counter medication. However, recurrent vulvovaginal thrush can cause frequent flare-ups and repeated medical visits. Many people with thrush symptoms present to their GP first (Lines et al. 2020), while others may self-refer to genito-urinary medicine (GUM) clinics (Opaneye 1999).

Existing studies across Europe, Australia, and the USA have found dissatisfaction with healthcare consultations for recurrent thrush. Patients report feeling poorly understood and ineffectively managed (Donders et al. 2010). This dissatisfaction includes feeling clinicians have a lack of understanding and empathy around recurrent thrush (Adolfsson 2017, Strydom 2022). Others report feeling dismissed, not taken seriously, and bounced between health services (Johnson 2010).

With the availability of over-the-counter medication, patients may feel little incentive to seek help from health services. Previous studies and a systematic review have shown people with recurrent thrush choosing to bypass healthcare professionals and self-treat (Theroux 2002, Theroux 2005). Self-diagnosis can leave this group of patients vulnerable to misdiagnosis and misuse of over-the-counter medications (Theroux 2005). Over-the-counter treatment and off the shelf options for thrush are

available in pharmacies, supermarkets, and online platforms across the UK. Thrush treatment has been available without a prescription in the UK since 1997, following the reclassification of fluconazole as a pharmacy medicine (Hydson 2001). These include oral antifungal tablets, vaginal pessaries, creams, and gels. The over-the-counter products, including popular brands like Canesten, make up a global market with an estimated annual cost of $600 million USD as of 2013 (Denning et al. 2018).

The increasing options of at-home test kits for thrush may also influence care-seeking patterns, but there is a lack of evidence on the effectiveness of these tests, and how people are using them (Hoffman et al. 2024).

1.2.6 Diagnosis and treatment

Current clinical guidelines recognise recurrent vulvovaginal thrush as a distinct clinical presentation with defined diagnostic and treatment recommendations (BASHH 2019, NICE 2023). Recurrent thrush diagnosis requires four or more episodes in a 12-month period with two episodes confirmed by culture of microscopy. Due to commensal carriage, isolation of *Candida* from the vagina, in the absence of symptoms, is not indicative of thrush. For this reason, diagnosis also relies on the presence of symptoms such as burning, itching, and thick discharge.

Recommended treatment is long-term suppression therapy with antifungal medication (NICE 2021). This typically involves an initial phase of antifungal treatment, followed by maintenance doses weekly for 6 months (NICE 2021). Antifungal resistance remains rare in the UK but is becoming a growing concern with increased reports of resistance to fluconazole since 2019 (Schelenz et al. 2024). Vulval care such as using emollients as daily vulval moisturisers and soap replacements has been shown to improve recurrent thrush treatment (Brown et al. 2022).

Determining the species and specificity of cultures is also recommended in national UK guidelines. Non-albicans strains of *Candida* often have reduced susceptibility to standard treatments like fluconazole and clotrimazole, and require other therapies such as nystatin. Yet accessing certain medications for non-albicans strains of Candida can be difficult.

Vulvovaginal symptoms can be caused by a variety of conditions that share overlapping signs and symptoms (Nunns & Murphy 2012). Other vulval conditions that cause itch can be mistaken for, or present at the same time as, recurrent thrush. These include lichen sclerosus, lichen simplex, contact dermatitis, vulvodynia, and genitourinary syndrome of menopause (GSM). This similarity makes accurate diagnosis challenging, delaying effective treatment and prolonging suffering (Thomas-White et al. 2023).

Multi-year delays between when symptoms are first presented to a healthcare professional and then diagnosed are reported across vulvovaginal conditions (Strydom 2022, Arnold et al. 2022). Calls have been made to improve services to ensure prompt and accurate diagnosis of these patients (Ascott et al. 2017). The FemTech priority setting partnership (EMPOWER) identified better diagnostic testing for vulvovaginal pain and infections in the top 10 priority areas needing improvement (Dixon et al. 2023).

1.3 Existing evidence gaps

Increasingly, scholars and clinicians argue that recurrent thrush should be taken more seriously and researched thoroughly to improve patient care (Denning et al. 2018, Fukazawa et al. 2019). Researchers including Fukazawa (2019) have argued that recurrent thrush is often trivialised as clinically insignificant and overlooked in research funding. Denning (2024) stated: "As a group, fungal disease is under-recognised, under-diagnosed, under-treated, and under-funded". Calls have been made for patients with recurrent thrush to receive serious attention from clinicians and researchers (Fukazawa 2019).

Despite increased calls for attention to recurrent thrush, little interview-based research has occurred. Few qualitative studies have examined patient experiences of thrush (Chapple 2000, Chapple 2001), and even fewer have addressed recurrent or chronic thrush (Adolfsson et al. 2017, Morgan et al. 2009).

Existing studies of patient experiences highlight themes such as brief and impersonal medical encounters (Chapple 2000, Chapple 2001, Theroux 2002, Karasz & Anderson 2003, O'Dowd 1996, Morgan 2009, Strydom 2022, Erfaninejad 2022). However, studies have not yet brought together the perspectives of patients and primary healthcare professionals, which is necessary to understand how to implement improvements in care.

Further, previous studies appear to have focussed exclusively on cis women, rather than capturing gender diverse experiences of recurrent thrush (including trans, non-binary, and genderqueer voices).

1.4 Policy context of this research

This research took place during a rapidly changing landscape of acknowledging gendered health inequities in the UK. The study was designed and undertaken alongside the reporting of investigations concerning gender bias in medicine, including the Cumberlege review "First Do No Harm" (2020) which detailed examples of how the medical experiences and concerns of women are often "dismissed, overlooked and ignored" (p3).

The launch of the *Women's Health Strategy for England (*2022) highlighted the need for targeted attention, research, and action on common gynaecological conditions. The strategy prioritised centring patient voices in evidence-based solutions and welcomed personal testimonies from across England. In the strategy consultation – "Women's Health – Let's Talk About It" survey – out of nearly 100,000 lived experience respondents, 84% reported feeling dismissed by healthcare professionals.

A report by the NHS Confederation, *Women's Health: Investing in the 51%* (2024) highlights that local authorities throughout England with higher ethnic diversity have poorer access to women's health services. The Women and Equalities Committee report *Women's Reproductive Health Conditions* (2024) found that "for some conditions, accessing diagnosis and treatment can take years, leaving women and girls to 'suck it up' and endure pain that interferes with every aspect of their daily lives".

Despite a growing awareness around gender bias in medicine and a lack of attention on conditions that differently or disproportionately affect women and people assigned female at birth, recurrent thrush has not been prioritised or specifically mentioned as a focus of these policy reports. It has received little public attention, despite evidence about its significant toll on those affected.

1.5 Aims and objectives

This doctoral study aims to understand the experiences and perspectives of patients and healthcare professionals managing recurrent vulvovaginal thrush, and how these insights may underpin improvements for clinical care and self-management. This research contributes to developing informational and support resources for patients and healthcare professionals.

The study objectives are as follows:

1. Determine what is currently known about patients and healthcare professionals' experiences and perspectives about recurrent thrush.
2. Understand the experiences of people who have had recurrent thrush.
3. Explore how healthcare professionals interpret patient experiences with recurrent thrush and its management.
4. Develop an online resource for those affected by recurrent thrush and their healthcare professionals.

To address these objectives, I first undertook a systematic review of existing published research literature to identify what information is known, available, or missing for healthcare professionals and patients. I then conducted narrative and semi-structured interviews with a diverse sample of 32 people who have had recurrent thrush. Next, I used these findings to inform interviews with 25 healthcare professionals in general practice and sexual health to assess how recurrent thrush experiences were being interpreted, understood, and managed. Lastly, I used findings to create a web-based resource for patients and clinicians based on qualitative analysis illustrated with multi-media excerpts from interviews.

1.6 Layout of thesis

This thesis contains nine chapters, five of which present findings. I begin in the next chapter (Chapter 2) with a systematic review of patient and healthcare professional experiences with managing recurrent thrush. I reflect on how research on recurrent thrush is thin and often embedded in studies on acute thrush, which fails to capture its complexity.

In Chapter 3, I outline the methods and theories I chose to fill the gaps identified in my systematic review. I explain my methodology for conducting interviews with patients and healthcare professionals, discuss my use of feminist theory, and outline my approach to sensitive and online research. I also highlight contributions from my patient and public involvement group.

Throughout this thesis, I present findings from interviews with patients and healthcare professionals. I locate these findings within an overarching narrative about how recurrent thrush is not equivalent to repeated acute episodes but instead is a fundamentally distinct experience. Differences are explored in the context of bodily experiences, healthcare pathways, and diagnostic journeys.

In Chapters 4-6, I provide thematic analyses of my interview data. In Chapter 4, I challenge previous sanitised accounts found in the literature by providing insight into the 'mess' created by recurrent thrush and how people attempt to manage it on material, microbial, and individual levels. I then turn my attention to how these 'messy' bodies fit into or disrupt healthcare processes and settings. In Chapter 5, I introduce findings from healthcare professionals and patient experiences to examine how people navigate care pathways and what experiences they accumulate along the way. In Chapter 6, I present diagnosis as a key process within this accumulative experience

where both patients and healthcare professionals attempt to unpick what is important for identifying recurrence through the lens of 'candidacy'.

In Chapter 7, I turn my attention to three patient accounts chosen from in-depth analysis from my interview collection to explore how recurrent thrush fits into individual lives in the context of intersectionality and multimorbidity.

In Chapter 8, I discuss my approach to generating impact through disseminating study findings. I reflect on the process of creating a multimedia patient-facing website at hexi.ox.ac.uk. At the start of findings chapters, images co-created with patient interviewees and the patient representative group for the resource are included to help illustrate study findings. At the end of this chapter, I present the visual collection in its entirety.

I conclude the thesis in Chapter 9 where I pull together key themes of the research and the contributions to the field as well as suggestions for further research. I present implications for practice, whether clinical recommendations (relevant to practice and policy) or recommendations for patients on working collaboratively with their practitioners (which have been co-written with my patient representative group). I also offer final reflections as a lived-experience researcher, exploring what this role has meant for me as an academic/advocate/patient.

2

Systematic Review

Contents

2.1 Introduction

Determining what is known about recurrent vulvovaginal thrush experiences was the starting point for this thesis. Systematic reviews are useful for providing a comprehensive knowledge summary of published research. Previous reviews on recurrent thrush have been mainly quantitative and examined medication effectiveness (Cooke 2011), clinical guidelines (Matheson & Mazza 2018), global prevalence (Denning et al. 2018), and self-treatment (Theroux 2005). This suggested a possible lack of research insight into patients' and healthcare professionals' concerns, expectations, and priorities in managing recurrent thrush.

This systematic review aimed to identify what is known about patient and healthcare professional experiences of managing recurrent vulvovaginal thrush by thematically synthesising findings from existing studies. I sought to explore how patients and healthcare professionals experience the management of recurrent thrush.

Findings from this systematic review were published in *Patient Education and Counselling* (see Ford 2024). In January 2025, I re-ran the search to look for recent papers; 34 papers appeared in the search, but none met the original inclusion criteria. This chapter therefore closely reflects the contents of the published systematic review, with edits made to better integrate it into the structure and aim of this thesis.

2.2 How the review was conducted

Five databases were searched for studies on patient and healthcare professional experiences managing recurrent thrush. Two reviewers (myself (TF) and my colleague Amelia Talbot (AT), a DPhil student in MS&HERG) independently screened, and quality assessed qualitative, quantitative, and mixed-methods studies. Findings from eligible studies were thematically synthesised.

Search strategy

The search strategy was developed with an information specialist to explore patient and healthcare professional experiences of managing recurrent vulvovaginal thrush. Patient representatives with lived experience of recurrent thrush reviewed our search strategy and added terms including ‘persistent’ and ‘returning’.

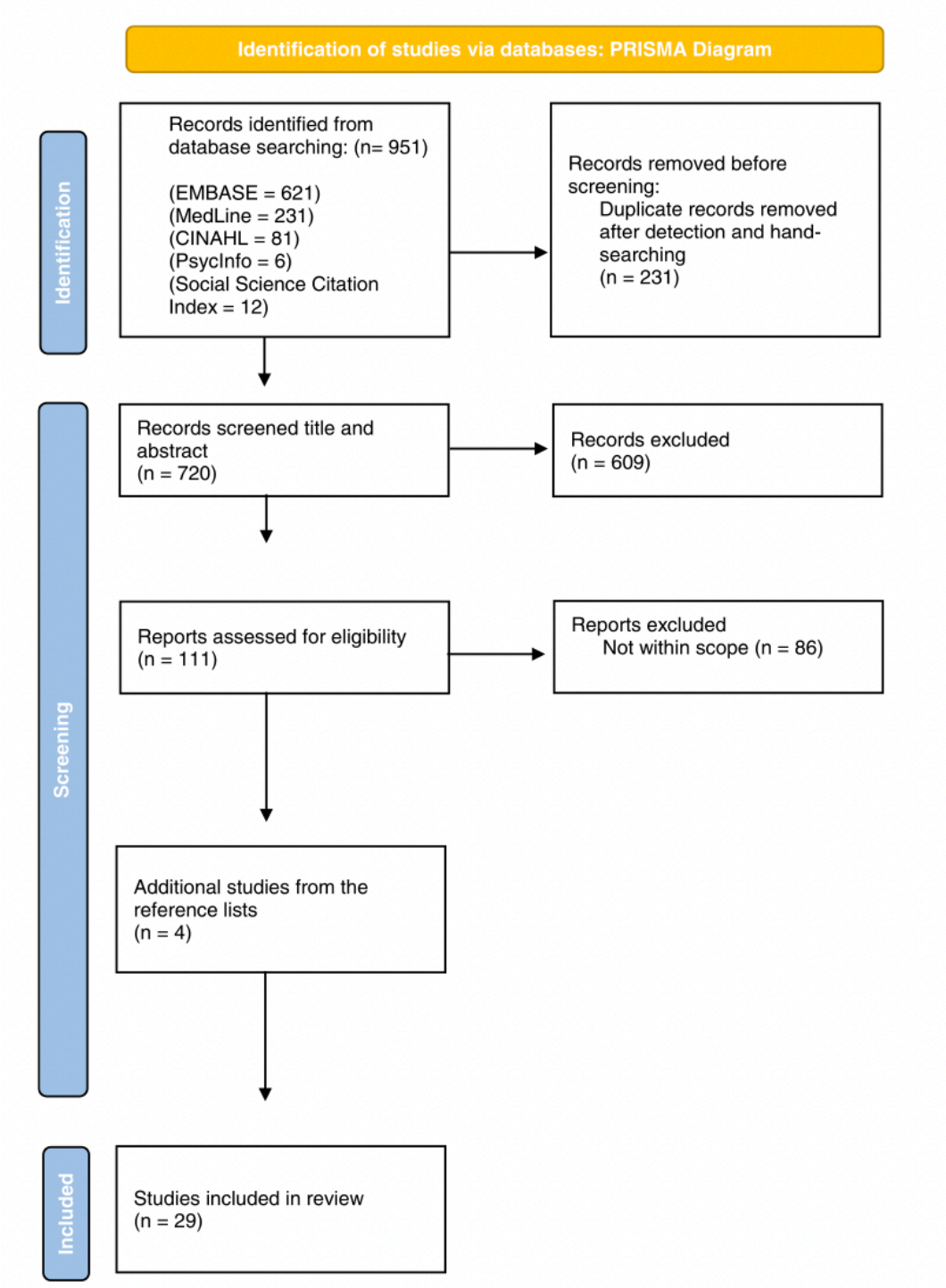
I searched the electronic databases Medline, Embase, Cinahl, PsychInfo, and Social Science Citation Index in December 2021 and in January 2025. Forward and backward citation searches were also conducted.

Study selection

The inclusion criteria were any peer-reviewed research article that included an element of patient or healthcare professional experience of recurrent thrush (including insights from pharmacists). No restrictions were placed on publication date, language, or country. Exclusion criteria were non-research papers, animal models, laboratory studies, background articles, and studies that only discussed acute thrush experiences. Books and dissertations were excluded for practical reasons.

Two independent reviewers (TF and AT) conducted double-blind title and abstract screening and then full-text screening in Rayyan (Ouzzani et al. 2016). During the full-text screening, papers were excluded if experience of recurrence was not mentioned. Papers of interest that were not in English were translated by myself or colleagues who spoke the relevant languages (French, Russian, Ukrainian). Disagreements were resolved through discussion. Figure 1 presents this process.

Figure 1: PRISMA Diagram



Data extraction and analysis

Data extraction was carried out by myself and checked by my colleague (AT) using a standardised form. A streamlined version of this extraction form is available below (Table 1).

Included papers were imported into NVivo12 (QSR International). The findings and discussion sections of these studies were analysed using thematic synthesis (Harden 2008). Thematic synthesis was chosen because it is congruent with my aim to map the existing evidence and identify potential knowledge gaps (Tong et al. 2012). I coded line-by-line with codes grouped based on similarities and differences to produce descriptive themes. The One Sheet of Paper (OSOP) (Ziebland 2006) mind-mapping approach helped refine and organise these descriptive themes. A high-order analytical theme was also developed through discussion to encapsulate the review's findings and address this study aims. This approach has been successfully used elsewhere (Talbot et al. 2022, Warr et al. 2020).

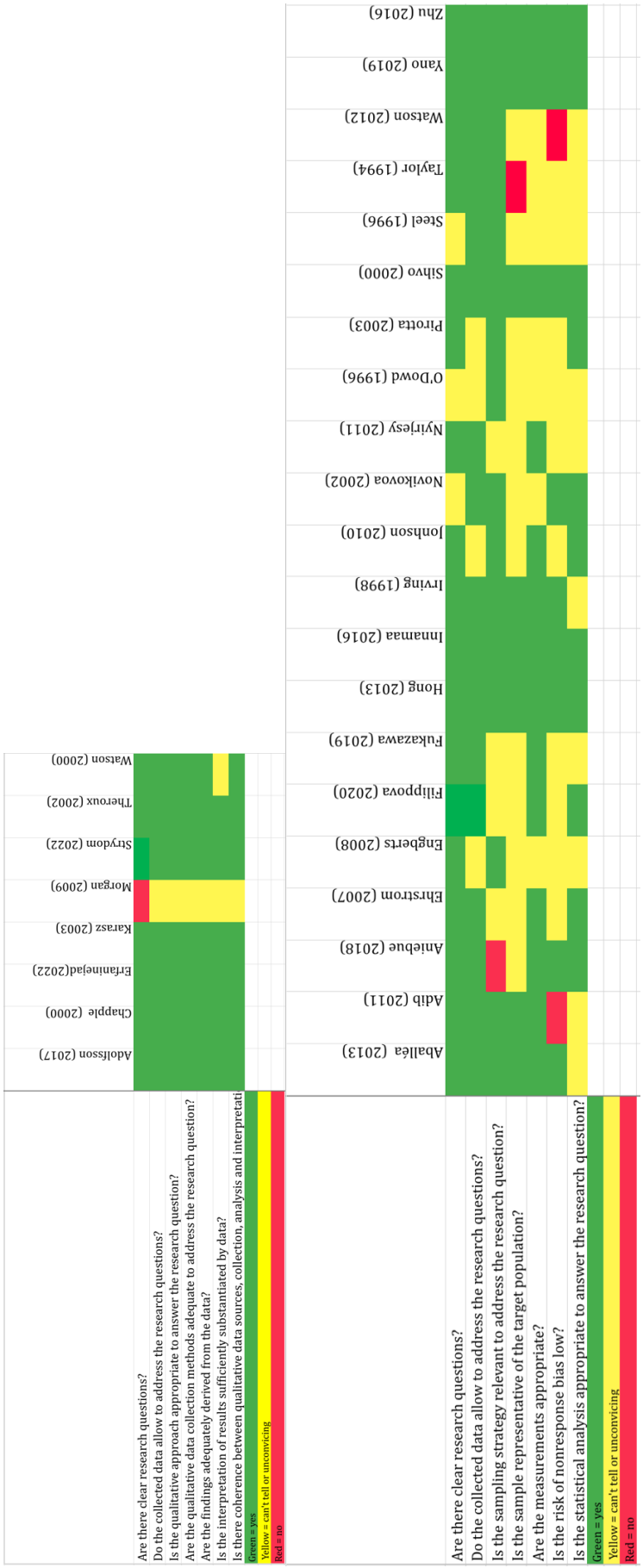
Table 1: Included studies and relation to the four themes identified

First Author	Year	Country	Population	Study Design	(Re)Experiencing Impacts	(Re)Identifying Recurrent Thrush	(Re)Considering Consultation	(Re)Trying Treatments
PATIENTS								
Steel	1996	UK	100 women with diabetes (12 with repeated episodes, 6 with vaginal swabs for thrush)	Interviews & Survey		X		X
O'Dowd	1996	England	490 women with vaginal symptoms (80% with recurrent symptoms, 75% diagnosed with thrush)	Survey	X	X	X	X
Irving	1998	UK	28 women with recurrent thrush	Interviews & Survey	X		X	X
Chapple	2000	UK	30 women with thrush (1/3 with recurrent thrush)	Interviews	X	X	X	X
Novikova	2002	Ukraine	83 women with recurrent thrush	Interviews			X	
Karasz	2003	USA	44 women (20 with recurrent thrush)	Interviews	X	X	X	X
Pirotta	2003	Australia	1298 women (over 7% reported 4+ thrush episodes in the previous year)	Survey			X	X
Ehrstrom	2007	Sweden	33 women with recurrent thrush	Survey	X	X		X
Morgan	2009	Australia	6 women with chronic thrush	Interviews	X		X	X
Johnson	2010	France, Germany, the Netherlands, Sweden, UK, USA	7955 women (thrush episodes 2-5 times = 45%, 5-20 times, 29%, and 9-20 times = 6%). Time duration not specified.	Omnibus & Survey		X	X	X
Nyirjesy	2011	USA	481 women with chronic vaginitis (448 with thrush)	Survey				X
Aballéa	2013	France, Germany, Italy, Spain, UK, USA	620 women with recurrent thrush	Survey	X			X
Hong	2013	Australia	50 women with chronic thrush	Prospective Cohort Study		X		X
Zhu	2016	China	102 women with recurrent thrush	Survey	X			
Adolfsson	2017	Sweden	16 women with recurrent thrush	Interviews	X		X	X
Aniebue	2018	Nigeria	209 women (22 with 3+ thrush episodes)	Interviewer-administered questionnaire		X		X
Yano	2019	USA	284 women (34% with recurrent thrush)	Survey		X	X	X
Fukazawa	2019	Brazil	100 women with recurrent thrush	Survey	X			
Strydom	2022	Australia	10 women with recurrent thrush	Interviews	X	X	X	X
HEALTHCARE PROFESSIONALS								
Taylor	1994	USA	123 family physicians, obstetricians and gynecologists	Survey			X	
Watson	2000	UK	19 pharmacists	Interviews			X	X
Engberts	2008	Netherlands	380 general practitioners	Survey		X		X
Adib	2011	Lebanon	359 OBGYNs	Survey				X
Watson	2012	Australia	66 medical practitioners, dermatologists, nurses and allied health professionals	Survey				X
Innamaa	2016	UK	41 clinicians	Survey			X	
Filippova	2020	Russia	150 pharmacy workers	Survey			X	
BOTH								
Sihvo	2000	Finland	299 women (29 who used thrush medication 2+ times in the past 6 months), 341 gynaecologists and specialists in general practice	Survey		X	X	X
Theroux	2002	USA	11 women (10 with thrush), 3 pharmacists	Interviews	X	X	X	X
Erfaninejad	2022	Iran	24 women with recurrent thrush, 2 gynecologists	Interviews	X	X	X	X

Quality assessment

Myself and my colleague quality appraised included studies using the Mixed Methods and Quality Appraisal Checklist (MMAT) (Figure 2) (Hong et al. 2018). We did not use this tool to exclude studies based on perceived low quality, but to be transparent about strengths, limitations and perceived quality of included studies.

Figure 2: MMAT qualitative appraisal



2.3 Findings

Variable definitions

Terms for recurrent thrush varied across studies, and it was also called 'recurrent vulvovaginal candidiasis' (RVVC) or 'recurrent yeast infections'. Most papers defined recurrent thrush as four or more symptomatic episodes of vulvovaginal candidiasis within a year (Yano et al. 2019, Fukazawa et al. 2019, Ehrsröm et al. 2007, Engberts et al. 2008, Adib et al. 2011, Aballéa et al. 2013, Watson et al. 2012, Zhu et al. 2016), while others did not offer a definition. Some papers used the term "chronic thrush" interchangeably with "recurrent thrush", while others used it to denote a distinct experience where symptoms may be ongoing or constant (Morgen et al. 2009, Chapple et al. 2000, Hong et al. 2014, Irving et al. 1998, Nyirjesy et al. 2011, Theroux 2002). These varying definitions influenced study sampling and the presentation of findings.

Further, all studies reported on cis-women's experiences. When reporting on the literature, I mirror the language used by the authors, but acknowledge that recurrent vulvovaginal thrush can also affect gender diverse people.

Acute versus recurrent experiences

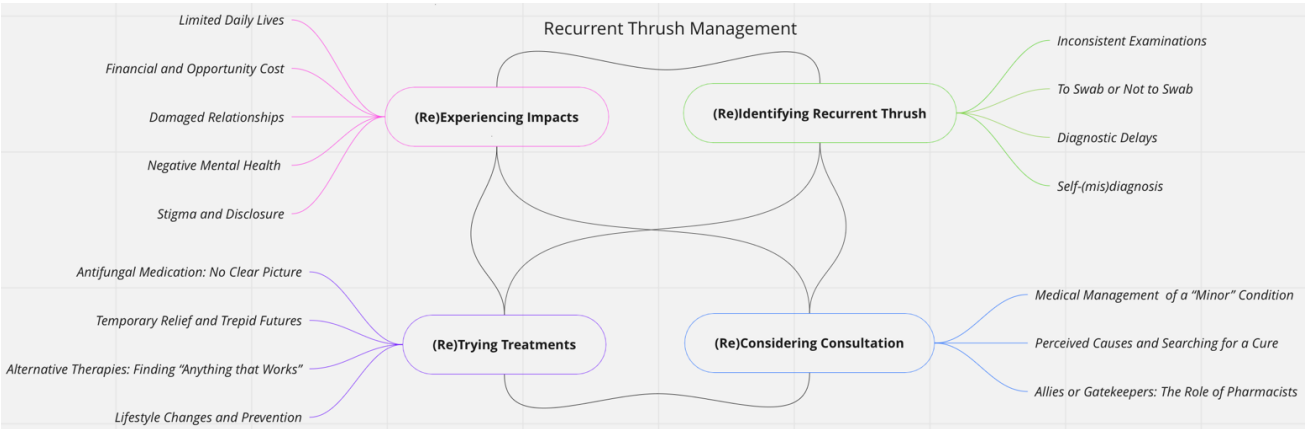
While the included papers offered insight into recurrent thrush experiences, they often presented unclear sample descriptions and non-discrete findings. For example, some interview studies focused on acute thrush but included participants who spoke about recurrent experiences (Chapple et al. 2000, Theroux 2002). Other papers examined persistent vaginal discomfort, including recurrent thrush, amongst other vulvovaginal conditions, but the authors did not separate findings based on patient diagnosis (Karasz et al. 2003, O'Dowd et al. 1996). Further, most literature on healthcare professionals focused on management of acute cases or conflated episodic and

recurrent experiences. If patients are consulting for their first acute episode, it is uncertain whether the treatment will be successful, or whether there will be recurrence. Therefore, I included papers on how healthcare professionals manage thrush with particular attention to mentions of recurrent cases.

Descriptive theme summary

I developed four descriptive themes covering the reported experiences of patients and healthcare professionals managing recurrent thrush. While many themes appeared in the papers, the descriptive themes presented highlight the repetitive and cyclical aspects of managing recurrent experiences. These themes described below are: (re)experiencing impacts, (re)identifying recurrent thrush, (re)considering consultations, and (re)trying treatments. Figure 3 illustrates the connected relationship between the themes. An analytic high-order frame of 'interwoven and reoccurring uncertainties' was then developed to understand these themes.

Figure 3: Descriptive themes and subthemes



2.3.1 (*Re)experiencing impacts*

Survey and interview participants expressed similar impacts from recurrent thrush, including limited daily activities, financial and opportunity costs, damaged relationships, negative mental health, stigma and disclosure.

Limited daily lives

Patients with recurrent thrush reported lower quality of life and reduced overall satisfaction with their health (Fukazawa 2019, Irving 1998). These findings were described in studies from the UK, USA, Europe, and Brazil (Aballéa et al. 2013, Fukazawa 2019, Irving 1998). Impacts included being unable to wear certain clothes, sleep at night, socialise, concentrate at work, or participate in hobbies and sports (Fukazawa 2019, Aballéa et al. 2013). A Swedish patient with recurrent thrush explained this frustration:

> *It doesn't really matter what I do. Nothing seems to work so why should I even get dressed to go anywhere? I don't feel like it. It's just to bite the bullet. If you haven't had a yeast infection...you don't know what you are missing.* (Adolfsson et al. 2017).

Participants expressed discontent with limiting their daily activities due to the discomfort caused by symptoms and concerns around further recurrence (Strydom 2022, Chapple et al. 2000, Theroux 2002). One study concluded that while the clinical pathology of recurrent thrush is "quite similar, if not identical, to acute vulvovaginal candidiasis", women with recurrent thrush reported more symptoms due to the "frequency of infection and attentiveness to the accompanying signs" (Yano et al 2019).

Poor mental health

The most common consequence of recurrent thrush that studies cited was poor mental health outcomes. While it is not clear to what extent poor mental health is a cause and/or symptom of recurrent thrush, patients reported feeling "agitated", "distressed", "frustrated", "inadequate", "stigmatized", and "unable to concentrate" due to their symptoms (Chapple 2000, Irving et al 1998). Patients reported that recurrent thrush was mentally all-consuming:

> *I feel very miserable. It's there all the time. Your whole attitude changes. You don't feel cheerful as you usually do. It's not a nice thing.* (Chapple 2000)

Intimacy and sexual relationships

Many women reported feeling "unsexy" due to thrush and that it negatively impacted their sex lives (Irving et al 1998, Karasz & Anderson 2003, Fukazawa et al 2019). Sexual relationships were reported as impacted as recurrent thrush caused the avoidance of, or pain from, sexual activities. Many women with recurrent thrush reported that yeast infections strained their relationships, and that it affected their sexual activity (Irving et al 1998).

Financial and opportunity costs

Costs of recurrent thrush included loss of time and money. Patients would sometimes see a primary care doctor to receive medication at a lower cost or free under healthcare coverage (Theroux 2002). However, they sometimes expressed frustration about the time required to contact a doctor's office, schedule appointments, and request leave from work (Theroux 2002). In health systems where patients pay for medication or appointments, there were also financial considerations. Costs sometimes prevented patients from continuing care or following long-term treatment (Strydom et al. 2022).

> *I want to express that it's insanely expensive; I must have spent well over a thousand dollars on this problem in the last 18 months. You know, for all the treatments.* (Strydom et al. 2022).

Stigma and disclosure

Patients perceived external stigma around thrush and its recurrence. Through interviews and surveys, patients reported feeling "stigmatised", "dirty", "inadequate", and "embarrassed" (Aballéa et al. 2013, Zhu et al. 2016, Morgan et al. 2009, Chapple et al. 2000). Many qualitative studies reported that these feelings were a barrier to seeking medical help or speaking to loved ones (Strydom et al. 2022, Chapple et al. 2000, Theroux 2002, Adolfsson et al. 2017). Some Australian interviewees reported finding support online by interacting with others anonymously (Strydom et al. 2022). In one American survey on vaginal discomfort, a patient described feeling that thrush was a particularly stigmatising gynaecological issue:

> *Women don't talk about it. I can talk more about my fibroids than I can about the yeast infection, which is more private. I don't want to talk to anyone about* it. (Karasz et al. 2003)

Papers reported that recurrent thrush significantly impacted patients' lives and influenced how they understood and approached the condition. However, papers on healthcare professional perspectives did not explore their awareness of the physical, emotional, financial, and social impacts.

2.3.2 *(Re)identifying recurrent thrush*

Multiple challenges with identifying recurrent thrush were connected to inconsistent examinations, sporadic swab collection, diagnostic delays, and self-(mis)diagnosis. Study samples included patients with "culture-positive" (Fukazawa 2019) or "proven" vulvovaginal candidiasis (Zhu et al. 2016), and those who self-identified as having recurrent thrush (Chapple et al. 2000, Theroux 2002). Therefore, papers offered insight into both clinical investigations and self-diagnosis. Healthcare professionals

and patients presented various perspectives which I now consider about the investigative process and the perceived utility of diagnosing recurrent thrush.

Inconsistent examinations

Many patients consulted healthcare professionals about symptoms of thrush, including when a pattern of recurrence developed. A common finding across various countries was inconsistency in the circumstances in which healthcare professionals performed pelvic examinations. One Dutch study found that a substantial number of general practitioners reported basing their diagnosis of thrush on pelvic examination alone without performing further swabs or microscopy (Adib et al. 2011). An international online omnibus found that roughly half their patient sample had not been examined "every time" or "most times" when presenting with thrush (Johnson et al. 2010). The lowest examination rates were reported in the UK, and the highest in Germany (Johnson et al. 2010). This inconsistency was reported between health systems and countries, but also within similar services. An Iranian gynaecologist explained that accurate diagnosis and treatment is less likely if based solely on patient report:

> *[If treatment is based only on patient explanations and not examination] this increases the possibility of prescribing the wrong medicine, and as a result, the patient returns to the doctor's office and expresses dissatisfaction with the recovery process.* (Erfaninejad 2022).

There may be cultural differences in attitudes to pelvic examinations – for example, while some studies have suggested that women in the UK are not particularly embarrassed or concerned (Chapple et al. 2000), some Iranian patients with recurrent thrush said they were worried about potential damage to the vagina or further infection (Erfaninejad 2022).

To swab or not to swab

A US survey that included patients with recurrent thrush found that laboratory tests were sporadically performed (Yano et al. 2019). While studies on healthcare professionals' practices often did not differentiate between a patient's first consultation and subsequent visits, a Dutch survey suggests that general practitioners obtained cultures more often when they suspected recurrent instead of acute thrush (Engberts et al. 2008). Some Australian patients felt their healthcare professionals did not follow structured diagnostic or testing guidance (Strydom et al. 2022). When swabs were performed, patients felt frustrated and confused when the results were negative for thrush; however, anti-fungal medication could influence these results (Strydom et al. 2022, Chapple et al. 2000). While positive cultures provided more answers, patients were irritated to undergo repetitive tests while awaiting a diagnosis:

> *It took quite a while [for a diagnosis], probably nearly a year even. I still don't feel like anyone's taking it particularly seriously. I've had a million swabs and a million blood tests. It always comes back as the same thing, as Candida.* (Strydom et al. 2022).

Ambiguous results led to patients worrying about whether other vulval health conditions were being overlooked and longing for timely answers (Strydom et al. 2022, Adolfsson et al. 2017).

Diagnostic delays

Diagnosing recurrent thrush often involved multiple appointments and repetitive investigations. Therefore, receiving a diagnosis could take considerable time, and one Australian study reported diagnostic delays up to three years (Strydom et al. 2022). A Chinese survey of recurrent thrush patients found repetitive symptoms enduring from 6 months to 10 years (Zhu et al. 2016). Although recurrent thrush is diagnosed as four

or more discrete episodes per year, there is no diagnostic nomenclature for those who had symptoms on a chronic or persistent basis (Hong et al. 2014).

Self-(mis)diagnosis

Patients and healthcare professionals supported self-diagnosis as a practical and responsible decision (Yano et al. 2019). Interviews suggested that American patients with a previous diagnosis of thrush and experience with recurrence were able to correctly self-diagnose subsequent episodes (Theroux 2002). Patients with recurrent thrush were able to monitor and "tune into" their symptoms and collect "bodily information" which they used to guide diagnosis and actions (Theroux 2002). However, some studies found higher frequencies of other vaginal infections such as bacterial vaginosis in women with recurrent thrush, raising concerns around potential misdiagnosis or co-morbidities (Ehrström et al. 2007). These ambiguities regarding how best to identify recurrent thrush influenced ideas about whether patients should self-manage the condition.

2.3.3 *(Re)considering consultations*

Differences in expectations, perceptions, and priorities mean that patients may seek care from professionals and/or self-manage at different points in their experience (Theroux 2002, Watson et al. 2000, Sihvo et al. 2000). Included papers highlighted tensions around what healthcare professionals and patients considered a serious condition, a cure, and an issue worthy of consultation.

Medical management of a "minor" condition

A consistent finding was that patients thought that recurrent thrush was considered a minor condition by healthcare professionals (Strydom et al. 2022, Morgan 2009, Chapple et al. 2000, Karasz et al. 2003, Filippova et al. 2020). In these cases, patients

said that healthcare professionals were not as supportive or understanding as they had expected or hoped. One UK patient who had episodes of thrush every six weeks explained:

> *GPs tend to pass [thrush] off as a minor complaint, and one they don't take very seriously*. (Chapple et al. 2000)

A pharmacist in an American study reflected similar sentiments:

> *I do think that there's a tendency to also say that it's not that big of a deal, which is one reason I think people self-medicate, "It's not that big of a deal, I will just deal with it myself.* (Theroux 2002).

Other dissatisfaction included the brevity of medical appointments and fragmented patient-practitioner relationships (Morgan et al. 2009). Further, patients perceived general practitioners to have limited knowledge and expertise on recurrent thrush, and this led to a "loss of confidence" in their management approach (Strydom et al. 2022, Chapple et al. 2000). Papers on healthcare professionals' views did not enquire into how clinicians understood or prioritised recurrent thrush.

Positive interactions with healthcare providers included an integrative and patient-centred approach that was tailored to the patient's particular management journey and acknowledged uncertainty (Strydom et al. 2022, Morgan et al. 2009).

Studies found that patients may be referred, or may self-refer where possible, to a range of other healthcare professionals, such as gynaecologists, vulval dermatologists, physiotherapists, nutritionists, or naturopaths (Strydom et al. 2022, Morgan et al. 2009, Pirotta 2003). GPs made referrals to offer further help as described by one Australian patient:

> *[A GP] said, you know, seeing as, we're not getting on top of it, you're probably going to have to go see a specialist, you have to work with somebody who kind of lives and breathes this.* (Strydom et al. 2022).

However, this approach was not always successful, as some primary care doctors did not refer, or the patient felt that the specialist also had limited understanding of recurrent thrush (Strydom 2022, Theroux 2002). A survey of nurse practitioners in UK vulval clinics found that while chronic thrush was identified as an area for follow-up care, patient information leaflets and guidelines were inconsistently and infrequently available (Innamaa et al. 2016).

Whether healthcare providers were able to meet expectations or not, patients often relied on self-education through the Internet, media, or friends to cope with their symptoms (Strydom et al. 2022, Chapple et al. 2000, Theroux 2002, Karasz & Anderson, 2003, O'Dowd et al., Johnson et al. 2010).

Perceived causes and searching for a cure

Willingness to consult was also influenced by understandings of recurrent thrush and outlooks towards potential causes and cures. Identifying a cause for recurrence was a priority for many patients (Yano et al. 2019, Chapple et al. 2000, Theroux 2002, Johnson et al. 2010, Sihvo et al. 2000, Novikova & Mardh 2002).

Some patients felt that their physical condition caused recurrence, such as their allergic tendencies, pelvic floor tone, vaginal tissue health, vaginal pH, weight, and excessive sweating (Strydom et al. 2022, Erfaninejad 2022). Many patients identified recurrent thrush seemingly operating in line with their menstrual cycle and hormonal changes (Strydom et al. 2022, Chapple et al. 2000, Theroux 2002, Adolfsson et al. 2017, Erfaninejad 2022). Contraception and intercourse were also perceived as potentially contributing to recurrence (Erfaninejad 2022).

Some patients considered genetics to be a cause and that recurrence would be inevitable, as expressed by one woman with 18 years of recurrent thrush:

> *I do not like to see a doctor because my mother, despite being 50 years old, still suffers from this infection and medical treatments have not been effective. I believe that genetics is very influential, and I think my genes are the same as my mother's, so treatment is useless.* (Erfaninejad 2022).

Beliefs that recurrence was unavoidable, or incurable could discourage patients from seeking consultations. US and Australian women interviewed about their recurrent thrush and vaginal discomfort stated concerns about clinicians' inability to explain the repetition of symptoms (Strydrom 2022, Karasz 2003). A UK patient survey found the most common patient concern was finding no cure for recurrent thrush (Irving et al. 1998). In another UK interview study, patients perceived that healthcare professionals offered temporary fixes for acute symptoms rather than permanent solutions for recurrent problems. A woman who had four attacks of thrush in six months said:

> *GPs prescribe short-term cures, not long-term cures. Self-management is better.* (Chapple et al. 2000)

Included papers suggested a mismatch between patient and healthcare professional understandings of recurrent thrush experiences and these perceptions impacted how patients approached healthcare professionals and/or self-managing.

Allies or gatekeepers: the role of pharmacists

Pharmacies occupy a pivotal space in recurrent thrush management as patients may visit them to collect prescriptions, purchase over-the-counter remedies, or seek guidance and recommendations. Due to their boundary-spanning role across clinical care and self-management, pharmacists may be understood and interacted with by people with symptoms as either allies or gatekeepers to receiving antifungal medication. A Russian paper found that patients who had previously consulted a doctor about recurrent thrush visited the pharmacy to find "something new" (Filippova et al. 2020).

Patients who had consulted a general practitioner previously were more likely to self-manage using over-the-counter medications (Chapple et al. 2000). A survey of US physicians found that if symptoms recurred, they would encourage patients to use antifungal medication without further consultation (Taylor 1994). Reasons included viewing antifungals as offering "earlier treatment", "empowerment of women" and involving fewer medical office visits (Taylor 1994). A US interview study found that many patients prefer to "bypass the middleman" and self-treat (Theroux 2002). However, concerns from healthcare professionals that women would self-treat incorrectly and no longer consult were also prevalent in papers published soon after anti- fungal medication was widely re-classified as 'over-the-counter' in the 1990s, making self-treatment more accessible (Taylor 1994).

Included papers found that pharmacists held divergent beliefs about whether patients could or should self-manage thrush and if consulting a general practitioner was necessary (Theroux 2002, Watson et al. 2000). An American interview study highlighted these pharmacist views:

> *A lot of times women have already had one [episode of thrush]. They know what it is, they know the products are available, so why go through that middle thing if this [over-the-counter treatment] is going to work?* (Theroux 2002).

> *It's so heavily advertised, in every women's magazine—that you can take care of it [thrush] yourself: what do you need a doctor for? I don't agree.* (Theroux 2002).

Pharmacists suggested that missing information made them cautious about providing medication. A UK survey of pharmacists revealed suspicion that patients did not always provide the "full story" nor "truthful accounts" when questioned (Watson et al. 2000). Yet, pharmacists recognised that if they refused to sell antifungal medication, women could simply go elsewhere.

> *If the customer has seen a treatment advertised but her symptoms do not suggest that thrush is the problem, the pharmacist could say no, I won't sell an anti-*

> *fungal, but the woman would go to another pharmacy to ask for the product.* (Watson et al. 2000)

While some pharmacists expressed concerns about patients' determination to attain antifungal medication, the root of these fears was not reported. Patients and healthcare professionals held various views on the appropriate management pathways for recurrent thrush, and these tensions also influenced attitudes towards available treatment options.

2.3.4 *(Re)trying treatments*

Patients with recurrent thrush often employed a "trial-and-error" process of trying and retrying different treatment options, including antifungal medication, alternative therapies, and lifestyle changes (Theroux 2002, Erfaninejad 2022). Barriers to (re)trying treatment included frustration with symptoms returning, a lack of collaborative care, and unknown side-effects.

Antifungal medication: no clear picture

Long-term antifungal maintenance therapy is the current treatment recommendation for recurrent thrush (Aballéa et al. 2013, Hong et al. 2014). However, included papers found that healthcare providers varied in prescribing patterns, but were likely to recommend various treatment forms and combinations of oral tablets, topical creams, and vaginal pessaries (Ehrström et al. 2007, Engberts et al. 2008, Adib et al. 2011). A paper on general practice in the Netherlands reported that clinicians' treatment of recurrent thrush was varied, making it challenging to create a "clear picture" (Engberts et al. 2008).

While antifungal medication could be prescribed or accessed through a pharmacy, an Iranian patient explained that it could be difficult to access maintenance treatment:

> *Nobody has actually offered me that [maintenance treatment]. Even the chemist has never mentioned it. Like, you know, when I go see the pharmacist for my creams, obviously I'm quite well known around the different shops when I go there. But nobody's said to me, hey, do you want to do this long term or anything like that.* (Erfaninejad 2022).

Further, while some patients became familiar with their condition over time, they felt "not included" in treatment decisions (Erfaninejad 2022).

> *[My GPs] don't listen, they don't understand the condition and they insist on choosing the treatment for me and would give me like a topical cream, which I say doesn't work for me. And it was really infuriating, again, because there was someone not listening to my clinical history or my experience and telling me what they know is best.* (Erfaninejad 2022).

