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*Abstract*

The recent sharp rises in the rates of diagnosis of chlamydia and gonorrhoea are a prime public health concern (House of Commons Health Committee Report on Sexual Health, June 2003). The evidence seems to indicate that it is young heterosexual men and women, and young men who have sex with men who are most at risk of contracting these infections. One of the tools used by sexual health services to break the chain of transmission of these infections is partner notification. However, there is little data about the consequences of this process for the person who may disclose their infection to their sexual partner(s).

This study uses a qualitative approach (interpretative phenomenological