Temporary relief and trepid futures

Antifungal medication offered temporary relief for many patients, only for symptoms to return shortly after (Strydom et al. 2022, (Theroux 2002, Adolfsson et al. 2017). As one Swedish woman described: "*The meds can give temporary relief but [...] the symptoms always come back*" (Adolfsson et al. 2017). A survey of patients across the US and Europe found that over 60% of patients who completed antifungal maintenance treatment experienced relapses (Aballéa et al. 2013). Temporary relief from symptoms had a pronounced and positive effect on patients' lives and their hopes for the future (Adolfsson et al. 2017). However, patients also worried about relapses and being on medication for months, years, or possibly decades.

> *I think fluconazole is a pretty hardcore drug and telling someone to take that three to six months, this is one thing, but taking it once a week for the rest of your life just seems really, really full on.* (Strydom et al. 2022).

Patients' concerns about long-term medication for unclear durations included fears of becoming tolerant to medication or enduring unknown long-term side effects (Aballéa et al. 2013, Irving et al. 1998). Several patients mentioned that their poor mental health had been a barrier to pursuing or adhering to treatment (Erfaninejad 2022). Frustration occurred for patients offered the same intervention repeatedly and finding it ineffective or only temporarily effective (Erfaninejad 2022). The prospect of long-

term medication concerned participants, especially those thinking of having children, as oral antifungal tablets are contraindicated in pregnancy (Aballéa et al. 2013, Chapple et al. 2000, Irving et al. 1998, Erfaninejad 2022). These concerns led some patients to avoid starting or completing antifungal medications.

Alternative therapies: finding "anything that works"

Some patients reported that complementary and alternative medicine practitioners offered more supportive environments and hope for the future (Morgan et al. 2009). Alternative therapies were sometimes used after other medication options had been exhausted or ineffective. Surveys found that patients previously diagnosed with thrush or who had seen numerous healthcare professionals were more likely to use alternative or complementary approaches (Nyirjesy et al. 2011). These methods included probiotics, yoghurt, garlic, vinegar, other homoeopathic remedies, and traditional medicine (Watson et al. 2012, Morgan et al. 2009, Chapple et al. 2000, Watson et al. 2000, Pirotta et al. 2003). A 50-year-old woman from the UK who had lived with recurrent thrush for 15 years said she had tried "every pessary, tablet, and cream" and only found relief from eating more yoghurt and applying it to her genitals (Chapple et al. 2000)

General practitioners and specialists had mixed views about the effectiveness of alternative therapies (Strydom et al. 2022). A survey of Australian gynaecologists found that they were eager to find "anything that works" for patients with recurrent thrush (Watson et al. 2012). Some gynaecologists suggested returning to the basics when patients had tried various treatments.

> *Exclude all treatments: return to warm water spray and non-touch dry. Patients I see already had more treatments than I could think of.* (Watson et al. 2012).

Lifestyle changes

Lifestyle changes were often identified by patients and healthcare professionals to help treat recurrent thrush symptoms or prevent recurrence. Patients consulted healthcare professionals and online resources for advice, but often found that information was lacking (Erfaninejad 2022).

Avenues explored included avoiding sugar consumption, perfumed soaps or detergents, panty liners, vaginal gels, and washing more or less often (Yano et al. 2019, Watson et al. 2012, Erfaninejad 2022, Johnson et al. 2010, Novikova & Mardh 2002). Others attempted to reduce the stress in their life caused by work and other factors (Erfaninejad 2022).

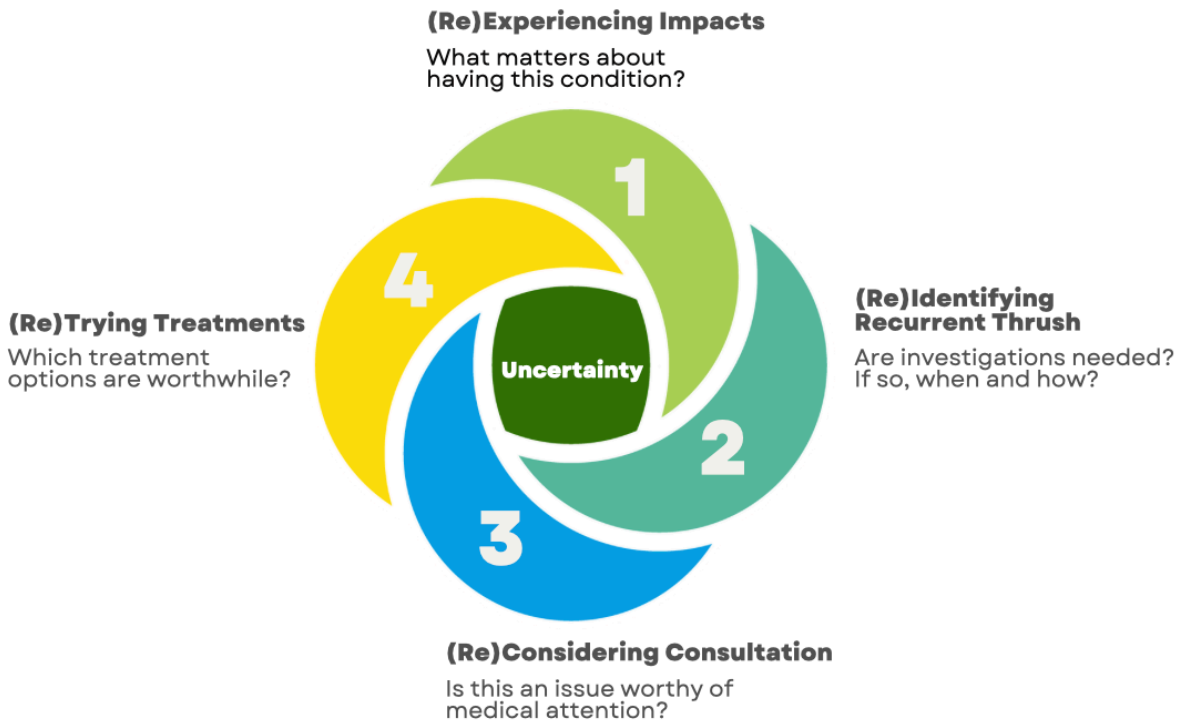
> *I still feel like there's a lot of information lacking. So, for example, I would drive myself crazy trying to work out, you know, if I'm somehow reinfecting every time it happened, I would hot wash my sheets, hot wash my towels, disinfect my lounge, and disinfect my chairs; it's not like I sit on them without underwear. I would just go crazy with everything.* (Strydom et al. 2022).

In cases that were not successfully remedied by treatment or lifestyle changes, patients and healthcare professionals expressed desperation for permanent solutions, but found that this was limited by unclear pathways, challenges with identifying symptom triggers, and continued recurrence.

2.4 Analytic theme: Interwoven and reoccurring uncertainties

The included studies reported different perspectives across various regions and a few decades, with similarities as well as differences in patients' and healthcare professionals' approaches to managing recurrent thrush. Each descriptive theme can be framed as an uncertainty. These uncertainties raised questions for both patients and healthcare professionals including: 1) What matters about this condition? 2) Are investigations needed? If so, when and how? 3) Is this an issue that needs medical attention? and 4) Which treatment options are worthwhile? These themes can be seen as knotted ambiguities that patients and healthcare professionals may understand and address differently. Further, these uncertainties may overlap, evolve, and fluctuate over time based on experience and changing priorities. Figure 4 illustrates this interwoven experience.

Figure 4: Interwoven uncertainties as an analytic frame across the four descriptive themes



When treatment attempts failed to stop recurrence, patients had to re-navigate uncertainties around whether they would ever get better, whether a diagnosis was useful or possible, who could offer support, and what treatments and services they should try now and next. The management of recurrent thrush, who was involved in it, and whether patients, pharmacists, and clinicians should operate exclusively, in combination with others, and in what order, differed among studies.

Managing recurrent thrush was further complicated by differing expectations between healthcare professionals and patients regarding what constituted a serious problem, a minor concern, a diagnosis, a treatment, and a cure. These uncertainties could contribute to diagnostic delays, disengagement from medical care, and hopelessness about moving forward. Recurrent thrush management is often construed as straightforward with one-off treatment plans and resolution. However, this model of knotty considerations helps unsettle these assumptions for patients and healthcare professionals.

2.5 Discussion

Included papers on recurrent vulvovaginal thrush present interwoven and recurring uncertainties around how to understand, prioritise, and manage this condition for both patients and healthcare professionals. These uncertainties involved (re)experiencing impacts, (re)identifying recurrent thrush, (re)considering consultations, and (re)trying treatments.

This systematic review was the first, to our knowledge, to examine patient and healthcare professional accounts of managing recurrent thrush. Strengths include the integration of both perspectives and inclusion of qualitative and quantitative studies across a wide geographical span and time, demonstrating a degree of consistency and

endurance of themes. The recent increase in publication of papers suggests a renewed interest in this topic and an unaddressed gap in knowledge about patients' experiences and their informational and support needs.

Limitations include diverse approaches across papers to defining, diagnosing, and documenting recurrent thrush. My synthesis must be read in this context as I attempted to locate recurrent thrush within papers that covered many different vulvovaginal conditions or focused primarily on acute thrush. Therefore, certain findings may overlap with other vulvovaginal health conditions, or have been overlooked, as it was sometimes difficult to isolate recurrent thrush experiences. This review raises concerns over the classification of recurrent thrush and points to a need for further research on understanding what is classified under this condition and why.

Most study participants were white, all were women, and many were involved in clinical trials, and therefore their experiences may not translate to other groups such as racialised and gender diverse people navigating everyday life. The papers rarely reported whether patients had comorbidities or other bodily circumstances which affected their experience. Insights from sexual health professionals and midwives who may treat recurrent thrush when delivering care were not covered in the literature. Further, while this review attempted to bridge patient and healthcare professional (mainly GP and gynaecologist) perspectives, drawing comparisons can be difficult as studies did not report asking equivalent questions to the two groups.

This review focused on how patients and practitioners experience the management of recurrent thrush. Tensions appeared in patients' reports of symptoms and perceived dismissal and trivialisation of recurrent thrush as a minor complaint. Uncertainty around navigating conditions often perceived as trivial was raised in several different

forms by both patients and healthcare professionals, building on a wide body of work on this topic (McNiven 2019, Alam et al. 2017). This uncertainty and trivialisation are also a gendered experience as existing literature reports that conditions that affect women and people assigned female at birth are often dismissed or overlooked, especially concerning common gynaecological conditions (Arnold et al. 2022, Marriott et al. 2008, Wugalter et al. 2023). This review contributes to a growing body of work recognising that recurrent, persistent, and chronic gynaecological conditions are overdue for academic and clinical attention (Leusink et al. 2018, Bilardi et al. 2016, Izett-Kay 2022).

Included papers demonstrated that recurrent thrush is often approached by health services and researchers within the framework of acute thrush, with episodes seen as distinctive and relatively easily resolved or resolvable. This approach leads to tension as recurrent thrush has unique impacts, considerations, and challenges. Many papers conflated acute and recurrent experiences, and overlooked that the impacts of recurrent thrush are not isolated occurrences but repeatedly interrupt and inhibit patients' lives. This review highlights the need for consistency across definitions, sampling, and capturing patient journeys.

Papers have yet to fully explore how patients' choices relate to past decisions, outcomes, and experiences. Further, there is a dearth of information surrounding how healthcare providers understand recurrent thrush and its impacts as this has not been explored. More research and resources are needed to help support patients and clinicians in managing this condition to promote more understanding, communication, and collaborative care.

2.6 Concluding remarks

This review identified four descriptive themes, representing the literature on patient and healthcare provider experiences of managing recurrent thrush. Recurrent thrush presents interwoven uncertainties including whether this is a condition worthy of concern, investigation, medical attention, and care.

Patients and healthcare providers face uncertainties when managing recurrent thrush. The inconsistencies raised across papers suggest an unaddressed gap in knowledge about patient experiences and their informational and support needs; this includes insights about this condition's diagnosis, management, treatment, impacts, and meaning. To address these gaps, I undertook a qualitative interview study of patient and healthcare professional experiences and perspectives on managing recurrent thrush. In the following chapter, I outline the methods and theories used to underpin this study.

3

Methods & Theory

Contents

3.1 Introduction

This chapter presents the methodological approach and theoretical framework behind my research. I begin with my decision to use feminist theory and qualitative methods as foundational to this study. I discuss the importance of sensitive research and the involvement of patient representatives. I then elaborate on my approach to sampling, recruiting and interviewing both patients and healthcare professionals. Finally, I offer insight into my analytic process and how my positionality influenced this work.

3.2 Feminist theory and practice

Recurrent vulvovaginal thrush could be explored through various theoretical perspectives. The biomedical perspective that examines thrush as purely biological did not align with my research goals of capturing social understandings (Butler 2015). I was interested in analysing this condition from a standpoint that explored the gendered, material and social aspects that mediated experiences. I focus on the bodily experience of recurrent thrush to explore how social, cultural and gendered norms are both institutionalised and lived in the body (Cislaghi & Heise 2020, Fournier 2002). These meanings can shape and be shaped by how biological processes and illnesses are understood and experienced.

This thesis uses the term "patients" to demark people who are navigating a health condition who may seek out care from healthcare professionals. This term has been challenged by some feminist scholars who caution that it can reinforce medicalisation and perceptions of passivity (Ehrenreich & English 1978, Okaley 1984). Since this study includes two groups of participants, some in 'patient' roles and others in healthcare professional roles, the term 'patient' is used as a label to identify those in an illness/care-seeking role, without essentialising people's experiences to a single nor passive health experience.

Feminist theory provides a lens through which health experiences can be analysed with particular attention to gender norms, social attitudes and structural inequities (Kuhlmann & Babitsch 2002). A feminist perspective deepens how we understand lived experiences of "marginalization, invisibility, non-normativity and oppression, in particular, gender oppression" (Freeman 2018). The feminist approach applied

throughout this thesis is inclusive and speaks to all those who experience gender marginalisation including trans, non-binary and gender diverse individuals.

3.3 Gender inclusive research

This thesis acknowledges that existing research is limited by sampling only cisgender women and not exploring the experience of trans and non-binary individuals who experience recurrent thrush. When reporting on past studies, I mirror the language used by the authors, but for the rest of the thesis, I use gender inclusive language to acknowledge that from the start I sought to include trans, non-binary and gender queer people to hear their overlooked experiences.

Gender inclusive language involves being mindful about the language used when speaking about gender and sex and choosing words that are accurate, affirming, and avoid assumptions. Inclusive language is essential for recognising, respecting, and articulating the experiences of nonbinary, trans, and gender diverse people (Dahlen 2021). Shifts towards inclusive language include using gender neutral terms like "people" when speaking about experiences that can affect women as well as trans and non-binary people (Moseson et al. 2020). Further terms like "people assigned female at birth" helps recognise that this can include people who do not identify as women. It also means being specific about discussing experiences such as "people with a cervix", "people who menstruate" or "people who can get pregnant", as trans and non-binary people might have these experiences, and not all cis women do (McGlothen-Bell et al. 2023). This language does not erase terms like woman, and I use these where appropriate, but gender-inclusive language helps us conduct and present research in a manner that is both more accurate and inclusive (McGlothen-Bell et al. 2023).

3.4 A qualitative approach

This study aimed to understand the experiences of people with recurrent vulvovaginal thrush and of healthcare professionals who care for people with this condition. I required an approach that would offer insight into the experiences both of people who seek and provide healthcare, and would also offer a way to consider the two sets of interviews together and in contrast. Qualitative research methods were most appropriate to address this aim and explore how people construct meanings and actions related to their illness experiences (Sofaer 1999). By focusing on narratives instead of numerical significance, qualitative methods recognise the potential to gain rich insights through collecting and interpreting people's accounts of their experiences, perceptions and interactions (Pope et al. 2020). Further, qualitative methods offered the opportunity to delve into the complex, nuanced and multifaceted aspects of health conditions (Silverman 2006).

As Cheshire and Ziebland (2005) said, "The stories we tell about our everyday lives are an important resource for making sense of our experiences". When a qualitative method centres on interviews, it does not naively interpret these accounts as replications of an objective truth but instead recognises that narratives are co-constructed between researchers and participants (Charmaz 2014). Participants are drawing upon not only "what happened" but their "earlier experiences, standpoints and agendas" in shaping the story (Lucius-Hoene et al. 2018). Therefore, I undertook an "experiential approach" which sees narratives as expressions of inner worlds and identities which provide insight into how people interpret and understand bodily experiences, help-seeking and coping (Ziebland et al. 2013).

3.5 Sensitive research

There is a long history in medical sociology of researching intimate topics with a sensitive approach. I was aware that discussing topics of recurrent thrush and its impact on self-esteem, relationships and social lives could be especially challenging (Fukazawa et al. 2019).

Within narrative interviews, participants were encouraged to speak freely including "the disclosure of shameful aspects and unusual and extraordinary experiences" (Lucius-Hoene et al. 2018). I tried to build research-participant relationships both before and during interviews (through email exchanges, offering pre-interview calls and having a short talk before the interview). I reminded participants that they were free to take breaks, skip questions, or ask for a section of the interview to be removed from their transcript.

I was prepared for individuals to become emotional in interviews, and if they did, I offered reassurance, initiated a break, or would tactfully move away from the topic before re-engaging with it at a later time. I recognised that expressing distress in an interview is not the same as the interview creating distress, therefore, I opted to sit with the distress while at the same time reading how the participant might want it attended to. Participants became emotional while discussing feeling alone and helpless, the impact of recurrent thrush on their gender presentation and relationship strains.

Sometimes patient participants were unsure what was "too much" to share and would ask whether they could discuss a certain topic before doing so, or apologise if they disclosed something they felt was off-topic. These instances included asking whether it was okay to discuss sexual experiences, intergenerational trauma, co-morbidities, and

details of recurrent thrush symptoms. In these instances, I told participants that I was willing to hear as much of their experience as they wished to share, but that there was no pressure to disclose more than that with which they were comfortable.

Taking part in an interview can sometimes be a positive, therapeutic and cathartic experience (Lowers & Paul 2006). Participants expressed gratitude to me for listening to their stories or helping them process their experience. For some, it was their first time talking about it with anyone. It is rare that we are able to speak at length about our medical history in a non-medical setting and some participants reflected on this.

> *It was quite therapeutic as well, so I mean just to kind of unload and unpack it. Yeah, thank you for listening - Ayesha*
>
> *Talking about it again, you sort of get that whole, 'oh my God, I totally forgot about that,' and it was really nice to sort of just sit to chat to someone about it - KJ*

While interviews focused on recurrent thrush, participants also spoke about difficult past experiences of sexual violence, pregnancy loss, and abusive relationships. I had support resources available that I sent after interviews concluded. Due to the potential emotional nature of interviews, I was also aware of the possibility of vicarious traumatisation (Lalor et al. 2006). To address this, I aimed to conduct no more than one interview a day and to debrief afterwards with supervisors. It was also important for my supervisors and I that support was built into this project not just on an interpersonal level but also structurally. We budgeted grant funding for counselling which might be considered for other researchers working on sensitive topics, especially if they have lived experience of the topic.

3.6 Ethics

Ethical approval was granted through the Berkshire research ethics committee (12/SC/0495HTO) for speaking with patients. These interviews were collected between May 2022 and June 2023.

The University of Oxford research ethics committee (R85678/RE001) granted ethical approval for speaking with healthcare professionals. These interviews were collected between May and July 2024.

3.7 Patient and public involvement

My perspective in conducting this research is that individuals are experts of their lived experience. At the early stages of this study, I established a patient representative group featuring individuals with recurrent thrush to design and guide this study. How we worked together is reported below and throughout this chapter in accordance with the GRIPP2 reporting standards on reporting patient and public involvement in research (Staniszewska et al. 2017).

Patient and public involvement (PPI) is increasingly recognised as foundational to rigorous health research, especially those analysing patient experiences. PPI involves meaningfully including people with lived experience as active members with "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (NIHR 2021). Involving patients in research helps make results more credible and relevant to others with the same health condition (Domecq et al. 2014).

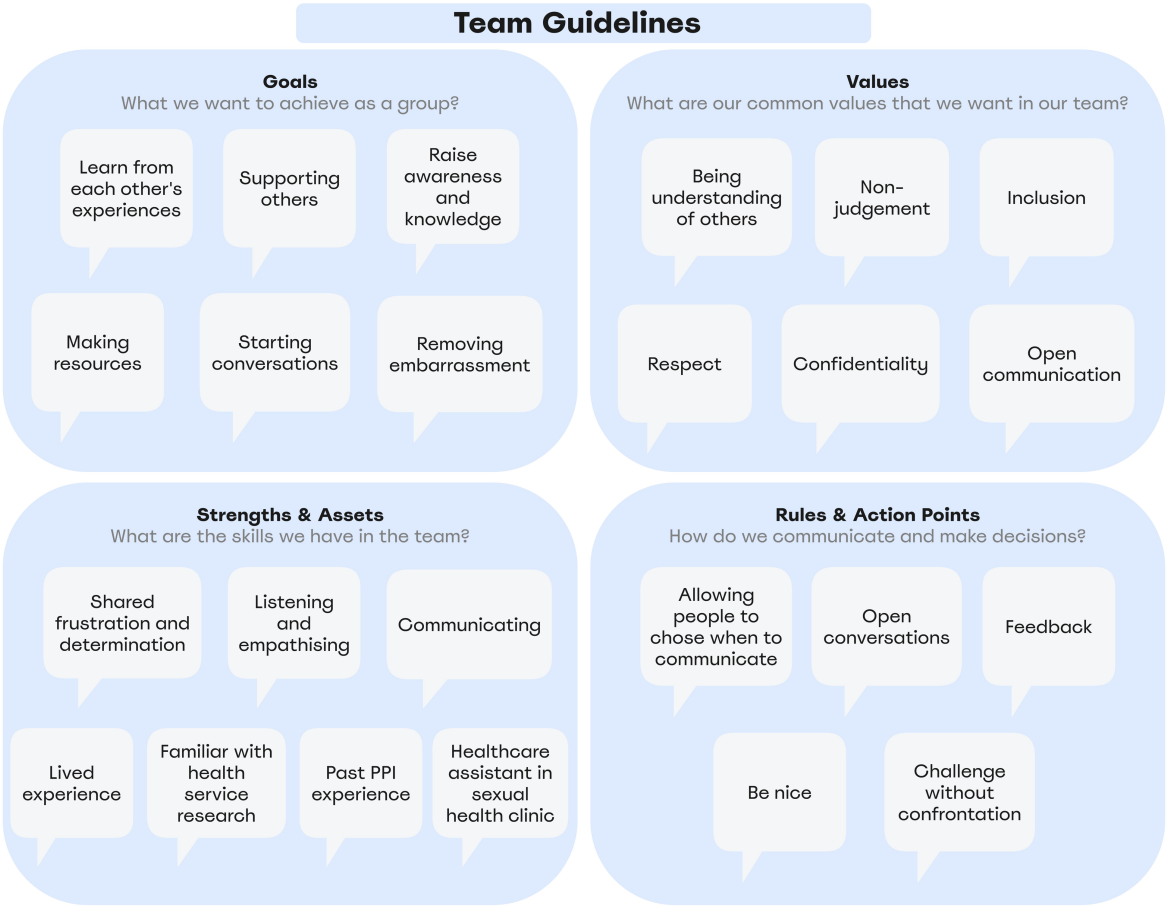
Patient representatives were recruited through charities, social media and word of mouth. Interested parties were invited to submit a form to express their interest and I held short informational interviews. I sought a diversity of experience and a range of

familiarity with public involvement. I selected eight members for the group. Ages ranged from 20 to 60 years of age. One participant was non-binary, and the others were cis women. One participant was Black British, and the others were white British. A range of sexualities and socioeconomic statuses were represented. Three had experience with public involvement in research and for five this was their first.

We met at key points in the study and had five all-team meetings as well as asynchronous communication through email and an established Slack channel. Our meetings resembled collaborative workshops where we used shared whiteboards to brainstorm, create materials and pose questions. This approach meant that everyone could share their perspectives. Images of these collaborative whiteboards are embedded throughout this chapter.

During our first meeting, we discussed our goals, values, strengths and ground rules that we wanted to establish for working together. The team canvas map for how we wanted to work together is outlined below. One patient representative, Patti, said about the group, “The knowledge we are helping other people is great.”

Figure 5: Patient representatives team canvas map



3.8 Recruitment

This section outlines how I recruited participants, looking first at patients and then healthcare professionals. The impact of patient representatives is illustrated throughout.

Recruiting patients

Recruitment began with a patient representative meeting to create patient-facing materials, including the research poster that would be circulated through various online and in-person channels.

Choosing language for recruitment materials was discussed at length. Patient representatives discussed using terms such as thrush, yeast, and candidiasis.

Candidiasis was said to be too medical, and yeast unclear. Therefore, thrush was chosen for its colloquial and familiar usage. How to capture recurrence was then discussed with terms such recurrent, persistent and chronic used by different patient representatives. We concluded that "recurrent" was the most inclusive term that could include various experiences. Yet, it was raised that people might not know what "recurrent thrush" means and that we should therefore say "thrush that keeps coming back, repeating, or returning". Patient representatives also encouraged the use of terms like vagina and genitals but said to avoid terms like "cottage cheese discharge" that were felt to be stigmatising. It was important that the poster be explicit about being trans and non-binary inclusive, and appear inviting.

We also chose what images were the most appropriate to include. Patient representatives said they wanted to avoid images of "someone in pain", "legs crossed/hand over crotch stereotype", "flowers or anything too girly" or anything "too medical". The final image we chose was selected as it was said by patient representatives to be the most inclusive and welcoming.

Figure 6: Patient representatives brainstorm on research poster

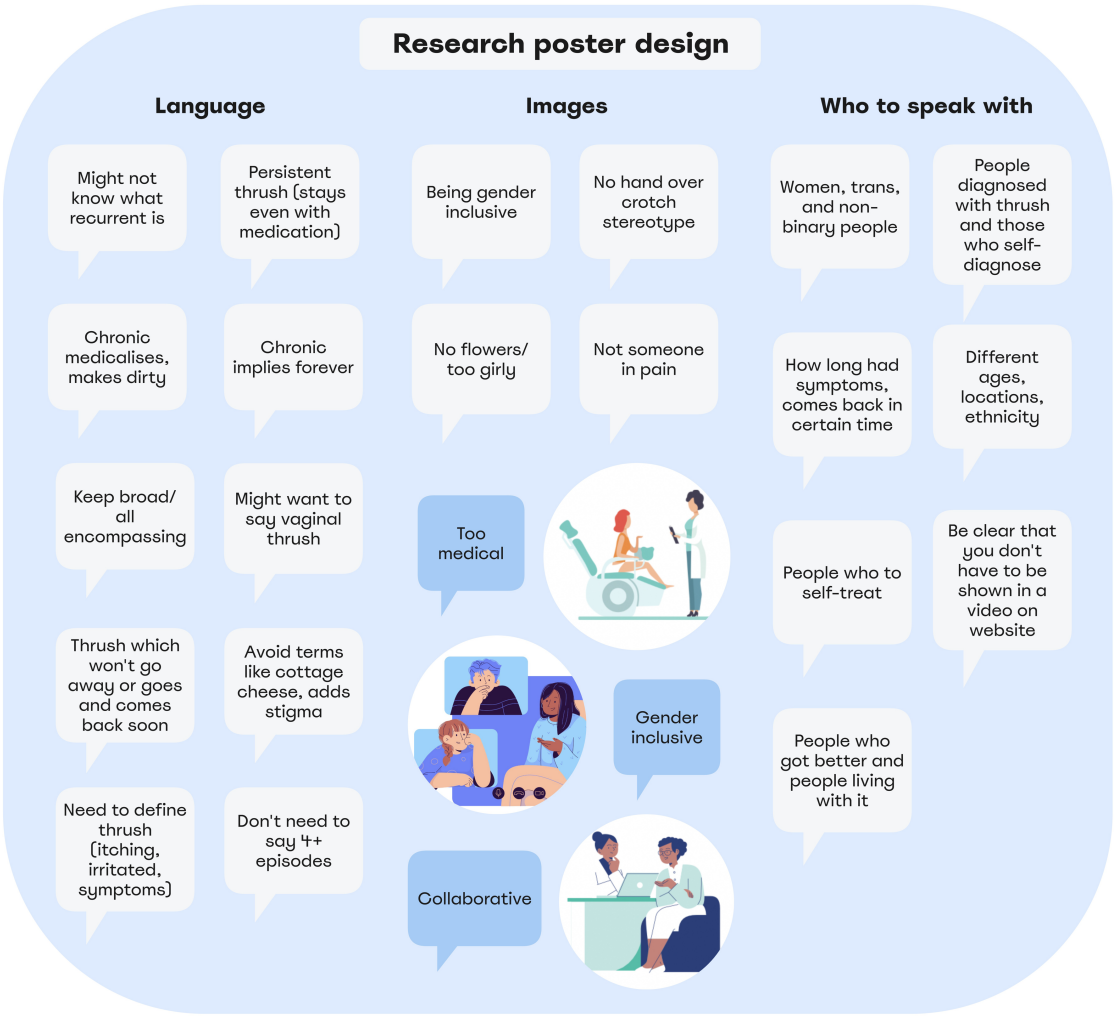
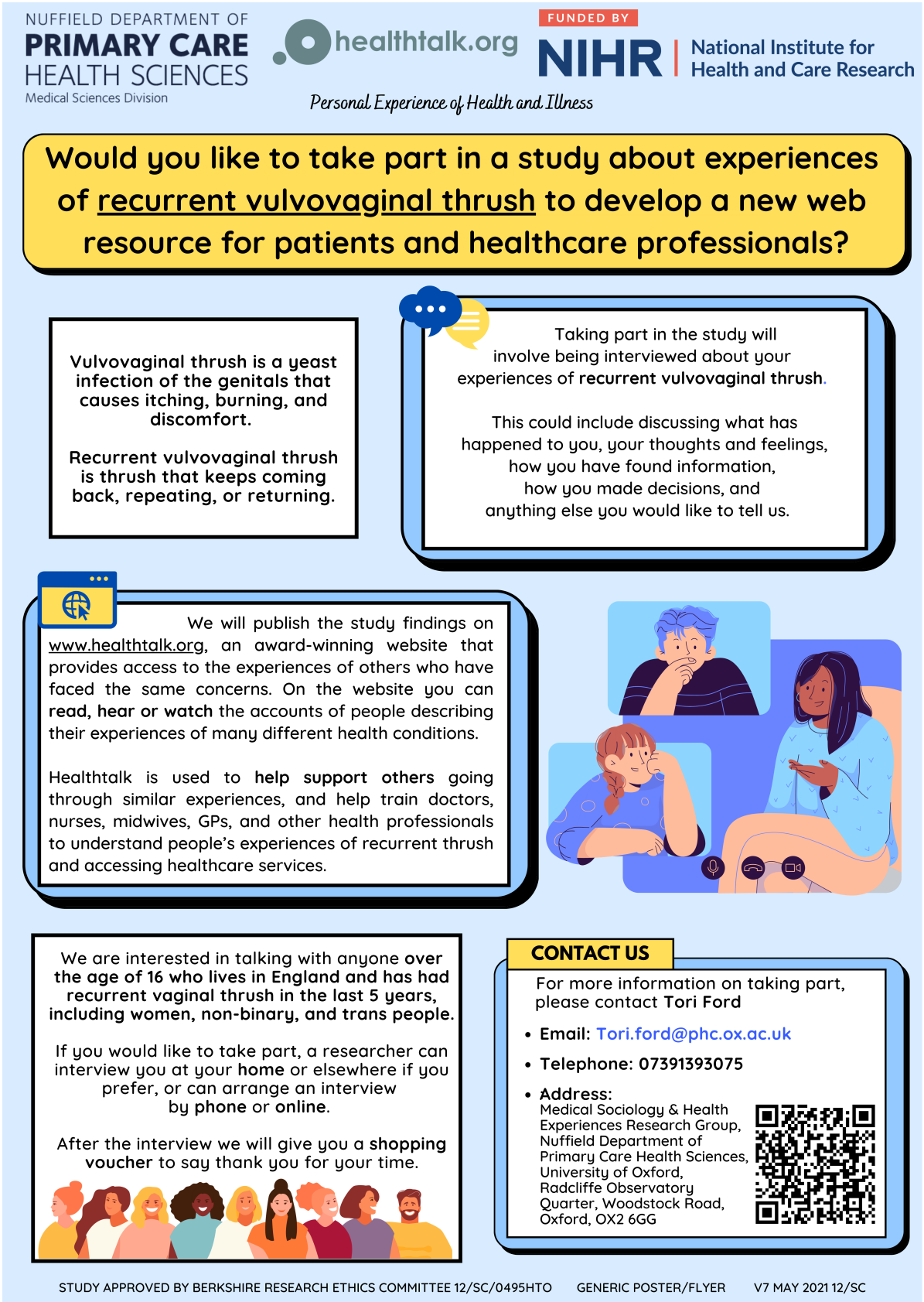


Figure 7: *Recruitment poster for patients*



I sought to balance recruitment through advocacy organisations where individuals might feel confident participating, with routes that would locate individuals who might be more reluctant or uncomfortable discussing this topic. Recruitment posters were placed in GP surgeries, sexual health clinics, pharmacies and community centres across England. I also circulated study information online through a dedicated departmental webpage, patient-facing newsletters, online support groups, and social media including Instagram, Facebook, LinkedIn, Twitter and TikTok. Patient representatives played a key role in aiding with recruitment, posting on WhatsApp support groups they were a part of and placing posters in their community centres.

I worked with charity groups to circulate the research recruitment to their patient audiences. This included my own social impact organisation Medical Herstory, as well as groups that focused on specific groups like Muslim Women UK, the Black OBGYN Project and Trans Actual UK. These organisations shared recruitment posters on their social media, in newsletters and by word of mouth. The study was also shared by UK influencers working within gender health spaces to their followers as well as through Internet-snowballing as individuals re-posted the content.

Other creative methods I took to increase engagement included hosting an online event with Medical Herstory on "Storytelling to Undo Stigma: Vulvovaginal Health" and inviting lived experience experts, physicians and community advocates to discuss recurrent thrush and overlapping conditions. This event reached over 100 individuals. I also created a social media campaign for Medical Herstory's Instagram and TikTok (with a combined following of over 10,000) about recurrent thrush, vulval health and the value of sharing experiences to help increase health literacy, awareness and encourage participants to come forward. I also engaged with the student press and wrote a piece for HerCampus about recurrent thrush to target young people who might

be embarrassed to discuss this issue. Lastly, I created video content by doing a Facebook Live with the Vulval Pain Society (an organisation working to support people with all forms of vulvovaginal discomfort) to make myself visible to potential research participants.

Interested parties contacted me directly and I sent them the participant information sheet and a reply slip asking for their demographic information.

Table 2: Recruitment avenues for patient interviews as reported by participants

Recruitment avenue	**Number of interviewees**
Instagram (various community groups)	15
GP Office	2
Through a Friend	2
Google search	3
Eve Appeal	1
Lichen sclerosus Facebook group	1
RCOG Women's Voice Facebook group	1
Clare project	1
Terrence Higgins Trust website	1
Vulval Pain Society Event	2
Nurses and Support Worker WhatsApp Group	1
Not known	4

Recruitment materials explained that study findings would be used to create an online resource (detailed in Chapter 8), which entailed demonstrating the site and a separate copyright form stating how participants wished to be represented on the website.

Some people may have been motivated (or discouraged) to take part in the study because of the tangible output. People who feel their health condition is rarely discussed openly might be especially motivated to participate (Ziebland et al. 2021).

Participants expressed enthusiasm that recurrent thrush was a topic gaining research attention and hoped that sharing their experiences would improve health outcomes for other patients. Imogen said, "*it does mean a lot to be interviewed and actually be heard and you know that your experience might be used to try and make things better for other people".* Leah said, "*Thank you for doing the study really, because without people like you, there won't be more information, and there won't be help for others".* Nysha saw this study and its public-facing output as especially useful for those who did not feel comfortable speaking out (whether in the form of a research interview, or in their own communities), as she explained:

> *There's still young girls in so many communities, I know in Asian communities and Black communities, that will be able to access the web and see things and not feel embarrassed or ashamed, so you know without you doing this, you know a lot of people won't be suffering in silence anymore, so we're grateful to you.*

Harry explained why a resource that would compare patient experiences would be welcome.

> *I would love to know some of those similarities or be able to see something of the research, just in the sense of that supportive element of, 'oh yeah, there's a ton of other people that have also flagged up that very same thing,' because at the moment... you know it does feel largely very isolating.*

Yet, while participants had read the participant information sheet, posters, or newsletters about the study which all described the online output, they did not always recall this, nor was it always a key motivation to participate. Some said that they forgot about the website component until the end of the interview when I mentioned obtaining a copyright form for the website. Teddy said: "*Oh yeah, I forgot about that, it did mention that, I just forgot".*

Other people may have been intimidated by, or uninterested in, a public-facing website and therefore did not participate. It is only possible to speculate on the motivations of those who did not participate (or the one person interviewed who did not

subsequently return their copyright form) but it is possible that the potential for extracts from their audio or video recorded interviews to appear on a public facing site may have deterred some people.

Recruiting healthcare professionals

Recruitment posters for healthcare professionals were reviewed by a general practitioner. The poster targeted those "working in primary care and sexual health who had experience managing recurrent vulvovaginal thrush". I used this language to include various roles including doctors, nurses, trainees and consultants, and to acknowledge that individuals might hold various roles. The poster proposed either individual interviews or focus groups, but after interviewing a few healthcare professionals and discussing with my supervisors, we decided I would solely conduct interviews to facilitate scheduling and convenience for participants.

Figure 8: Recruitment poster for healthcare professionals

Healthcare professionals were recruited through GP and sexual health professional networks, relevant social media pages and word of mouth. This poster was shared by professional networks including through the Royal College of General Practitioners, NHS Networks, The British Association of Sexual Health and HIV (BASHH) and Brook. A few academic primary care departments also shared the poster, but I limited this approach as I also wanted to hear from healthcare professionals not involved in research. I also strategically used social media to leverage connections with doctors who had large followings. I was able to have the poster shared by individuals with both a special interest in gendered or sexual health and also those with a general interest in health promotion or primary care.

I also spoke at several conferences and meetings targeting healthcare professionals and encouraged participation in the study. This included speaking at the Women's Health Influence conference in London and presenting to the Society for Academic Primary Care Women's Special Interest Group.

Table 3: Recruitment avenues for healthcare professional interviews

Recruitment avenue	**Number of interviewees**
Colleague	8
Instagram	3
WISE GP	1
RCGP Overdiagnosis group	3
Department email	1
BASHH	5
Brook	1
Not known	2

3.9 Sampling

I wanted to understand the widest practicable range of experiences related to recurrent thrush. Therefore, I pursued a maximum variation sample (Meyer & Xyländer 2018) for both patients and healthcare professionals. Maximum variation sampling is a form of purposeful sampling focused on selecting a wide range, variation and diversity of participants, understanding that these variables hold significance (Herxheimer & Ziebland 2000, Sandelowski 1995). Unlike convenience sampling that selects the most accessible participants, purposeful sampling asks researchers to think deeply about who is being heard and who is missing (Patton 2002).

Deciding when the sample was complete was guided by the principle of data saturation. While new interviews can always offer different information, data saturation refers to the point when interviews no longer add new findings to analytic categories (Ziebland 2006). Therefore, I began analysis alongside data collection where I became familiar with initial findings and assessed what was missing to ensure a diversity of experiences was covered in enough analytical depth (Braun & Clarke 2021).

Patient sample

For patients, a diversity of experience included those with varied care pathways, duration of symptoms, treatment outcomes, and experiences with shame and stigma. I sought to hear from people across different demographics including age, gender, race, disability, socioeconomic status and geographical locations. I hoped to hear from people both with an official diagnosis and those who were in the process of seeking one, recognising from the literature and patient advocates that this is not always a straightforward or rapid process (Strydrom et al. 2022).

To facilitate a maximum variation sample, I took a cautious approach to recruitment, recognising that those who were quickest to volunteer might be those most comfortable discussing the topic. Instead, I gathered initial information from potential participants and prioritised interviewing those from marginalised or seldom-heard populations. Intersectional feminist approaches recognise a spectrum of gender oppression and how sexism affects trans, non-binary and gender diverse individuals. Therefore, it was important for my study to include these voices.

This study's sample included 32 people with recurrent thrush in England. Two people consented to be interviewed, but after the interview decided they no longer wished to participate in the study. One stated that they worried the study was asking for too much personal information, and another stopped replying to emails without specifying a reason. Three people were interviewed twice due to needing to take a break during the first interview (one for emotional reasons, two for logistical ones). Methods for sensitive interviews and how I handled such situations are described above.

The sample included people who heard about the study through their GP surgery, charities, forums, social media, Internet searches and friends. The sample included 28 people who identified as cis-women, two as non-binary, one as a trans man and one as gender fluid. Nine people were from ethnic minority backgrounds including Black, Indian, Pakistani, and mixed race. Nine people identified as queer, bisexual, asexual or lesbian. Ages ranged from 21 to 60 years-old. Twenty-nine people described their thrush as recurrent, cyclical, or repetitive, and three labelled it as persistent or chronic. Participants reported having recurrent thrush for a range of durations from a few months to over a decade. A table of the sample's demographics and recurrent thrush experiences are presented below.

Table 4: Demographics for patient sample

Name	Age	Gender	Sexuality (self-described)	Ethnicity
KJ	42	Gender fluid	Heterosexual	White British
Ayesha	25	Woman	Heterosexual	Pakistani
Teddy	21	Non-binary	Gay	White
Nancy	37	Woman	Straight	White
Emily	32	Woman	Straight	White
Aditi	22	Woman	Straight	Indian
Sai	24	Woman	Straight	Indian
Ella	50	Non-binary	Bisexual	White
Nysha	40	Woman	Straight	Black British
Beth	25	Woman	Bisexual	White
Laura	42	Woman	Straight	White
Imani	35	Woman	Hetero	Black
Jody	26	Woman	Bisexual	White
Elliott	30	Trans man	Queer	White
Billie	25	Woman	Straight	White
Joy	43	Woman	Straight	White
Sasha	34	Woman	Straight	Black
Zoya	33	Woman	Straight	Pakistani
Kayla	42	Woman	Lesbian	White
Lydia	26	Woman	Straight	White
Leah	26	Woman	Straight	White
Anna	34	Woman	Bisexual	Mixed race
Georgia	27	Woman	Straight	White
Emma	41	Woman	Straight	White
Marie	60	Woman	Straight	White
Harry	25	Woman	Straight	White
Julia	36	Woman	Straight	White
Hannah	31	Woman	Straight	White
Chloe	30	Woman	Straight	White
Imogen	29	Woman	Bi-romantic	White
Rowan	24	Woman	Bisexual	White
Sarah	35	Woman	Straight	White

Table 5: Patient sample information

Name	Duration (years)	Frequency	Swab results	Treatment (prescribed)
KJ	>10	Every few months	Positive	Over-the-counter
Ayesha	4	Persistent	Negative	Over-the-counter
Teddy	3	Every few months	None taken	Over-the-counter
Nancy	6	Monthly	Positive	Over-the-counter
Emily	10, resolved	Every few months	Positive	Over-the-counter
Aditi	2, resolved	Every few months	None taken	Over-the-counter
Sai	4	Monthly	None taken	Cream
Ella	6	Monthly	Positive	Pessary, cream
Nysha	>10	Monthly	Positive	Pessary, cream
Beth	10	Monthly	Positive	Pessary
Laura	>10	Every few months	Positive	Pessary
Imani	2, resolved	Every few months	None taken	Cream
Jody	5	Every few months	Positive	Fluconazole
Elliott	2	Every few months	Positive	Fluconazole
Billie	7	Every few months	Positive	Fluconazole
Joy	9 months	Monthly	None taken	Fluconazole
Sasha	1	6-8 times a year	None taken	Fluconazole
Zoya	3	Monthly	Positive	3-month fluconazole
Kayla	6	Persistent	*Candida glabrata*	Long-term pessaries
Lydia	1	Persistent	*Candida glabrata*	6-months pessaries
Leah	10	10-11 times a year	Positive	6-month pessaries
Anna	10, resolved	8-9 times a year	Positive	Maintenance therapy 2x
Georgia	4	Every few months	Positive	Maintenance therapy 2x
Emma	>10, resolved	Monthly	Positive	Maintenance therapy
Marie	5	Monthly	Negative	Maintenance therapy
Harry	2	Monthly	Positive	Maintenance therapy
Julia	>10	Monthly	Positive	Maintenance therapy
Hannah	2	Every few months	Positive	Maintenance therapy
Chloe	>10	Monthly	Positive	Maintenance therapy
Imogen	>10, resolved	Every few months	Positive	Maintenance therapy
Rowan	2, resolved	Monthly (cyclical)	Positive	Maintenance therapy
Sarah	10	2-3 weeks	Positive	Maintenance therapy

I continued to sample for more participants whilst undertaking interviews and analysis. For example, half-way through undertaking the interviews, I had rarely heard about participants receiving the recommended long-term antifungal therapy. Therefore, I emailed those interested in participating stating that I was interested in hearing more about this treatment regime and selected additional participants from this group.

I aimed for a maximum variation sample, while also recognising potential limitations. This study focuses on a sensitive topic, and I recognised that those who did not want to speak about this topic due to embarrassment, shame, or discomfort may not come forward for an interview. However, those with recurrent thrush who volunteered to be interviewed included those who described ongoing embarrassment trying to speak with healthcare professionals or in disclosing their problem to friends and family. However, those most affected and most marginalised are likely not included in the sample which raises questions around the limits to maximum variation sampling when certain people and experiences are likely not captured.

Some groups that I intended to include in the sample were not represented. For instance, while the study includes gender and racial diversity, there is little overlap. For instance, all gender-diverse participants were white, and all individuals from ethnic minorities were cis women. Further, the trans and racialised individuals I spoke to did not access long-term antifungal therapy. This meant that certain intersectional identities and experiences could not be explored.

Healthcare professional sample

For healthcare professionals, I sought to speak with individuals with different years of experience, expertise, special interests, and living in various locations and settings.
I interviewed 25 healthcare professionals in England. Fourteen worked in primary care and 11 worked in sexual health settings, although sometimes people currently worked, or had previously worked, in more than one clinical setting. Within primary care, 12 people worked as GPs, one as a Physician Associate, and one as a Trainee. One GP also worked in community gynaecology. Within sexual health, I spoke to a range of physicians working as consultants, trainees and one nurse. One sexual health doctor was training to be a GP. The sample included 20 women and five men. Eight people were from ethnic minority backgrounds including Asian, Black, Indian, Pakistani, and mixed race. Ages ranged from 24 to 59 years of age. Years of experience ranged from two to 29 years, with one interviewee still in training. The range in which healthcare professionals reported seeing patients with recurrent thrush ranged from weekly to every few months.

With healthcare professionals, clinicians sometimes offered to snowball recruitment within their own centres, which was helpful but risked over-representing urban areas over rural ones. Thus, I made efforts to recruit a wider geographical spread.
Recognising that female healthcare professionals often see (or are assigned) most vulvovaginal complaints, I also asked participants if they would help to recruit male healthcare professionals. Some advertised for male participants in their centres, and a few volunteered.

Table 6: Demographics for healthcare professional sample

Name	Age	Gender	Ethnicity	Location
GP Dr A	52	Woman	White British	Oxford
Trainee Dr B	24	Woman	White British	Plymouth
GP Dr F	35	Woman	White British	Oxford
GP Dr H	32	Woman	British Pakistani	Leicester
Physician Associate I	35	Woman	Indian	South Yorkshire
GP Dr K	51	Woman	White British	Oxford, Shetland
GP Dr M	33	Woman	White Irish	Stalybridge
GP Dr P	44	Woman	White British	London
GP Dr Q	53	Woman	White British	Clitheroe
GP Dr R	37	Woman	White British	Birmingham
GP Dr T	36	Man	White British	Manchester
GP Dr U	33	Man	Black African	Nottingham
GP Dr W	35	Woman	British Chinese	Stockport
GP Dr X	40	Woman	White British	Oxford

Name	Age	Gender	Ethnicity	Location
SH Nurse C	31	Woman	White British	Manchester
SH Dr D	38	Man	White British	London
SH Dr E	34	Man	Asian British	London
SH Dr G	43	Man	Asian	London
SH Dr J	59	Woman	White Other	London
SH Dr L	32	Woman	Black/White	London
SH Dr N	42	Woman	White Irish	Manchester, Glasgow
SH Dr O	47	Woman	White British	Devon
SH Dr S	29	Woman	Asian/White	Cornwall
SH Dr V	38	Woman	White British	Manchester
SH Dr Y	59	Woman	White British	Sussex

3.10 Conducting interviews

I considered various research methods to elicit patient and healthcare professionals' experiences including ethnography, focus groups and structured interviews (Creswell et al. 2024). These options all had potential to answer my research question, but I wanted to make sure I could hear participant accounts of their perspectives and experiences in their own words and to share what was most important to them.

Interviewing patients

My decision to interview patients centred on my awareness that I would be handling a private, delicate, and often embarrassing health experience that would need a sensitive approach (Lowes 2006). The observational focus of ethnography, the less private discussion of focus groups, and the rigidity of structured interviews did not align with the needs of providing a safe space for vulnerability and disclosure, as well as participants having control over how they shared their experience (Corbin et al. 2003). Informed consent was discussed before interviews. Then, the interviews began with a narrative section where participants were invited to say what had happened since they first started to suspect there was something wrong (Grob & Schlesinger 2016). They were encouraged to speak openly and without interruption to capture the aspects that were important to them. People chose to start their account at different points, including the first time they experienced symptoms or a memorable doctor's visit. Some told their stories in a linear sense, and one had written a timeline, while others asked for more guidance and prompts. At different points in the interviews, participants often recalled earlier details or sometimes circled back to a topic discussed previously.

After participants concluded the narrative section of their interview, a semi-structured interview guide was then used to direct the conversation and expand on areas that participants raised in the narrative section of the interview (Ziebland 2013). This topic guide was designed with patient and public representatives, and I then reviewed the questions with my supervisors to ensure they were accessible, clear and relevant. One patient representative also helped me to pilot the interview guide by answering the questions and giving feedback on the interview flow. This topic guide included questions on noticing symptoms, seeking help, trying treatments, finding support and looking forward. My line of questioning was largely guided by the participant's own account, but I used the topic guide as a flexible tool covering different areas of inquiry to delve into if they were not mentioned by the participant. Questions were added as interviews went on to reflect new points of interest (Braun & Clarke 2013). For example, after one participant mentioned how recurrent thrush affected their future help-seeking decisions, I added a question about this. Participants were reminded that they were able to skip any questions they were not comfortable answering. Interviews lasted between 45 minutes and 2.5 hours (over two sessions).

Figure 9: PPI input on patient interview topic guide

Figure 10: Final topic guide for patients

Interview Schedule for Experiences of Recurrent Thrush

Preamble

Hi, my name is Tori Ford. I'm a PhD student at the University of Oxford and someone who has lived with recurrent thrush for the past few years.

Thank you very much for agreeing to take part in these interviews. I'd just like to go through a few things with you before we start. In this interview, I would like to hear about your experiences of recurrent thrush. Have you read the participant information sheet? Are there any questions which you would like to ask me about the study?

In the first part of the interview, I will ask you to tell me about your experiences. I will let you speak uninterrupted and share your experience freely. I will then ask you a few follow-up questions to ask for a little more information.

Please feel free to talk about anything that is important for you and which you feel comfortable talking about. If at any point you wish to stop or pause, or if there are questions you don't wish to answer, just let me know.

Now I'd like us to go through the consent form. (Read each line of the consent form and ask if they agree, sign the form.)

To start, I have a few demographic questions. (Fill in the demographic sheet)
Is it alright if I start the interview recording now? (Start recording)

Part 1: Open-ended narrative

- Can you tell me about your experiences of having recurrent thrush?
- *Optional prompt: You can start from whenever you wish (maybe when you first noticed symptoms)*

Part 2: Semi-structured topic guide

Recognising bodily changes

- Can you tell me a bit about the symptoms you have experienced? (how did they make you feel, how often)
- Have these changed over time?
- What did you do when you had these symptoms? (*see whether they turned to self-management or seeking healthcare first)*
- Did you have any questions or concerns about these symptoms? (if so, can you tell me more?)
- Has anyone ever given you a label for your symptoms, or do you have a label that you've found yourself?)

Impacts

- How has recurrent thrush impacted your everyday life? (prompt for sex life, work, finances, hobbies, etc.)
- Has recurrent thrush impacted other aspects of your life (family planning, relationships)
- How did thrush affect you at the start of having symptoms? Has the impact on you and your life changed over time and as symptoms recurred?
- Has having recurrent thrush impacted how you feel physically and emotionally? (How so?)
    - Can you tell me about any effect this has or has had on you as a person, and your sense of self? (Mental health, feeling dirty, body image)
    - Are there any activities that you feel you can no longer do or which you don't enjoy as much as before?
- Could you run me through a typical week when you are experiencing recurrent thrush? (how does this compare to when you do not have symptoms)
- Some people I have spoken to said they feel there is shame and stigma around recurrent thrush. What are your thoughts on that? Have you experienced it?

Medical encounters

- Have you seen a healthcare professional about thrush before? (why or why not) *If yes, continue, if no, skip*
- Can you tell me more about who you have seen about recurrent thrush? (e.g. pharmacist, GP, etc)
- Could you describe what has happened in your appointments about recurrent thrush? (what have most of your appointments been like, and have you had any appointments where things have been different?)
- What information and advice did they give you? (HCP perceived causes)
- How did you feel about the information you were given? (level of detail, format, language used)
- If seen multiple physicians: did you receive conflicting or similar information from different healthcare professionals?
- What were your expectations when going to see the healthcare professional? Did anything surprise you?
- Was there anything you thought you and the healthcare provider might have been on different pages about? (do you feel like you and the healthcare provider understood each other?)
- Did you follow up? Go back? Why or why not
- How did you feel about the care you received? (what was good, anything you would have liked to be different?)
- Does having recurrent thrush ever impact on other aspects of your health or healthcare? (prompt: having pelvic examinations smear tests, concerns about taking medication that may cause a flare-up, etc)

Help-seeking decisions

- Has your approach to seeing healthcare professionals about recurrent thrush changed over time? Has your approach changed for any other reason or circumstance? (What made you decide this? When? Why at this point? What were your thoughts and feelings here?)
- What did you hope and expect to get out of seeing a healthcare professional? (then vs. now)
- Did you have any concerns about seeking healthcare when you first suspected you had recurrent thrush?

Diagnosis

- Have you ever been tested or self-tested for thrush, or to rule other things out? (Can you tell me about your experience of this? Did you expect, want, or ask for a test?)
- How did this diagnosis (or not getting a diagnosis) make you feel?
- How do you understand recurrent thrush? (how did you find out about it, has anyone explained it to you?)

Self-management

- Can you tell me about your experience of self-management? (what does self-management look like for you?)
- What information were you given or did you seek out? (Who from? How was it explained to you? How did it impact you? Would you have liked a different amount of info? What kinds of things?)
- How confident do you feel about managing recurrent thrush yourself?
- Do you have any concerns about self-managing recurrent thrush?
- Have you come across any misinformation or misunderstandings? (or conflicting information)
- Has your management approach changed over time?

Treatment

- What treatments have you tried for thrush before? (what were those treatments like?)
- How did you find out about different treatment options?
- How did you decide which medications you would try?
- Has treatment been effective? What did you expect?
- Is there anything that makes it hard or easy to get these treatments?
- Have you had any side effects?
- Have you identified anything that triggers your symptoms?
- Do you plan to try any new treatments or seek healthcare in the future? Why or why not?

Support Systems

1. Do you feel able to talk to others about this? (ex. Family, friends, partners, colleagues, employers)
2. Can you tell me about your support system? (family, friends, support groups, social media) what kind of support do you have, how did you find it, is there anything missing?)

Looking forward

- Have your understandings or expectations around recurrent thrush changed over time?
- What do you think your future will look like regarding recurrent thrush? (Do you have any future hopes or concerns?)
- What would an ideal healthcare encounter look like for recurrent thrush?

Advice to Others

- What would your advice be for other people with recurrent thrush? (was there anything from your experience that you think might be useful for others to know)
- Is there any advice you would give to current or future healthcare professionals about treating people with recurrent thrush? (based on your experience, is there anything you think they should know?)
- Is there anything you would do to improve services and support offered for people with recurrent thrush? (what is the one change you would most like to see?)

Closing

- Those are all the questions I have for you at the moment. Is there anything about your experience of recurrent thrush that we haven't covered or that you would like to expand on?
- Do you have any unanswered questions or things you would like to know about other people's experiences who live with recurrent thrush?
- Is there anything else you would like to talk about related to this study or the topic of recurrent thrush?

Thank you so much for participating in this interview. I will follow up by sending you a copyright form to complete, and I can provide you with a copy of the interview transcript (and/or a summary) for you to look over if you wish. I will follow up via email with a voucher as thank you for your time.

Interviewing healthcare professionals

For healthcare professionals, I chose interviews for ease of scheduling and to better combine and compare data with patient interviews. I also wished to avoid potential issues of power dynamics or group tensions that could happen in focus groups (Spalding & Philips 2007).

I employed a vignette technique where I offered a brief clinical scenario to guide the interview. Vignettes involve the researcher presenting a fictional scenario and inviting the interviewee to reflect on it and what they might do in that situation (Spalding & Philips 2007). I built the vignette based on data from the patient interviews. The scenario began with "Jay is 30 years old. She is experiencing vulvovaginal itching and a change in discharge. She thinks she has thrush". I asked clinicians if this was a reasonably familiar scenario and then asked them how they would proceed. As the interview went on, I added in details about Jay's symptoms recurring, treatment avenues that had been tried, and how healthcare systems influenced these interactions. This vignette was designed with the help of a GP, a sexual health practitioner, and patient representatives to ensure it was an accurate and useful account. This technique has been shown to be effective with gaining insight into people's attitudes, perceptions and beliefs (Hughes & Huby 2002). It has also been particularly helpful when speaking to healthcare professionals who may be (rightly) hesitant about disclosing information about their actual patients (Dixon et al. 2021). Semi-structured questions were laid out in a topic guide between layers of the vignette to hear more about key areas highlighted from patients. Interviews lasted between 30 minutes and 1.5 hours.

Patient representatives also helped build the topic guide for healthcare professionals. We spent considerable time reviewing the patient vignette as we did not want to

represent a patient who was overly well-informed about recurrent thrush or necessarily able to self-advocate. We therefore edited some prompts such as changing "she wants to talk to you about the option for preventative treatment" to "she doesn't know what to do next". Other questions patient representatives saw as important were collected and integrated into the semi-structured follow-up.

Figure 11: PPI input on vignette for healthcare professional interviews

The scenario	Feedback
Jay is 30 years old. She has made an appointment to talk to you about vulval itch. She thinks she has thrush.	More realistic, patient says I have a really itchy vulva How does age influence?
She reluctantly explains this happens often and she is worried (frustrated) (having trouble explaining self)	Patient who is shy vs. self-advocating Don't want this patient to be the one who can self-advocate
She has tried over-the-counter medication and it helped for a while, but symptoms came back	With time constraints what questions do they see as most important to get answered?
She wants to talk about the option for preventative treatment (She doesn't know what to do next)	Jay seems comfortable being assertive in what they want (others may not) Don't want this patient to be overly well-read and informed about thrush
Would you approach or do anything differently if Jay had visited multiple healthcare professionals for this issue before?	Does GP think Jay being dramatic? do they think it's just a small issue or serious? What do they see their role as? (reassurance, solving it?) or just small cog in the journey?
Follow up questions	Have some questions that bring it back to their actual experience Is this something you've encountered before?

Figure 12: Patient representative areas of interest for healthcare professionals' interviews

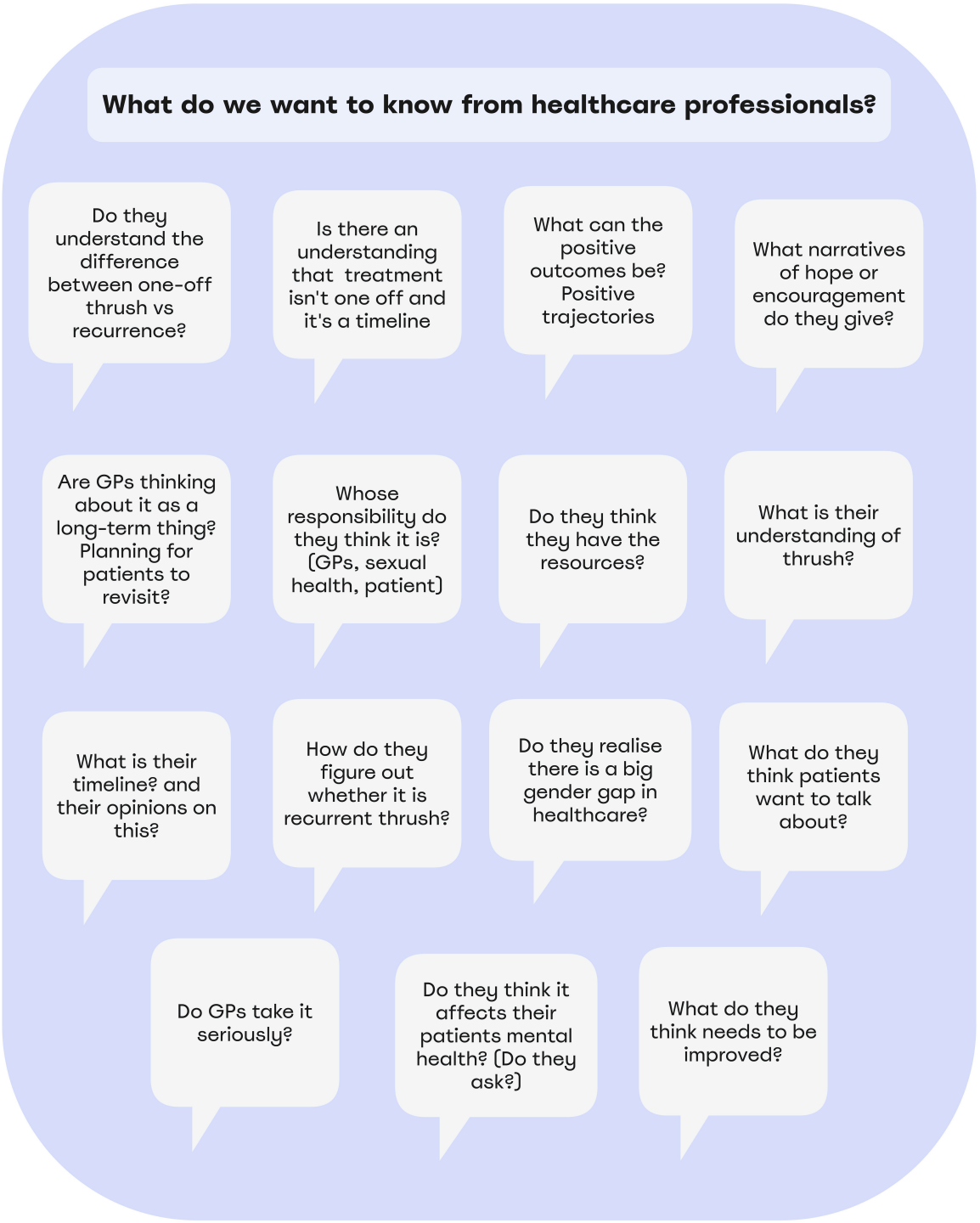


Figure 13: Final topic guide for healthcare professionals

Topic Guide for Healthcare Professionals

Preamble

Thank you so much for meeting with me today, I know you are very busy so we will get started straight away. The interview will take around 30 minutes, but do you have any time limits I should know about?

I'm interested in hearing how you approach thinking about real world situations so to start our interview I'll present a short clinical scenario which I would like you to respond to, based on your own experiences and knowledge.

I'll be introducing the scenario in stages and asking questions in between.

Clinical scenario

1. Jay is 30 years old. She has made an appointment to talk to you about vulval itch, soreness, and discharge. She thinks she has thrush.

Questions:
- Just to start - is this a reasonably familiar scenario?
- What are your initial thoughts?
- What (else) would you want to know? What would you ask Jay?

Prompts if not said:
- What might you do to find out whether it is thrush?
- Would you ask about recurrence?
- In what circumstances might you do a swab?

Clinical scenario continued

2. Jay explains that this happens often where symptoms go away with treatment but then come back

Questions
- How would you respond?
- What difficulties (if any) would you be anticipating in helping Jay?

Prompts if not said:
- How would you usually diagnose recurrent thrush?
- Might you use the term 'recurrent thrush' when talking to Jay? Or in her notes?
- Are there other explanations you might be considering? In what circumstances would you start to investigate other conditions?
- Would you treat recurrent thrush differently from (apparently) one-off thrush?

Clinical scenario continued

3. Jay expresses frustration with the recurring problem which she wants resolved. She doesn't know what to do next.

Possible changes to scenario (assuming HCP suggests long term anti-fungal)

- Jay wants to talk about the possibility of preventative treatment
- Jay says that she has tried long-term antifungals before which helped but symptoms came back

Questions

- Is this a situation you have experienced? What would (did) you do next?
- What would be your approach to managing this?

Clinical scenario continued

4. Would you approach or do anything differently if you could see from the notes that Jay had consulted about this issue many times before?

Questions

- In your experiences do you think care pathways for recurrent thrush are OK? If not, what are the problems you are aware of?
- Do you get the impression that people like Jay are able to get an appointment to see you reasonably quickly when they have this problem'? Do you think it matters if they see the same doctor?

Follow up questions:

- Are there any situations or circumstances when you might respond differently?
- What would help patients and doctors manage this better?
- Do you feel there are adequate resources to support people with recurrent thrush? Are there any info and support resources you might refer patients to?

Closing

- What else would you like to say, that we haven't talked about, that you think is important in terms of managing patients with thrush?
- Anything else you would like to add?

Thank you so much for sharing your insights. I will follow up by sending you a voucher as a thank you for your time.

Some risks of vignettes are having a purely hypothetical discussion around patient care that is not rooted in real experiences (Wilson & While 1998). However, to avoid this, I prompted with questions that located the interview in actual events such as "What does that look like in practice?". In doing so, interviewees were prompted to draw on their expertise and experiences, or to use the vignette to illustrate their thinking.

3.11 Online and phone interviewing

While online interviews have been critiqued in the past as a lesser version of a face-to-face encounter, this view is being increasingly challenged (Lobe et al. 2022). Researchers now recommend offering different routes to participation and allowing participants to choose (Davies et al 2020).

Interviewing online offered greater flexibility as I often met with participants on weekends and evenings to accommodate individuals' childcare or work schedules. Online interviews meant that participants could speak within the comfort of their own home and have control over their surroundings by positioning their background in a certain way, using an automated background, or keeping their camera off (Thunberg and Arnell 2021). Individuals were able to easily end the call (if needed) with the click of a button instead of having to navigate home from an unknown location, or manoeuvre asking an in-person interviewer to leave (Lobe et al. 2022). While online interviews offered flexibility, they also featured unanticipated elements such as featuring children who had woken up from naps, pets who appeared on screen, and interruptions from delivery drivers.

Risks included not being able to see what else (or who else) may be influencing the interview (Davies 2020). Online interviewing can miss some types of body language

such as fidgeting hands, while highlighting others like facial expressions due to looking directly at each other in a manner less prominent to in-person research.

Other limitations of the online method also include participants needing technological literacy and access to an Internet-connected device (Lobe et al. 2020). If participants did not have access to the internet, I had budgeted to post them a tablet and a sim data card for Internet access, but this was not necessary. Some technological difficulties occurred through screens 'freezing,' lines 'dropping' or connections 'lagging'. This could interrupt the participant's thought or potentially lead to frustration. Luckily, this was a rare occurrence, and participants all appeared to persevere when technology challenges were experienced. Sometimes, this included changing devices, moving to another location, or calling back.

Online interviews with patients

Patient participants were given the choice of having an interview in-person, on the phone, or via an online video call, depending on their preference. One took place in person, six on the phone, and 27 on video calls. Patients called from their own homes, partner's homes, and one while commuting home from work. The one in-person interview was hosted in a meeting room at the Nuffield Department of Primary Care Health Sciences, University of Oxford, with the participant local to Oxford. All interviews were audio or video recorded. The one interview that took place in person was not video recorded, after the interviewee noted that the video camera set-up appeared intimidating. In contrast, the discretion of the recording on Microsoft Teams appeared to be a comfortable setup.

Online interviews with healthcare professionals

Healthcare professionals were offered online or telephone interviews to facilitate easy access and busy schedules. One took place on the phone and 24 on video calls. Healthcare professionals often took calls in their clinical offices, on lunch breaks, or from home on days off. All interviews were audio recorded.

3.12 Analysis

All interviews were recorded, transcribed verbatim and analysed thematically. A professional transcriber prepared the transcripts, which I then checked against the recording, and edited. I removed identifiable features such as names of family members, doctors, places, or clinics.

Patient participants were offered the opportunity to review their transcript and/or to receive a summary. All but one opted for a summary only. I sent summaries and sometimes asked for clarification or more detail about timelines. All edits made by participants were minor.

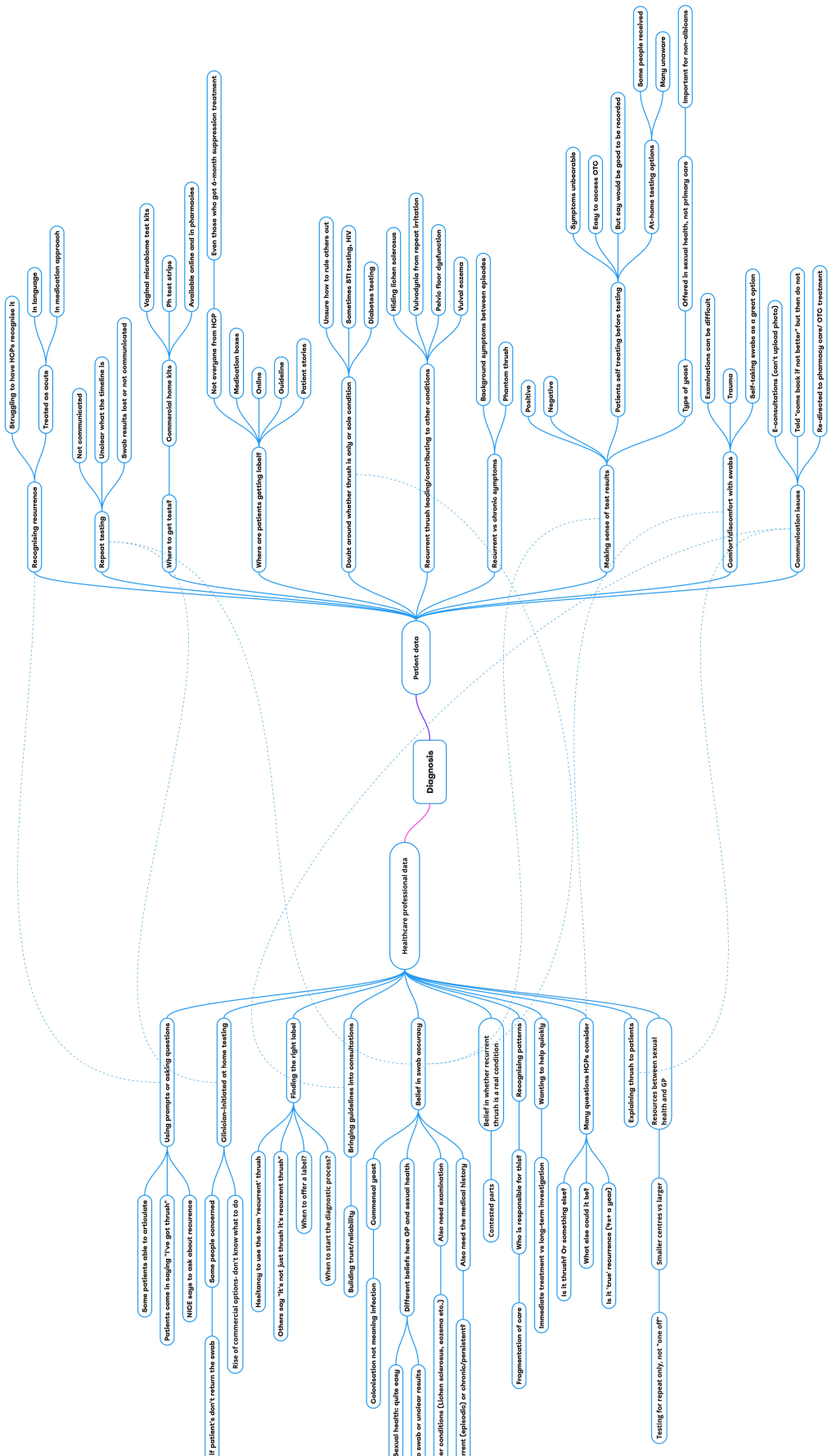
I began coding during data collection to identify early areas of interest and explore these more in interviews and analysis (Charmaz 2014). A qualitative interpretative approach was taken where transcripts were read, re-read, and compared to each other (Braun & Clark 2006). This left space for both developing themes, and those found in the literature, to be identified (Ziebland 2006, Pope 2020). I undertook a thematic analysis where sections of transcripts were coded into large categories such as "Looking for a diagnosis" and then detailed sub-codes such as "Finding the right language" or "Experiencing doubt and uncertainty". I used NVivo12 software to store and retrieve these codes. The coding structure was reviewed and revised as my

analysis progressed. During analysis, I was interested in what participants said about their experience as well as what larger social narratives they built upon.

I first analysed my data from patient interviews and those with healthcare professionals separately, which allowed me to fully immerse myself in the narratives of these two groups. I then combined datasets around specific areas of interest and examined where existing coding overlapped. In doing so, I brought together lived experience and clinical expertise to better understand information and support needs. In my analysis, I quote from interviews often to bring in patient and healthcare professional voices. This thesis presents findings chapters where both perspectives are presented together and compared (Chapter 5 and 6), and a few where patient perspectives stand alone (Chapter 4 and 7).

Interviews produced great richness and depth, and I therefore could have pursued multiple avenues for writing up my analysis. I discussed early themes with my supervisors and at conferences until a few key themes were identified as areas where I could contribute a new perspective to existing knowledge or improve understandings between patients and providers. Once a theme was selected, I used the one sheet of paper (OSOP) method to map out all coded data and ensure that I had a comprehensive analysis (Ziebland 2006). This involved noting on a large single sheet of paper every issue raised in interviews that related to the main theme (I used an online endless whiteboard called Miro as a digital equivalent). This method was helpful to identify and organise the 'story' in the data. An example OSOP is provided below (Figure 14). This diagram was then linked to relevant participant IDs and illustrative quotes to ensure the full depth and breadth of data was presented. At this point, I also returned to the literature to examine what contributions my data was able to make and to further inform my analysis.

Figure 14: OSOP example



In my last analytic chapter, I conducted a detailed case study of a few patient interviews in their entirety. The aim of this approach was to consider a single experience instead of slices of the topics across all the interviews. This approach allowed me to delve into how people constructed their narratives and pay attention to the intersectional aspects of individuals' accounts.

Further, analyses and extracts from patient interviews were used to create a multimedia online resource. The process of creating this resource and its potential impact is reflected on Chapter 8.

3.1.3 Positionality and reflexivity

Positionality and reflexivity are central pillars of feminist research as they help to acknowledge how the researcher's own identities are not neutral or insignificant, but central to all studies (Dinçer 2019). Positionality refers to the position, characteristics, and situation of the researcher in relation to the social and political contexts of the community and participants they study (Coghlan & Brydon-Miller 2014). Feminist scholars reject the possibility, or even desirability, of detached and value-free research that stems from a disembodied and neutral "gaze from nowhere" (Levesque-Lopman 2000, Tuana 1996). Instead, they advance that the researcher's social location, lived experience, and embodiment are "epistemically significant" and advocate for a "view from a body" (Haraway 1988). Researchers' positionality affects each step of the research process, including the questions asked, methods used, and data analysed (Davis and Khonach 2020).

Disclosure of lived experience is often framed in feminist literature as a means of demonstrating to participants that you understand their experience, and to build a reciprocal relationship by decreasing power inequities (Dickson-Swift et al. 2006).

Increasingly, a turn has been made towards patient-led research recognising the strength of patients researching conditions they live with (Snow 2016, Greenhalgh 2019, Riggare 2020). This approach brings together evidence-based research and experiential knowledge and recognises them both as powerful (Page 2012, Greenhalgh 2019). It also raises questions and concerns about how the identities of 'patient' and 'researcher' are often framed as at odds, with "real patients" on one end and academics on the other (Snow 2016).

Within feminist research, there has been considerable debate spanning decades around the role of an insider or outsider identity in relation to researchers and their participants (Alcoff 1992, Dwyer & Buckle 2009, Thomas 2000). Throughout the interviews, I employed various positions as both an insider and an outsider, which I reflect on below. When speaking to patients, I disclosed my lived experience as a patient and public advocate to build rapport. With healthcare professionals, I used my position as a non-clinician to pose questions that clinician colleagues may have hesitated to or had a perception of a shared understanding about.

Some scholars caution that revealing one's positionality risks emotional labour by sharing intimate details about oneself, or having the research dismissed as a self-discovery project or "me-search" (Davis and Khonach 2020). Another way of looking at this is that the researcher's lived experience is always integral to research, whether explicitly acknowledged or not. Feminist scholars have also argued that interviews may benefit if the researcher invests some aspects of their own experience into the interviewer/interviewee relationship (Oakley 1981). These shared experiences are "more than a dangerous bias" but rather the conditions under which we can learn about each other's lives (Oakley 1981). This is especially important when dealing with topics such as gendered health, because women, alongside other marginalised

communities, were historically excluded from research for being seen as too emotional, less objective, and carrying a "disqualifying and polluting bias" (Haraway 1988). Offering disclosure can potentially help build rapport, but boundaries must be maintained so the interview does not turn into a conversational exchange of experiences and views.

Further, while self-disclosure can be incredibly powerful, there are circumstances in which researchers (including myself) can feel unsafe or uncomfortable about sharing their own experiences. I have felt tensions with how much of my own story belongs, or is owed, to research accounts. I believe in the strength of patient-led research or lived experience research, but I am also aware of its risks. When and how I draw upon my own experiences with recurrent thrush or vulval pain has been a constant consideration throughout this research project. I would begin patient interviews by disclosing that I was interested in the topic due to my lived experience as this helped participants feel at ease, especially if they were unsure about where I was situated within a primary healthcare department.

Teddy explained that this disclosure helped them feel more comfortable during the interview.

> *It's good to know that you have experiences as well, because I was a bit like, 'oh, I am more comfortable now because this person knows what it's like, —this person has been there,' I don't have to convince you that it's an inconvenience because you will know that.*

During interviews, this shared understanding meant that I also paid attention to areas where participants might assume I understood their experience. Phrases such as "*You know*" were common and I asked participants to further elaborate in these situations. Sometimes participants would ask me questions about my own experience or advice in which I would gently redirect the interview back to their account. During interviews, I

often found myself surprised by people's accounts, uncovering new angles and aspects of the experience I had not previously considered. This helped confirm that I was hearing different experiences and capturing variation.

Outside of interviews, for example at conferences, or in my writing, my position about sharing my lived experience reflects the same approach I provided to my interviewees, a freedom to share as much or as little of their story as felt right.

However, the decision of whether to disclose lived experience was complicated by the fact that I hold multiple other roles outside of academia where I had little control over how participants would perceive my public profile. In 2019, I founded a social impact organisation called Medical Herstory to advance gender health equity through storytelling. This began with sharing my own story of living with recurrent thrush and chronic vulval pain and has since grown into an international organisation working to eliminate sexism, shame, and stigma from health experiences. The benefits of this position meant that I could leverage Medical Herstory's reputation and community to reach out to patient groups with whom I had a history of collaborating. This helped ensure that relationships with these groups (often working with marginalised or vulnerable populations) were ongoing and reciprocal.

Feminist research has the potential to "reconcile the dichotomy between academia and activism" (Dinçer 2019). My research study sits within my two roles as an academic and activist. However, my public position and the digital footprint involved also meant that interviewees could be aware of my work, medical experiences, or my advocacy and a few brought this up (often towards the end of interviews). There may be unintended consequences of this, as people may have altered their stories based on perceptions of myself or what they thought I wanted to hear. Yet, this visibility might

have also made people more comfortable to come forward as a few people mentioned that this was their first time talking about this issue. Nysha had been motivated to join an interview after following Medical Herstory's work on social media:

> *It's because of you. It's you, you're the reason why, because from the moment I saw it and I messaged you- you put yourself forward knowing that you've had it and you were vulnerable enough to admit... like say these things, and you know you could have done research into any other area that you know, but you chose to do something to make a difference, and so we're grateful to you for that.*

Imogen recalled the first time she heard about recurrent thrush as being when I shared my story on Medical Herstory in 2019.

> *I don't think I've met anyone who's had recurrent thrush ever. And I remember actually one of the posts on Medical Herstory, maybe it was a blog you wrote, or something, I don't know, but I commented on it and I was like, "This is the first time I have seen this talked about – ever," and it's just that visibility.*

While this visibility often helped build rapport with participants, it surfaced how difficult it can be to draw artificial lines between patient/researcher/advocate identities. I found myself sometimes falling into one category or another in certain circumstances but most often uncomfortably straddling these lines.

On the other hand, in healthcare professional interviews, I sought to primarily adopt an outsider perspective. Scholars have argued that there are benefits to having an insider-outsider research team as both offer useful insight (Kersen et al. 2000). While healthcare participants could still have been aware of my position as a patient/advocate, it had different implications and opportunities.

Within healthcare professional interviews, I often started by stating that my background was non-clinical. This disclosure allowed me to prompt further discussion and explanation as there was no assumed shared knowledge. This was especially useful to gain insight into diagnostic processes, system dynamics, or NHS policies, that somebody with a shared clinical background might be assumed to know or perceived

as naïve for asking. Further, healthcare professionals may have also been aware of my advocacy work, and one mentioned it during their interview. This meant that there may have been preconceived notions about my own views that could make some healthcare professionals hesitant to participate or provide socially desirable answers. However, other times, it could also be seen as having a stake in the research and determination to see improvements.

Other parts of my identity also came into play during interviews as a young non-British white woman. In both settings, I used my outsider position as a Canadian to allow greater insight and explanation into healthcare systems. I would often start interviews by introducing myself and then mentioning that I was from Canada and therefore might ask questions about English health experiences and structures that may seem obvious to somebody who grew up here. My age was sometimes brought up in interviews, as some participants began statements with "*I'm older than you*" or "*You're too young to be dealing with this*". Sometimes this meant that participants offered me advice they would have liked to have had at my age, which blurred some of the power dynamics that can occur in interviews.

Being a patient/advocate/researcher often meant that I held multiple insider and outsider perspectives at once, allowing me to recognise the challenges and opportunities that multiple positionalities can afford.

3.1.4 Concluding remarks

This chapter has outlined the methodological and theoretical underpinning for the data used in this study. I reflected on my considerations, decisions, and experiences in study design, data collection, and analysis. The following chapters now present empirical findings from these interviews.

We think [our bodies] are supposed to be these perfect beautiful things for people to look at, but that's not what they are, it's literally just bodily fluids and like bacteria. – Anna

4

Managing the 'mess' of recurrent vulvovaginal thrush

Contents

4.1 Introduction

This chapter examines the bodily experiences of recurrent vulvovaginal thrush through a feminist materiality lens. Previous social science research on gendered experiences of thrush and vulval pain largely overlooked, or inadvertently sanitised, the materiality of having a body. I return attention to how people experiencing recurrent thrush embody unruly and uncomfortable bodies that produce secretions, residues, sensations and spillages. Drawing upon concepts of the "leaky body" and microbiological imaginaries, I consider how participants attend to 'cleaning up' the microbial, material, and gendered 'messes' that recurrent thrush and its attempted management can cause. In doing so, I provide insight into how individuals weigh up the needs of their body, microbiome, and self.

4.2 Background

4.2.1 Gendered narratives around recurrent thrush

Previous social science research has focused on social impacts of recurrent thrush, including emotional, mental, and psychological impacts (Fukazawa 2019), but predominantly without examining physical materiality. Few have detailed how these feelings of shame and stigma interact with the embodied, material, and microbial realities of living with recurrent thrush. These linkages remain unspoken.

Existing studies examine how thrush interacts with gendered meanings, centring cis women's experiences. Chapple (2001) found that women with thrush felt a sense of "shame" and "spoiled identity" because thrush was not immediately visible, but something that they saw as being "discreditable". Adolfsson (2017) highlighted how people with recurrent thrush felt "undesirable as women".

Wider literature on vulvovaginal conditions that produce similar symptoms to thrush such as itching, burning, and discomfort, are also located within similar frameworks. Vulvodynia, persistent vulval discomfort, has been highlighted as resulting in perceptions of 'failed' or 'threatened' femininity (Kaler 2006, Marriot 2008, Ayling & Ussher 2008). Experiences of feeling 'defeminised' have been reported with regards to lichen sclerosus (Rees & Arnold 2024). Research into experiences of recurrent thrush typically aligns with these larger gendered narratives around ongoing vulvovaginal discomfort. While the emotional and psychological discomforts are presumably premised on the material, corporeal and sensorial realities, often these are backgrounded and left unspoken in the context of research on experiences of vulvovaginal conditions including thrush.

Further, this approach can present an oversimplified understanding of gender as research has not yet included the voices of gender-diverse, non-binary, or trans people with recurrent vulvovaginal thrush who may disrupt this prevalent narrative.

4.2.2 Bodily fluids, filth, and femininity

Attempts to reckon with "academic squeamishness", as Longhurst puts it, have been explored through literature which foregrounds physical bodies and materiality (Longhurst 2000). The concept of the 'leaky body' has been described by Grosz (1994) regarding how female bodies have been socially constructed as "leaking, uncontrollable, seeping liquid; as formless flow; as viscosity, entrapping, secreting". This idea of the "leaky female body" contrasts female embodiment as defiling boundaries unlike the (white, young, non-disabled, cisgender) male body that is positioned as regulated, contained, and in control (Longhurst 2000, Chrisler 2011, Jenkins et al. 2018, Shildrick 1997).

The aversion to bodily fluids is rooted in multifaceted social and cultural understandings of filth, purity, and pollution. As Lupton (1996) described, "bodily fluids threaten to engulf, to defile; they are difficult to be rid of, they seep and infiltrate". A prominent way to understand leaky bodies has been through the lens of disgust and abjection. Douglas (1966) first articulated 'dirt' as matter out-of-place which speaks to the bodily, emotional, and social dimensions of illness. Kristeva (1982) defines the abject as that which "disturbs identity, system and order. What does not respect boundaries, positions, rules. The in-between, the ambiguous, the composite".

Previous work on leaky bodies has included exploration of how people manage bodily fluids such as menstrual blood (Bobel 2010), breast milk (Amsterdam 2015), urine (Jordan 2007), faeces (Priddis 2015), and those associated with birth (Lupton 2013). One notable contribution is Overend's (2011) exploration of the leaky body and the contested illness of Candida. However, less attention has been paid to vaginal discharge as a fluid and secretion.

Vaginal discharge has been seen as particularly polluting, due to notions of femininity, cleanliness, and containment. Female bodies have previously been framed as mysterious, dirty, and naturally prone to infection (Braun & Wilkinson 2001), with the dark and wet vagina being seen as the "ideal breeding ground" for yeast (Overend 2011). Karasz (2003) showed that people with "healthy" vaginas often see their genitals as "unclean" or "disgusting" with all vaginal discharge being highly stigmatised. Therefore, vaginal secretions, fluids, and flows are particularly met with these visceral reactions, especially when associated with disease.

Stereotypes of vaginas as inherently "unclean" have material consequences. People who embody "leaking" are socially expected to monitor and regulate their bodies

(Shildrick 2015). There is a billion-dollar industry of 'feminine-hygiene' products which promote 'body work' such as deodorising and grooming vulvas and vaginas to be "attractive," "clean," and "fresh," with soaps, sprays, wipes, and douches (Crann et al. 2017, Jenkins et al. 2018). This language around 'hygiene' implies that there is dirt to clean up, whether that be blood, discharge, or smell. Further, there is a tension here between presentation, containment and comportment, which do not always align with the reality of having a leaky body.

These attitudes and some practices around promoting 'clean' vaginas can pose risks for thrush, as deodorising and douching products have been documented to disrupt the vaginal microbiome and potentially lead to infection, establishing a vicious cycle (Crann et al. 2017). Alongside 'feminine hygiene' products, the same brands often supply treatment for thrush, identifying it as another form of dirt to clean up, while also profiting from this cycle or causing other complications.

The concept of leaky bodies effectively highlights the social and cultural implications of bodily fluids and boundaries but can overlook sensorial dimensions, such as itching, burning, and irritation. These sensations can be understood as a "leak" of (in)attention, that reinforces bodily awareness and distress and often compels an action (such as scratching) (Leder 1990). Whereas fluid leakages challenge the boundary between inside and outside, a sensation like itch disrupts the very relationship between embodiment and attention, dragging attention back to the affected body parts and their "dys/appearance" (Leder 1990). With recurrent thrush, this discomfort is not only bodily but also shaped by social discourses around femininity and pathology. Leder's framework between sensations that 'disappear' and 'dys/appear' can expand the discourse of leaky bodies beyond fluid boundaries, offering a means to theorise how discomfort itself functions as a form of leakage.

4.2.3 Microbiological imaginaries

The microbiome – an intricate ecosystem of bacteria, fungi, and viruses – is increasingly gaining attention in biomedical and sociological thought. As a site of both balance and disruption, the microbiome challenges traditional notions of bodily boundaries, often blurring the lines between self and other. Within this framework, scholars have explored how individuals experience the microbiological inhabitants of their bodies as both integral to and alien from the self, often described as being experienced simultaneously or at different times as "me," "not-me," or "not-not-me" (Langdridge & Flowers, 2013, Cohen, 2017; Laursen, Meinert, & Grøn, 2022). These studies on microbiological relations focus on conditions such as irritable bowel syndrome (IBS), HIV, and Candida. A gap remains in understanding how people relate to their vaginal microbiome, and yeast, as a natural inhabitant of the vaginal microbiome, when it can overgrow and becomes pathogenic. An exploration of thrush, as yeast which grows (and overgrows) in the microbiome and how people contend with its existence or attempted eradication, is missing.

4.3 Findings

This chapter presents findings from interviews with 32 people who identified as living with recurrent thrush. This included cis women as well as gender-diverse, trans, and non-binary individuals (see Methods Chapter for demographics). Below I present the multidimensional experiences of managing recurrent vulvovaginal thrush, examining the sensorial, corporeal, and material 'mess' it creates, the vigilance required to monitor microbial imbalances, the negotiation of gendered perceptions of 'grossness', and the compromises individuals make regarding dis/comfort.

4.3.1 *Handling material and sensorial mess*

Participants spoke about how, the first few times they encountered recurrent thrush, they had believed that elimination was possible and that once symptoms were 'cleaned up' they would not return. However, as recurrence continued, this signalled to participants that they had to establish management and monitoring practices and possibly stop aiming for eradication of recurrent thrush and towards a new reality of thrush repeatedly returning.

While vaginal discharge was often a sign of a healthy self-cleaning vagina, participants discussed recognising that thrush was different. Differences were noted in quantity, texture, colour, and odour. Sasha said, "*the discharge was just not the way it usually is, it was more like cottage-cheese*". Others said the discharge was "curdy" or "creamy". Zoya described the texture of thrush as "*it's really different, it's little bits of discharge*". Imogen added it is "*thicker, whiter*". The amount of discharge was also noted, as Sai explained "*my panties used to get properly drenched*". Thrush discharge was often described as odourless, but others said it could be "yeasty" and Zoya said it has *"a really distinctive smell".*

The sensations caused by recurrent thrush were described as viscerally uncomfortable. Sasha described an "*itchy burning sensation, it's just raging, raging, raw".* Georgia said her genitals were "*very sensitive to touch, very, very itchy, and very itchy on the inside, but like really burning, feeling very painful, and really difficult to relieve".* Teddy said: "*I wanted to claw my insides out, which is a really gross image".*

Itching could sometimes cause participants to scratch, potentially bringing them into contact with blood, scabs, weeping wounds and pus. Leah explained: *"It's just constant*

really, itch, itch, itch, and it makes it bleed, then two weeks later I'll get it again". Aditi detailed the cycle of itching and scratching caused by recurrent thrush:

> *It was painful because maybe this is weird but like the little blob it would turn red and very... very soft and very painful just in general, overall having to itch all over that area was painful.*

While scratching could provide short-term relief from itch, it also often also led to further stinging, irritation, and discomfort. Beth said that "*with the constant scratching, I've got lots of abrasions down there*". Some people spoke about how they used to scratch, but over time found other ways to relieve itch – as Nysha explained:

> *I was having to go into the bathroom and get the shower head, turn it up as hot as I could just to clear [the discharge that] was inside my vagina... I'd blast it to try and get clear it and it probably sounds weird, but I found it quite soothing because all I wanted to do was itch, which you're not supposed to do.*

Participants also described visual signs of irritation. Emma said, "*It's uncomfortable because the skin is a lot more delicate, it's a lot redder*". KJ described, "*red raw, split skin".* Ella felt "*little tears, kind of stinging",* and that her vulva was "*really inflamed*". People described how recurrent infections made it difficult for the skin to heal between episodes.

Participants further spoke about "soreness" and feeling "tender". Kayla described the sensation as "*a constant toothache in your vagina area*". Anna said, "*it just felt, or feels, so dry and sore*". The slippage here between both 'felt' and 'feels' speaks to the ways in which recurrent thrush would repeatedly appear throughout people's lives.

The presence, sensation, and appearance of discharge, itch and irritation led people to 'clean up' during episodes of recurrent thrush. With recurrent thrush, the 'mess' keeps coming back after each time it is cleared away or (temporarily) relieved. Participants had various desires to both clean up material messes of thrush, but also relieve its discomfort, and these factors were sometimes at odds with each other.

Attempting to 'clean up' thrush discharge, participants changed their underwear more frequently or attempted to hide it in their washing. KJ carried extra pairs of underwear every day in her bag. Ayesha explained spending years worried about concealing her discharge:

> *I'm quite conscious of when I do my washing just making sure it's all very hidden because I know that in all my underwear you can see that discharge, it's been like that for years.*

Participants said that while they could wipe away discharge or conceal it, they knew the 'mess' always returned.

Participants found going to the toilet during a flare-up could be challenging due to increased irritation due to interactions with other bodily fluids (urine, faeces, menstrual blood, sweat) and related materials (toilet paper, menstrual products like pads and tampons). Participants described developing specific cleaning routines after using the toilet. Harry identified a "vicious cycle" of potential over washing: "*I feel like I just want to clean [the vulval area], and then the more you clean, the worse it gets*".

Trying to 'clean up' recurrent thrush could itself be messy. Treatment options such as pessaries were described as "leaking" or "falling out". Using antifungal creams and emollients could offer relief and generate material mess simultaneously. Julia said that pessaries "*make a right mess of everything*" as "*they fall out of you over like a three-day period and make an absolute mess*". Lydia similarly recalled that after putting pessaries in at night, the next day she felt "*the remnants of the pessary, the rest of it coming out*". Joy found it hard to insert pessaries "*I couldn't even put the pessary in, because sometimes it can be that red and swollen*".

The repeated presence and appearance of abnormal discharge influenced people's intimate relationships. Laura explained "*when I've got the itching and the burning and*

the discharge, we won't have sex because I don't want to pass it onto him" and that "*if I've got it vaginally, then oral sex for me is out*". Anna asked, "*can you get thrush in your mouth from oral sex?".* Kayla said, *"because of the discharge, I wouldn't want any intimate activity happening*". Beth added that she had to "*arrange my sex life around whether or not I have thrush".*

Participants also worried about the material mess of recurrent thrush leaking out into shared spaces and contaminating the senses of others. Laura avoided swimming due to fear that the discharge could spread to others:

> *I used to go swimming more often. I wouldn't generally go swimming when I've got the vaginal thrush because I'd be worried it would magically float out and then pass onto other people [laughs], which is probably unlikely.*

These examples highlight the key concept of 'dirt' in terms of matter as a problem because it is also a social transgression.

Discharge and itch were often understood as the materialisation of an unbalanced vaginal microbiome that also required managing. Yeast is a microscopic material that participants thought of as appearing on their skin and in their bodies, which was underlying the visible and material symptoms of recurrent thrush.

4.3.2 *Self-monitoring the vulvovaginal microbiome*

To manage or prevent recurrent thrush, participants described self-monitoring their bodies and microbiomes. Participants described multiple ways that they understood and imagined their vagina and its microbiome, which made it a site for recurrent 'mess' to be monitored. This monitoring occurred not at the level of what was visible or felt in the body, but instead at a microscopic level. This process often began with trying to modify a few daily habits but might then move onto detailed routines and adjustments over time.

The idea of the vagina as a "breeding ground" for yeast and bacteria was shared by participants. Ella said, "*we know that moulds, yeasts, whatever, like warm, sweaty, dark, you know all that*". Anna recalled, "*the doctor was like, 'Your pH balance in your vagina is off, it's like a breeding ground'".*

Participants had different forms and amounts of knowledge, reflecting how they had been taught or found out for themselves about their bodies. Joy described learning about the vaginal microbiome from a relative who was a nurse and told her about the vagina having its own "flora and fauna" that could become unbalanced and cause irritation. Chloe said, "*I didn't really know what it was, I just knew it was an imbalance of some sort and I had an excess of yeast*". This 'excess of yeast' could be confusing for participants, as they wondered whether this is something that should be eradicated or brought back into balance. Nysha asked whether thrush was "classed as an infection".

Participants described needing to be 'vigilant' before and between recurrent thrush episodes which often required self-monitoring not only their behaviours but the imagined materiality of their microbiomes. This involved scanning the body and microbiome to act before material, visible, or sensorial signs even materialised. Recurrent thrush could re-appear at any time and therefore participants often felt the need consistently to self-monitor to predict flare-ups. KJ said, "*I'm a lot more vigilant*, *I'm looking out for things*". Nysha said, "*I'm a bit more proactive nowadays with regards to noticing what's going on*". Ella described the 'job' of self-monitoring:

> *It is my job to be vigilant and notice its early warning signs* […] *I'm much more proactive: what can I do to kind of prevent, prevent, prevent.*

Over time, participants also developed carefully coordinated cleaning routines before and between thrush episodes to manage their microbes. People often took care to avoid irritating products like 'feminine washes', shower gels, douches, soaps, bath

bombs, and scented pads, liners, or wet wipes that could all trigger a flare-up. Aditi would "doubly cleanse" to avoid being "dirty" but had also been told that she might be washing too often, making the skin dry and irritated. A few people were recommended emollients by their healthcare professional to be used as a soap substitute, daily moisturiser, and barrier cream, but many had not heard this advice. Over time, cleaning routines were often influenced by a larger community, such as online forums offering advice.

After washing, routines also extended to drying off thoroughly, patting dry instead of rubbing with a towel, changing towels often, and using a hairdryer on the affected area. Some people changed their washing powder, ironed the gusset of their underwear, or modified their clothing. Participants noted that these behaviours were practiced not only while having a flare-up, but as a daily routine since having recurrent thrush.

Ayesha said that this self-monitoring required her to be hyper-vigilant of her body, not just while symptoms were active, but in the liminal space before a flare-up, especially following sexual intimacy:

> *I always have this kind of niggling feeling in the back of my mind […]. I feel like everything has to be set in place, and everything has to be in specific things, and I've got to have things on hand ready for a flare-up, or I'm always thinking, 'OK, do I feel a symptom; is it getting worse,' during those moments where I'm meant to be fully relaxed and not worrying about it.*

Others spoke about particular times when flare-ups intensified, often in relation to their menstrual cycles, pregnancy, or stressful life circumstances. Therefore, while there was a tendency to self-monitor continuously, it was punctuated with intense self-monitoring around these particular periods.

The pressure to self-monitor the microbiome sometimes led participants to pre-emptively take antifungal medication. Leah said "*if it's a bit yeasty, start to get that*

twinge, I'll take a tablet […] *it's like when you get headaches and stuff, if you suffer with headaches you'd take paracetamol with you, wouldn't you, so it's the same sort of thing as having that safety blanket"*. Noticing the first 'twinge' of discomfort signalling that thrush may be imminent was seen as an important responsibility. This "safety blanket" approach to having easy access to medication spoke to the unpredictability of recurrent thrush. Leah continued to say (while acknowledging that she saw this as 'naughty') that vigilance could also include taking medication pre-emptively:

> *It's really naughty, I do... very occasionally I'll take it pre-emptively, like a just-in-case, if I'm going away with my husband or I know that it's the right time and I'm just before my period, I'll just take a capsule without symptoms.*

Therefore, being vigilant required constant monitoring, being prepared and also having the right strategy or 'equipment' to manage as necessary and in any situations.

Managing the microbiome also involved trying to increase the presence of 'good' bacteria. This included participants taking probiotic supplements or making their own as Ella did: "*It's a bit extreme, but I grow my own kefir and kombucha, which are good for positive bacteria*". Zoya said that antibiotics had "*wiped out all the good stuff*" in the vaginal microbiome and she found probiotics helpful in restoring this balance.

How people chose to manage their microbes also related to how they imagined or perceived their relationships to these "others". The language used around microbiomes sometimes conceptualised recurrent thrush as an attacking invader to be anticipated, located and removed, while others saw it as constantly present and requiring care and balance.

Some participants articulated a struggle for control over their bodies. However, this struggle was not framed as one active agent fighting to eradicate a passive infection, but an active negotiation between two agents: their selves and their vaginal

microbiome. This relationship was sometimes framed as antagonistic, with a personified 'angry' vagina. Militaristic language of being 'at war' with one's vagina was used by some participants. Teddy said, "*it's like my vagina was just out to get me*".

People's views and approaches could change over time. Anna said that she used to view her body as the "enemy", but now saw thrush was her vagina's way of "talking" to her.

> *When I think about that period of time, I really think I was like at war with my vagina, and I just wanted to have a different one; whereas I think now, when I get thrush, […] I normally go, 'oh hang on, let me just figure out what's going on: am I stressed? Am I eating properly? Am I tired? Have I been drinking too much?' I view it as my vagina talking to me; whereas I used to view it as my vagina trying to ruin my life.*

Another collaborative approach was described by some participants who saw yeast and bacteria as a part of themselves that had to be lived with and even cared for. Ella described becoming "friends" with the bacteria that protect the vaginal microbiome and understanding that there is a delicate "internal ecology".

> *I've got more of an attitude now of it's either under control, or it's not, and there's a spectrum of that, but I'm not sure it's ever something that's completely neutralised, and if it was, then you might actually be really poorly because we need bacteria to function, they're a big part of our internal ecology. I think it's trying to make friends with the right bacteria.*

4.3.3 *Negotiating gendered perceptions of 'grossness'*

Recurrent thrush also carried self-perception considerations, particularly linked to societal notions of shame and femininity. The experience of recurrent thrush left participants to grapple with societal perceptions of "grossness" and femininity.

Participants describing the sensorial experience of recurrent thrush would often apologise for their descriptions or label them as "gross", or "weird". While describing her experience, Zoya said, "*oh, it sounds really disgusting, I don't want to describe it, but*

I'm going to try and give you a picture of [thrush] without grossing you out". Similarly, Nysha said "*please forgive me if I'm being too graphic*".

Nancy said that there was a social perception around recurrent thrush and grossness, even if it was not articulated aloud:

> *No one's said anything to me directly, but, I do get the feeling that in society you don't discuss it, thrush is a bit, 'eww,' and maybe people think you're dirty*.

Feelings of being 'dirty' or 'gross' were acknowledged to be linked to notions of femininity. Yet, these narratives were also well resisted.

Participants reflected on perceptions that linked recurrent thrush to a lack of femininity. Sasha said that recurrent thrush was "*really very uncomfortable and it… sometimes makes you feel you're less of a woman than other women are […] because other women don't go through this*". The perception that others did not share their experience was another factor that led some participants to feel "wrong" or "broken". Anna felt different from her friends, stating "*I was the anomaly in my circle of friends, so I did feel like there was something wrong with me, and I think I carried that for quite a long time that there was something wrong with me, […] like my body was wrong*" and that at one point she felt "*defective as a woman*".

While acknowledging these frameworks, participants also challenged them or presented alternatives. Anna, now in her 30s, explained that when she was in her 20s, she was expected to see herself a certain way, but that this evolved over time.

> *Just being a 20-year-old woman, a 20-year-old person in a cis-female body, I don't know how you do it without being full of shame because there's so much oddness that happens. Whereas now like all my friends have pushed babies out of their vaginas and ripped themselves open and had fibroids and had miscarriages and you're like, 'oh right, these are just like wild vessels'.*
>
> *But we don't know that when we're 20 and we think they're supposed to be these perfect beautiful things for people to look at, but that's not what they are. [laughs] There's nothing to be ashamed of, it's literally just bodily fluids and like bacteria."*

Anna reflected on the traditional links between bodily fluids, uncleanliness, and grossness with unfemininity. However, she was more accepting about the realities of messy bodies and fluids linked in with other biological processes and a shared experience of having a 'messy' body.

Others reflected that discourses around vulvovaginal health that centred notions of femininity were unhelpful or obscured more important issues. As Teddy said:

> *Everything centred on getting your... getting some sense of womanhood back, and I was like, 'that's not why I want this, I would like to stop being in pain.*

From another perspective, Teddy acknowledged that while other people may feel like 'less of a woman', being non-binary complicated gendered narratives.

> *A lot of people do feel like [recurrent thrush] makes them less of a woman in the way that a lot of cis-men with erectile dysfunction can feel they're less manly. It's that stereotype of like, 'ah, pristine condition woman,' but I do think that being non-binary has kind of meant that I didn't particularly get that.*

While Teddy could avoid gendered stereotypes commonly associated with recurrent thrush, being non-binary also added other layers of complexity to managing dis/comfort. KJ and Teddy reflected that having gender dysphoria could also potentially contribute to their vulvovaginal discomfort. Teddy said, "*I think you know it doesn't surprise me because it's like if you have discomfort with your genitals because of like dysphoria or something, then it might be that you are struggling with other conditions".* Drawing attention to their genitals through discomfort could include or be linked to dysphoria. Therefore, while avoiding stigma around aspired femininity, recurrent thrush could be distressing in other facets.

4.3.4 *Making compromises about dis/comfort*

Sometimes the need to manage bodily discomfort came at the expense of the ability for participants to feel comfortable in their gender presentations. This involved people balancing different options that brought discomfort whether it be physical, physiological, or psychological.

One way that people sought to increase physical comfort was through clothing choices, by avoiding tight, rubbing, or rough fabrics that could cause irritation or additional sweating.

However, this could cause discomfort when these choices influenced people's self-expression and outwards presentations. As Emily said, "*I wasn't able to wear the clothes I wanted at specific times*". Jody had to give up wearing jeans. Ella said that being non-binary, the inability to express their gender comfortably through clothing was emotionally difficult. They explained "*I can't wear the clothes that I want to wear and express my identity in that way, is a big deal, it's a big deal*".

> *I haven't figured out an alternative to dresses and no underwear, if there is one I'd love someone to tell me what it is. I'm trying to find dresses that I feel comfortable in, but I just don't, they're just not my bag. It means I have a particular look that doesn't reflect my inner landscape and that's really painful.*

Ella's description of pain here speaks to the multiple layers of discomfort that people could be managing simultaneously. While wearing dresses and no underwear could provide physical relief, it led to a "really painful" emotional experience.

In contrast, for KJ, exploring their gender fluid identity helped them find clothing options that allowed them to feel comfortable in both their body and gender.

> *I was embracing my masc side a little bit more. I would wear men's cotton pants because I found that they breathed a lot more, and I had a lot less problems with thrush at that point.*

Another area of concern raised by participants was physiological discomfort, often tied to medical treatments like hormonal therapies or contraceptive use, which could bring both relief and complications for recurrent thrush.

Some participants recalled having to make difficult choices between multiple health considerations with a balance of producing and relieving discomforts. Marie began hormone-replacement therapy to ease the symptoms of menopause but had to stop this when it was thought to be worsening the recurrent thrush. She explained: *"I think the oestrogen can feed the thrush, so I had to stop the HRT patches as well*."

For Elliott, testosterone, used to affirm their gender identity as a trans person, was a double-edged sword. Elliot worried that taking testosterone was contributing to recurrent thrush and was unsure what this meant for their gender-affirming journey.

> *As soon as I stopped taking T, I stopped having thrush, so then I was just like, 'oh, maybe I'm just not going to bother because I really can't be bothered with all of these hormonal changes. I'm on the fence, I don't really know, I'm in my own sort of journey, 'do I want to keep taking it, do I not?'*

This tension of being "on the fence" between what aspects of comfort to prioritise highlighted the compromises around discomfort that came with recurrent thrush.

Similar considerations around contraception were also described as a double-bind within recurrent thrush care**.** Emily saw a doctor about the connection of contraceptive pills and recurrent thrush and said, "*they took it very seriously, and she wanted to find out the root cause, which I think she's now said is my contraceptive pill which I'm not coming off that".* Anna described a conversation with her doctor about the link between contraception and recurrent thrush and described his attitude as *"Do you want a baby?" "No." "Keep taking the pill."*

Sarah found that the contraceptive coil exacerbated her recurrent thrush:

> *So me and my partner, we were umming and ahhing it because the coil, if you disregard the thrush, it really suited me, was problem-free […] eventually it just got to the stage where it's just like, 'We don't need to be on any contraception at all at this stage because we're not having sex'.*

Despite feeling the coil was the most suitable contraceptive option for her, Sarah concluded it was not worth the discomfort of recurrent thrush. Zoya said fears of exacerbating recurrent thrush led her to delay getting a contraceptive coil, explaining: "*I'm already getting [thrush] every other month and I don't want to get in this situation where it's even worse".*

Lastly, some participants worried about how they would be perceived in public spaces while care-seeking. The gendered marketing of thrush could cause tension with people's needs to manage their physical suffering. KJ said that they found the labelling around vulvovaginal thrush to be "feminine looking" and Teddy found the marketing "very pink".

Teddy expressed how they had to weigh the discomfort of being perceived as a woman when seeking medication against the discomfort of living with an untreated thrush flare-up, with the latter often taking priority:

> *Whenever I go to order medication for thrush, I'm mostly seen as a woman when I go out in public anyway unless I'm in my little no makeup, I'm dressed like an eboy [masculine-presenting] look, but that is a time when I'm really like I'm being perceived as a girl right now and I do not like it.*
>
> *But I just kind of have to deal with that because I need the medication, so it's like: I'll tolerate being misgendered for five minutes so that it will stop me from being in pain.*

Teddy here acknowledged competing discomforts, one around being misgendered and another from being in physical pain. Further, Ella expressed the emotional pain of not being able to speak freely about these deeply intertwined layers of discomfort, stating that this silence added "another inauthenticity".

4.4 Discussion

Through attending to the microbial, material, and gendered imaginaries and realities involved in managing the 'mess' of recurrent thrush, this chapter explored the additional considerations and challenges experienced by those with lived experience currently missing from research. This involved handling material mess, self-monitoring microbiomes, addressing gendered notions of grossness, and making compromises about dis/comfort. This research captures accounts that do not sanitise the experience of recurrent thrush and in doing so deepen our understanding of why and how it matters to patients without relying on oversimplified understandings of gendered meanings.

Previous research on recurrent thrush and larger discourses of vulval pain have presented gendered notions of 'failed' femininity and a loss of 'womanhood' (Karasz 2003, Adolfsson 2017, Marriott 2008, Rees & Arnold 2024). This research tends to overlook or inadvertently sanitise the physicality of recurrent vulval discomfort. Previous research on recurrent thrush has focused on the emotional and social impacts of recurrent thrush, omitting the material realities of this condition, and further reinforcing that aspects of this condition are too 'disgusting' or 'dirty' to discuss. Discourses about 'leaky bodies' have opened up new ways to understand bodily fluids yet have overlooked vulvovaginal discharge, smell, and itch as being imbued with meaning and material considerations (Longhurst 2000, Grosz 1994).

My findings demonstrate that prevalent narratives around recurrent vulvovaginal discomfort reported in previous studies miss out on the complexity of gendered and material experiences of embodying a "leaky body". While participants spoke about dominant narratives around "failed femininity", they did not easily subscribe to these

notions nor feel this captured the full depth of their material difficulties. Instead, participants foregrounded the difficulties of managing a materially messy body with a vagina that internally aches and oozes discharge with a vulva that externally itches, splits, and scabs.

Participants continuously explored how recurrent thrush was both a genital and gendered problem and the difficulty of managing the sometimes competing needs around affirming identity versus eliminating infection. Participants attempted to make sense of living with a condition that did not fit comfortably in their body, nor within existing gendered narratives of vulvovaginal pain. By adding gender-diverse voices to this study, I gained further insight into the multiple considerations and compromises being made around gendered health and gender affirming care. This opened up new ways to challenge, complicate and expand previously taken for granted links between gender, genitals and infection.

Mess

This chapter returns attention to how recurrent thrush materialised in bodily fluids, flows, and sensations. While physical discomfort was often the first sign of a thrush episode, as recurrence continued, unease seeped into other areas of people's lives. Recurrent thrush often appeared as a 'mess', both in terms of its material inconvenience, but also how it disrupted existing expectations around gender, cleanliness, and comportment.

Participants managed the 'mess' of recurrent vulvovaginal thrush in relation to not only the practical aspects of living with a leaking body, but the gendered, temporal, and emotional dimensions of embodying messiness. I invoke the concept of 'mess' to open up a discussion about how people worked to avoid, predict, anticipate, contain, conceal

and clean up leaky bodily fluids and sensations. The process of managing the mess of recurrent thrush therefore took place through microbial, material, and gendered imaginaries and realities.

The 'mess' speaks to the physical leaking, unexpected timelines, and uncertain identities of recurrent thrush, as well as its boundary-spanning nature which does not fit neatly into pre-defined categories or frameworks. With recurrent thrush, people had to regulate the 'mess' created by their bodies on an enduring, frequent, and repeated basis. The recurrence of thrush moves it from a minor inconvenience requiring short term-self-care, and into an all-consuming occupation with monitoring and managing the body to be kept in 'balance'.

The repetitive and cyclical nature of recurrent thrush also meant that understandings of management and self could evolve over time. This evolution often looked like adding multiple steps to choices around bathing, clothing, activities, socialisation and sex, and other times it meant shifting perspectives and perceptions of the body and its processes.

As Douglas (1966) and Kristeva (1982) posit, dirt is classified as 'matter out of place' which defies boundaries. The fluid of vaginal discharge and the physical experience of this spreading, leaking out of, or existing within the body were described by participants as illustrating their physical discomfort as discharge was produced and moved from inside to outside the body. Within 'leaky bodies' discourse, a false binary is often challenged between a closed and contained body, and an excessive and polluted one. Participants provided further insight into what happens when leaking becomes a recurrent, cyclical, and excessive process whose ever-possible presence trickles into their everyday lives. Recurrent thrush truly exists in "the in-between, the

ambiguous, the composite" space that Kristeva (1982) describes because it creeps up and reappears at different times. Within Leder's (1990) framework of dys-appearance, participants were also constantly paying attention to the parts of their bodies that were always already in discomfort.

Towards an understanding of gyn-ecology

This chapter calls attention to how patients conceptualise and manage the microbiome and recurrent thrush 'in' and 'as' themselves. Participants raised questions around how to live in a body that produces a mess, and when it recurrently enters a space of messiness. A range of metaphors from military language to notions of friendship were used by participants to describe their relationships with their microbiomes. Managing recurrent thrush involved not only cleaning up its (visible) material messes, but self-monitoring the (invisible) microscopic and microbial changes. Exploring thrush through this lens offers an opportunity to deepen our understanding of gyn-ecological relationships within microbiological imaginaries, particularly as they intersect considerations around the needs of the body and the self.

The vulva has been described as embodying the abject and it transgresses internal/external boundaries as "it is elusive, with dark corners and folds, requiring mirrors and a level of mobility to visually self-examine or self-explore" (Rees & Arnold). Rees & Arnold (2024) continue that there is shame "simply in relation to *having* a vulva, let alone a vulval *disease*". The appearance of leaking discharge highlights a disjuncture between the anticipated biological function (that the vagina is self-cleaning, and that discharge is a sign of a healthy vaginal microbiome), and the material reality of a yeast infection (discharge that is irregular, abnormal, or imbalanced). Therefore, a doubling of discomfort and disgust can occur when vulvas and vaginas are stigmatised for their fear of being 'gross', and 'normal' (non-thrush)

discharge is already stigmatised as dirty – infected vaginas then bring this anticipated or imagined stigma to one that is viscerally felt. Further, when this experience affected gender-diverse bodies, already seeped within the discomfort of dysphoria and anti-trans rhetoric of disgust, these experiences are further multiplied.

Discourses of leaking, yeast, and vulvovaginal infection have been previously linked with self-abjection and disgust (Overend 2011, Braun & Wilkinson 2001). However, participants presented the possibility of moving towards a 'leaky' sense of self. Images around "wild vessels", help us reimagine ways to resist often limiting gendered narratives. By embracing the idea of "literally just bodily fluids", people were able to reframe their experiences of leaking and yeast overgrowth as part of a wider experience that did not deserve to be shamed. Yet, despite new narratives emerging around vulvas and leaky bodies (Mowat 2020), stigma was evident in interviews when participants worried about how much of their experience was 'too much' to describe.

4.5 Implications for practice

The findings presented in this chapter have implications for clinicians and patients which I present below (co-created with patient representatives).

<u>For clinicians and patients</u>

- Acknowledge the 'mess' of recurrent thrush and the toll that its management takes on emotional, material, sensorial, and gendered realities;
- Be mindful about using stigmatising language and recognise that these symptoms are often distressing and shaped by wider gendered narratives;
- Co-develop a personalised management plan by thinking about preventive strategies, treatment, and symptom tracking;
- Promote vulval skin health: using emollients, avoiding soaps and scented products, and wearing loose clothes.;
- Discuss using antifungal treatments as a "safety blanket," and explore longer-term treatment.

4.6 Concluding remarks

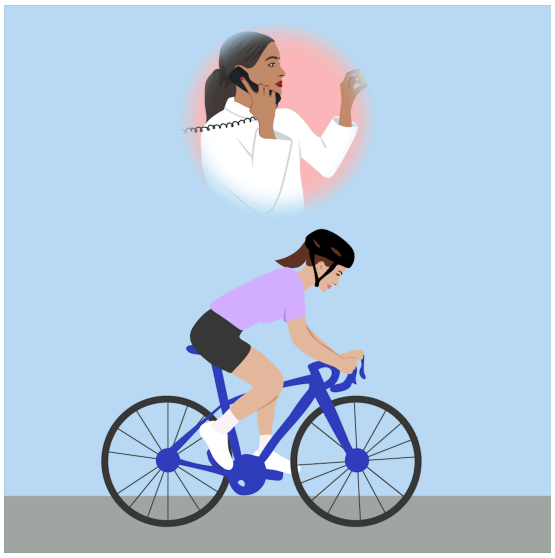
In this chapter, I demonstrated that recurrent thrush has both material realities and gendered meanings that demand repetitive, cyclical, and constant consideration. As thrush recurs, participants often enter a hypervigilant state in monitoring their behaviour, self-presentation, self-perceptions, and bodily awareness. Foregrounding the 'mess' of recurrent thrush and how people 'cleaned up' leaks, sensations, and spillages, I highlighted the issues that are often side-lined or sanitised out of research, possibly due to taboos around bodily fluids and vulvovaginal health. In doing so, I re-centre bodily materiality as a site of lived experience, challenging prevalent narratives that reduce discomfort to psychological distress around 'failed femininity'. I returned attention to the complex material, microbial, and gendered discomfort that persistently troubled people with recurrent thrush.

Next, I turn my attention to how patient bodies and the 'mess' of recurrent thrush moved through healthcare pathways and what experiences they accumulated along the way.

I say, 'I am going to help you, but you need to persist with me, and this will be the plan'. Then they'll trust you. Even if they have a blip, they'll still trust you. The plan is sound. – SH Dr Y

5

Accumulative Experiences: Mapping Care Pathways for Recurrent Vulvovaginal Thrush



Contents

5.1 Introduction

This chapter examines the care pathways people navigated while seeking and providing help for vulvovaginal recurrent thrush, and the experiences they accumulated along the way. I draw upon interviews with patients and healthcare professionals working across primary care and sexual health services (details in Chapter 3).

I begin by outlining existing models for care pathways that may be applicable to recurrent thrush. Next, current research on healthcare encounters for recurrent thrush is presented. I then place these experiences within larger gendered narratives around inequity, trust, and patient-provider relationships. In my analysis, I demonstrate how recurrent thrush differs from acute cases not due to symptom presentation, but in its repetitive, cyclical and accumulative nature that fundamentally alters how patients move through care pathways. I then place these care journeys within existing models of recurrent thrush help-seeking and present a structural (re)model of how to visualise these encounters.

5.1.1 Existing models of care pathways

Attempts to trace how and when people seek healthcare are abundant. Medical sociologist Irving Zola (1973) compiled a list of triggers to consult, including an interpersonal crisis, perceived interference with social and personal relations, perceived impact on vocational and physical activity, sanctioning by other people, and symptom endurance.

Models have since been created to illustrate care journeys and better understand or anticipate patient movements (Simonse 2018). These models have highlighted the importance of individuals' perception of illness as well as social factors in influencing

help-seeking behaviours in healthcare (Wyke et al. 2013). Within sociology, these models include the Illness Action Model (Dingwall 2001) and the Network Episode Model (Pescosolido 1991). In psychology, they include the Health Belief Model (Becker et al. 1974) and the Common-Sense Model (Leventhanl 1998).

Recognising that these various models existed, but were often limited to disciplinary silos, Wyke et al. (2013) propose an integrated symptom-response framework that highlights how the self, social interaction, cultural expectations and social structures overlap to influence symptom interpretation, evaluation and action. This model foregrounds how changes in knowledge, embodied state, and emotions are connected, changeable and simultaneous.

My systematic review demonstrates that studies on recurrent thrush often conflate care-seeking experiences for episodic and recurrent experiences of thrush (Ford et al. 2024). Existing models for recurrent thrush care pathways wrongly combine acute and recurrent experiences through linear steps moving forward where patients navigate care towards a desired outcome, or return to the start of the care-seeking journey.

Theroux (2002) presents a model based on a qualitative analysis of how women make decisions to self-treat vaginal symptoms with over-the-counter antifungal medication. It highlights how patients noticed their symptoms, engaged in sense-making and then chose a treatment path. The treatment path often involved bypassing healthcare professionals and choosing to self-treat (Theroux 2002). If symptoms remained after self-treatment, then patients are shown to return to the sense-making stage. Theroux's pathway does not expand on what movements occur if a patient chooses to see a healthcare professional.

Donders (2022) created a care pathway model based on a systematic review on vulvovaginal thrush. Similar to Theroux's model, a juncture is placed where patients choose whether to see a healthcare professional or self-treat. However, unlike Theroux, this model illustrates the steps that take place after a healthcare professional is consulted. Donders offers that patients with recurrent thrush could experience either a misdiagnosis or mistreatment, or a correct diagnosis. Following this model, a misdiagnosis sends patients back to the start. A correct diagnosis of recurrent thrush leads to treatment and the pathway ends with a course of maintenance/suppression antifungal medication being prescribed. This model does not show how patients with recurrent thrush are managed or continue to interact with care pathways.

5.1.2 Healthcare encounters for recurrent thrush

Previous studies report patient dissatisfaction with recurrent thrush management. Patients perceived general practitioners to have limited expertise on recurrent thrush, which led to a "loss of confidence," exacerbated by brief appointments and strained patient-practitioner relationships (Morgan 2009, Strydom 2022, Chapple 2000). A UK interview study illustrated that patients perceived healthcare professionals as offering limited help, as explained by one woman who had four episodes of thrush in six months: "*GPs prescribe short-term cures, not long-term cures. Self-management is better*" (Chapple 2000). Self-managing recurrent thrush has also been widely documented, with individuals sidestepping healthcare encounters (Theroux 2002, Watson 2000, Sihvo 2000). Positive interactions with healthcare professionals were reported in complementary and alternative medicine settings where participants reported feeling heard and seen holistically (Morgan 2009).

A consistent finding across previous studies is that patients thought that recurrent thrush was considered a minor condition by healthcare professionals (Strydrom 2022, Chapple 2000, Morgan 2009, Karasz 2003, Filipova 2020). In these studies, patients found healthcare professionals were not as supportive or understanding as they had expected or hoped. However, studies on recurrent thrush have rarely enquired into clinician perspectives or brought these perspectives together with those of patients. Where researchers have spoken to healthcare professionals, these have largely been pharmacists (Taylor 1994, Watson 2000, Theroux 2002).

My systematic review demonstrates that studies on recurrent thrush often conflate care-seeking experiences for episodic and recurrent experiences of thrush (Chapter 2, Ford et al. 2024). In these cases, recurrent thrush is constructed as an additive experience that is simply the sum of repeat episodes, instead of seeing it as an ongoing process worthy of its own consideration (Chapter 2, Ford et al. 2024). Research has yet to fully examine how recurrent thrush care pathways become cyclical, accumulative, or expansive as patients' behaviours and perceptions relate to past decisions, outcomes and experiences (Ford et al. 2024).

Current research often frames recurrent thrush through the lens of acute, episodic, one off-cases appropriately managed in pharmacy settings. Studies are lacking that investigate the implications of this approach and whether patients and healthcare professionals might experience recurrent thrush management as distinct. This chapter aims to address this gap and use this learning to identify ways to improve care pathways.

5.1.3 Gender Health Inequity

Experiences of care-seeking for conditions like recurrent thrush that affect women and people assigned female at birth have increasingly been framed within the context of gender health inequity (Dusenbery 2019). Studies and reports have shown that women are more likely to report feeling dismissed in health settings. The Women's Health Strategy for England (2022) reported that 4 in 5 women who took part in the consultation had felt that they were not listened to or believed by a healthcare professional. This survey did not ask participants how many times they sought care, how often they had felt dismissed, or how this might have changed with repeat visits, but nonetheless highlights a concerning issue. Many women reported their debilitating pain being labelled as 'normal' or 'natural' (Grace & MacBride-Stewart 2007). The Cumberlege report (2020) found that healthcare systems for women's health are "disjointed, siloed and unresponsive". Research also remains under-funded and under-researched, with less than 2% of total public funds being invested into reproductive and maternal health over the past decades (Gorham & Langham 2024).

Further, this also impacts gender diverse individuals who experience recurrent thrush and access similar services. Studies have found that trans men and non-binary individuals with a cervix had difficulty accessing cervical screenings due to fear of discrimination, gender dysphoria, and non-inclusive language in patient-facing materials (Berner 2021). No previous studies on recurrent thrush have included trans or non-binary voices, leaving a gap to be explored.

Recurrent thrush also does not impact people in isolation, but past experiences of gender health inequity may be relevant. Past experiences can influence how patients interact with health systems. A recent review by Eriksen et al. (2023) reported how

negative experiences with health care hampered patients from continuing to seek care. This may be relevant for a condition like recurrent thrush that often requires repeat appointments.

5.2 Findings

Below I present a thematic analysis of interviews I conducted with people living with recurrent thrush and healthcare professionals with experience manging this condition (see Chapter 3 for more information about methods). Pseudonyms are used throughout this chapter with first names used for patients and the labels GP and SH to refer to healthcare professionals working in general practice and sexual health respectively (see demographics in Chapter 3).

Patients and healthcare professionals agreed that acute, transient and one-off cases of thrush could be self-managed effectively through pharmacy care. However, when thrush returned, persisted, or evolved, it was felt that a different approach, management plan, and care pathway were needed.

When thrush was no longer an isolated occasional occurrence, but instead something that was affecting people's lives longer-term, remaining engaged with healthcare was important, but often more difficult. Patients and healthcare professionals held certain expectations around how thrush should be managed that conflicted with the needs of a recurrent condition. Both groups might initially perceive the issue as a one-off problem that requires short-term treatment, leading to a misalignment of expectations when ongoing management was deemed necessary.

As people kept returning to get help, considerations and experiences were amassed by both those seeking and providing care. The themes identified highlight current challenges within care pathways including: (1) Navigating disjointed health services,

(2) Taking recurrent thrush seriously, (3) Reaching for explanatory gender narratives, and (4) Building ongoing healthcare relationships.

5.2.1 *Navigating disjointed health services*

Participants found that recurrent thrush did not conform to anticipated care pathways based on acute one-off thrush that emphasised pharmacy care but instead required ongoing navigating of primary care services. The first point of call for patients included general practices and sexual health centres. Identifying, understanding and navigating these systems was described as challenging.

Patients were unsure about the "right level of concern" and who they should ask for help, as Rowan explained:

> *Every time that [thrush] came back, like, am I doing the right thing? Like when I went to the pharmacy, or making a GP appointment, like is this the right level of concern? Should I just be going to the pharmacy, am I making a big thing by going to the GP?*

Leah, a 34-year-old woman with recurrent thrush for 10 years, described receiving mixed-messaging from healthcare professionals about where this condition should be managed:

> *The thing is with the chemist, if they say to you, 'Oh, how many episodes of thrush have you had in past so many months?' and I'm honest – they won't give [medication] to me, they'll say, 'You've got to go to your GP,' well then, your GP will say to go to the pharmacy.*

GP Dr F hoped for *"some information that says when it is something that you should be going off to see your GP, or whoever you need to see about it"* as this would be "*giving patients permission that they don't have to just grin and bear it".*

Patients said knowing who to see, and how often, was opaque and difficult to navigate. Healthcare professionals had differing opinions about into which service's remit recurrent thrush fell and where it could most effectively be managed. A need for

clearer messaging around available services, especially sexual health services, was identified.

Many patients were unaware that sexual health services could help with vulvovaginal issues beyond sexually transmitted infections. Some participants who worked in sexual health had specialist vulval clinics or complex genitourinary medicine (GUM) departments where they felt recurrent thrush could be effectively managed. Some sexual health clinicians highlighted how they were often not commissioned to manage recurrent thrush, but instead offered services that went beyond their remit. What was offered in sexual health clinics varied by geographical location, commissioning and available resources. SH Dr D explained: "*smaller sexual health services will not have dedicated clinics to manage patients with recurrent thrush*". SH Dr O explained this challenge within their sexual health centre:

> *The biggest challenge is that patients don't know where to go and there is nowhere for them to go, properly. […] At [our sexual health clinic] we are not supposed to see these patients. We are supposed to say, go back to your GP. […] I've masses of respect for GPs, but, sexual health doctors are trained in management of this sort of condition. There isn't any joined up commissioning.*

Further, gaps in note-sharing between services were identified as potential barriers. For instance, sexual health services can offer care not linked to notes to protect confidentiality. Further, there was no note sharing from commercial pharmacies. GP Dr X described this 'blindside':

> *You aren't necessarily seeing the same GP each time, maybe not even a GP, you could easily go to the pharmacy for your first set of treatment, a nurse practitioner, maybe sexual health. We can't see sexual health notes. From general practice, we often have this blindside.*

Patients who visited different services were unclear about what a particular physician would be able to see or not in their clinical history. Teddy, a 21-year-old non-binary person with recurrent thrush and diabetes, said: "*I assumed all my records would be together. I'm starting to actually think they're not".*

To address these challenges, some healthcare professionals tried to increase communication between sectors like SH Dr Y with written plans:

> *I'm a big believer in writing a plan so that other [clinicians] know what you were thinking and what we're going to do, because I'd hate [the patient] to come back and then what I'd said was going to happen doesn't happen*.

SH Dr O said that with patient permission she would "*write to the GP and say 'this is what the swab showed, this is the medication that we started, and this is what the plan is'*". SH Dr S explained creating a 'two-way system' between sexual health and primary care:

> *What we tend to say to the patient is […] 'make an appointment with your GP and say, I have sent an email with the plan'. So then, it's kind of a two-way system.*

Patients were also able to ask for their notes to be shared with them and then bring those to their appointments. This also helped patients understand what was being noted in their file and participate in the collaborative plan.

Recurrent thrush was often framed as an issue that could be adequately managed within primary care and sexual health services, but that if symptoms persisted or evolved, referrals to secondary care were considered. Some healthcare professionals saw gynaecology as their first call for referrals, while others said that vulval dermatology would be more appropriate (especially when thinking about lichen sclerosus). However, primary care professionals reported being hesitant to put patients on long wait lists when the treatment options would not differ from that available in primary care. GP Dr F wanted advice on "*at which stage you need to refer, and who to refer to*".

Guidance regarding which cases could be managed by primary care, sexual health, or additional secondary care was mentioned by SH Dr O, who said those with chronic,

persistent, or unremitting symptoms may require different care than those with intermittent symptoms.

When thinking about joined-up care, some healthcare professionals shared what they thought an ideal system would encompass. GP Dr F added: "*I wish that vulval dermatology was sat within gynaecology and sexual health, rather than being off out in dermatology*". SH Dr S said that GPs could refer to sexual health where there would be "*a dedicated clinic or three dedicated clinics for vaginitis and there is some vulvodynia, recurrent thrush and dermatological conditions".* SH Dr O said:

> *The expertise already exists, it doesn't have to be in a women's health hub, but I feel a clear system that everybody understands would be really helpful*.

Further, confusion about where recurrent thrush 'fit' within health services was influenced by larger conversations around whether recurrent thrush was 'serious' or 'complex'.

5.2.2 *Taking recurrent thrush seriously*

It was important for patients to feel they were taken seriously, and this often involved having their experiences acknowledged as different from one-off cases. Harry, a 25-year-old woman with recurrent thrush for two years, explained how recurrent thrush was distinct:

> *The difference is how it impacts your life really. Because if I had it once or twice in my life, it would be uncomfortable, but the fact that when you get it recurrently, when you get it every month […] it's a completely different condition in my eyes. I think they should almost be treated completely separately and not related.*

When making decisions about how, when and where to engage with healthcare, patients often drew from past experiences of whether they had felt the issue was treated as 'serious'. Nancy said that she did not plan to re-engage with healthcare professionals in the future because "*people don't take me seriously*". Beth thought she should go back to see a healthcare professional but said "*my previous experiences are*

probably hindering me getting support now. It's not been taken seriously at all in the past". Ayesha said, "*because I've come back so many times with the same issue, I've been taken less seriously because I've come back time and then I'm getting even less help*".

Leah explained feeling dismissed:

> *I just feel like you get fobbed off at the doctor's because... I know it sounds ridiculous, but to them it's not really a serious illness though, is it? But to people who suffer with it, it is a bad thing to have, isn't it?*

Leah's hesitancy around using the label 'serious' in relation to thrush highlights the tension that patients felt when trying to classify recurrent thrush. SH Nurse C echoed this tension, stating "*it sounds a bit dramatic, but it can be debilitating sometimes for some people having recurrent thrush*". This idea that recurrent thrush having a substantial impact was seen as 'ridiculous' or 'dramatic' was often in the context of it being equated with a one-off episode that could be easily managed.

Recurrent thrush often entered into dialogue with the common remark that this condition is "*just* thrush". Kayla said:

> *Healthcare professionals don't really seem that interested in [recurrent thrush], they just kind of say, 'oh, it's just thrush'.*

The use of *just* both marks recurrent thrush as trivial and also lumps all types of thrush together regardless of frequency and endurance. Similarly, comments from healthcare professionals that thrush was "normal" or "common" could be intended as reassuring, but patients said they were often unhelpful as it did not recognise the distinct experience of recurrent experiences.

SH Dr Y said that since thrush was common, recurrent thrush was not always seen as 'a serious health issue':

> *It is incredibly common. Most women will have at least two bouts through their lifetime, whether they're pregnant or bit run down or had antibiotics. And I think that's very normal. I think we need to separate out those very common episodes*

> *from once it starts getting to be more recurrent, because then that's a different scenario.*

When healthcare professionals suggested that recurrent thrush was something to "live with," patients took this as meaning there was not help available. GP Dr F acknowledged that this language could "*feed into sometimes a bit of dismissal about these kinds of symptoms*". Further it led patients to worry about 'over-using services'; for example, Sarah said she worried about "wasting the doctor's time" and taking time away from "serious conditions".

Healthcare professionals were approaching recurrent thrush in the context of many different health needs which needed to be triaged. How they were able to communicate this with patients was sometimes difficult. GP Dr M said:

> *It's really difficult because on really busy days, if you've got really sick kind of elderly patients that need a home visit or if you've got really poorly kids then they would usually take priority over an adult that has, that has thrush even though it's really bad for them.*

In addition to drawing on their professional roles, healthcare professionals also invoked personal experiences to assess how recurrent thrush should be prioritised. SH Nurse C explained that the classification of an ailment as "minor" or "major" was relative to what others, including herself, had experienced before.

> *To a teenage girl, thrush might be really painful, the end of the world, they've never known anything like it, but to maybe me who's been through like childbirth, and it was a really horrendous experience, to me probably thrush is not... I don't see that as a major problem, I'd see it as a mild problem, but it's all... it's relative to the individual I suppose.*

By drawing on her own experiences, SH Nurse C highlights how healthcare professionals are not stoic, indifferent, nor disembodied. Instead, their bodies and health experiences are present within the consultation room, although usually not alluded to or apparent.

Differences between acute and recurrent thrush were also significant in terms of psychological impact. GP Dr K thought the impacts on people's body image and relationships made it "*really complex for everybody*". GP Dr Q said recurrent thrush was "*underestimated as to what discomfort and distress it causes*". SH Dr S stated:

> *It's interesting to think that something that can start off as just like a one-off acute episode of irritation could then have such wide-reaching impacts on someone's life.*

Healthcare professionals reflected on other language that they used in healthcare encounters and whether it was helpful or harmful. For instance, GP Dr K reflected on how using terms like 'minor illness' could sometimes offer reassurance but might also carry unintended consequences of seeming trivialising:

> *I mean it's not a great phrase, is it: 'minor illness'? We're saying it's minor, it's not important, which makes people think it's not important to you as a clinician, and in fact, you know, having a cough, or a UTI, can really disrupt your week and your life.*

Further, GP Dr F wondered about referring patients to the "complex" sexual health or GUM service which she found able to help patients with recurrent thrush.

> *They're then hearing the term that we have for the clinic, which is the 'complex clinic', that's probably a little bit daunting as well hearing that term. […] 'But it's not a complex... is this a complex issue?' so I imagine it can be quite confusing because I don't think they're complex as such, I think it needs some other sort of title*.

SH Dr J echoed this query "*I would say it is complex*" but that she does not "*like labelling people with something that is then perceived as complex and might give them the idea that they've got something serious".* Concerns of labelling recurrent thrush as 'complex' because patients might see this as 'serious' contrasted with patient views expressed above.

Feeling heard and seen could be an extended journey. Leah and Anna said it took 10 years and 7 years respectively to find a doctor who took them 'seriously'. This involved healthcare professionals acknowledging that recurrent thrush required a specific

treatment plans, investigation, and validation of its impacts. Anna, a 34-year-old woman whose recurrent thrush has now resolved, explained:

> *I remember most doctors not seeming that concerned or interested in what I was talking about, until I saw this amazing doctor. He was really listening and took it really seriously. I was in his office for like 25 minutes and he was like, 'This is really serious, and I'm so glad you've ended up here'.*

Sophia said she felt a GP took her "seriously" when they prescribed longer-term treatment for recurrent thrush.

> *I had a really positive experience initially with the GP who took it quite seriously and gave me six months' worth of capsules to take once a week and she took me seriously. I think there's an element of not wanting to bother your GP over thrush. But I did go to her, and she was really quite good.*

However, after a longer-term treatment did not resolve her symptoms, Sophia chose to self-manage. She said, "*I don't think I've had any negative experiences; it's just thrush, it's just a minor thing, isn't it?*". She concluded "*I don't really feel it's taken seriously. And I mean, I don't know, that's probably right because they probably see lots of very serious things*". Sophia's experience shows how larger narratives of thrush as 'small' or 'minor' influenced care-seeking decisions even with positive healthcare encounters.

5.2.3 *Reaching for explanatory gender narratives*

Participants often framed their care-seeking experiences within the context of wider narratives around gender inequity in medicine. These gendered narratives often framed recurrent thrush as something to tolerate. These accounts were rooted in participants' own experiences, but also largely drew on ongoing social conversations around gender health inequities.

Recurrent thrush was framed as a "woman's issue", which impacted how participants (including cis-women, trans, non-binary and gender fluid people) understood the

condition. Julia, a 36-year-old woman with recurrent thrush since she was a teenager, said that:

> *I think they might think [recurrent thrush] is normal because they're women and they've just got to carry on and you know that's probably kind of put into society, or we're like, 'women can go through this', which it's true, but this is quite debilitating*.

Participants who were non-binary or trans spoke about expectations to deal with pain while inhabiting a body that was assigned female at birth. Ella, a 50-year-old non-binary person who was diagnosed with recurrent thrush and then lichen sclerosus, said: "*so much of the female experience is just 'get on with it*'". Teddy who is non-binary and KJ who is gender fluid, said people with vaginas were told to expect discomfort, "*tough it out*", or "*soldier on*". This acceptance was not a positive or desirable outcome, but the result of participants perceiving that they must deal with recurrent thrush alone.

Healthcare professionals also acknowledged these larger discourses, and criticised how recurrent thrush was minimised because it was a condition that primarily affected women and people with vaginas. GP Dr F who also worked in gynaecology explained that recurrent thrush was wrongly minimised because of the perception that "*oh, it's a women's issue,' so it's a minor thing*". GP Dr K echoed this sentiment that recurrent thrush was not "high up the agenda":

> *Well, I mean, it's women's health, isn't it? I know it's never been high up the agenda – probably. Not always women, but often women. So I suspect that hasn't helped over the years.*

GP Dr H explained that perceptions of not being listened to were common across women's health:

> *I certainly hear it from patients: "Well, I just felt like my GP wasn't listening, I had to go multiple times, and I felt like I wasn't being heard, nobody took my symptoms seriously," and, you know, we see that across all aspects of women's health really. If I go through a day without hearing that, I'd be very surprised.*

The idea that recurrent thrush was "sidelined" as a women's issue was present in multiple accounts. Through this lens, recurrent thrush was framed as not receiving much attention, research, or funding. Nancy explained that she had hoped healthcare professionals would have "done more research" regarding recurrent thrush.

> *I hoped they'd done more research and understood the problem better, but again from my experience, I knew that that was unlikely because it's just a sort of... one of those chronic things that affects women and doesn't really get looked into.*

Nancy links her own past experiences with help-seeking to a larger gendered narrative that recurrent thrush belonged to a group of issues that was not deemed worthy of investigation nor investment. Laura expressed her view that if men suffered from recurrent thrush, there would be more research and funding.

> *I think if men suffered from recurrent thrush, I think it would probably be different, and that there would be more money into you know trying to develop treatments and preventative measures and things like that, but because it's a women's issue I think it's sidelined.*

Healthcare professionals agreed that research and insight into recurrent thrush was lacking. SH Dr V explained that recurrent thrush was undervalued due to the lack of a "spotlight" on women's health.

> *Is it just that women's health generally, is still catching up, you know, in terms of, you see, the studies done about, you know, and treatments for things like that are predominant. Again, I'm going to use the word female in a kind of cisgendered way, but, you know, compared to other conditions, women's health probably hasn't had the spotlight on it and valued as much over the years.*

SH Dr Y echoed this sentiment that recurrent thrush was not focused on in research which tended to favour "more exciting conditions". She expanded that recurrent thrush had *"not been attractive to people trying to get ahead with their research. You're not going to save any lives. It just seems as dull, I suppose. I mean, I don't think it's dull, but I imagine a lot of people would".*

Looking forward, participants were asked if they thought the situation would improve. Harry replied, "*I don't hold that much hope to be honest, because women's health is so*

underfunded as well in general, so I don't hold out too much hope on it". Laura said: "*I don't think anybody is going to make any real effort to try and get rid of it, or to do research into ways that you could stop it or minimise it, reduce flare-ups, that kind of thing".* Billie acknowledged some positive steps taken towards systemic change towards gender equity but remained sceptical.

> *I know that the Government's just appointed someone that's essentially going to manage women's health for England, which is something that it's a bit [like] closing the door after the horse has bolted, you know we're got an enormous issue with women's health.*

The idea that the "horse has bolted" spoke to a pessimism that was present across the gendered narratives that participants presented. While these narratives often captured what patients experienced, the perception that seeking care for recurrent thrush would be dismissed based on gender bias could lead some people to avoid help-seeking. To address this gender health gap, participants pondered how best to build trust, ongoing relationships, and self-advocacy.

5.2.4 *Building ongoing healthcare relationships*

Getting help for recurrent thrush necessitated repeated care, which meant that ongoing and enduring relationships with healthcare professionals were important resources. Trust was a critical factor in patients feeling able to return to see healthcare professionals. As people returned to healthcare professionals over time, questions arose around how best to contribute to care, collaboration and self-advocacy.

Patients described frustration when clinicians offered advice about acute thrush and did not provide any follow up, longer-term treatment, or a management plan. Further, patients found it difficult to see a different clinician each time and re-explain their experience when there was no care plan.

In contrast, an ongoing relationship with a healthcare professional enabled follow-up care and monitoring progress and changes over time. Georgia appreciated seeing the same doctor who she felt "comfortable" with and "*didn't have to overcome the barrier of telling somebody new about my thrush problem again*". Emily said, "*I was very lucky that I've got a good GP who knows me*" who she felt able to "*discuss anything with*". Nysha found her advanced nurse practitioner (ANP) was "*very empathetic and understanding*". Rowan, a 24-year-old woman who lived with recurrent thrush for 2 years, explained:

> *I'm lucky that I have a very good relationship with my GP. Now this has happened in the past, I am kind of confident that I'd be listened to and it wouldn't be minimised.*

Some people experienced negative encounters with healthcare professionals and found it difficult to seek out care again. Imogen found it difficult to access healthcare appointments and recalled the disappointment of losing a strong GP relationship that she had built: "*I remember trying to book an appointment with her again when I had it the next time and they were like, 'Oh, no, she's at another practice', and it was just like, 'No! I've lost the one person who's actually listened to me on this*".

Patients and healthcare professionals agreed that trusting relationships were built or shaken through small acts. Trust was damaged when follow up phone calls were not made, samples were lost, and tests were not explained or administered sensitively. SH Dr Y explained:

> *A small example would be, you know, I would say to them 'Okay, I've sent your swab away. I will ring you when the result comes, and then we'll decide on the plan'. You need to ring that person at the time that you said. It's no good not writing it down and not doing it, because then they will lose hope, or they'll think you weren't interested.*

Managing expectations was also seen as a central pillar to building ongoing relationships. During early consultations, participants emphasised that they thought there would be a 'quick fix', or 'cure' for recurrent thrush. However, over time, they

realised it would require ongoing management. SH Dr V told patients that "*this is a long process, a kind of a journey, it isn't just a one-off thing*".

Continuity of care was often described as important to building patient trust. However, this was not always possible. Physician Associate I described the typical process for seeing recurrent thrush where follow-up was patient-initiated:

> *I don't think I've ever seen a thrush patient and said, "I think we need to see you again in a few weeks to see how you're getting on – let me book you in." I've probably just said, "If things aren't improving, or your symptoms change, please come back" and left the ball in their court.*

However, other healthcare professionals noted that saying "please come back" was often not enough when patients were unsure whether recurrent thrush warranted further attention or may get lost in a disjointed system. SH Dr E explained their approach to continuity of care:

> *In GUM [genito-urinary medicine] land, which is sexual health services, if they see me one week, I can easily put them into my clinic list two weeks later, and three weeks later, a month later.*
>
> *If they're in a chronic GUM list, there's usually only one or two doctors who work in that service, and so there is a great level of continuity of care, and I think that really helps seeing the same face a lot of the time, because I think you build a stronger patient doctor relationship.*

By presenting a plan for recurrent thrush, patients felt listened to and healthcare professionals were able to gain trust towards managing this condition. SH Dr Y explained her approach to encouraging patients to return:

> *I say, 'I am going to help you, but you need to persist with me… I say you must come back to me at this time and we will review it again, and this will be the plan. Then they'll trust you. Even if they have a blip, they'll still trust you. The plan is sound.*

SH Dr V told patients: "*this is a long process, a journey*". SH Dr L said they tried to establish trust with patients by saying: "*you are not on your own*" and approach longer-term treatment with the lens of: "*we're doing this together, teamwork thing*".

Continuity of care, collaborative management plans and follow-up strategies were identified as essential for improving outcomes.

Self-advocacy

For some people, learning more about health services, whether accumulated over time through repeat engagement or through advocacy organisations and support networks, helped them gain confidence in seeking care. Emily felt that over time she learned how to ask questions. Kayla found herself becoming more open to asking for additional appointments or advice. Nysha said that online communities helped her learn more about her body, anatomy, and "*not being ashamed to say words, like vagina, vulva*". However, others found that continuing to return to consultations was disheartening and some gave up with seeking further care.

Self-advocacy was described by some patients as necessary in systems that were resource limited. Marie, a 60-year-old woman with recurrent thrush for five years, said: "*The NHS is breaking at the seams so I think [you've] got to be your own self-advocate*". Regarding GPs, Emma, a 41-year-old woman who lived with recurrent thrush since she was a teenager, said she *"did not have a lack of confidence in their ability, it's a lack of confidence in the system*".

Questions arose around how best to self-advocate and navigate relationships with healthcare professionals. Jody encouraged others to "*not be afraid to stand your ground with healthcare professionals to get your point across and to really explain how things are affecting you*." Harry said, "*I'm more pushy*". Billie encouraged self-advocacy to open up conversations around collaborative care:

> *It's really hard to sit in front of a doctor and go, 'I don't agree with you,' but it might be the one thing that makes them question it and go, 'oh right, OK, if you don't agree, you don't think this is right, how can we work together to sort it out?'*

GP Dr M explained some hesitation around self-advocacy that framed as combative instead of collaborative:

> *Some of it I feel is quite negative like you need to be really bolshy and go in and say, you want this and demand this and I, I don't think that's healthy and I don't think that's a healthy thing to be on kind of Instagram and things. But, I think, generally [self-advocacy is] not like that. It's just helping women.*

However, within an overstretched health system, healthcare professionals recognised that patients often had to take on an active role in coordinating and navigating their care journeys. GP Dr A expanded:

> *There's a bit of fragmentation […] The person now that most notices the pattern, is the person experiencing the symptoms. If anyone in the system knows what's going on, it'll be the person. […] They're the one unifying feature*.

However, GP Dr A also recognised some challenges with over-relying on this role and self-advocacy more broadly when not all patients were comfortable or able to "argue" for their care such as those "*who can't speak English, who haven't been given resources or information in a way that's accessible to them".* GP Dr F expanded on this issue.

> *I always worry about the patients that struggle to advocate for themselves with this kind of stuff, and there's loads of barriers and taboos around women's health. Some they're very determined they will keep going back to the doctor, you know, those patients I'm not worried about because they will get there in the end, but the patients who have language barriers, or who have access issues, those ones are always concerned about.*

Building these ongoing healthcare relationships was not always straightforward or linear and were complicated by disjointed healthcare systems.

5.3 Discussion

This chapter examined the care journeys people tried to navigate while seeking and providing help for vulvovaginal recurrent thrush, and the experiences they accumulated along the way. By combining interviews from both people receiving and providing care, I highlight overlapping and diverging perspectives. In this discussion, I

compare my results with existing literature and care pathway models and present an alternative framework to visualise these encounters.

My findings align with previous studies reporting dissatisfaction with recurrent thrush management (Strydrom 2022, Chapple 2000), but place this within the context of a disjointed system constraining both patients and healthcare professionals. While this study also found recurrent thrush labelled as a 'minor' condition (Strydrom 2022, Chapple 2000, Morgan 2009, Karasz 2003, Filipova 2020), it also captured the thoughts of healthcare professionals weighing up the challenges of treating a condition that was straddling the line between commonality and complexity. Patients and healthcare professionals were attempting to navigate constrained and fractured care structures that both parties can either tolerate or work together to improve.

Further, my findings align with current policy reports and research on gender health inequity and women and gender diverse patients feeling dismissed in healthcare (Grace 2007, Gorham & Langham 2024, Department of Health & Social Care Great Britain 2020 and 2022, Government Equalities Office 2018). However, while narratives position care providers as disinterested (or antagonistic) regarding conditions like recurrent thrush, we found healthcare professionals (mainly women themselves) were acknowledging, and often challenging, the same narratives as patients.

Remodelling recurrent thrush experiences

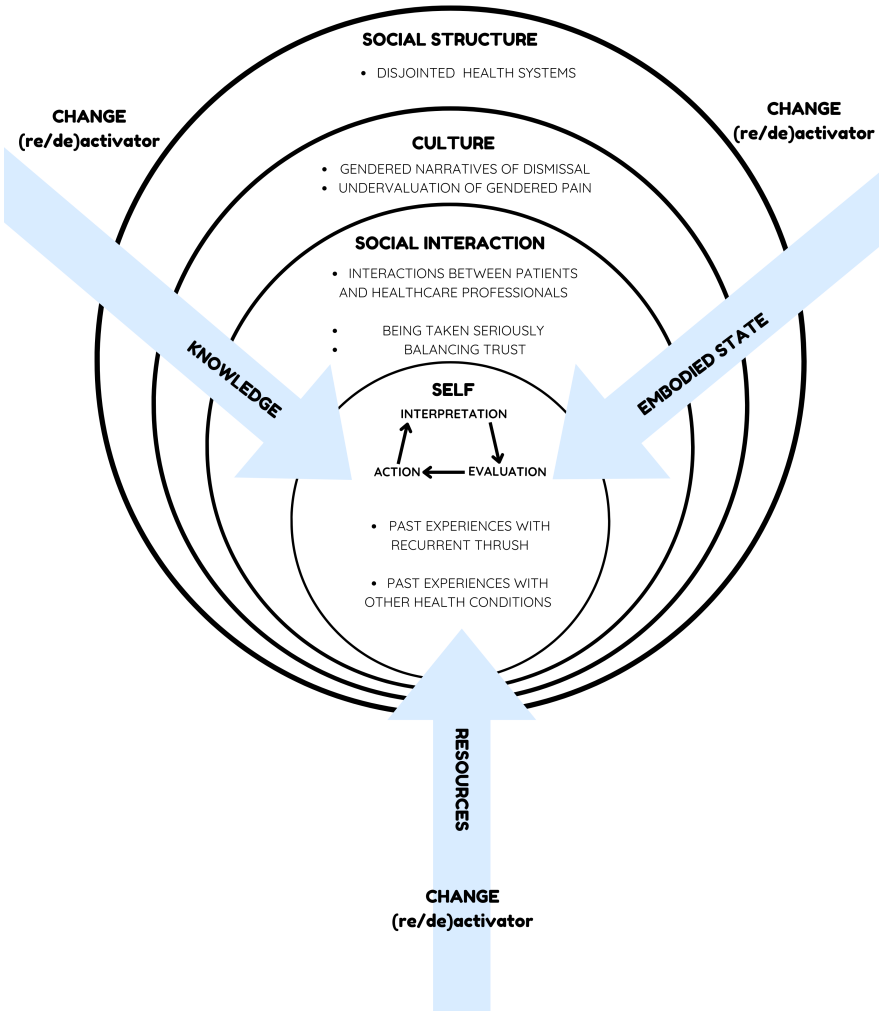
Recurrent thrush experiences were comprised of convoluted care pathways, concerns around being taken seriously, cultural narratives of gendered dismissal and building ongoing trust within healthcare relationships. The underestimated impact of recurrent thrush could make patients doubt themselves and wonder whether it was a condition that was appropriate for help-seeking or one they would need to manage alone.

Creating models for recurrent thrush has certain limitations inherent in trying to compress complex experiences into simplified diagrams. However, these models can help make sense of convoluted interactions by unpicking different influencing factors in seeking care.

The integrated symptom-response framework can be used to map recurrent thrush care pathways into an enmeshed schema where a complex interplay occurs between the self, social interaction, cultural narratives and social structures (Wyke et al. 2013) This model demonstrates how no element exists detached from the others but instead, every layer is subsumed by the next.

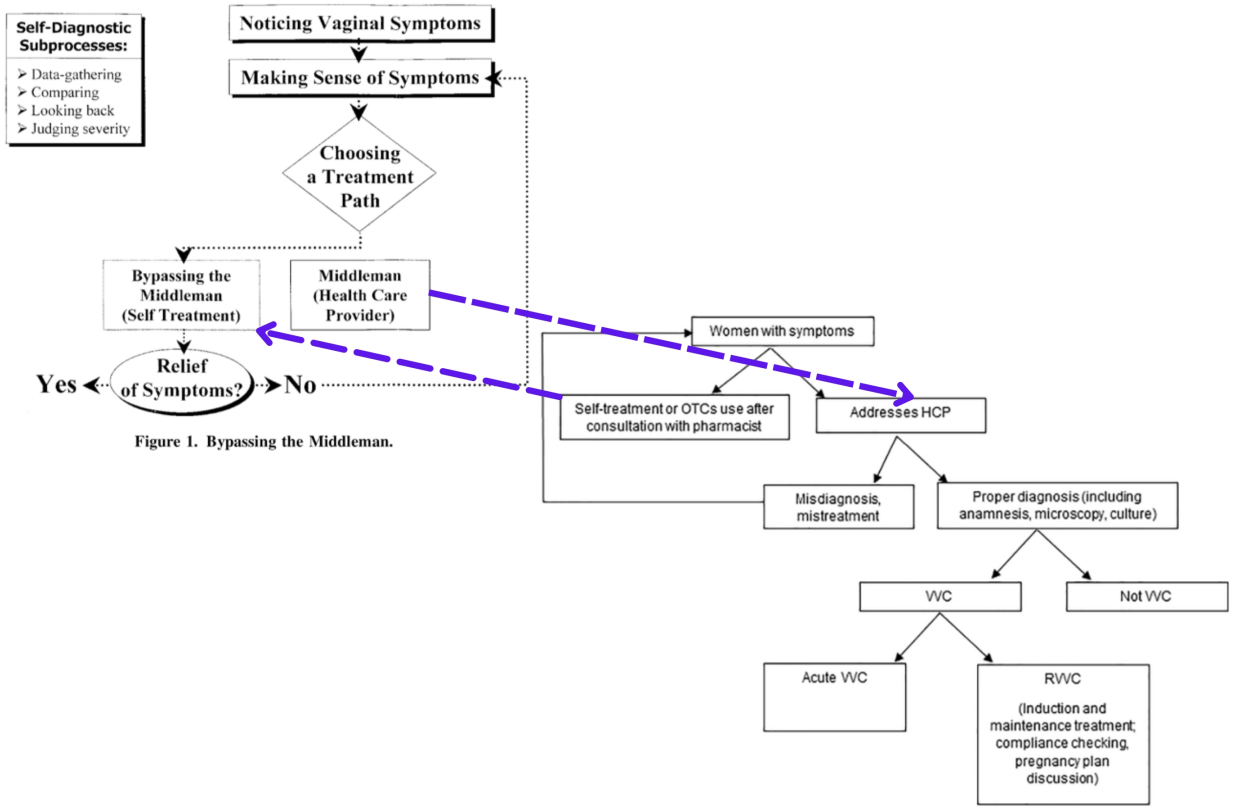
This model helps understand the multiple influences on help seeking before, during, and after consultations. Previous studies have found the integrated symptom-response framework useful for emphasising the changeable and cyclical nature of symptom appraisal (Cunningham 2019). While previous applications have focused on care-seeking, my study demonstrates how this model is also relevant for understanding care-providing. Healthcare professionals did not operate in a separate schema detached from patients but were instead embedded within the same social structures and narratives that influenced clinical interactions. While the integrated symptom-response framework offers insight into the intertwined factors that people consider when making healthcare decisions and has features of recursivity, it does not map the movements, order, and direction of care-seeking. To explore these dimensions, I turn my attention to examples of patient care mapping (Bate 2006, Simonse 2018, George 2023).

Figure 15: Main themes applied to the integrated symptom-response framework, adapted from Wyke et al. 2013



Models for recurrent thrush help-seeking are inadequate and oversimplified. Despite being published 20 years apart (Theroux in 2002, and Donders in 2022), the models could be superimposed to reveal aligning care pathways with corresponding elements. The models complement and expand each other as Theroux focuses on movements around self-treatment, while Donders expands on encounters with healthcare professionals. The participant journeys captured in my study could be mapped onto these structures, however, it would be a limited portrayal of the care pathway and missing vital considerations.

Figure 16: Combining existing recurrent thrush models, adapted from Theroux 2002 & Donders 2022



Existing models for recurrent thrush present a misleadingly simple journey, with series of discrete steps with a linear path, sequential order, and single direction (Theroux 2002, Donders 2022). The models appear stagnant, straightforward and unchanged as people move through them. The lines do not overlap or intersect to acknowledge how patients are navigating multiple care systems and considerations simultaneously. These models frame recurrent experiences as identical to acute ones, as in Theroux's (2002) model, or only relevant as an endpoint, as in Donders' (2022) model. This approach fails to capture how recurrent thrush experiences are markedly different for the entire care-seeking pathway which is marked by repetition, reversal and retraction.

Further, evidence from my study demonstrates that recurrent thrush care pathways are far from linear, straightforward, or one-dimensional. Care pathways were described as "fractured" and "fragmented" with patients "slipping through cracks".

They were overlayed with structural, interpersonal and social "hurdles" that people had to approach, avoid, or confront.

Routes designed for acute care such as pharmacy management may close down pathway options, while directing patients to specialist care may open up options. Therefore, the pathways are not linear or unidirectional but instead involve multiple pathways that open up or close down options for patients and healthcare professionals.

Existing care pathway models often present the option for patients to return to the start and re-enter the path in a circular fashion (Donders 2022, Theroux 2001). My findings demonstrate that care-seeking is not a loop but instead leads to new paths filled with different outcomes, experiences and expectations. Patients and healthcare professionals are not moving through these systems unchanged, but instead amassing experiences during and between care-seeking. After a care-seeking avenue is explored, the outcome, experience and expectations do not lead that person back to the start of decision making, but into a new path.

Recurrent thrush was incongruent with typical care pathways. While one-off thrush was agreed to be a minor event easily self-managed, recurrence required further consideration and care. A mismatch in expectations between acute and recurrent cases impacted not just patients' current encounters, but their future ones.

Accumulative experiences

Health services and researchers often approach recurrent thrush within the framework of acute thrush, with episodes seen as relatively easily resolved or resolvable and appropriately self-managed via pharmacies. Recurrent vulvovaginal

thrush requires distinct care pathways emphasising continuity, trust and systemic improvements to address gaps in care provision.

Recurrent thrush differs from acute cases not due to symptom presentation, but in its repetitive nature – with implications for services, care pathways and healthcare relationships. Recurrent thrush keeps coming back, making people repeatedly encounter the same questions, challenges and queries. As experiences – of recurrent thrush and of help-seeking – *accumulated* over time, during and between healthcare encounters, there were implications around the limits of care pathways primarily structured around one-off episodes.

By invoking the concept of 'accumulation', I speak to the process in which summative experiences are amassed over time, into a complex amalgamation of everything that has come before, whether lived, anticipated, or absorbed from others. Lived experience, professional interactions, and social discourses, during and between clinical encounters all contributed to this accumulation. It goes beyond adding together multiple one-off experiences and instead speaks to the experience of recurrence as exceeding or changing in nature the sum of its parts. These accumulations also engaged with larger social factors such as scant research and clinical attention, funding and resources invested into recurrent thrush and gendered health conditions. Care pathways became cyclical, accumulative and expansive as people's choices relate to past decisions, outcomes and experiences.

5.4 Proposing a Snakes and Ladders approach

To capture these accumulated experiences, I propose adopting a "Snakes and Ladders" approach to understanding care-seeking and care-providing for recurrent thrush. In the game "Snakes and Ladders", players roll dice and seek to reach the 'final' square of the board. However, the board is covered by 'snakes' and 'ladders' which can help or hinder the players' progress. Ladders help players find shortcuts, while snakes cause setbacks. To complete the game, you must roll the exact number needed to land on the final square, or else you are 'bounced' back and must await the next turn.

Here, people try to seek out care and hope to land on a 'ladder' (ie: successfully navigating a health system, taking thrush 'seriously', acknowledging gender bias, building trusting relationships). However, the board is also full of 'snakes' (ie: structural barriers, perceptions that it is "*just thrush*", gendered narratives of dismissal, and losing trust) that lead the person astray. When a player makes a move up a ladder or down a snake, they do not end up where they started, nor back at the beginning, but into new territory, having to assess their culminating and evolving experiences. To make care decisions, they then draw upon their accumulated experiences and understanding of the ever-changing landscape.

Both people help-seeking and help-providing play this game, but they are not competing. Instead, when their journeys come together and interact, they enter dynamic spaces where they meet and negotiate a gameplan. Other times, they speak to each other from different areas on the board, creating a mismatch in expectations, understandings, and assumptions. Healthcare professionals and patients might not even agree where they are on the board, what constitutes a snake, what constitutes a

ladder, or which snakes and ladders the patients and their previous healthcare professionals may have been down.

The process of accumulation is not visible, obvious, or predictable, but instead forms a complex ground through which new experiences emerge and are understood. When looking at the 'Snakes and Ladders' model, it is unknown how long the players have been playing, what moves they have made, or how many rounds have taken place. Similarly, when a patient presents with thrush, the healthcare professional will only find out about past experiences if the patient offers, or if they ask and the patient feels comfortable answering. Managing recurrent thrush rarely presented a single linear 'ladder' that would be a direct path to resolution, but instead patients have had to try different approaches and management options.

With every dice roll, players do not restart the game but add onto their previous score. These rolls add up over time, but do not always lead to linear progress. Similarly, in recurrent thrush care pathways, some people made progress, while others ended up in cycles, loops, or infinite spirals. Others stop playing the game entirely.

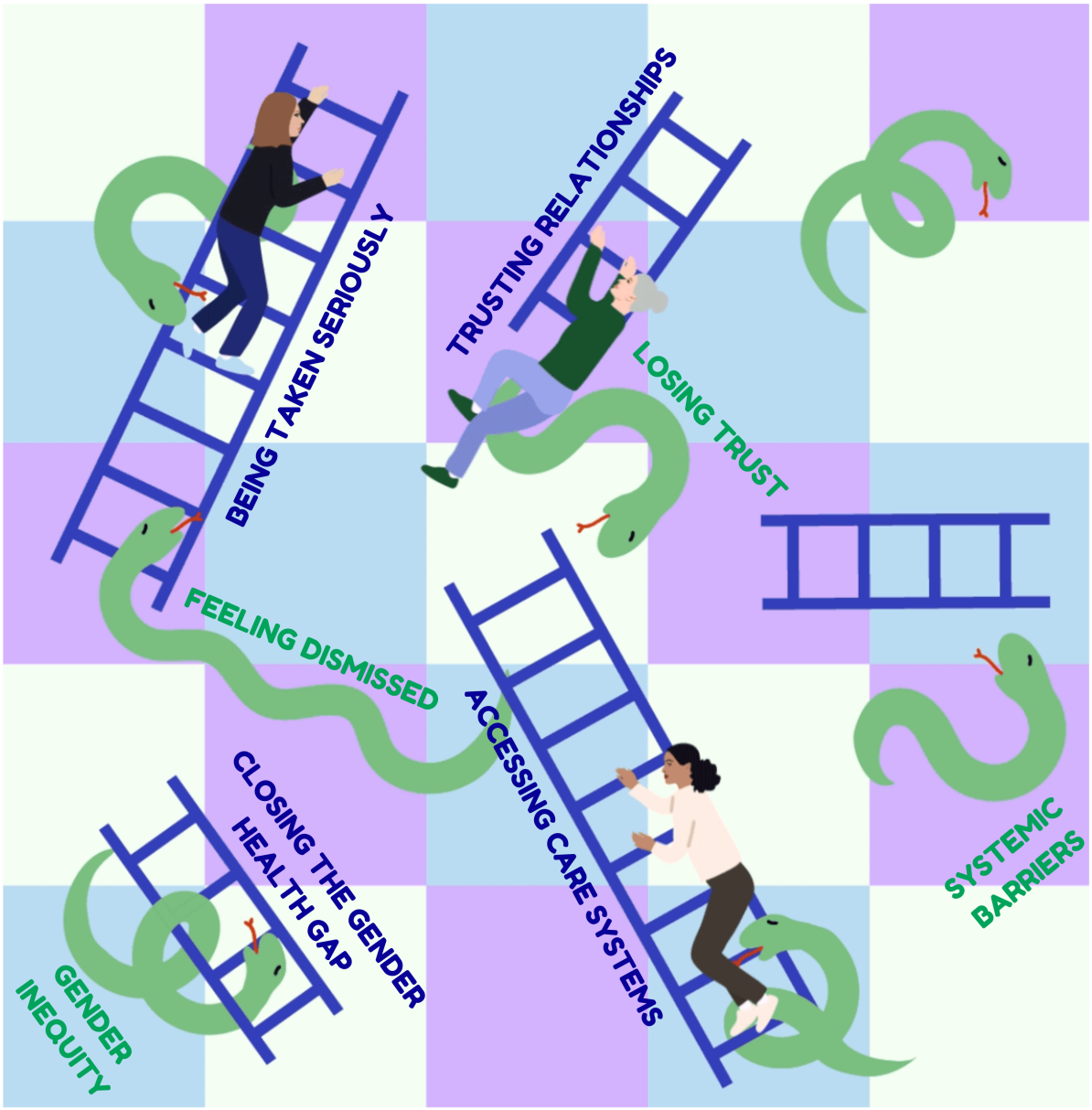
Navigating care systems is not entirely a game of chance. Certain individuals face more opportunities to encounter 'snakes' as they move through these systems (such as not speaking the same language as their healthcare professional, or being unable to access the same health literacy framework). The ladders are not always the same length or available with equal frequency nor ease.

People with recurrent thrush might have different 'end points' in mind at the end of their 'turn' and these might not be the same point the healthcare professionals envision. Further, some patients may not have a specific 'finish' point in sight that they are aiming for, but instead one that varies and changes with experience and time. The

'final' square therefore is not necessarily about a cure but could involve recognising that recurrent thrush is different, building ongoing trust, designing long-term management plans, and receiving/providing continuous care.

The snakes and ladders represented here are not comprehensive, but a starting point to think differently about gendered health issues, especially when they become recurrent, persistent, and enduring.

Figure 17: The Snakes and Ladders Model of Help-Seeking and Help-Providing



5.5 Implications for practice

Recurrent thrush requires distinct attention and care pathways that differ from acute, transient and one-off episodes. Patients found that they required multiple appointments and follow-up care to receive an effective management plan. Primary care professionals are well-positioned to help patients with recurrent thrush, but structural, systemic and social barriers are making this more difficult.

Patients often faced disjointed health systems that could undermine their confidence and lead to disengagement from healthcare. Establishing ongoing relationships, follow-up appointments and a management plan were shown to increase trust and improve patient outcomes. Clear communication around recurrent thrush being acknowledged as a distinct experience was seen as important. Limited healthcare resources, a lack of continuity in care, and gender health inequity were identified as barriers to care.

Current healthcare systems are overburdened and there are limited general practices and sexual health centres, each facing their own local conditions and challenges. Therefore, any recommendations must be considered in this context.

Recommendations are offered below, based on participant experiences:

<u>For clinicians:</u>

- Recognise recurrent thrush as a distinct experience with different impacts and considerations (avoid labelling it as '*just* thrush');
- Do not trivialise recurrent thrush (which may include labelling it as 'normal' or 'common');
- Write down management plans involving follow-up and next steps for patients;
- Prioritise continuity of care with the same clinician;
- Enhance communication between sexual health services and general practices through patient-approved note sharing and signposting;

For patients:

- Recognise that recurrent thrush requires remaining engaged with care pathways and reflect on what steps need to be taken to make this possible for you;
- Come to healthcare appointments with questions and don't be afraid to take notes during appointments;
- Ask for management plans and next steps. Think about what else you could integrate into your plan to feel better as a whole;
- Request to see the same doctor, or ask if the next appointment could be scheduled during an existing appointment;
- Explore what options are available in your area. Is there a complex sexual health/GUM clinic available? Are longer appointments available?;
- Remember that sexual health services can often treat more than STIs;
- Inform healthcare professionals if you find it difficult to be examined, are nervous, or if there are any worries on your mind.

5.6 Concluding remarks

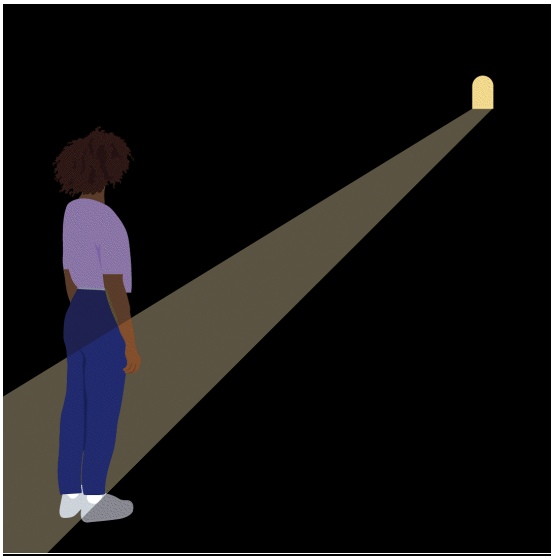
This chapter traced the care pathways of help-seeking and help-providing for recurrent thrush. Recurrent vulvovaginal thrush has significant impacts on patient lives and the literature reports dissatisfaction with existing care pathways. I explored the moments and movements that intersected, converged, or fluctuated between patients and healthcare professionals. In doing so, I revealed how both groups invoked past experiences, anticipated futures, and social narratives to conceptualise, interpret, and assess their care journeys. By placing my findings in conversation with existing models, I demonstrated how people's experiences, expectations and perceptions of giving and receiving care *accumulated* over time. This accumulation fundamentally altered how people made decisions, and speaks to broader gendered health experiences.

Next, I turn my attention to diagnosis as a key moment in this care pathway where patients and healthcare professionals found themselves struggling to speak to each other from across the game board.

Sometimes the formality of a phrase,
rather than 'thrush that keeps coming back',
feels like a positive medical label they can use:
'it's not just thrush, it's recurrent thrush'. – GP Dr X

6

Exploring Candida-cy: Diagnosing Possible Recurrent Vulvovaginal Thrush



Contents

6.1 Introduction

Diagnosing recurrent thrush is a multifaceted process. This chapter aims to understand how patients and healthcare professionals experience and understand the diagnostic process for recurrent thrush in UK primary care, and how might these insights might improve clinical encounters. I begin with a discussion of current challenges and clinical guidelines on diagnosing recurrent thrush. I then present an analysis of the journeys that patients and healthcare professionals went through to recognise and label recurrent thrush. These findings are considered alongside the model of candidacy and considered in the context of national guidelines.

6.2 Background

6.2.1 Current diagnostic challenges

Recurrent thrush is defined in UK national guidelines as four or more thrush episodes in a 12-month period *with two episodes confirmed by microscopy and/or culture*. The route to diagnosis occurs in primary care or sexual health services with symptom assessment and investigations. Unlike acute thrush, which can be diagnosed and treated within one session, recurrent thrush diagnosis necessitates identifying a pattern and patients remaining engaged with healthcare services.

Vulvovaginal discomfort can have diverse causes and conditions with neither a straightforward nor definitive diagnosis (Nunns & Murphy 2012, Neal 2022). A focus group study with Dutch GPs found that healthcare professionals seeing patients with recurrent vulvovaginal symptoms reported frustration, discomfort and helplessness when diagnosis was unclear or treatment unsuccessful (Leusink et al 2018).

Patient dissatisfaction and perceived delays for recurrent thrush diagnosis have been widely reported amongst patients. In an Australian interview study, patients reported frustration about waiting 9 to 24 months for a diagnosis and needing repeat appointments, repetitive investigations, and encountering clinicians who they saw as having "a perceived lack of awareness of the diagnostic criterion" (Strydom et al. 2022). Other studies have found that patients self-diagnose and self-treat what they perceive as recurrent thrush (Theroux 2002, Theroux 2005, Sihvo 2000, Erfaninejad 2022). Information about diagnostic processes and perceived delays are missing, presenting a gap this study seeks to address.

Further, research highlights a potential mismatch in primary care between patients' perceptions of care and GPs' considerations, particularly when symptoms are undifferentiated, and this is not due to simply lacking awareness (Dixon et al. 2021).

Vulvovaginal itching is often associated with thrush by patients and healthcare professionals (Farage et al. 2010). Where over-the-counter treatments are available, people often self-treat genital discomfort as thrush (Ascott et al. 2017, Schwiertz 2006, Ferris et al. 2002, Hoffstetter et al. 2012). However, numerous studies report that conditions like lichen sclerosus are repeatedly misdiagnosed as recurrent thrush, leading to delays in treatment, worsening symptoms, and other potential complications (Farage et al. 2010, Wehbe-Alamah et al. 2012, Leusink et al 2018). There have been calls to develop better services for prompt and accurate diagnosis of recurrent and persistent vulvovaginal discomfort (Ascott et al. 2017).

6.2.2 Clinical guidelines on recurrent thrush

National guidelines in the UK exist to guide healthcare professionals in supporting patients with vulvovaginal thrush. The National Institute for Health and Care

Excellence (NICE) and The British Association for Sexual Health (BASHH) publish guidelines. Both focus on acute vulvovaginal candidiasis with a subsection on recurrence.

The NICE guidelines state that they are largely based on the BASHH guidelines. Below, I compare the two current guidelines with a focus on diagnosis. The BASHH guidelines are intended for a sexual health practitioner audience and provide a more laboratory-based approach to diagnoses, focusing on specific testing methods often available in these services (microscopy, culture, sensitivity testing). The NICE guidelines apply to primary care and emphasise clinical judgement, flexibility and using lab testing selectively.

Until 2019, both guidelines divided thrush into two categories: 'uncomplicated' and 'complicated' (Soni et al. 2018). The BASHH guidelines then introduced the terms 'acute' and 'recurrent' to differentiate these experiences as they "are felt to be more reflective of how women with vulvovaginal candidiasis typically present to clinical services and are subsequently managed" (BASHH 2019).

Symptoms for acute and recurrent cases are the same in each guideline. The NICE guidelines describe "vulval itching, soreness, irritation and white 'cheese-like discharge'". The BASHH guidelines expand on this: "burning, swelling, fissuring, erythema and vaginal discharge that is typically non-offensive and curdy but may be thin or absent".

Acute thrush is defined as the 'first' or 'single' *isolated* presentation of thrush (BASHH 2019, NICE 2023). Recurrent thrush is defined as four or more episodes in a 12-month period with two episodes confirmed by microscopy and/or culture (BASHH 2019, NICE 2023).

Swabbing is recommended when symptoms recur and not for acute cases. Full speciation and sensitivity testing is also encouraged, and BASHH highlighted that microscopy services are available in many sexual health centres. Both guidelines endorse clinician-initiated self-testing where patients can swab themselves at home and return the sample to be tested if the initial vaginal swab results were negative.

The NICE guidelines encourage clinicians to ask about the frequency, duration and severity of symptoms to distinguish between acute and recurrent cases (NICE 2023). The BASHH guidelines does not offer guidance on communication.

Within recurrent thrush, two subgroups are identified: those responding completely to treatment with asymptomatic intervals between episodes, and those with partial response and persistent symptoms. In persistent cases, guidelines suggest it may involve azole-resistant candida, not be candida, or that the candida might not be (solely) responsible for symptoms (BASHH 2019, NICE 2023).

The guidelines emphasise genital examinations and ruling out other vulvovaginal conditions such as lichen sclerosus, vulvodynia, contact dermatitis, eczema and chronic lichen simplex (BASHH 2019, NICE 2023), genitourinary syndrome of menopause and cytolic vaginitis (BASHH 2019).

Recommended treatment for recurrent thrush involves long-term 'suppression therapy', with an initiation dose of antifungal medication, followed by weekly maintenance for six months (BASHH 2019, NICE 2023).

An audit found that adherence to BASHH guidelines improved patient outcomes specifically for recurrent cases (Brown et al 2022).

6.2.3 The Candidacy Framework

The Candidacy Framework presents an entry point into understanding how people become deemed eligible for healthcare and are processed through systems as "candidates" for care (Dixon-Woods et al. 2006). It presents features for understanding access: identification, navigation, permeability, appearances, adjudications, offers and resistance, and operating conditions (Dixon-Woods et al. 2006). These stages include 'identification', where individuals assess themselves as eligible for care. This can lead to 'navigation' where people try to access services and 'permeability' where they asses the criteria needed to be a candidate. Next is 'appearances' when people are able to make their claim for candidacy, and 'adjudications' where professionals offer judgements about an individual's candidacy and access to care. This can lead to 'offers and resistance' where care may be accepted or refused. This entire process occurs within larger 'operating conditions' that speak to the perceived or actual availability of local resources (Dixon-Woods et al. 2006).

This model has been used to explore access to general practice as a dynamic, negotiated process between patients and healthcare professionals (Sinnott et al., 2024). It has also been applied to various settings, including vulnerable populations, heart disease, cancer, and maternal care (Tookey et al. 2018, Macdonald et al. 2016, Hinton et al. 2023). Koehn et al. (2024) noted how the candidacy model needed to be expanded when considering chronic conditions and proposed "Candidacy 2.0" with the inclusion of recursivity and the possible return to or disengagement from any of the candidacy stages.

6.3 Findings

Below, findings are presented through the lens of the Candidacy Model stages of (1) identifying candidacy, (2) navigating services and permeability, (3) appearing at services, (4) adjunction and (5) offers and resistance. Throughout these sections, I also speak to recursivity and local operating conditions.

The findings presented here are from interviews with 32 people with recurrent thrush (including cis women, trans, non-binary and gender queer people) and 25 healthcare professionals working in general practice and sexual health (see Methods Chapter for more information). Pseudonyms are used throughout this chapter with first names used for patients, and the labels GP and SH to refer to healthcare professionals working primarily in general practice and sexual health respectively (See demographics in Chapter 3).

I explore how decisions were made about investigation, expectations around establishing time commitments, valuing a diagnostic label, and following clinical guidelines. These findings highlight areas where clinicians were largely following national guidelines, but differing expectations, perceptions, or understandings from patients led to perceived missed opportunities. Diagnosis was recognised as a process that involved identifying patterns of recurrence, documenting this recurrence, accessing testing, interpreting test results, and forming a diagnosis as a label which enabled management pathways.

6.3.1 *Identifying candidacy*

Recognising patterns of recurrence

In interviews, patient participants often described a key moment where they moved from seeing thrush as a one-off condition, to something requiring diagnostic investigation. It was when patterns of recurrence were recognised that people suspected that the frequency of their symptoms had become abnormal. Harry said, "*I think it was just after... maybe about month four or month five, when I was like, 'this is every month, this is obscene,' I thought maybe it was a recurring issue*".

Many patients assumed their symptoms were caused by thrush and began self-treating with over-the-counter medications without being assessed by a healthcare professional. This approach was appropriate for one-off cases but became problematic when thrush became recurrent. Identifying recurrent thrush involved noticing when thrush moved from an acute, one-off and transient issue to something repetitive and enduring.

Teddy, a 21-year-old non-binary person, explained:

> *I did a WebMD, worked out that it was probably thrush, started taking the medication, and it went away. Then I got it every two months for a year and a half. […] It was like, 'I don't think this is normal, WebMD doesn't like this anymore,' [laughs] that was kind of when I realised, 'I think this is a recurring thing'.*

Laura, a 42-year-old woman, first read about recurrent thrush while using over-the-counter antifungal medication: "*There's a leaflet in the box, that says if you have so many episodes in a period you should go and see the doctor*". Others gathered information through adverts, magazines and forums. Comparing experiences with others helped some participants become aware that something was wrong, as Julia explained, "*I*

asked my friends about it, and they maybe had it once. I asked my mum: she's had it twice in her life. If I get it twice in six months, that's a good six months for me."

Healthcare professionals explained that existing systems were not well-equipped for conditions that are typically one-off, but could become recurrent.

> *The gap is the transition between seeing thrush as a self-limiting one-off condition and having it be often. For our health systems, making the jump between those is difficult.* (GP Dr A)

6.3.2 *Navigating services and permeability*

Having recurrence treated as acute

When patients sought out care, they reported frustration that recurrent thrush was often approached through the lens and treatment plan of acute cases. This included being repetitively prescribed one-off doses of medication or being directed to the pharmacy. Elliott, a 30-year-old trans person, said that after three visits to the doctor, they were still receiving one-off treatments. Rowan, a 24-year-old woman, explained:

> *They did a swab and were like, 'You have thrush, here's fluconazole'. Then I had telephone appointments, and they said, 'oh yeah, it sounds like you have thrush again,' treating it like a discrete one-off thing.*

Trainee Dr B agreed:

> *It's frustrating for patients because we just write them a tablet or pessary and say, 'Deal with it on your own,' but if you've done that over the counter seven times already in the past month, that is disheartening.*

Offering immediate treatment to ease symptoms was often prioritised by healthcare professionals aiming to help patients with suspected thrush. However, patients also wanted discussions with healthcare professionals about longer-term follow up investigation and treatment plans.

There were different views about whose responsibility it was to offer or elicit information about potential recurrence. In consultations, some patients were able to

articulate the problem of recurrence to their healthcare professionals. SH Dr V said: "[*Patients] can be really clear: 'I've had it this many times, it happens every time I have sex, or it happens every time after my period'*.

Others recognised a need to prompt patients and asking questions about recurrence was recommended in the NICE guidelines. SH Dr L said: "*I normally ask [patients]: 'How often is it happening? In terms of day, weeks, months?'".* GP Dr F stressed the importance of using prompts to recognise recurrent as different than acute cases:

> *We'd just say, "I can see you've been in quite a few times," and actually mention it, and then usually you've just got to say something like that and they go: "Oh, you've realised that," and then they tell you all about it.*

However, other patients were unsure how to bring up recurrence. Sasha, a 34-year-old woman, felt she was not asked "*the pertinent questions in terms of giving me a proper diagnosis"*:

> *I don't think anyone asked me how often I had it or had those conversations, just people saying 'Go to the doctor if it doesn't go away or if you have that a lot'. I have gone, but it is treated like an acute episode.*

Expectations around repeat testing

Guidelines require two positive tests in a 12-month period to diagnose recurrent thrush, meaning at least two appointments within a year and presumably two appointments recorded by a healthcare professional. However, these timelines were not always understood or adequately explained to patients who held differing expectations.

While guidelines state that acute thrush does not require swabbing and recurrent cases do, in practice this was more complicated to differentiate. GP Dr A explained:

> *You only swab if the symptoms recur, and that's fine if this is a first-ever episode, but if what you get is fragmented care and people keep saying, "We don't swab because it's a first episode," and you didn't join the dots and realise it's the fifth episode*.

Patients found it difficult to return to see healthcare professionals for swabs when they thought recurrent thrush had already been documented. Zoya, a 33-year-old mother of two, expressed frustration trying to build up enough positive swabs to show recurrent thrush. She explained: "*It was six to nine months and then I felt like I was getting somewhere. They were like, 'OK, recurrent thrush'".* However, after becoming pregnant, recurrence stopped, only to return a few months after birth. When Zoya returned to the GP, she was disappointed to have to re-start the process of documenting recurrence:

> *I said, 'Look at my old records, how many times I'd been, look at my swabs'. I had to do more swabs again to get them to diagnose me [with] recurrent thrush. I needed a certain number of swabs or episodes.*

While this practice aligned with guidelines requiring two positive swabs within a 12-month period, some patients said they were not given adequate plans or communication about timelines for the diagnostic process.

Patients self-treating before testing

It could be difficult to make repeat appointments with healthcare professionals while symptomatic, due to fluctuating flare-ups, time commitments and limited appointments available in primary care.

Others said it felt impossible to endure discomfort while awaiting an appointment and would self-treat which would then affect test accuracy. Harry, a 25-year-old woman with symptoms for two years, said "*I can't wait every time four days before I take [medication] to go and show [a doctor] that I've got it, it's not something I'm willing to do*". She continued:

> *I would just go and take a pill the day I spotted it, from over-the-counter, but by the time I'd go to the GP, which was two or three days later, most of the symptoms had cleared up. Because of work commitments, all of that stuff, I'd have to time it to get there, so [the GP] only actually saw active thrush maybe once.*

Emma, a 41-year-old woman who had recurrent thrush since a teenager, thought it would be beneficial to record thrush episodes but found it challenging:

> *You're so symptomatic you just think, 'Yes, I know having this recorded on a system would be hugely beneficial because [the GP] can record how many episodes I've had,' but the symptoms become too intolerable.*

GP Dr Q recognised that patients self-treating complicated accurate swab results:

> *There can be challenges when either they couldn't get the appointment in time and then it's gone and we can't prove it. […] There can be problems when [the patient] comes, but they were so desperate, they tried to treat it the night before. And then the swab comes back negative. And you don't know - it could've been thrush or not.*

To address these challenges, some healthcare professionals and patients explored the options for self-testing whether through clinical supervision or commercial options.

6.3.3 *(Re)Appearing at services*

Clinician initiated at-home swabs

Primary care professionals are often able to offer swabs for patients to take at home and return them to the clinic in the context of an agreed plan. Self-swabbing at-home for suspected recurrent vaginal thrush is approved by national guidelines. However, not all healthcare settings offered this option, and patients reported confusion about knowing when and where self-testing was available.

Self-swabbing meant patients could test when they were most symptomatic and before self-treating. Patients often found self-swabbing helpful, as Emily said she was told: "*When I had symptoms, to swab myself, which is easy enough to do, and then hand it back into the clinic and then they would go and test it, and it was simple*". Trainee Dr B said that evidence showed "*people doing self-swabs is pretty much as reliable as clinicians doing swabs*".

Other healthcare professionals had concerns around offering self-swabbing. Physician Associate I explained: "*I think self-swabs can be tricky in terms of are they complying and handing it back, because sometimes if they walk away with the prescription, they might be less likely to bring the swabs back*". However, giving clear instructions and agreeing on a plan with patients could help prevent this. Despite these concerns, self-swabs were identified as a key opportunity by both patients and healthcare professionals to help document a diagnostic picture.

Commercial self-testing kits

Some patients investigated a diagnosis independent from (or in addition to) healthcare professionals. Self-testing kits, such as pH test strips and vaginal microbiome test kits, are available at pharmacies, online, and some supermarkets. Patients sometimes interpreted these results themselves, or other times presented them to clinicians. For self-testing pH kits, a swab changes colour for BV but remains unchanged for thrush or a healthy pH, offering limited information beyond ruling out bacterial vaginosis. SH Dr J acknowledged that current at-home tests available to consumers were not necessarily reliable, accurate, or informative:

> *I know Canesten has this litmus paper for patients, if it's acid, you've got thrush, if it's alkaline, you've got BV, but I don't think that's good enough. It would be great if there was a reliable home test.*

Ayesha, a 25-year-old woman with four years of symptoms, found reassurance in using these self-testing kits, although she acknowledged some shortcomings:

> *I felt more confident in the self-test kits than going to a GP or a nurse, because every time they did a swab they said, 'It's fine,' so I wouldn't get any sort of treatment or help.*
>
> *[The commercial tests] were temperamental. One week I could do one: I'd have evidence for what I was feeling. The other week it would be the other way. They weren't entirely reliable, but at the time they gave me the reassurance I needed that it wasn't in my head.*

Emma noted that if patients bought their own self-testing kits it was unlikely that the thrush episodes were being recorded, making pattern recognition more difficult.

> *A GP will recommend, 'just get a self-testing kit,' but what do you do with the results? I appreciate it's a convenient option, to try and identify whether you genuinely have thrush, and then subsequently to treat it, but it's not being recorded in your medical notes.*

At the time of interviews, at-home vaginal microbiome test kits were being offered in pharmacies. Ayesha was awaiting an at-home vaginal microbiome test kit that she was hopeful would provide answers. GP Dr X had some patients bring in test results from commercial at-home vaginal microbiome test kits, but reflected that many healthcare professionals were currently unable to interpret or action the results as evidence for how such tests can inform care is lacking.

> *I don't advise people to do them, because I don't know enough about them. I don't know if it's met the threshold for us to actually recommend them to people in clinic.*

After evidence was gathered, some people made decisions for themselves about whether they had recurrent thrush, while others relied on judgements from healthcare professionals.

6.3.4 *Adjudication*

Belief in reliability and accuracy of test results

Interpreting test results for recurrent thrush was not necessarily straightforward and needed to be understood within the larger clinical context of each patient. Further, what test results were available, and how reliable they were deemed, differed across healthcare practices.

SH Dr J explained patients can have asymptomatic carriage of candida species that is picked up on swabs, but is not necessarily causing vulvovaginal irritation:

> *If you look at 100 women or people with a vagina, 10 to 15 will have Candida if you swab them, but they're not having any symptoms.*

GP Dr P added: "*I wouldn't rely on a swab, it's not the sort of thing that everything hinges on. It would be part of a jigsaw puzzle, but it's not the particular thing".*

Patients sometimes worried about the reliability of swabs. Leah said that she relied on tests to confirm thrush, but worried that if the cause of her symptoms was not thrush, the swab would not tell her what else it could be:

> *If they send [a swab] off to the lab and its thrush – they know it's thrush, but if it wasn't thrush and I was getting similar symptoms, it could be something else. I've read this on the internet.*

Within sexual health, SH Dr G said diagnosing recurrent thrush was "*straightforward, with the history, examination, and the availability of testing*". SH Dr E added: "*it's quite easy. It's a swab and you just send it for fungal speciation, and culture and speciation*." However, as SH Dr D explained, general practitioners often did not have access to the same testing as sexual health centres such as investigation into fungal species and sensitivities: "*There are far greater challenges in primary care where they don't have microscopy services to label something as a recurrent problem".* GP Dr F described some limitations with testing thrush in primary care:

> *Our Candida testing in primary care isn't brilliant […] What we get back from microbiology are samples saying 'insufficient', or broadly saying 'Normal vaginal bacteria'.*

However, current guidelines do not acknowledge this discrepancy between the emphasis on swabbing, and inadequate testing options in many primary care practices.

Separating recurrent from persistent cases

Patients and healthcare professionals noted variation in duration and frequency within recurrent thrush cases. Recurrent thrush was presented by GP Dr A as, "*A textbook case would be 'I use the treatment, it goes away, and I feel all right for two weeks and then it*

*comes bac*k'". Persistent or chronic thrush was described by SH Dr D as: "*It never fully goes away, it runs in the background, maybe it gets a bit better for a few days then has another flare-up*". GP Dr X thought these cases were often conflated: "*we pop them in pigeonholes of 'recurrent'; whereas, 'persistent' might be a better phrase*".
To differentiate these cases, SH Dr N said "*the history itself is telling you something, that tells you the answer*". GP Dr X suggested, in line with national guidelines, that "*Somebody who doesn't fully resolve between like after treatment and has chronic symptoms, either has fluconazole resistance strain of candida or two things going on*".

Most patients we spoke to described recurrent infections with relief between periods, but a few described chronic experiences. Ayesha experienced symptoms which did not seem to ever go away, which she labelled 'persistent thrush'. Sarah said that between episodes of recurrent thrush there remained a "*background kind of itch or irritation*". Other times, patients described a mix of both, with distinct flare-up periods of intense irritation, and then lingering sensations which Elliott referred to as "phantom thrush". Sometimes persistent thrush was due to a non-typical strain of *Candida*. The people we spoke to that had persistent symptoms, all learned that they had a strain of thrush that was uncommon. Lydia had candida glabrata, Kayla had saccharomyces cerevisiae (Brewer's yeast), and Ayesha had resistance to the antifungal medication fluconazole. After learning she had an unusual strain of thrush from a culture for sensitivity and specificity testing, Lydia was frustrated about receiving ineffective treatment:

> *I had quite a rare type of thrush that fluconazole isn't able and never was able to treat. That was difficult at the time because I had taken quite a lot of fluconazole. When you were told that actually none of that was ever going to make any difference – it's quite a difficult thing to hear really, because it's time*.

In cases where 'persistent' or 'chronic' cases were present, treating with a long-term fluconazole course and re-testing was seen as a way to help identify whether the symptoms were due to thrush or a different diagnosis as SH Dr O explained:

> *What we would try to do is cure, as in get rid of the candida. Then take a swab. If they still have symptoms, well there was no candida. So let's leave the candida alone, that's not the cause of symptoms. Let's focus on, is it lack of oestrogen or another condition.*

While this approach of trialling treating and re-testing is not outlined in guidelines, it signalled a need to distinguish between recurrent and persistent cases.

Recognising not all itch is thrush

Patients presenting with suspected recurrent thrush often reported symptoms that were vague, nonspecific, or undifferentiated. Both patients and healthcare professionals reflected on how symptoms of thrush could overlap with other conditions, adding complexity during initial evaluations. SH Dr D said, "*One of the big challenges managing recurrent thrush is whether or not it is actually the thrush".* In these cases, GP Dr F said, "*I think it's because I know that there's an element of diagnostic uncertainty with some of these*".

There was the possibility of receiving a recurrent thrush diagnosis when another condition was present that could be resolved with different treatment. GP Dr Q said:

> *It's just a perception that itching is thrush, but it might or might not be. Do not just say: 'you've got thrush'. You could be two years down the line and it was never thrush, it was lichen sclerosus.*

GP Dr A explained all the considerations that appear when a patient presents with vulvovaginal discomfort:

> *You're thinking, 'is this lichen sclerosus, which can happen at any age? Is this menopausal atrophy? What's happening with the periods? Is this allergy? Is it contact dermatitis? Is there eczema anywhere else, or is there something going on? I do think about trauma. You're constantly kind of rapidly thinking and responding.*

Patients reported uncertainty about whether recurrent thrush was their final or only diagnosis. Ella, a 50-year-old non-binary person, was treated for recurrent thrush over decades before being diagnosed with lichen sclerosus. Some felt recurrent thrush

caused hypersensitivity or other conditions. Harry's doctor linked her vulvodynia (persistent vulval pain) to recurrent thrush. Sasha found overusing antifungal cream brought on dermatitis. Beth, a 25-year-old woman with symptoms for 10 years, thought having repeated irritation led to vaginismus (involuntary vaginal muscle spasms). Sometimes patients had underlying health conditions such as diabetes, like Teddy, or HIV, like Joy, that predisposed them to recurrent thrush. A misdiagnosis, or missing other conditions, could lead to delays in care, prescribing unhelpful treatment, further hindering receiving a proper diagnosis, and contribute to other complications.

6.3.5 *Offers and resistance*

Finding the 'right' language and labels

Patients and healthcare professionals held differing beliefs about the 'right' words or label to use. Jody, a 26-year-old woman with symptoms for 5 years, said:

> *They never gave me an official diagnosis [...]. It was never a label or diagnosis where they said, 'oh, you've got recurring thrush, this is how we deal with that'. It was more, 'we can see you've got a history of repeated episodes of thrush'. It was all dealt with as isolated episodes rather than looking at the bigger picture.*

Emma explained that despite being prescribed a six-month course of antifungal treatment (as recommended in the guidelines for treating recurrent thrush): "*Nobody ever said to me, 'this is recurrent thrush,' it's an assumption that I made myself because the symptoms kept coming back".*

These examples highlight the different meanings people placed on words. Some healthcare professionals expressed reluctance to use the label "recurrent thrush" unless the patient did. GP Dr H said:

> *I might describe recurrent as: 'It keeps coming back and it's difficult to treat,' but I don't know if I've ever said, 'You have recurrent thrush'. It seems quite final, like they're always going to have recurrent thrush. I want to sound more hopeful.*

Similarly, Trainee Dr B explained*:*

> *It's not that I would avoid the term 'recurrent thrush', but I tend to sort of mirror the language they're using, so unless they say, 'I have recurrent thrush,' I might say, 'Look, you're somebody who's very prone to thrush, and what are we going to do about it?' and I might document it as such in the notes as well.*

By documenting it in the notes, Trainee Dr B explained that the term carried clinical significance as "*I think thrush is often brushed off, so if you can say 'it's recurrent', people might pay a bit more attention to it*".

Other healthcare professionals asserted that offering a diagnosis could help patients better understand their condition, plan a management approach, and validate their experience. Aditi reflected on receiving a recurrent thrush diagnosis: "*I just felt like I finally knew what the name was for what I was feeling*." GP Dr X said:

> *Sometimes the formality of a phrase, rather than 'thrush that keeps coming back', feels like a positive medical label they can use: 'it's not just thrush, it's recurrent thrush'*.

Labels of recurrent thrush enabled patients to receive long-term antifungal medication, have repeat appointments, and be investigated for possible underlying causes or other co-current conditions or explanations.

Bringing the guidelines into consultations

Healthcare professionals discussed how they explained to patients their reasoning around reaching a recurrent thrush diagnosis (or not). To establish authenticity, transparency and trustworthiness, some healthcare professionals showed patients the clinical guidelines and explained their thought process. In primary care, GP Dr A found it helpful to show patients the NICE guidelines on recurrent thrush: *"I usually bring the guidelines up and say 'Would you say you fall into this category? And if so, what are we going to do?'."* Showing the guidelines demonstrated that her judgment was "objective" and *"not just making something up to make it difficult".* Similarly, in a sexual health

setting SH Dr S said: "*I would probably just get up the BASHH guidelines, just going through it with them and be like 'this is the criteria you are meeting or not*".

Some patients had consulted national guidelines during their own research into recurrent thrush, and this helped them better understand the process and label of recurrent thrush. Sarah offered this advice to others:

> *Be persistent with your GP and make sure that they're swabbing you, make sure that they are doing it. I looked on the NICE guidelines. I thought, 'oh actually, I'll have a look at that,' and then I looked at it and it was like, 'right, OK, I can say that to them now' and I went to the GP.*

By bringing the guidelines into consultations, healthcare professionals and patients were better able to manage expectations, establish follow-up plans, and encourage the need to remain engaged with healthcare to find answers.

6.4 Discussion

This chapter aimed to understand what patients and primary healthcare professionals identify as important considerations when assessing possible recurrent thrush to inform practice and future guidelines. By combining the views of patients and healthcare professionals, this chapter highlights contrasting experiences possibly creating difficulties for both sides.

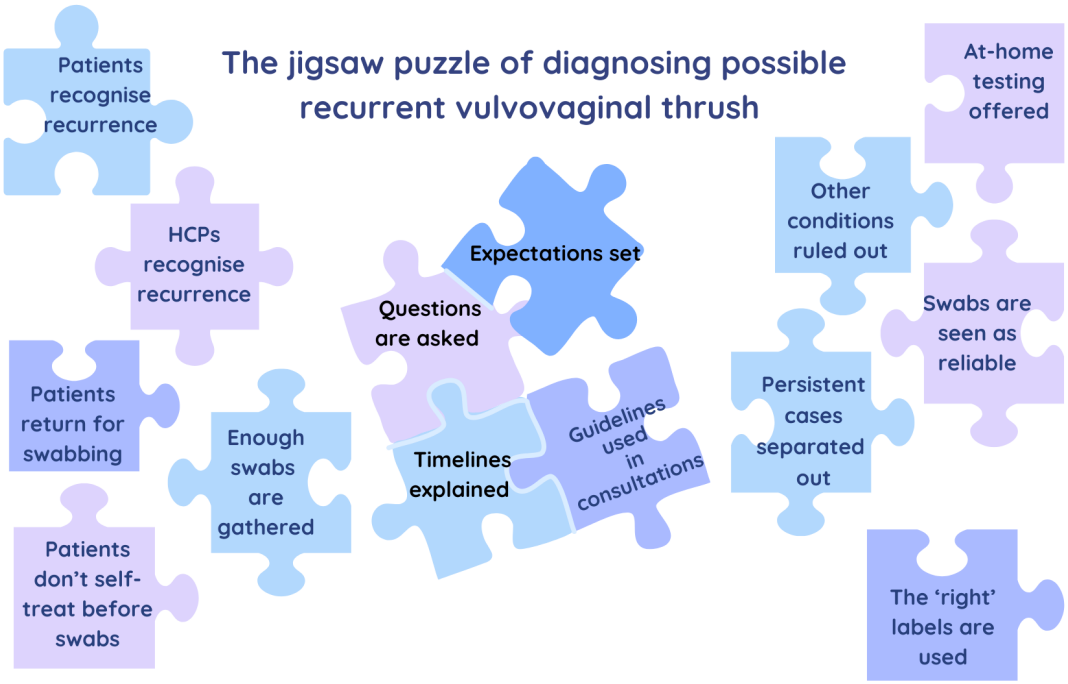
Existing studies reported inconsistencies in healthcare professional understanding of recurrent thrush and diagnostic guidelines (Nunn & Murphy 2012, Ascott et al. 2017). While our study supports that diagnosing recurrent thrush is difficult, it is not simply due to a lack of knowledge or guidance. Instead, our findings highlight areas where clinicians were largely following national guidelines, but differing expectations, perceptions, or understanding from patients led to perceived missed opportunities. My

findings demonstrate that the label of recurrent thrush may, for a variety of reasons, not be easily accepted or applied in healthcare settings.

A salient challenge with recurrent thrush diagnosis was identifying when an acute and transient condition became recurring or persistent. Numerous steps were needed for recurrent thrush to be diagnosed and communicated, some of which required action from patients and others from healthcare professionals. Diagnosing recurrent thrush was not solely a matter of locating biological proof of a fungal organism, seeing symptoms, or hearing medical histories, but a careful choreography of both healthcare professionals and patients making a condition legible and actionable.

As one healthcare professional described, recurrent thrush presented a 'jigsaw puzzle' for diagnosis, with multiple pieces picked up and considered before attempting to click them all together. The figure below outlines the multiple pieces of the puzzle that patients and/or healthcare professionals were holding, comparing, and trying to make fit.

Figure 18: The jigsaw puzzle of recurrent thrush diagnosis



My findings provide insight into previously reported perceived diagnostic delays for recurrent thrush (Strydom et al. 2022). Once the diagnostic process was initiated, by definition and following the guidelines, it involved the need for repeated contacts and swabs. However, the timeline for establishing a pattern of recurrence, a number of positive swabs, and the need for repeat appointments, necessary for diagnosing possible recurrent thrush, were not well understood by patients who held different expectations. Patients sometimes were waiting to be asked about recurrence, or assumed a healthcare professional would connect the pieces. Further, some healthcare professionals also reported hesitancy around using the term 'recurrent' because of connotations around permanence and hopelessness, and would mirror patient language. During this diagnostic process, patients were not always continually engaged in healthcare and often had periods of disengagement.

Further, both patients and healthcare professionals were balancing the need for immediate treatment with the need for ongoing diagnostic investigation. For patients, the need to reduce discomfort could mean that when investigations were taken, results could be altered due to self-treating. For healthcare professionals, offering one-off treatments could be perceived by patients as not recognising or responding to recurrence.

These research findings align with others that demonstrated a potential mismatch in primary care between patients' perceptions of care and GPs' considerations, particularly when symptoms are undifferentiated (Dixon et al. 2021). Previous papers report general practitioners feeling frustrated and helpless with diagnosing vulvovaginal symptoms (Leusink et al 2018).

Candidacy

Applying the lens of candidacy to this experience has highlighted the overlapping and interconnected stages of diagnostic processes and how both patients and healthcare professionals recognised "candidates" for care (Dixon-Woods et al. 2006).

The Candidacy model offers insight into the different features for identifying a problem, seeking care, and negotiating outcomes related to diagnosis, however, it is missing some elements regarding conditions that are recurrent (Dixon-Woods et al. 2006). While the 'stages' are presented as a clear path with discrete steps in a specific order, I found many 'stages' were occurring simultaneously or in different orders. As recurrent thrush returned, patients and healthcare professionals had to re-assess the diagnostic process, re-consider questions and re-establish authenticity. While some patients had the confidence, time and perseverance to seek out a diagnosis, others did not. The Candidacy framework highlights individual agency, but many people did not have the resources to have themselves recognised as candidates for care.

Some updates to the candidacy model have been presented for chronic conditions that acknowledge the possible return to any of the candidacy 'stages', recursivity, as well as possible re-engagement and disengagement with care (Koehn et al. 2024). These updates are helpful in understanding the recurrent thrush pathway, which often required patients and professionals to repeatedly revisit stages. However, in recurrent conditions, this recursivity is not optional, but the key pillar on which candidacy centres.

Candidacy for recurrent conditions hinges on *when* a symptom is recognised as part of a pattern, and *whose timeline* defines "recurrence." This model could better incorporate the temporality of symptoms, including the mismatch between patient experiences and institutional abilities to capture recurrence. My findings

reveal asynchronous timelines: symptoms flare up unpredictably, and not always able to be captured in a consultation.

With recurrent thrush, patients have the option to self-treat and self-manage this condition. My findings demonstrate how people tried to participate in finding a diagnosis through different self-testing options. By applying the candidacy model to this population and condition, we can expand the model to understand how people attempt to establish legitimacy for having a recurrent condition that may (re)appear and disappear at different intervals.

Guidelines

Guidelines exist to diagnose and manage recurrent thrush, and primary care is well placed to manage this condition but faces several challenges. While acute cases are defined in guidelines as the 'first' isolated presence of thrush, there are likely distinctions between when thrush is first experienced by an individual, and when they present to a healthcare professional. Healthcare professionals may tell patients to come back if thrush returns at their first appointment, signposting that recurrent thrush diagnosis is unlikely to be a one-off occasion. However, when this is not communicated, individuals may not know they should return to get care, or may see the pharmacy as more appealing or appropriate after receiving one-off treatment from a clinician.

Further, while the guidelines recommend two positive swabs for diagnosis, they do not capture challenges with getting swabs, interpreting results, or addressing at-home test kits. While swabs were often seen as the gatekeeper to diagnosis and accessing long-term antifungal treatment, accessing and understanding them was not necessarily

straightforward. Therefore, what 'proof' counted, when it was needed, and who could gather and document it, were contested areas.

Recurrent thrush diagnosis requires time, as current guidelines necessitate repeated appointments with a healthcare professional. For instance, the guidelines require two confirmed episodes of thrush with a swab or microscopy. Yet, clinicians may be more familiar with seeing patients for acute, one-off and transient episodes.

There is complexity in diagnosing conditions in their early or undifferentiated stages. Therefore, uncertainty is inherent during initial presentation(s). During repeat and follow-up visits, patterns can begin to be recognised, documented and actioned. However, ensuring that this engagement remains consistent requires that patients and healthcare professionals felt aware of timelines, testing options and test results.

6.5 Implications for practice

This chapter highlighted where healthcare professionals followed current national guidelines, but patients identified different expectations, perceptions, or understandings. There is a need to close this gap, learning from clinicians, patients and guidelines. To complete this picture, some suggestions are outlined below.

<u>For clinicians</u>

- Prompt patients in consultations about recurrence (ask how many episodes of suspected thrush they have experienced in a year) to ensure timely initiation for the diagnostic process;
- Ask about self-treatment before appointments and explain how this may influence test results;
- Offer clinician-initiated self-swabs to document recurrence with convenience;
- Explain to patients the requirement for 2 swabs confirming thrush within a 12-month period for a recurrent thrush diagnosis;
- Clarify to patients that thrush can be present on a swab but not necessarily be causing symptoms;

- Discuss the limitations of commercial self-testing kits;
- Bring the guidelines into consultations to build trust with patients and set expectations around timelines and follow-up.

For patients

- Be proactive in offering information about how many episodes and how long the problem has been occurring;
- Record when you took treatments and when flare ups occur;
- Ask about self-swabbing from your clinician and inquire about what is offered at other centres (whether at the GP or sexual health);
- Ask for a follow-up plan for documenting episodes of recurrence, ruling out other conditions, and trialling and re-testing for long-term treatment.

6.6 Concluding remarks

This chapter explored patients' and healthcare professionals' experiences of diagnosing recurrent thrush. By drawing upon the candidacy framework, I explored how recurrent thrush diagnosis was neither simple nor straightforward. Instead, I highlighted where healthcare professionals followed current national guidelines, but patients identified different expectations, perceptions, or understandings. There is a need to close this gap, learning from clinicians, patients, and guidelines.

Next, I present a narrative analysis of a few patient stories to provide an intersectional and multimorbidity analysis into how recurrent thrush impacted individuals on multiple layers.

7

Interwoven conditions: Narrative Case Studies of Recurrent Thrush

Contents

7.1 Introduction

The previous analytic chapters have presented a horizontal thematic analysis drawing out themes across all interviews. In doing so, I have been able to analyse key topics in the recurrent thrush journey around feeling, seeing and managing symptoms; navigating healthcare systems; and seeking a diagnosis. However, by bringing multiple voices together thematically, the larger context and nuance of individual stories can be obscured. Therefore, in this chapter, I analyse and present the data from a vertical perspective, taking a deep-dive into three individual patient interviews.

7.2 Background

7.2.1 An intersectional approach

Intersectionality, as coined by Kimberlé Crenshaw (1989), highlights the complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism and classism) combine, overlap, or intersect. Inequality is not just the result of a single factor, but of multiple systems colliding, creating compounded vulnerabilities that are often invisible when viewed through a single-axis framework.

> *Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars traveling from any number of directions and, sometimes, from all of them (*Crenshaw 1989).

In the context of gendered healthcare, intersectionality is crucial for understanding disparities in healthcare and outcomes, as well as barriers to help-seeking. Research in the US and UK shows that Black women are more likely to experience health inequities, such as delayed diagnosis and treatment due to systemic racism and implicit bias in healthcare (Bailey et al. 2017). Non-binary and transgender individuals face additional barriers to care such as misgendering, stigma and lack of inclusive language (Reisner et al. 2015).

Previous research on experiences of recurrent thrush focuses predominantly on white cis women's experiences (Ford 2024). No qualitative studies on this topic have yet reported including trans or non-binary voices. Only one study (Chapple 2001) explored potential ethnic differences in a British context with experiences of (acute) vaginal thrush. This paper found that women of South Asian descent have additional anxieties and difficulties, reporting a greater sense of stigma (Chapple 2001).

Traditional intersectional frameworks have primarily focused on social identities such as race and gender, but have not extensively addressed overlapping health conditions. In the context of recurrent thrush, expanding an intersectional approach to include health and illness can help highlight how overlapping social and health factors shape relationships with healthcare, symptom management, and lived experiences.

7.2.2 Recurrent thrush and co-existing health conditions

Previous research tends to focus on recurrent thrush as the sole (or only relevant) health condition that participants are navigating as an isolated experience (Ford 2024). A few exceptions exist with the relationships between recurrent thrush and diabetes being explored (Steel 1996) and a potential relationship between frequent antibiotic use (Pirotta 2003).

Research into co-existing health conditions have highlighted the importance of studying the relationship between multiple conditions that can interact, amplify symptom severity, complicate diagnosis and influence treatment decisions and efficacy (May et al. 2009). Within this research, a cumulative burden has been acknowledged, highlighting the physical, psychological and social burden of managing multiple conditions simultaneously (May et al. 2009). However, this research has largely overlooked vulvovaginal conditions.

7.3 Three narrative accounts

By delving into individual accounts of living with recurrent thrush, I am able to explore how the themes analysed in previous chapters play out in individual lives.

Focusing on the whole interview, we can glean how individuals make sense of events in the context of their lives (McAlpine 2016).

The narratives presented below are not meant to be representative exemplars of certain groups but instead are rich accounts of the recurrent thrush experience. Each account features an individual navigating complex intersectional experiences and placing recurrent thrush within the larger context of their health and lives. The three individuals chosen were managing multiple health conditions alongside recurrent thrush, and provided insight into navigating intersectional identities including gender, age, race and disability.

7.3.1 *Nysha*

> *[Recurrent thrush] is not treated with the same respect or level as other things that I have, and yeah, some things are minor and some things can be a bit major, but at the end of the day it's still affecting the body and it's affecting everything.*

Nysha (she/her) is 40-year-old Black Caribbean straight cis-woman and a retired teacher. "*Over the years, I've had thrush many, many times*", she said, explaining that her symptoms have worsened with age as her body now "*clings to infection*" as recurrent thrush occurs on a monthly basis. She also has fibromyalgia, depression, recurrent urinary tract infection (UTI), and hidradenitis suppurativa (a chronic skin condition causing painful recurrent boils and abscesses in areas where skin rubs together). She has also had episodes of Bacterial Vaginosis and a positive smear test for HPV of the cervix.

In Nysha's account she relates how her past health experiences have impacted how she relates to healthcare encounters, and her management of recurrent thrush. She

felt that recurrent thrush was not prioritised to the same extent as her other health conditions:

> *So, with chronic pain, say, like you're ill, always in pain and whatnot, they know that affects your mood, so I don't understand why they can't understand why thrush wouldn't do the same thing.*

While speaking about other health conditions and their relationship to recurrent thrush, despite reassurance, Nysha often apologised for going "off-topic". This remark highlighting a perception that the interview's purpose was to isolate one health experience separate from other conditions that were not 'relevant'.

> *I'm sorry if I go off topic a little bit. If I say to someone, "I'm in pain," or there's an issue, there really is an issue. Like I said because I have a lot of other health issues, I can manage things, you get on with it. There are certain things that you just don't go to your GP for because you know you can get treatments over the counter for, but this was at the point where I was saying to them, "This is going on far too long, I'm uncomfortable, what am I supposed to do now?*

While Nysha was uncertain whether comparing recurrent thrush to her experience with other health conditions would be relevant to this study and my interests as a researcher, it reveals insight into how she was contextualising and framing herself as a responsible health service user who was struggling to understand where recurrent thrush care could or should be accessed.

When Nysha sought out healthcare, she felt that she was missing information and open communication from healthcare professionals. Nysha said that her advance nurse practitioner (ANP) was very empathetic and understanding and referred her to specialist care at the hospital.

Nysha recalled having swabs taken at the hospital, and while she said this would have made her uncomfortable when she was younger, she had become used to them due to having smear tests done:

> *At that point I was used to having like smears done and things. I think... going off, side topic, I think around the age of 30 I just thought, 'you know what, these are things that are going to have to happen, as a woman, these are things that I'm going to go through, [erm] and yeah, they can be uncomfortable but what you can do is just try and relax and just do it,' but at the point where they were doing the swabs, you know you... I was just so desperate, I didn't care, I was like, 'do what you've got to do,' [er] didn't bat an eyelid, and now I don't even... it doesn't faze me*

However, Nysha was disappointed when her results (showing thrush and bacterial vaginosis) were not communicated to her for six weeks.

> *They forgot to send me the letter with the results and it was almost like, 'oh, oops, we forgot,' and I'm like, 'this isn't simply I've got a cold which I can just... this is something that I need to try and get on top of'. I remember putting in a complaint about that.*

Nysha saw two different gynaecologists at the hospital about recurrent thrush. She said "*the first gynaecologist was brilliant—straightforward and honest*." But said that the second gynaecologist was dismissive: "*When I was trying to discuss the whole thrush issue, he was just very much like rolling his eyes and it was almost like, 'what... what... what do you want from me?' [erm] That also then impacted how I felt and, once again, just made me feel a bit like, 'well, sorry, am I causing problems by asking this*?". Nysha felt that there was a power imbalance with this gynaecologist "*because he was a professor and [erm] at his level: I wasn't worthy enough to talk to him*". His manner led Nysha to switch to a different hospital and return to care from her ANP.

> *I don't want to sound like I'm needy, it wasn't that... it was just that you get to a point where you're just so frustrated because you're trying to do all the right things and no one is explaining anything to you, and it's just... I'm just like, 'can you just tell me what we can do,' and I don't mind taking ownership of my health, that's not a problem, 'but what I need you to do, as the professional, is explain and try and help me get to that point where I don't have to keep coming back to you for the same thing.'*

Nysha was prescribed an antifungal pessary and cream but not given a follow-up plan. Despite seeing multiple healthcare professionals, Nysha felt that recurrent thrush was not explained to her. "*[Sighs] it's hard because they were helping me but*

they weren't explaining anything to me". For instance, she was not told about oral antifungal medications and only became aware of these when a friend mentioned using them. She explained "*I didn't actually know there was an oral tablet you could actually take, which sounds a bit silly because there's probably a tablet for everything*". Further, Nysha said that it was online communities on Instagram where she had an anonymous account that taught her about her anatomy such as the difference between the vagina and vulva.

Cycles of other health conditions and recurrent thrush

Nysha thought that some of her multiple health conditions were interacting with recurrent thrush. A cycle of taking antibiotics for recurrent urinary infections and occasional bacterial vaginosis and the development of recurrent thrush, felt like an unrelenting battle. This back-and-forth between antibiotics and thrush added to Nysha's distress.

> *My bladder doesn't empty fully properly, so I'm prone to infections, so it's just been... like I said, it was just this non-ending cycle of, 'well, the thrush is there, OK, the thrush has now gone, OK now you've got a urine infection, OK can we try and do this without using antibiotics? Well, actually no,' knowing that it then... that's going to spark it off and it's going to come back, it's just so draining, it really is really draining.*

Further, living with hidradenitis suppurative meant that Nysha had to carefully attend to her vulval care. She explained:

> *I get a lot of cysts and abscesses from ingrowing hair follicles, so I have to make sure that I maintain my pubic hair area, I can't take off too much hair continuously, but then I also can't leave it too long because then I also then... bacteria get in there and that also causes me problems*.

During the COVID-19 lockdowns, Nysha also received news of having human papilloma virus (HPV) after a smear test. This led to confusion as she was thinking this was a sexually transmitted infection, until this was clarified to her:

> *A side note: sorry, I'm going off track, but I was told two years ago I had HPV after a smear, and then again no one would tell me how I could have contracted it, they were like, "Well, it must have been through sex," and I was like, "But we've been in lockdown, so where... you know I wasn't going..." and it's like these kind of things and these kind of conversations need to happen because I always assume that you could... like you could only get it through sexual contact.*

Two years later, Nysha was able to have an open conversation with a different nurse:

> *I went for my smear this year, I saw a different nurse and she sat down and she explained it to me, because I was looking online and I was getting really confused but then also like panicking. She sat down and spoke to me, and all it takes is, like you say, one conversation and then that's it, because if they tell me the information then I can tell my friends, and it's a conversation that can start being generated within communities as opposed to you having this kind of shame that you're... kind of... a stigma of shame attached to it.*

Nysha's experience here with an HPV diagnosis highlights a theme of feeling she was not provided with enough information, which left room for confusion**,** shame and stigma to seep into her health experiences.

Cascading emotional effects of recurrent thrush

Nysha felt that recurrent thrush was not seen as a serious issue when she saw healthcare professionals which impacted her mood. She explained: "*I felt desperation, pleading for someone to take me seriously. This isn't simply, 'I've got a little itch.' This literally took over my whole life*." *"It brought up my depression; I felt so low",* Nysha said about recurrent thrush. Nysha said that with other health conditions she was able to stay positive, but not with recurrent thrush.

> *I've got a lot of chronic illnesses. I always think, 'well, you know what, in a couple of weeks you'll be in a better situation, you're going to be in a better situation,' that's how I kind of pull myself through. […] With [recurrent thrush] it was like, 'this is it now how it's going to be, this is literally how it's going to be,' and it completely knocked my confidence and it made me so low, I was so irritable, I didn't want to talk to anyone.*

Nysha said that due to recurrent thrush, she stopped dating and having sexual contact. "*It just felt like I was in a never-ending cycle of woe",* she described, explaining that she had lost time and the opportunity to start a family due to this condition.

> *It was never addressed and I've actually said to [healthcare professionals], "My life was put on hold." I'm now at the point now where I feel, because of my health and my age, I'm too old to have children. I'm 41 this year and I could have potentially met someone and we could have started a life and then probably looked at having a family, but I didn't feel that I could do all this because of all the other issues with the thrush nonstop, and the BV... you know it just took my confidence away.*

This feeling of not wanting to talk to anyone was also linked to broader concerns around culture and taboo.

Conversations, culture and taboo

> *In the culture that I'm from, my family are Caribbean, it is considered a taboo subject*.

Nysha reflected on how cultural taboos made it difficult to speak openly about recurrent thrush.

> *I feel shame, like my mother didn't shame me for it, but growing up it was very much like I said anything below the waist was like you don't talk about it. I haven't got a sister I can speak to, my aunt's kind of shut down and it's like, 'well, who am I supposed to be speaking to about these things?*

Therefore, the shame that Nysha felt was not necessarily in what was verbalised, but in the omissions, silences and avoidances of her familial, community and wider social relationships.

In her 40s now, Nysha reflected on how she built confidence to speak with friends:

> *My friends were like, 'You've got nothing to be embarrassed about'. And that kind of then started a conversation between us all of what was going on in relation to our vaginas, vulvas, everything, just understanding why our bodies react the same, thinking... I think it was taking away the stigma that it's just you*.

Through conversations with friends and online communities, Nysha said that her perspective, language, and phrasing shifted.

> *I remember saying, "Don't think badly of me, I'm not dirty but..." but now I don't use that... [erm] that before I say anything, I'm like, "Do you know what this is, what's happening at the moment…" that's how I now have the conversation. It was the fact that I could speak to them without judgement and not feel judged, that's what really helped, [erm] it kind of broke down the stigma.*

Nysha also endeavoured to speak to her family but found there were layers of complexity in these intergenerational conversations.

> *It was a lot of me saying to my mum like re-educating on her on things saying, "It's not a bad thing," like periods where... when she was growing up, were told were dirty things and all the rest of it, and I was saying, 'No, they're not, they're not dirty, it's part of life,' so it helps conversations with my mum as well, so I could speak to her about things, like, "Have you had this, and what did you do?"*

Nysha concluded her interview by emphasising she is trying to change the experiences of others: "*where I can help, I will always help and just learning and just being open with my nieces, my goddaughters, so they're aware*". Nysha acknowledges broader societal impacts of breaking taboos, generating research and creating resources on recurrent thrush: "*There's young girls in Asian and Black communities, that will be able to access the web and see things and not feel embarrassed or ashamed […] you know a lot of people won't be suffering in silence anymore*".

Nysha's interview presents rich imagery, emotive accounts and candid self-reflections. As she spoke, she often made asides about other health conditions and apologised for these being "off-topic" or "off-track". She often revisited key themes of shame, stigma and communication. There are repeated mentions of not being given information and not having an 'open conversation' which Nysha suggests could help people to feel heard and respected. Despite continuing to suffer from recurrent thrush, she remained hopeful for a better future and improved experiences for others who share her identities and experiences.

7.3.2 *Teddy*

> *It's all just a vicious cycle, like loads of stuff interconnects with it and I'm like, 'how many [ughh] comorbidities are we going to end up with here, how many things are going to just like Venn diagram over each other.*

Teddy (they/them) is 21-year-old white British lesbian non-binary person. They work as a teaching assistant and part-time drag performer. Alongside recurrent thrush, Teddy lives with diabetes and vaginismus. In Teddy's account, they trace how their multiple health conditions interacted and impacted their experience and identity.

Teddy explained the first time they experienced acute thrush at 17 years of age it was stressful as they did not know what was going on. Teddy turned to online research to self-diagnose and began treating with over-the-counter options. When Teddy went off to university at age 18, they began experiencing thrush every two months for a year and a half.

> *It felt like my body was out to get me. That's how I kind of felt in the first year, it was just like, 'are there any more problems you'd like to give me?' like, 'what else... what else would you like to go wrong here; are you targeting me personally?' at this point*.

In January 2020, (two years prior to the interview) Teddy was diagnosed with vaginismus at a sexual health clinic. Teddy found the healthcare professional was "absolutely lovely", "so nice" and "really affirming of all the stuff I'd gone through with it". This made Teddy feel comfortable enough to say, "*You know what, while I'm here, and this has also happened for the past four months*" and bring up recurrent thrush.

Due to vaginismus, Teddy was uncomfortable taking swabs and was therefore unable to be officially diagnosed with recurrent thrush. This meant they were unable to

access a prescription for long-term antifungal medication and instead continued to self-treat with over-the-counter medication. Further, due to vaginismus, Teddy found oral tablets were the only (and most expensive) option available as pessary use was uncomfortable. Teddy explained that purchasing medication was a financial burden but a compromise they were willing to make:

> *It's like I have to pay for this [over-the-counter medication] but it's at the expense of me not having to put myself through a... a fairly painful medical procedure, so there's swings and roundabouts*.

Teddy explained their frustration with having multiple intertwined health conditions, saying thrush was "*just another thing to add to the list*". Teddy also found it difficult when their multiple conditions interacted or exacerbated a problem, such as with poorly controlled diabetes contributing to recurrent thrush (Sihvo et al. 2000).

> *I found out that my two conditions [diabetes, recurrent thrush] make it kind of comorbid, so I was like, 'oh, am I just kind of stuck with this now?' which was... [erm] a little bit, like, 'oh, am I not... just not going to be comfortable again*?'**.**

While the sexual health centre and diabetes team were geographically close, Teddy found there was a lack of communication between the two:

> *The sexual health team are next door to my diabetes team, so I'm like, 'they've really streamlined everything, they've got everything wrong with me in one building'.*

> *I didn't bring [recurrent thrush] up with my diabetes team because I assumed they would know because I assumed all my like records would be kind of together. I'm starting to actually think they're not, so I probably will bring it up at my next appointment.*

Teddy continued that they would consider linking these health experiences together: "*At my next annual review I'm probably going to be like, 'hey, so bonus fact, I have this and also my diabetes is probably related to it'. I think it would be good for them to know because I think it is all interconnected*".

Gender identity and not fitting into boxes

Teddy also reflected on how being non-binary and having gender dysphoria could also potentially contribute to their vulvovaginal discomfort.

> *I think having multiple gynaecological issues and being non-binary is very weird to a lot of people. I think you know it doesn't surprise me because it's like if you have discomfort with your genitals because of like dysphoria or something, then it might be that you are struggling with other conditions.*

Recurrent thrush further influenced Teddy's relationships. They found themselves worried about dating and passing it onto partners**:** "*because I sleep with women it's a lot more common to pass on than it is-, to pass it onto people with vaginas than it is to people with penises*".

Teddy weighed up the benefits of being able to speak openly about recurrent thrush, with the reality that they did not fit neatly within pre-existing expectations or support systems. Teddy found that the advertisements for thrush medication were heavily gendered:

> *I've got the Canesten advert ringing in my head that's like the only one I don't like, and it's like, 'oh my God, talk to your mum, your bestie, your nan,' I'm like, you don't need to talk... to discuss it like it's a... like, oh my God, girl gossip kind of condition, it's like this is a medical issue, you don't need to [er] frame it in that way***.**

Here, Teddy challenged the labelling of thrush as a "girl gossip" condition and instead advocated for it to be seen as a shared health condition that could be discussed through different lenses.

Looking for further support, Teddy turned to anonymous online forums such as Reddit. Teddy had not found a platform about recurrent thrush on its own but found that people on forums about vaginismus would share similar experiences. Being anonymous allowed Teddy more freedom to communicate.

However, Teddy found that some of the forums were not very inclusive and made them feel left out as they "*centred on cis women, very specifically married cis women, a lot of them were Christian*, *which was an interesting one because it was like, 'these people do not relate to me at all*".

> *Everything centred on getting your... getting some sense of womanhood back, and I was like, 'that's not why I want this, I would like to stop being in pain.".*

Teddy continued that being non-binary meant they did not subscribe to the same narratives are others.

> *I remember one comment on some subreddit talking about having thrush and vaginismus and being like, 'oh, doesn't this make you feel like a broken woman?' and I was like, 'well, I'm not one' so it couldn't be me.*

While not all trans and non-binary people experience vulvovaginal conditions, Teddy wonders whether there might be some link:

> *It wouldn't surprise me if vaginismus and being trans and nonbinary were linked at all, but were not supposed to be at all, the marketing for things for thrush in particular is very, very pink and feminine in the way that like a lot of period products are.*

This problem was not limited to recurrent thrush or vaginismus, but instead occurred across all vulvovaginal products being marketed in a feminine way. This made Teddy uncomfortable as "*it felt like they were trying to shove me into this like box of woman*". This raises questions around gender neutral marketing for products traditionally intended for consumption by a certain gender.

Looking forward

At the end of their interview, Teddy was weighing up different considerations around their co-existing, and sometimes conflicting, health needs. Teddy said that their vaginismus was slowly improving, and they were considering re-visiting health services to get an 'official diagnosis' of recurrent thrush. However, they worried that

having an examination or swabs for recurrent thrush would then worsen their vaginismus:

> *I'm worried that if I try to get diagnosed with recurrent thrush it might put me back to square one vaginismus healing wise, so I had to kind of take them into balance sort of***.**

Themes of balance, interconnection and "swings and roundabouts" re-appeared frequently in Teddy's account as they attempted to manage the needs of their non-binary identity and multiple health conditions of vaginismus, diabetes and recurrent thrush. Teddy used humour, colourful language and observations to ground their interview. By drawing upon the emotional and physical toll of managing comorbidities and competing needs of the body and the self, Teddy highlighted the dynamic and layered challenges and resilience in their experience.

7.3.3 *Lydia*

> *I definitely feel this anxiety around, 'do I have it, do I not?' as if it's suddenly going to come back, because probably that whole sort of journey that I've told you about, span over between nine months to a year, so it was a long time constantly having it.*

Lydia (she/her) is a 26-year-old straight white cis-woman working as an assistant practitioner. She had previously experienced persistent thrush for a year. She also lives with vulvodynia, vulvar dermatitis and endometriosis. Lydia explained how her experience with recurrent thrush and healthcare was shaped by her multiple conditions, as well as her profession and role as an online patient advocate.

"*I think I'm uncomfortable anyway*", Lydia said when she explained what it was like to have multiple vulvovaginal health conditions. Having persistent symptoms of vulval itching, burning and pain caused by vulvodynia made identifying recurrent thrush

difficult. Instead, it was during an appointment for vulvar dermatitis that a thrush test came back positive.

During the hospital appointment, Lydia was given a prescription for antifungal medication and a follow-up plan to return for subsequent testing. Lydia was surprised to have the test return positive once more. Her healthcare team began referring to it as a recurrent issue. Learning about recurrent thrush brought up mixed feelings for Lydia:

> *I'm so used to having diagnoses and labels that part of it just goes straight through you. Then the other part is here is another thing that I have to cope with, deal with, seek treatment for, take time out of my day to [erm] resolve and [erm] another thing that's wrong with me*.

Accumulating an interdisciplinary care team

Lydia first sought care for her vulval pain with a GP who was "*really understanding*" and "*did everything that she could in order to get me support*". This included referrals to the hospital for specialist care.

For the past four years, Lydia has been amassing a team of healthcare professionals to help support her vulvovaginal conditions. This includes a dermatologist, gynaecologist, pain specialist and physiotherapist. Some of these healthcare professionals offer joint appointments (her dermatologist and gynaecologist), while others she sees separately or privately. She acknowledges that she had to "fight" to put this team together using her own research and knowledge as an assistant practitioner.

> *I have been able to accumulate a group of professionals, [erm] dermatologists, gynaecologists, pain specialist, physiotherapist, in the NHS, and then privately I have my own psychosexual therapist, so I've been able to kind of, [erm] yeah, get... get referred into all those professionals and... and seek with... support from all of them, some of which my treatment has been helpful, some of which where it's been completely unsuccessful, but my experience with those... those four professionals [erm] have all been positive.*

As Lydia accumulated diagnoses, her care team expanded with a better understanding of what treatment would be helpful. She found that healthcare professionals who specialised in treating vulvodynia and vulval dermatitis were able to help her with persistent thrush. Lydia's role as an insider in the health system as an assistant practitioner may have also granted her the access and knowledge about which healthcare professionals she could see.

At appointments, with a joint dermatology-gynaecology team, Lydia was able to look at the multiple layers of conditions that were causing her vulvovaginal discomfort:

> *I didn't just have appointments to talk about the thrush; the appointment was [erm] to talk about everything. So, we talked about things as a whole and the different elements together: the vulvodynia, the dermatitis, the thrush and how they affect each other*.

Lydia explained that this experience contrasted with most GP care where she did not see the same doctor and where vulval pain conditions may not always be well understood. While Lydia sought most of her care through her hospital-based practitioners, she visited her GP practice to get swabs for thrush (which she mainly self-administered) and when she needed urgent care.

> *Previously, maybe like I've had a really bad flare-up and I'm noticing things that are a bit different, perhaps I'm very swollen or I'm very red, then I'll go in and say, you know this is... 'I've got this and this is happening,' and I'm just thinking you know I can't... because with the hospital team you can't just get in, you can't just call them up and say, 'can I be seen?' you know, well you can, but you'll be waiting until they have their next clinic*.

During this time, she had negative experiences where she saw a nurse who was about to perform a vaginal swab when Lydia disclosed her vulvodynia, and the practitioner did not know what this was: "*it's worrying that you were about to do something that involves a woman's vagina and vulva and you don't know about vulval pain conditions*". Lydia self-advocated to take a self-swab in this instance, but felt hesitant to seek help from her GP again.

Lydia said that having an interdisciplinary care team meant that she was taken seriously: "*I think when you do have less professionals involved, which a lot of people do because a lot of people find it really hard to get referrals, [erm] to get the right professionals, people are less likely to hear your views and what's important to you, and that's so bad, you know*?".

Having continuity of care and a joined-up approach, Lydia explained that she felt "lucky":

> *Because I don't like to use this word, because it shouldn't be this word, but in a sense I'm lucky: I'm lucky moving to the city where I have had a good experience of most health professionals. I have fought for what I've wanted and I'm confident in that way and, [erm] yeah, so that's definitely helped. But for people that may be less confident, for people who know less information [erm] and for people who find it really hard to even get a telephone call from their GP, let alone an appointment at the hospital, [erm] you know it's... it's not good enough. I know people that have recently made calls [erm] because they need support and they've been told that the... the... the appointment that they're having is in [erm] six months, that's the earliest appointment that they... that they've been given.*

However, recurrent thrush also impacted Lydia's ability to continue with other healthcare treatments. Her physiotherapist would not work with her during this time as she worried about teaching the body and brain to tolerate the thrush. However, Lydia's psychosexual therapist continued to work with her. Lydia explained "*when you have different professionals, I'm sure lots of people are in the same boat as me, they experience different opinions, different medical opinions*". She continued:

> *It does make you anxious about the situation really. Who's right? How much of a difference is it? What should I be thinking myself? [erm] Should I be continuing with the psychosexual therapy if the physio's saying that she won't work with me? It's just a lot of toing and froing really*.

Building community and social support

> *I made my own community of people because I didn't feel I had it*.

After being diagnosed with vulvodynia and endometriosis, Lydia began building an online network of support, including an Instagram page, WhatsApp group and Zoom meetings to offer support to others in a similar situation. Lydia said that existing support groups for vulvovaginal pain and vulvodynia were targeted at older women; she felt unable to relate to due to different priorities, concerns and life stages. She now shares her multifaceted experience with multiple vulvovaginal conditions online.

> *People really wanted to talk about it. People had the same experiences as me both in the support group I run and on the social media account. I had lots of interaction with posts that I posted about thrush, and when I put messages in my support group chat, there were lots of people in the same situation as me.*

By finding support online, Lydia said she became more confident to self-advocate and speak out on taboo topics and encouraged others to do the same:

> *The more we talk about things – the more we make noise. The more noise we make – the more stigma we will break, the more research we demand and the more we come together as a community of people*.

A "new" chapter

After multiple tests, Lydia's care team undertook further testing including a microscopy culture and sensitivities testing which revealed that Lydia had a rarer strain of thrush, *Candida Galbrata,* that required a different treatment approach.

> *I believe I did this [test] at home, and I then sent it off and they did the test, and they found out that I have quite a rare type of thrush and that fluconazole it isn't able, or, and never was able to treat it.*

Lydia was then prescribed a suppression therapy course of nystatin pessaries. She found using these difficult as they irritated her vulvodynia but persevered to complete the 6-month course.

> *I find it really difficult to take the pessaries because I find that they really flare up my vulvodynia. I put them in at night reluctantly, which is difficult when you*

> *feel sort of anxious about it because you know the next day you're going to be in pain with the with the remnants of the pessary, the rest of it coming out always caused me quite a lot of pain with my vulvodynia.*

After a year-long experience with persistent thrush, Lydia's test finally came back negative. When I interviewed Lydia, she no longer had persistent thrush, but her symptoms of itching, burning and pain associated with vulvodynia have remained. Her care journey with thrush focused on addressing the test results, but not on remedying the symptoms which existed within a complex web of multiple vulvovaginal health conditions.

Lydia said that the resolution of her recurrent thrush, coincided with closing a chapter on her interdisciplinary care relationships.

> *My gynaecology and dermatologist actually told me that they were going to be putting me on something called 'patient-initiated appointment', so it... I suppose you could say it is like a semi-discharge from their services, so at any time if I want to see them, I can call them up, or if I have any issues again with recurrent thrush*.

> *When I left the hospital, I felt two different ways: one part was very anxious because the cocoon of professionals that I have built over the last four years was breaking in my head. But the other side of me is going, 'actually I understand,' because no medication, with regards to gynaecology, has helped me.*

Despite continuing to live with vulvovaginal discomfort, Lydia said that she has begun to see improvement which she attributes mainly to psychosexual counselling.

> *Actually, what's beneficial for me is the psychosexual therapy – that's what I've made great progress with, and now that the thrush has gone, what I'm keen to get back to is the physio.*

In her account, Lydia acknowledges how she had the social capital, language and confidence to self-advocate for a care team that took her seriously. This meant that her multiple vulvovaginal health conditions were addressed together and not separately, or one at the cost of another. Lydia highlights how professional knowledge, being 'lucky' and having a strong community allowed her to navigate her

persistent thrush journey. While her persistent thrush has resolved, her symptoms still persist, leading to complexity of what truly constitutes the resolution to this account.

7.4 Discussion

This chapter uses three individual case studies from my interview data to gather insights on how recurrent thrush interacts with other health conditions and intersectional identities. By re-visiting the data through a different lens, I re-explore themes from past chapters around bodily experiences, healthcare encounters and diagnostic challenges. Therefore, this chapter offers new insight by leaning into the complex layers and multidimensional aspects of experiences.

Recurrent thrush has been presented in the literature as a condition siloed from other health conditions and identities (Ford et al. 2024). However, the three accounts considered in this chapter demonstrate how people were navigating recurrent thrush within a larger social, structural and bodily experience. This chapter challenges the tendency in health research literature to present a health condition in isolation from other health conditions, identities and bodily experiences. Focusing on a single health condition has merit in being able develop a deep understanding, interpret results and provide specific recommendations to improve care. However, by treating recurrent thrush in a silo, this neglects the complexity of how it exists within people's bodies, lives and how they present to healthcare professionals.

Each identity and health context occupied by participants – whether it be Teddy's non-binary gender, vaginismus and diabetes, or Nysha's Black Caribbean ethnicity, chronic illnesses and depression – interact with their health in ways that create

unique challenges or – as with Lydia's multidisciplinary care arrangements, advocacy experience, and profession insights – and advantages. These findings are also relevant for the other participants. Recurrent thrush has been shown to be a condition that impacts people's lives on multiple levels that all may need to be addressed to provide relief.

Comparing accounts

All three participants explained how navigating multiple health conditions and identities exacerbated the challenges of living with recurrent thrush, underscoring its interconnected nature with some other health conditions. For Nysha, the combination of chronic illnesses like fibromyalgia, hidradenitis suppurativa, and recurrent UTI amplified the physical and emotional toll of recurrent thrush infections. She described the frustration of managing multiple conditions and the de-prioritisation of recurrent thrush. Teddy's diabetes made them more likely to develop recurrent thrush, but their vaginismus also complicated its diagnosis and management. Meanwhile, Lydia's account revealed how her interconnected conditions (vulvodynia, vulval dermatitis and recurrent thrush) were better addressed through a multidisciplinary approach, demonstrating the benefits of integrated care. Although Lydia's care took place within secondary care, there are learnings here that can be applied to primary care. These accounts highlight the cumulative burden of managing multiple conditions and recurrent thrush, and the need for conditions to be treated in combination rather than in isolation.

Each individual presented a unique relationship to healthcare systems, shaped by their past experiences and trust with medical professionals. Unable to yet have swabs taken, Teddy relies on over-the-counter medication and self-management. Nysha

struggled to find continuity of care and the explanations she had needed. Lydia, in contrast, had access to a specialised care team of a dermatologist, gynaecologist, pelvic floor physiotherapist and psychosexual counsellor as a result of her other conditions (vulvodynia, vulval dermatitis). She described having to "fight" to put this care team together and recognised that many other people would not have similar access. Her role as an assistant practitioner may also have influenced her ability to advocate for herself and to resolve persistent thrush within a year, although her vulvodynia meant that symptoms were ongoing.

Further, the accounts present different approaches to communicating with healthcare professionals. Nysha felt a lack of information and open communication hindered her healthcare experiences. On the other hand, Teddy wanted minimal conversation with pharmacists and to receive medication discretely. Meanwhile, Lydia was able to have open, multifaceted conversations with multiple healthcare professional with whom she had developed ongoing relationships for over four years and who sometimes offered joint appointments.

Nysha, Teddy and Lydia's accounts illustrate how intersectional identities shape healthcare experiences and outcomes. Nysha, a Black Caribbean woman, highlighted cultural taboos surrounding vulvovaginal health, which had at one time limited her ability to discuss recurrent thrush with her family. She also found these difficulties with communication regarding healthcare professionals. As a non-binary person, Teddy worried about being misgendered during pharmacy visits and felt excluded by cis-centric online forums, highlighting a lack of online support for non-binary individuals navigating vulvovaginal health issues. In contrast, Lydia, an assistant practitioner with strong self-advocacy skills and access to a multidisciplinary team,

described a more positive healthcare experience, seemingly underscoring the role of privilege, information, and confidence in navigating healthcare systems. Together, these accounts illustrate how intersecting identities significantly influence access to care, stigma, and support networks in managing recurrent thrush. Further, they highlight how online spaces were used to overcome some of these challenges, find information, and generate conversations.

7.5 Concluding remarks

By examining three case studies of interviews, this chapter explored the multidimensional, intersectional and layered nature of recurrent thrush. This approach provides insight into how individual experiences exist within a larger context that shape healthcare encounters and outcomes. It emphasises the need for care that acknowledges the overlapping needs and complexity of people's health and identity.

Recognising the challenges with accessing information, benefits of online communities, and addressing stigma, the findings presented in this thesis were used to create a multimedia resource for patients and healthcare professionals on the HEXI platform. The potential impact of this research and its dissemination are discussed in the next chapter.

It does mean a lot to be interviewed and actually be heard and you know that your experience might be used to try and make things better for other people
– Imogen

8

Creating a Multimedia Resource for the Health Experience Insights (HEXI) Platform

Contents

8.1 Introduction

Increasingly, calls are being made for health research to generate impact through demonstrable contributions to society, individuals, communities, and organisations (NIHR 2025). This chapter contributes to ongoing discussions on how best to transform study findings into impactful resources by critically examining my dissemination process of creating an online multimedia resource.

This thesis sought to answer the question: "What are the experiences of patients and healthcare professionals managing recurrent vulvovaginal thrush, and *how might these insights underpin improvements*". While earlier chapters have focused on understanding patient and healthcare professional experiences, this chapter focuses on the process of translating these insights into practical tools used to improve patient experiences and healthcare practices.

In this chapter, I explore how the interviews conducted with patients – which form the basis of the analysis presented in Chapters 4-7 – were also used to create a public-facing online multimedia resource for the Health Experience Insights (HEXI) platform. This resource aligns with the overarching approach of this thesis in patient-centred research, inclusion, and generating insights for improvements. It also underscores the goal of this thesis to improve patient experiences and better inform healthcare professionals. By reflecting on creating and disseminating this resource, I explore the methodological and practical considerations involved with balanced rigorous qualitative analysis with generating accessible and impactful outputs.

8.2 The need for online resources on recurrent thrush

Research participants report a strong preference for receiving study findings, especially regarding health research, to feel a sense of ownership over the research and foster a reciprocal relationship with the researcher (Purvis et al 2017). Online resources are a powerful tool for those living with health conditions, especially those couched in stigma, shame, and silence such as vulvovaginal discomfort (Lupton 2013). In my systematic review (Chapter 2), a lack of accessible and comprehensive information about recurrent thrush was identified. Too often, recurrent thrush research was framed through the lens of acute thrush, and this rings

true for online resources. In interviews, participants said recurrent thrush was often side-lined as a subsection to acute thrush (both metaphorically in public perceptions, and literally in national guidelines and patient-facing websites). Therefore, I sought to centre recurrent thrush with the HEXI website, not as a subsection of acute and episodic experiences, but as a distinct condition that deserves attention in its own right.

8.3 The Health Experience Insights (HEXI) platform

HEXI (Health Experience Insights) is a website that presents analysed interview collections from qualitative health research. It aims to help others by seeing, hearing, and reading about other's health experiences. Each section features a specific condition, offering thematic analyses alongside video, audio, and written clips from interviews.

HEXI was created out of the DIPEx project (The Database of Personal Experiences of Health and Illness) which was originally established in 2001 with the aim to "describe the widest range of individual experiences from the patient's point of view and to provide a rich information resource for patients affected by diseases and for those who look after them" (Herxheimer & Ziebland 2003). The HEXI platform is published by the Nuffield Department of Primary Care Health Sciences (NDPCHS) at the University of Oxford and based on research from the Medical Sociology & Health Experiences Research Group (MS&HERG) and our close collaborators in other universities. It currently comprises 115 sections on different health and illness experiences based on rigorous qualitative research. The process of creating a website for HEXI is outlined in a *Researchers Handbook*, providing guidance on how best to write, format, and structure sections.

I chose a HEXI output for this study as it offered an accessible platform to disseminate my findings that were patient-centred and contributing to larger discourses on gendered health. There are currently 17 modules focusing specifically on women's health and more are forthcoming, but none had previously focused on thrush or recurrent thrush. I saw strength in adding my study to an existing collection that is widely recognised, instead of building and promoting a new platform. I saw the HEXI platform as a way to create a useable resource for patients and healthcare professionals that is long-lasting and influential. Previous modules have been used to support patients, train healthcare professionals, and inform policy, and the datasets used in secondary research analysis (Ziebland & Hunt 2014).

8.4 Creating a public-facing multimedia resource

Creating the HEXI resource began with rigorous qualitative research methods and analysis described in Chapter 3 (Methods and Theory). I completed the HEXI resource between winter 2023 and spring 2024. The website section was published in November 2024 (link available here: https://hexi.ox.ac.uk/Recurrent-Vulvovaginal-Thrush/overview).

After patient interviews, participants could choose whether they preferred to appear on the website in video, audio, or text-only formats. It was emphasised that all formats were equally welcomed. However, the prominence of video recordings shown in other HEXI resources could have impacted participant decisions.

Participants could decide to remain anonymous or not. If they did not want to use their first name, they were asked to choose a pseudonym to represent themselves. Some people chose to remain anonymous, but for others it was important to feature

their real first name. Participant decisions were not limited to a binary decision between full anonymity (with just written text) or full identifiability (with their first name and video presence). Instead, participants made nuanced decisions about which aspects of their identity were represented or omitted. The various ways that people chose to represent themselves included having their voices present but not their image, or having their name present but an actor stand in for their voice.

After conducting patient interviews, I designed a site map with key topics raised in patient interviews with input from patient representatives, my supervisors, and the study advisory panel. Each topic was then transformed into a 'topic summary', written to capture the full range of experience or views of those interviewed so that anyone in a similar situation should find experiences akin to their own. The focus of this project was to represent the widest practicable range of patient experiences (Ziebland et al. 2021).

The homepage of the resource features a description of the study and a montage video with clips from various participants and provides a preview into the themes available to explore. Then each topic summary acts as an individual webpage offering a wide array of perspectives. In the 20 topic summaries produced, patient interviews were carefully analysed, and I arranged video, audio, and text clips reflecting the full range of experiences covered in the study. Over 200 excerpts from the interviews were extracted and embedded throughout the resource.

I created the HEXI resource after I had interviewed patients, but before I interviewed healthcare professionals. The resource brings together insights from patients but does not integrate findings from my data collection with healthcare professionals. Instead, putting patient and healthcare professional perspectives in

dialogue is explored in the findings chapters of this thesis and publications. A healthcare professional perspective was, however, provided through "Doctor Speaks" clips, where a GP and I wrote and recorded clips to add context or clarification to the patient interviews. Topics included explaining how to make a physical examination more comfortable and the importance of ruling out potential underlying health conditions.

My supervisors took on a reviewer role as a "research buddy" where they were given an analytic coding report for a specific theme and a topic summary draft to compare and edit. This process ensured that there was coherence between the empirical data and my analysis. For one of the topic summaries, my supervisor Dr Abigail McNiven and I switched roles where she drafted a topic summary (TS: Sex and relationships) and I went through the buddying process.

The development of the HEXI resource was also guided by a panel of experts on recurrent thrush (including those living with it) as well as charity representatives and clinicians. We met after a third of the patient interviews had been collected and again while I was half-way through writing topic summaries. Advisory panel members helped identify topics for interviews, design recruitment strategies, review the sample, and suggest revisions for the site map and topic summaries. Meetings were held in September 2022 and November 2023. All topic summaries were reviewed by one or more members of the advisory board and patient representative group for clarity and accuracy. Assigning topic summaries to advisory panel members was based on their expertise.

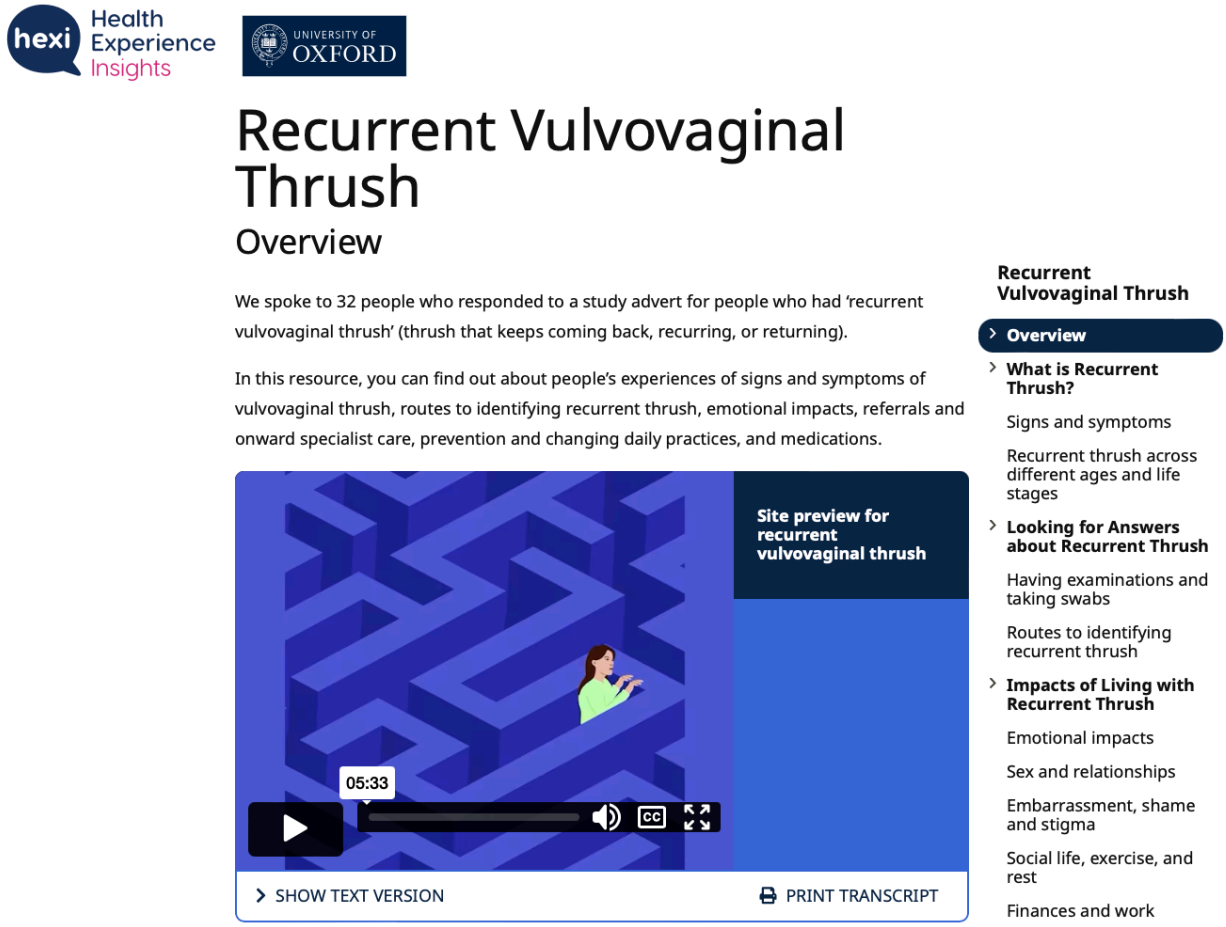
Table 7: Advisory Panel Members

Advisory panel members
Dr Riina Rautemaa-Richardson, Senior Lecturer in Infectious Diseases and Medical Education in the Institute of Inflammation and Repair, University of Manchester
Dr Caroline Owen : Consultant Dermatologist, Chair of British Association of Dermatologists Vulva Workstream, Education Lead for BSSVD
Dr Sharon Dixon, NIHR Doctoral Research Fellow and General Practitioner
Professor Claire Anderson, Professor of Social Pharmacy, University of Nottingham
Dr Jillian Pritchard, Consultant in Genitourinary Medicine and Sexual Health
Dr Claudia Chisari, Vulval Pain Society Representative, Vulvodynia Researcher, CEO of Femspace
Two members of the patient advisory group were also present at every meeting including Bethan, Corina, Jessica, and Patti

Alongside the topic summaries which featured patient interview clips, I also represented patient accounts through 'biographies' which provided individual summaries (See examples in Appendix 1). These summaries were reviewed and approved by participants who took the opportunity to make any changes to redact, correct, or clarify the content. It was this process that also piqued my interest in further exploring whole patient stories through narrative analysis in Chapter 7.

While qualitative research often focuses on highlighting the words of patients through lengthy quotes and blocks of text, it is rare to include actual clips of participant voices (Chandler et al 2015). By including audio and video clips of participants, the audience was able to engage with participant accounts in visual and auditory ways often not afforded through traditional research dissemination.

Figure 19: Preview of the HEXI resource on recurrent vulvovaginal thrush



8.4.1 Writing in accessible and inclusive language

A key pillar of the HEXI website includes the use of accessible plain language, and writing in a simple and clear manner (Stableford & Mettger 2007). This method has been shown as a promising avenue for improving the public's understanding of medical information and addressing current challenges with health literacy (Stableford & Mettger 2007). However, this process is not necessarily easy as "The process of developing plain language materials requires knowledge and skills; a clear understanding of the target audience" (Stableford & Mettger 2007). The process of writing in plain language was sometimes difficult, as it meant challenging my own assumptions and recognising which terms might not be widely understood by the public.

An important decision for the HEXI resource was the use of the gender inclusive language also used throughout this thesis. I used terms like “people who experience recurrent vulvovaginal thrush”, and “the people we spoke to”. This helped ensure that gender diverse people did not encounter the gendered language often present in resources that only refer to women (including current thrush guidelines from NICE and BASHH, and online resources from the NHS).

However, a challenge with using gender inclusive language for a public audience was that using anatomical terms such as “people with vulvas” or “people with recurrent vulvovaginal thrush” might be inadvertently inaccessible. A 2022 study found that 71% of UK women were able to correctly identify the vagina in a diagram and 49% could identify the labia (El-Hamamsy et al. 2022). I therefore had to carefully consider the language used and balance being inclusive with being accessible. To do this, I offered definitions of terms (such as the vulva, vagina, cervix) and chose accessible terms where possible.

8.4.2 Considerations around presenting patient accounts

Throughout the creation of the HEXI resource, a key concern was around preventing the spread of misinformation or contributing to misunderstandings. One of the key areas of concerns raised by the advisory panel and my supervisors was around diagnosis. Questions arose around how participants would be defined and there were worries about possibly including people who may not have recurrent thrush, since a number of different conditions cause symptoms which are often ascribed incorrectly to recurrent thrush.

A member of the advisory panel suggested that I only speak to individuals with a diagnosis through microbiological testing. However, I saw importance in capturing the experiences of both those who were able to receive a diagnosis, but also those who had not yet engaged (or had disengaged) with healthcare for various reasons, or were facing difficulties with diagnosis. However, I also acknowledged that it was possible my results could include people who did not have recurrent thrush or had multiple conditions that needed to be addressed.

Therefore, throughout the resource, I present information on other health conditions (such as lichen sclerosus) that present similarly but are often missed and misdiagnosed as recurrent thrush. To address concerns around representing the sample on the HEXI website, relevant topic summaries about signs, symptoms, and diagnosis also included the following disclaimer:

> *We present first-hand accounts from individuals who responded to a study advert for people who had 'recurrent vulvovaginal thrush' (thrush that keeps coming back, recurring, or returning). The symptoms of vulval and vaginal discomfort can be caused by a variety of conditions. Therefore, these accounts represent a range of experiences which include thrush, but may also include other conditions that contribute to or exacerbate the symptoms described.*

These conversations helped guide my thinking and identify an opportunity to further investigate current diagnostic journeys with recurrent thrush, and this became the focus of Chapter 6.

8.4.3 Presenting accounts with authenticity and sensitivity

Patient experiences as shared on the HEXI website are essentially deconstructions of individual narratives that are then (re)constructed to form a collective experience (Koschack and Himmel 2018). In doing so, the researcher and the participants are

both ‘creators’ trying to tell a coherent yet nuanced account (Koschack and Himmel 2018). Therefore, I had to make several decisions around how best to construct the website, especially around what to include or exclude.

It can be difficult to avoid over-use of those participants who shared vivid, plentiful, and powerful accounts, and I had to pay close attention to also featuring those who were more hesitant, cautious, or reserved in their interviews.

It was important for me not to sanitise people’s accounts when they spoke explicitly about their experiences (a topic also explored in Chapter 4). This meant, for instance, including clips of individuals speaking about the challenges of recurrent thrush with oral sex, descriptions of how individuals attempted to remove their excessive discharge, or the sensation of scratching skin until it bled. These clips could make viewers uncomfortable and often fell into areas that others might find too uncomfortable to discuss. However, omitting them would have further censored individuals who had already expressed that these issues were difficult to vocalise.

I also sought to not sensationalise patient stories. I was careful to not take patient quotes out of context or use them in an inflammatory or provocative manner. Instead, I provided context around clips with headings and surrounding text.

8.4.4 Balancing positive and negative experiences

Another tension that ran throughout creating the HEXI resource, and in this thesis, was balancing the presentation of positive and negative accounts.

While all research interviews involve performance and self-presentation, this may be even more relevant for studies with intended public outputs (Lucius-Hoene et al.

2018). During interviews, participants sometimes spoke to an 'imagined' audience of the public or other patients who would potentially listen to their interview. This was particularly relevant when asking participants if they had advice for other patients. For instance, Sophie shared that she had been experiencing thrush for "*half a lifetime*". However, when asked what advice she had for others, she stated: "*Don't tell them it's a 20-year journey; I would never have wanted to know that as a teenager*". This quote highlights a potential conflict between sharing openly while also being conscious of how it could affect future listeners.

Similar concerns were present among the patient representative group who thought it was important to share difficult or challenging realities of recurrent thrush, but also did not want to "scare" readers or make them feel "hopeless". Patient representatives also reviewed the content and flagged areas they felt could lead to despair if not balanced with other perspectives or experiences. Trying to start and end a topic summary with a positive perspective was one approach I took that has been used by others (Koschack and Himmel 2018). However, this was not always possible.

This consideration also extended towards an intended audience of healthcare professionals. Patients spoke frankly about negative experiences, and it was important that these be captured. However, if healthcare professionals felt that participants were being overly critical or unfair, this could cause defensiveness and a lack of engagement with the resource (Hinton et al. 2018). Therefore, I took caution to create materials that would facilitate conversation between patients and healthcare professionals and build opportunities for better communication. This involved having topic summaries shared with healthcare professionals for their feedback.

8.4.5 Innovating imagery: Creating GIFs

Considering how best to represent participants was something I considered not only regarding interview clips, but also the images used throughout the HEXI resource. Previously, when participants have preferred not to have their video or image on a HEXI website, generic images or videos have been used to play alongside audio recordings. Example imagery has included footsteps, nature, or actors. Potential drawbacks of using images unrelated to the condition include an impersonal presentation or limited differentiation between participants. I therefore saw an opportunity to innovate by adding a new element to the HEXI website: personalised images co-created with participants to represent their stories visually.

The images were not interpreted to generate new analyses but instead to illustrate existing findings. Arts-based knowledge translation has been used to disseminate findings in a way that is "a creative, complex and dynamic process, rather than one that is passive or linear" (Parsons & Boydell 2012). Instead of creating still drawings, I sought to explore animated avenues that would enliven patient accounts. Animation can "bring into view what cannot be captured by a camera – the oneiric, the absurd, the surreal" (Morelli 2021: 340). Further, I wanted a format that would capture the repetitive, cyclical, and oftentimes seemingly endless nature of recurrent thrush experience that was spoken about in interviews. I chose to create animated GIFs (Graphics Interchange Format) which involve a sequence of digital frames to create an infinite image loop. The GIF seamlessly blends image frames together, making it difficult or impossible to identify a clear start or end point (Miltner & Highfield 2017).

A previous study on chronic vulvovaginal thrush (Morgan et al. 2009) had participants draw images to represent their health experience. However, while participants may have had a distinct image in their head, a lack of artistic experience or confidence might make it difficult to execute. In Morgan et al.'s (2009) study, the drawings produced by participants presented similar styles often using pencil drawings with simple designs and stick figures. Recognising this challenge, I decided to recruit a graphic designer to help bring participant stories to life without this limitation. I selected a graphic designer for this project (Julie Winegard) based on her extensive GIF-making experience and feminist subject matter. I was familiar with this process as I worked with a graphic designer to co-design images for patients who published their accounts on Medical Herstory's online platform.

Creating GIFs with participants was optional, and when agreed involved multiple drafts, iterations, and edits to images until participants fully saw themselves represented. I had a phone, video call, or email exchange with participants about what imagery appeared when they thought of their experience. I inquired into any colours, symbols, or wording they would like included. Participants offered various levels of guidance, with some offering a single sentence while others offering 4-5 detailed ideas. I then sent their ideas to the graphic designer who created rough drafts based on participant ideas. At this stage, the participant was able to provide feedback and make changes before the next draft. They then offered feedback and requested various levels of changes to the images. Examples of these exchanges are represented below (Figure 25 and 26).

Images were accompanied by audio recordings from interview clips. Sometimes this was the participant's own voice. Other times, participants opted for a stand-in to read

their clips, and my colleagues volunteered to lend their voices to this project. Matches between ethnicity and age were made when possible. In one case, an AI-generated voice was used.

Seven participants were content to be shown on video, 12 chose to not be on video but have their voices used, and 13 chose to have neither their video nor audio used but were happy for someone else to read aloud their clips. I emailed participants who had preferred their interview to be featured as audio or text clips rather than video recordings. Nine participants replied that they would like to design the image. Four asked for patient representatives to design their image. Two participants said they were not interested and 11 did not reply, but all gave prior permission for their interview to appear on the HEXI website.

Adding a graphic designer helped participants to be able to ideate without limitation and see their image appear. Yet, there are of course potential limitations with using a graphic designer as a third-party to create art. Elements of participants' designs may have been lost in communication, or mis-represented. Frequent check-ins and gathering consistent feedback were intended to mitigate this problem.

Some participants preferred others design an image on their behalf. For these cases I held a patient representative meeting where we brainstormed representations of recurrent thrush. Suggestions included "a maze you can't get out of", "feeling dirty, washing hands constantly, asking will I ever be clean?", and "seeing the light at the end of a tunnel". Patient representatives did not want to portray overly pessimistic images or unrealistic ones such as flowers or fruits that may representing sanitised presentations of genitals.

When we did not hear back from participants, we opted to create generic images with elements pulled from other designs. These included: images of swabs, medication, and underwear. We chose to have doors opening and closing around these images to illustrate the ongoing nature of opportunities and challenges presenting themselves.

Including creative images for the HEXI website helped provide a new way to understand, illustrate, and translate research findings. The complete collection of creative images is found in the Appendix.

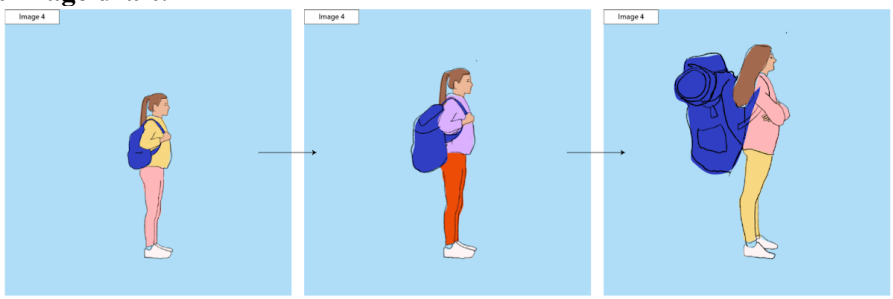
Figure 20: Example of creative image process: Imogen

1. Imogen's Image

Idea sent to graphic designer after conversation with participant:

The shame and invisible baggage. Growing up it felt like a "weighty backpack of shame" to carry but that nobody else could see. There would need to be an age progression from childhood to teenage years with the feelings of shame developing slightly later on.

First image draft:



Stop motion - getting older and backpack getting bigger and heavier

Participant feedback:

I think that the backpack should be transparent - maybe just the outline? It would be good to see the figure having to bend a little because of the weight, perhaps with head angled down a bit in despondence? I felt the weight of the shame most keenly around peers, so perhaps the first two could be in a school uniform? Lastly, for me, I don't feel like the backpack changed size that much, particularly on reaching adulthood. So if the change could be a bit less extreme! Wonder whether we could explore having one or two words in the backpack as I do feel the shame changed shape!

Second image draft:

Participant feedback: Much better, though feels like the extent of the leaning forward in the third one is a bit overkill! And that rucksack could be a bit bigger. Shame, fear, and disgust come to mind for words inside.

Final GIF:

Figure 21: Example of creative image process: KJ

2. KJ's image

Idea sent to graphic designer after conversation with participant:

Convey an emotion that having thrush is okay and alright and that people should not be afraid to reach out for help. The participant also wants to represent that it's okay to talk about it and said that a loudspeaker or radio could be a symbol of this. They would like to see the gender-fluid flag incorporated into the image whether that is through the background, an actual flag, or the colours in the flag being used.

First image draft:

Message to participant:

The designer said that the lines coming out of the speaker could instead be icons or symbols for feelings. Let me know if you like that idea and what feelings or symbols we could represent.

Participant feedback:

I love this and I think symbols coming out would be amazing! Well done you guys! The subtle gender fluid flag is awesome. Would emojis help at all for the symbols? For the feelings. Relief emoji sad emoji frustration emoji?

Final GIF:

8.5 Dissemination and impact

The HEXI resource has thus far been disseminated through an event with the Vulval Pain Society to over 200 patients and healthcare professionals and a health literacy campaign with infographics to Medical Herstory's 5,000 followers. It has been embedded on the Bristol Vulval Pain Support Group website, the Lichen Sclerosus Guide website, and the Tight Lipped resource guide. It has also been included in the new recurrent thrush template for Get It Right First Time (GIRFT) Advice and Guidance (NHSE outpatient transformation).

The resource was shared with participants, and they provided feedback. One participant said: "*I've been reading through the section on recurrent thrush and have discovered things I did not know. I'm even wondering whether to start returning to the GP when it occurs to get swabbed*". Another commented:

> *It looks great! There's so many stories. There's very similar themes running through them of not getting the right help within a sensible time frame. I hope this helps people and helps educate medics*.

The website respects that participants have ownership over their own stories and are permitted to request edits to the website at any point (including removing clips, changing names, or adjusting how they are represented whether it be video, audio, or text clips). One participant followed up after the website was published that hearing her own voice was difficult and requested to have an actor re-record her clips and remove one about her partner; this was done promptly.

The HEXI resource fits within a larger dissemination strategy of this research, underscoring the importance of bridging academic research and real-world practice. Throughout my doctoral study, I disseminated findings through a wide range of dissemination routes including publishing academic papers, presenting at

conferences, writing blogposts, and newsletters. I also hosted multiple events online and in-person about vulvovaginal health and created social media campaigns on recurrent thrush. This varied dissemination strategy was used to ensure that findings gathered during this study could be accessible to the widest audience possible.

8.6 Concluding remarks

Using interviews from my doctoral study to create a public-facing resource is a key output from this study. The website offers patients, healthcare professionals, and trainees a dedicated resource about recurrent thrush that captures diverse understandings, approaches, and outcomes for navigating this health experience. Writing, revising, and deliberating the HEXI output meant that I had a strong grasp of my data and the themes within it which helped inform the in-depth analysis that is featured in this thesis.

Further, the new section on the HEXI resource centres the issue of recurrent thrush and provides a comprehensive profile of this condition, not as a subsection of acute thrush, but as a distinct and impactful experience. By being rooted in rigorous research methods, and reviewed by experts, the resource offers reliability and credibility. Written in plain, accessible, and inclusive language, this resource seeks to engage a wide audience. This website is a key contribution from this study, helping patients feel more informed, empowered, and supported in managing their health condition, and providing healthcare professionals with valuable insight into patient experiences to improve care.

This chapter has illustrated how creating a multimedia resource enabled research findings to be translated for patients and their healthcare professionals.

In the next chapter, I conclude this thesis by further pulling together how this study underpins improvements by delving into what this study adds, and presenting recommendations for researchers, clinicians, patients, and policy makers.

9

Discussion & Conclusion

Contents

9.1 Introduction

In this final chapter, I outline the key contributions made by this thesis. I describe how this research adds to existing knowledge by expanding previous literature, informing practice, and generating impact. I highlight the strengths and limitations of this programme of work and suggest further research directions. I then place my thesis within a wider conversation around gender health equity and offer some final reflections as a lived-experience researcher.

9.2 What this study adds

This doctoral study explored how patients and healthcare professionals experience and manage recurrent vulvovaginal thrush and how these insights could underpin improvements in clinical care and self-management. Each findings chapter offers new empirical understandings and theoretical engagement, with implications for both healthcare professionals and patients.

A cross-cutting theme of this thesis is that recurrent thrush cannot be understood as simply acute episodes on repeat. Instead, it is a distinct experience which requires specific attention in research, practice, and patient information. My findings demonstrate that recurrent thrush is much larger than the sum of its episodes.

The recurrence of thrush presents a shift where a condition that was once temporary and transient, becomes enduring and overwhelming. The shift here in temporality, fluctuating timelines, and uncertain prognoses of recurrent thrush leads it to occupy a boundary-spanning space where it does not fit neatly into pre-defined categories or frameworks. It is a "messy" condition not only due to its physical realities but also because of its nonlinearity, ambiguity, and fluid nature. This thesis traces how recurrent thrush is characterised by nonlinear pathways and feedback loops, with unpredictable symptoms requiring approaches that embrace complexity and account for interconnected variables. Ambiguity and uncertainty are central to the experience of recurrent thrush, arising from competing understandings, goals, and perspectives. The condition involves dynamic, fluid phenomena that evolve over time and resist static categorisation, often exhibiting emergent properties from interactions among various factors. Consequently, individuals exist in a perpetual state of waiting,

anticipating the recurrence of thrush and navigating its implications for their bodies, healthcare journeys, and management strategies.

My systematic review (Chapter 2) highlights that recurrent thrush has largely been understood through the lens of acute experiences – with the research literature often framing repeat episodes as an additive experience of one-off thrush. Unclear participant samples meant that recurrent thrush was often lumped into studies on acute cases or inserted as a footnote or considered as an outlier experience. It was this context that became the springboard for my research to address this gap and centre recurrent thrush as a distinct and unique experience presenting interwoven uncertainties that repeatedly present for patients and their healthcare professionals.

As discussed in the Methods and Theory chapter (Chapter 3), my research is foregrounded in qualitative methods, feminist theory, and centring the lived experience of both interviewees and patient representatives who guided this study. While remaining patient-centred, this thesis brings these voices together with those of healthcare professionals. In doing so, I gather a fuller picture of recurrent thrush experiences, often overlooked by only focusing on one perspective. I was able to ask both groups about the same situations, challenges, and concerns and hear about how they may be perceived, approached, or understood differently. This approach allowed for more informative thinking about how to support better delivery for primary care.

In Managing the Mess (Chapter 4), I emphasise how previous research has focused on emotional and mental aspects of recurrent thrush but overlooked the material and physical aspects of managing this condition. This chapter helps draw attention back to bodies and the material messes they produce which is often overlooked in health experience research. This was especially important for me, addressing a topic that is

often labelled as “gross” or “disgusting” to acknowledge how these perceptions led to self-monitoring and management on material, microbial, and gendered levels. In doing so, I hope to show the reality of embodying a ‘leaky’ body without sanitising or censoring these experiences. This opens up possibilities to work towards de-stigmatising this condition to facilitate discussing the condition with support systems and healthcare professionals. This research contributes to discussions on the material and social realities of living with conditions that provoke feelings of shame or embarrassment. By centring the embodied experiences of recurrent thrush, we can work towards breaking down stigma and fostering environments where individuals feel able to seek care without fear of judgement. These insights are not only relevant to research, but also serve as a call to action for more inclusive and comprehensive approaches to medical education, policy, and practice.

In Accumulative Experiences (Chapter 5), I trace how these bodies then move through healthcare pathways. In exploring the role of both primary care and sexual health, I was able to highlight discrepancies between systems, but also commonalities in what patients desired from their care providers: to be taken seriously, for gender health inequities to be acknowledged, and for trusting relationships to be built. This chapter offered insight about how healthcare professionals and patients could better work together through acknowledging recurrent thrush as distinct from acute cases, building clear follow-up plans, and providing continuity of care whenever possible. Examples of positive encounters with care highlight how slight changes in language, offering validation, and managing expectations can make a large difference in patients feeling taken seriously and encouraged to return for care. This chapter also highlights the collaborative role that patients can play in self-advocacy, recognising

patterns, and understanding systemic barriers that might make remaining engaged with healthcare more difficult. This chapter opens up an opportunity for materials to be created to support implementation of follow-up plans, communication training for healthcare professionals, and resources for patients to build self-efficacy in advocating for themselves.

Looking at diagnosis (Chapter 6), I explore what patients and primary healthcare professionals identify as important considerations when assessing possible recurrent thrush. This chapter draws on how bodies once again enter healthcare settings for examinations and investigation through the lens of 'candidacy'. It highlights key moments where healthcare professionals and patients come to recognise (or not) recurrent thrush as a distinct health experience. This line of inquiry highlights current diagnostic challenges and opportunities to generate improvements such as creating accessible diagnostic pathways, awareness about overlapping conditions, and breaking unhelpful cycles where patients self-treat before diagnostic testing.

The narrative chapter (Chapter 7) takes a different approach to three interviews, by looking vertically into a few individual experiences, instead of horizontally across the entire data set. I demonstrate the complexity of recurrent thrush as it is embedded within the context of other health conditions and intersectional identities. This allows for recurrent thrush to be understood within a larger health context and recognise how patients will present to clinicians, not as a single clear condition or diagnostic label, but as complex people with multiple lived experiences.

9.3 Creating impact through HEXI

The HEXI (Health Experience Insights) resource, detailed in Chapter 8, is a key contribution from this study that has allowed my research to have practical implications and impact beyond academia. A need for clear, sensitive, and specific information about recurrent thrush was identified across literature and in interviews. I created an online resource that provided balanced, relevant, and accessible information about recurrent thrush intended for a variety of audiences including patients and healthcare professionals. The website, now available (https://hexi.ox.ac.uk/Recurrent-Vulvovaginal-Thrush/overview), is a dedicated resource which brings together all the insights gleaned from analysis of the interviews that may be helpful to others with similar experiences, and to inform clinicians, researchers, educators, and policy makers.

The HEXI resource grapples with recurrent thrush in its complexity, not alongside or as a footnote to acute thrush. In doing so, it recognises recurrence as a distinctive condition that influences every aspect of the health experience. The resource shares details of the material and social aspects of recurrent thrush, diagnostic challenges, experiences of care, and highlights areas for improvement. These are all areas which were identified as gaps in research and addressed throughout this thesis.

The resource does not provide a homogenised experience, but instead insight into the various ways people experience recurrent thrush, the challenges they encounter, and solutions they attempt. By providing balanced, accessible, and practical information, the HEXI resource provides insight often reported as missing from health information, educational materials, and online resources by patients and their healthcare professionals. My hope is that the HEXI resource will improve the

experiences of patients and inspire other resources to be made available on recurrent thrush and vulvovaginal health.

9.4 Strengths and limitations

This study has taken a broad approach to recurrent thrush by including people of varying ages, ethnic backgrounds, and gender identities. It brings together experiences of both patients and healthcare professionals to identify areas where understandings may differ, and where improvements could be made. Additionally, I analysed the experience through multiple lenses using theories of 'leaky bodies', care pathway modelling, the candidacy framework, and case studies.

By using narrative and semi-structured sections in the interviews, I was able to develop an in-depth understanding of recurrent thrush experiences and identify areas for impact. However, there are limitations with my research as single interviews represents only a snapshot in time and must be interpreted in this context. Patient experiences are not static, but are ongoing, embodied, and lived. For instance, after interviews, patients shared how their experiences or understandings had evolved even during the follow-up stages of this research, as we were in contact to create animations for the HEXI resource or review the final website. Therefore, these accounts must be read as moments in time, and not the summation, nor final chapter of people's experiences which will continue to change. A longitudinal approach to recurrent thrush specifically, and vulvovaginal conditions more broadly, could be used in future research to capture how people's understandings evolve alongside new bodily experiences, healthcare relationships, and diagnostic labels.

A concern raised throughout this research project by supervisors and advisory panel members was that some participants I spoke to may not have had recurrent thrush but be dealing with another health condition(s). It was important for me to speak to both people who reported a confirmed diagnosis of recurrent thrush and those who self-identified with this condition. This allowed insight to be gained about different points of diagnostic journeys, understandings, and perspectives. The inclusion of participants who thought they had recurrent thrush, but may have had other conditions, can risk misrepresenting experiences. However, it also speaks to the uncertainty and challenges with identifying and isolating this condition. This is a potential limitation of the study but also opens up questions about how people approach a problem and the care pathways they engage with, rather than the cause.

This study was able to capture diversity in terms of ethnicity, gender, location, and various health experiences. However, there are limitations with an interview study on a taboo or embarrassing health condition. Speaking about vulvas and vaginas remains difficult for many, and this is an obstacle to hearing these voices in research. Despite having varied recruitment avenues in person and online, there are some perspectives missing, including gender diverse people from ethnic minorities.

Existing research on recurrent thrush has largely focused on cis-women's experiences. This study is the first to my knowledge to include trans, non-binary, or gender-diverse voices on this topic. Choosing how best to integrate these perspectives was nuanced. It did not feel appropriate to sub-section or bracket off these experiences, but necessary to integrate throughout the entire project. The voices of trans, non-binary, and gender fluid people run throughout all my findings chapters and the HEXI resource. However, in doing so, the specific needs of these

groups may be obscured or more difficult to identify. At times, I felt tension in trying to bring together diverse perspectives through thematic analysis without erasing difference. This is what led to a desire to explore some stories in depth through a narrative analysis in Chapter 7.

9.5 Further research, practice, and policy directions

This thesis opens up new avenues for examining what is missing from research, practice, and policy. Below I present an overarching review of further directions of inquiry and improvement.

9.5.1 Moving towards closing the gender health gap

This study contributes to a growing conversation around inequities within gendered health conditions that differently or disproportionately affect women and people assigned female at birth (including trans, non-binary and gender queer folks). My findings around understandings of the body, self-advocacy and seeking support and information are therefore framed within, and speak to, these larger conversations, and may offer potential ideas for improvement.

This thesis also highlights the need to bring together patient and healthcare professional voices to design collaborative care, instead of falling into antagonistic tropes between the two groups. My findings caution against overly pessimistic approaches to healthcare, while acknowledging the reality that women and gender diverse individuals face additional barriers in getting the care they need and deserve. My study demonstrates that gender health inequity is not a tale of all-powerful healthcare professionals and patients without agency, but instead a system which we can work together to improve.

During interviews, patients compared their experiences with other health conditions that affect people assigned female at birth such as menopause, period pain, or endometriosis which are often downplayed, underestimated, or overlooked. While these issues have received growing policy attention, recurrent thrush has remained unacknowledged in a policy context. My study highlights a need for recurrent thrush to be explicitly named and addressed in policy on gender health needs.

9.5.2 Advancing gender inclusive research and care

My findings highlight the value of including gender-diverse participants in research. Including these voices in my research was paramount to gain a fuller picture of who is living with, and requiring care for, recurrent thrush. Including gender-diverse voices is also necessary to have data that reflects and speaks to (and with) these communities to avoid making recommendations that risk further marginalisation. There were many issues specific to gender-diverse people that were beyond the scope of this thesis but hold rich avenues for inquiry. For instance, what role does gender-affirming care play in relation to recurrent thrush? How do intersecting identities of ethnicity and gender-diversity shape the way individuals experience and respond to recurrent thrush? What resources would best support these groups? Current resources and guidelines on recurrent vulvovaginal thrush address an audience of women and do not include gender diverse people who are also accessing services and require care for recurrent thrush and improvements could be made in these areas.

9.5.3 Embracing and inquiring into 'messy' bodies

In Chapter 4, I explored what a potential 'gyn-ecological' approach might look– one that embraces the exploration of the vulvovaginal leaks and sensations and relationships to one's own internal ecology and microbes. A more embodied, affective, and sensorially attuned framework would allow for a richer engagement with how gendered bodies are lived, managed, and understood.

New avenues of inquiry could be explored, such as:

> *What new perspectives open up when we decouple stereotypical gender narratives from the bodies that experience them to explain health experiences?*

Leaky bodies have been tied to notions of failed femininity and often framed as a lack of bodily control and purity. By decoupling these narratives from the bodies that experience them, we can explore how leaks, sensations, and disruptions are lived across diverse gender identities. This invites a rethinking of trans, non-binary, and gender-diverse experiences of bodily discomfort, illness, and medical treatment, offering a more inclusive and intersectional approach to health and embodiment.

> *In what ways does language of leakage, itch, and dys-appearance offer new analytical tools for understanding chronic and recurrent conditions?*

Leder's (1990) concept of dys-appearance, which describes the return of the body to conscious awareness in moments of disruption, dysfunction, or pain, provides a useful framework for thinking about chronic and recurrent conditions. Just as a leaking body demands attention, sensations like itching, burning, and irritation bring the body into sharp focus. Exploring leaks not just as boundary violations but as demands for attention allows for a deeper engagement with the affective, temporal, and embodied aspects of chronicity, where discomfort oscillates between moments of urgency and invisibility.

What assumptions become evident when we foreground the sensorial, rather than the symbolic, in gender health research?

Much feminist scholarship has focused on the symbolic meanings of the leaky, porous, and fluid body, but what shifts when we turn toward the raw, felt experience of bodily disruption? Centring the sensorial over the symbolic reveals implicit biases in medical and cultural narratives—such as the pathologisation of certain bodily experiences and the feminisation of certain discomfort(s). This approach also raises questions about whose bodily sensations are deemed worthy of medical intervention and whose are ignored or normalised within gendered health discourses.

9.5.4 (Re)Framing recurrence

Recurrent thrush occupies an interesting space where it is often understood as mundane or trivial due to its association with acute thrush. In contrast, this study demonstrates how recurrence fundamentally changes health experiences in ways that deserve attention from researchers, healthcare professionals, and policymakers. I anticipate my findings also speak to experiences of other vulvovaginal conditions that can become recurrent (such as urinary tract infections or bacterial vaginosis) that encounter similar issues of being overlooked, underestimated, and often (mis)understood through an acute and episodic lens.

While recurrent thrush is defined as four or more episodes in a 12-month period, many of the people I spoke to had much more for frequent experiences, with flare-ups often monthly. For some people, symptoms were felt to linger or never truly leave. This study has highlighted not only how recurrent cases differ from acute episodes, but how further research is needed on how “chronic” and “persistent” cases require different investigation, treatment, and management approaches.

9.5.5 Improving diagnosis of vulvovaginal conditions

Recurrent thrush symptoms can overlap with many other vulvovaginal health conditions such as lichen sclerosus, vaginismus, vulvodynia and dermatitis. Untangling the array of different conditions that lead to recurrent or persistent vulval pain requires more clinical and patient-experience research. Clearer information is needed for patients around what conditions present with similar symptoms, and how to work collaboratively with healthcare professionals to rule out conditions and find a diagnosis and a treatment plan that can be actioned. It must also be made clear where testing is offered, by which healthcare professionals (whether it be primary care, sexual health, or pharmacies), and what an effective, accessible, and safe diagnostic pathway would entail. Better diagnostic tools are needed for healthcare professionals, as well more research to establish whether improved access to diagnostics could be more cost effective or used efficiently.

Further areas of research include addressing the rise of commercial self-testing kits and their role, differentiating recurrent from chronic, persistent, or unremitting symptoms, and exploring recommendations for treating and re-testing patients when persistent or chronic symptoms are present to determine if thrush is the (sole) cause of symptoms. A piece of work that clarifies the capacities of general practices and sexual health regarding access to testing such as microscopy, sensitivity and specificity testing is also needed.

9.5.6 Key takeaways

This thesis has outlined recommendations relevant to findings from each chapter and overarching aims of this study. Below I distil three key takeaways from this thesis to support further dissemination among patients, healthcare professionals, policy makers, and researchers.

- **Recurrent thrush is a distinct condition, not simply acute episodes on repeat**: It is experientially different and requires different support needs, investigation, and management plans.

- **Recurrent vulvovaginal discomfort can be managed; it does not need to be tolerated**: Help is available, but clinicians and patients need to establish trusting relationships and work together to find long-term solutions.

- **Recurrent thrush is not a catch-all for vulvovaginal discomfort**: Many conditions can cause vulvovaginal discomfort and different treatment and support – bearing in mind that not all vulval itch is thrush.

9.6 Final reflections as a lived-experience researcher

Lived experience is what first piqued my interest in studying recurrent vulvovaginal thrush and I continue to reflect on how my own journey has evolved alongside my research. My own story with recurrent thrush began a decade ago and has since taken on many forms, labels, and care pathways. While my experiences have influenced my work as explored in Chapter 3: Methods and Theory, I also want to recognise how this research has shaped my own experiences navigating healthcare.

Being a health researcher means that our own bodies and experiences are often influential on this work. Previous work has acknowledged the role of shared experience in research, but has overlooked shared sensations. As Longhurst (2000) puts it, often when researchers call attention to their bodies it has tended to be "theoretical, discursive, fleshless bodies". The materiality of my own body was viscerally felt during interviews. For instance, when participants described the sensations of itching and burning, I could often feel the same sensations crawling on my skin. This shared bodily experience often stood in contrast with the etiquette of online interviews where an interviewer shifting in their chair or appearing uncomfortable could risk the participant perceiving them as disinterested or distracted. In these paradoxical moments, interviewing about discomfort while uncomfortable, I was reminded how research is not simply an intellectual pursuit, but a deeply human experience where our own bodies and emotions often respond.

The start of my DPhil coincided with moving to a new country and navigating a new healthcare system. New information, challenges and understandings emerged as I was simultaneously studying and living with recurrent and persistent vulvovaginal discomfort. However, similar challenges also remained. Often, we believe that our

issues within health systems are specific to the location where we find them. However, having navigated two healthcare contexts in the UK and Canada, I was surprised to see that the biggest challenges were not isolated to a specific health structure, but instead to larger systems of gender health inequity, shame and stigma and a lack of resources and information.

I began this thesis with a note from my reflexive researcher journal which I kept throughout this thesis. *"My doctor turns to me and asks: 'You're doing your PhD on this topic, what do you think is going on?' In that moment, I don't know how to articulate that no amount of knowledge stops my body from being in pain".* As I moved through primary care, sexual health centres and secondary care, I queried how somebody who is studying the very processes of navigating these services could feel so lost within them.

Throughout my studies, I have walked the fine line of patient and researcher, falling into one category or the other in certain circumstances, but most often uncomfortably straddling this line. I have learned that the dual-role of patient-researcher often crosses boundaries and fails to fit expectations. I do not present sometimes as a patient and other times as a researcher, but these identities are constantly intertwined and often at odds with each other. I put up posters in waiting rooms of clinician offices that I would later find myself glancing at as a patient. I would speak to healthcare professionals who knew me as a researcher first and patient second. These encounters raised questions which I documented in my researcher reflexive diary: "*what are the implications of seeking out healthcare and knowing the provider as a colleague?*", "*Where does vulnerability, professionalism and intimacy fit within these encounters*?". These are just some of the additional questions

that patient-researchers add to their repertoire of potentially already fraught considerations about whether, when and how to seek care. However, patient-led research has allowed me to capture these messy, complex and multifaceted questions instead of attempting to sanitise these experiences. It has given me a space to embrace the patient-researcher identity and be authentic about my experiences instead of attempting to fit pre-moulded boxes.

Before starting this thesis, I had never spoken with a healthcare professional who was not my own doctor. Interviewing healthcare professionals offered profound insight, as I could better understand how clinicians are thinking and how they are operating within limited systems. In my own experience, I also saw first-hand the difference that a single clinician can make when they validate concerns and say, "we're going to figure this out together".

My own journey continues with uncertainty, but also with hope, bolstered by all those who shared their story with me and all the healthcare professionals who have reaffirmed my belief that compassionate and comprehensive care exists and continues to persist, despite all the challenges.

I began my DPhil study with a desire to developed new understandings and tools that could contribute to improvements for those with recurrent vulvovaginal thrush. The voices of these individuals have inspired my work from the very start, with my own experience intertwined amongst theirs. This thesis is written by and for those most affected and my desire is that the outputs of this study can start to ensure our experiences are used to inspire change.

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Appendix

Appendix 1: Example participant biographies published on HEXI

Appendix 2: Creative images created with patient participants and PPI

Appendix 1: Example participant biographies published on HEXI

1. Ayesha (25 years old)

Ayesha (she/her) is a straight woman currently in a relationship. She works in learning and development. Her background is Pakistani. Ayesha first experienced recurrent thrush in 2018 after being treated for a UTI that required 12 rounds of antibiotics. Since then, Ayesha's thrush symptoms have been "constantly there" for the past 4 years, but that she sometimes becomes "more symptomatic" than usual.

Her symptoms include itching and a change in discharge which makes her feel "gross", "uncomfortable", "raw" and "sore". While on her period, Ayesha finds that her symptoms alleviate and that this is a brief "sigh of relief".

Ayesha feels there is a clear version of her before and after her health issues. She now experiences anxiety and feels "not as confident" and is "quick to doubt". Ayesha's hobbies, like swimming and going to waterparks, have also been affected. Further, recurrent thrush has impacted Ayesha's sex life. Although her partner is "laid back and very understanding", she feels it's not something he "signed up for".

Ayesha is anxious talking to doctors and nurses as she fears not being taken seriously. She first went to the GP when she had "enough of the symptoms". Ayesha has also seen sexual health practitioners and found them "friendlier" but still lacking "knowledge".

Over the last few years, Ayesha has been swabbed "over five or six times". The results often come back "barely there or negative". Ayesha says this makes her worry her symptoms aren't "real" or all in her head. Ayesha feels the attitude of GPs was "you're fine, please go away and stop wasting our time". Ayesha feels her doctors take her "less seriously" as she returns with the same issue. Ayesha uses self-testing kits which reassure her that her symptoms aren't all in her head. However, she says the test kits are "very temperamental" and can show "evidence" of thrush one week but not the next.

The online information Ayesha found about recurrent thrush was "quite contradictory". She discovered many suggestions from others with thrush – many of which Ayesha has tried, with mixed results and some which she now thinks were "quite dangerous". To manage her symptoms, Ayesha uses coconut oil and tea tree oil baths and suppositories but finds "long term they don't help". When she can access it, Ayesha buys probiotics from France. She also cuts out sugar and foods containing yeast from her diet.

In 2020, Ayesha sought out private remote care from a GP in the US after finding an expert online. Ayesha felt she was "believed the first time". This physician provided a microflora test which revealed that she was resistant to fluconazole. Ayesha was then prescribed boric acid for two weeks and a maintenance dose twice per week along with probiotics. Ayesha reported that this treatment plan worked for a few months but then "stopped working". While private care helps Ayesha "massively", the cost is a "struggle" as she must work a second job.

Ayesha struggles to talk to family and friends about recurrent thrush and feels "quite alone in it". She worries that others will associate thrush with "bad hygiene". However, when she has opened up, others have been "supportive". Ayesha also follows people on social media who have similar issues, this makes her feel "more seen".

Currently, Ayesha awaiting a MicroGen test from her private GP that she is hopeful will provide more answers about her vaginal microbiome. Her advice for healthcare professionals is to actively listen and empathise with patients and run diagnostic reports. She wants other patients to know that they are not alone and that this condition is real.

2. Joy (43 years old)

Joy (she/her) is a straight woman. She has a daughter. She works in machine operative manufacturing. Her background is white British. Joy began experiencing recurrent thrush nine months ago. Her symptoms occur monthly and before or during her menstrual cycle. Joy said "sometimes it's quite mild and then sometimes it's there and it's just raging, raging, raw".

Her experience with thrush affected her emotionally. In her work environment, the condition occasionally required her to step away to manage symptoms. In relationships, she admits to feeling "embarrassed" and often delaying intimacy due to thrush as thrush worsen with sexual activity. Since being single, she has found her symptoms milder.

Joy's hobbies were also affected as she enjoys walking and running. However, during a bad episode, she found walking difficult. In terms of mood, she found herself feeling more "crabby".

Initially, Joy managed recurrent thrush with over-the-counter pessaries and creams. However, frequent visits for the same treatment prompted the pharmacist to advise her to seek medical help. Despite this, the participant hesitated to consult her GP, partly due to her perception that thrush is a hormonal imbalance that does not necessarily require medical intervention. She wonders if her age and being perimenopausal could be causing the problem.

Despite her hesitation, Joy brought up recurrent thrush during an appointment for another health issue to get antibiotics for a skin condition. The GP provided some cream but did not offer any tests for thrush. This appointment made Joy think "it's just one of them, you just get your cream and you deal with it". She wonders if she went to the GP about recurrent thrush and asked for more help if the response would be any different.

The doctor also offered an antifungal oral tablet or pessary, and Joy chose the pessary as she had not tried to oral option before and felt a more localised approach was better. While pessaries have been helpful, Joy finds them difficult to use while "red and swollen" so would consider taking oral tablets in the future.

Joy expressed frustration over the lack of clear answers regarding self-management, especially considering her HIV-positive status. She has been on HIV medication since 2015, and wondered about its potential role in her recurrent thrush episodes and "why now" this issue has occurred.

Joy found it difficult to discuss recurrent thrush in her HIV clinic, feeling it may not be directly related to her HIV treatment or care. She was not sure whether recurrent thrush would fall under the umbrella of sexual health services so had not consulted there. Joy has also had a negative experience in the past where a sexual health did not want to see her for a contraception appointment after learning her HIV status. Other than that, she has found GPs supportive.

To manage recurrent thrush, Joy wears cotton underwear, avoids tight clothes, and uses soap-free products to reduce irritation. She also avoids over washing and uses a cold compress.

Joy does not feel stigma around recurrent thrush and finds herself about to speak openly with her family and daughter. Looking forward, Joy plans to see a GP if her symptoms worsen and to get an examination and tests done. She thinks recurrence will continue and is hoping to get more answers soon.

3. Ella (50 years old)

Ella (she/they) is a bisexual non-binary person. She is currently in a relationship and has a child who is 20 years old. She is on sick leave from work at the moment. Her background is white British.

Ella has experienced two phases of recurrent thrush in their life. The first was during their 20s when they experienced thrush a couple of times a year. The second was within the last 10 years, during which time they have had several other gynaecological health issues including endometriosis and a full hysterectomy in 2016 which led to surgical menopause and HRT. In March 2022, Ella was diagnosed with lichen sclerosus, a chronic inflammatory skin condition, alongside thrush.

Ella's thrush symptoms include itching, soreness, "little tears", and stinging. This led them to feel frustrated and to avoid sex. They described a psychological impact from recurrent thrush as it leads them to be more "irritable, grumpy, and cross".

When Ella first began having problems with thrush 30 years ago, it was not common to have swabs tested at labs. They feel that most patients were told it was thrush and to "go away and get on with it". Whilst Ella feels that the GPs, they have seen more recently still hold attitudes of "it's just thrush" and "here's the medication, go away", they have found nurses more sympathetic and validating on the whole.

Currently, Ella visits the chemist to get medication over the counter for thrush and will only see a GP when symptoms get "too bad". Ella has used the eConsult service to get prescriptions which, whilst offering "more autonomy", can feel "quite laborious" - especially as Ella estimates they have submitted "50 to 100 [requests] over the last couple of years". Further, the consultation forms ask for pictures which is not feasible, but without them, Ella worries it is difficult to make an appropriate diagnosis. In terms of treatment, Ella has tried pessaries and creams such as clotrimazole which offer temporary relief but as a "band-aid" solution. They have also used lidocaine to numb particularly painful areas. Ella had not heard of oral antifungal options.

As they have gotten older, Ella has recognised that their thrush symptoms are "cyclical" and notices early warning signs. In their 20s, Ella remembers not taking the best care of themself and not knowing how to tend to recurrent thrush. Currently, self-care feels "like a job" as it affects their daily routine. For self-management, Ella checks their vulva in a mirror every day to notice changes. Other self-care strategies include using diluted organic apple cider vinegar to wash themselves after going to the toilet. They try to reduce sugars in their diet and consume probiotic foods like kefir and kombucha. Ella also no longer wears pants or underwear, but, as a non-binary person, not wearing trousers and instead wearing dresses and skirts feels "inauthentic" to Ella. Regarding upcoming appointments, Ella has asked the doctor for a candida test but was refused. They have a referral to a vulval health specialist but, because of waiting lists, may not be seen for another year.

Ella has found community in social media groups that share "woman's wisdom" and offer a "smorgasbord of little tools and tricks" for vulval and vaginal health. These groups have been a "lifeline" for Ella. Ella also visited in-person support groups for vulva pain where they felt supported. Ella stresses to others that recurrent thrush is not their fault, and encourages healthcare professionals to take this condition seriously and not "brush it off".

Click here to see the GIFs:

https://bit.ly/GIFGallery-RecurrentThrush

Or scan the QR code below:

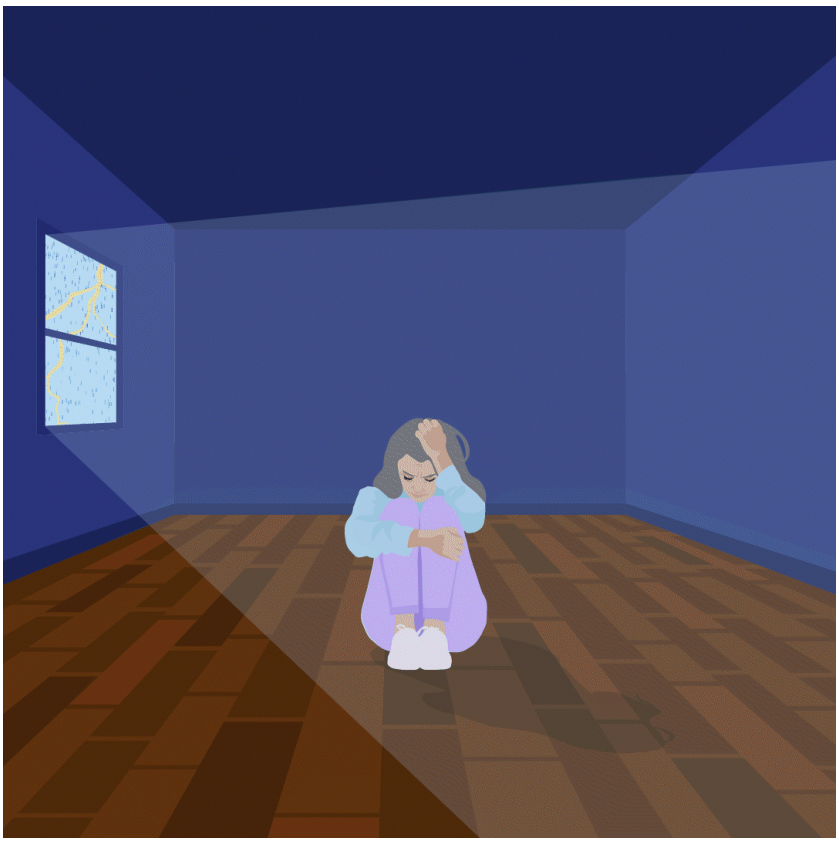
Images created with patient participants

Anna

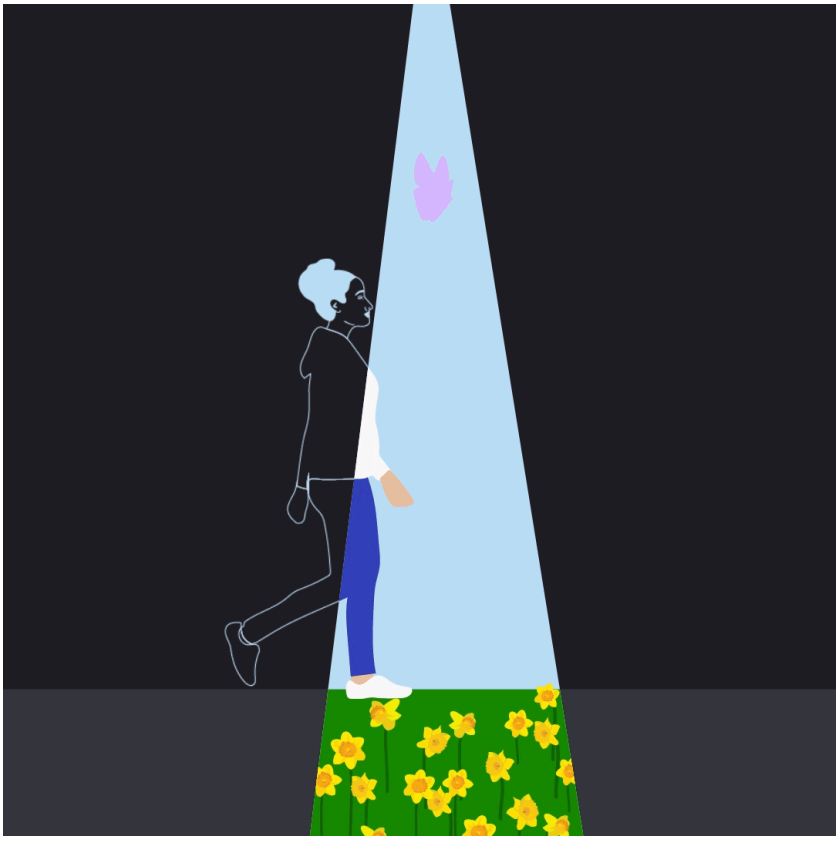
Imogen

Zoya

KJ



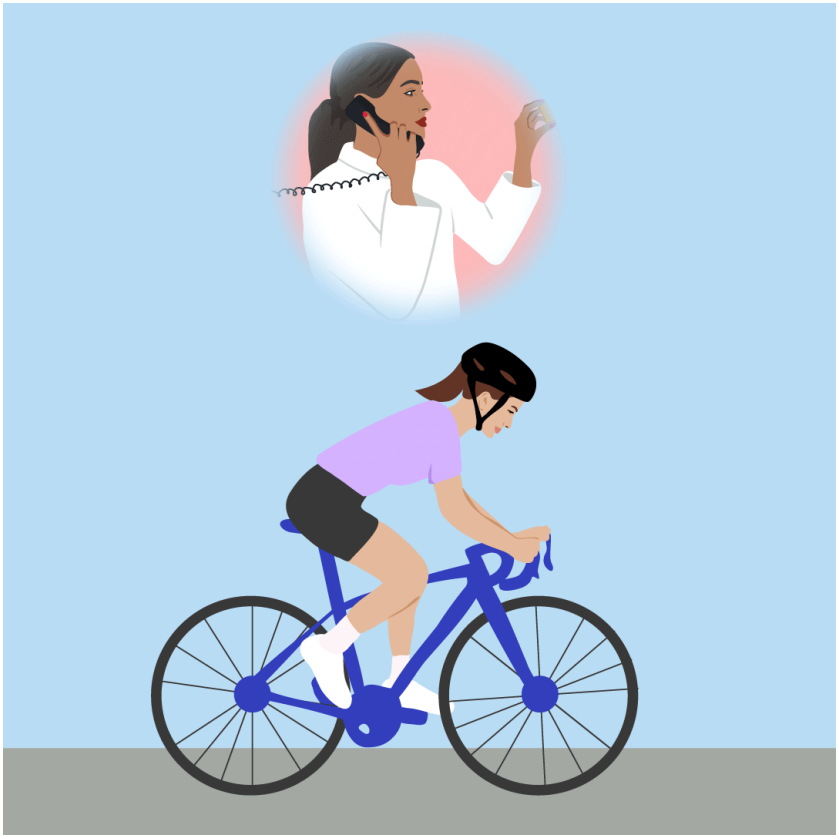
Marie



Lydia

Sarah

Elliott

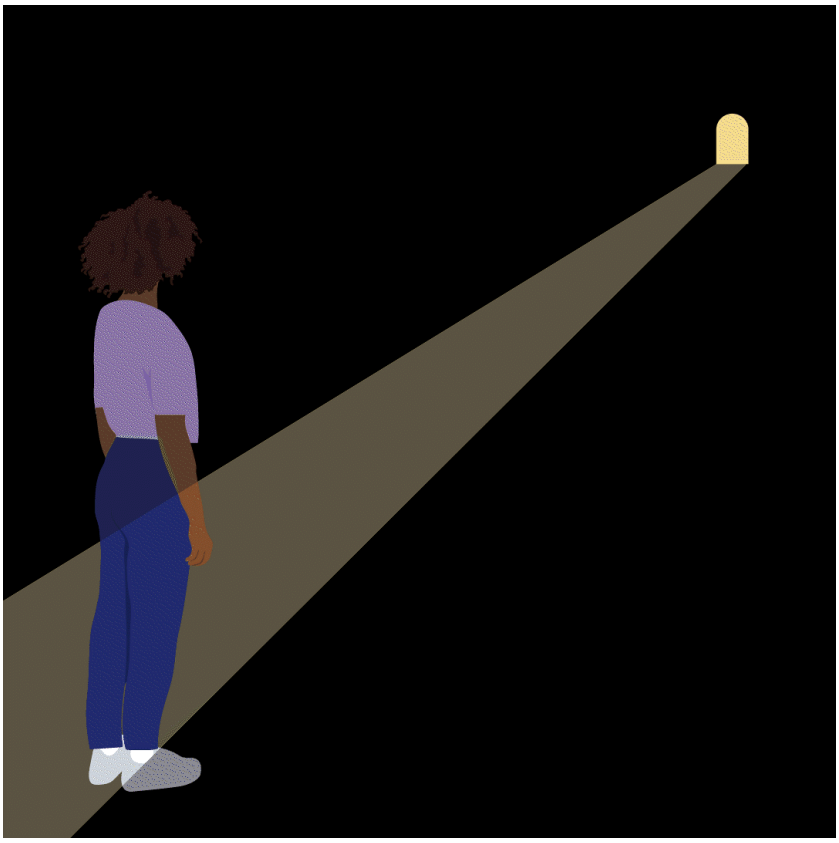


Jody

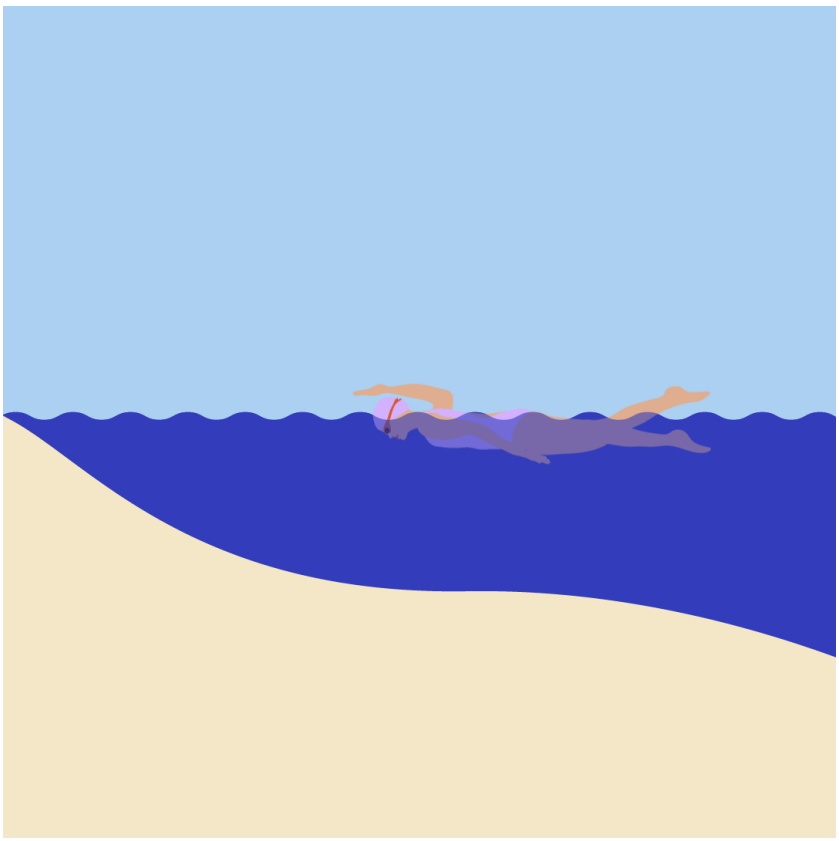
Images created by the patient representative group

Ayesha

Georgia



Imani



Leah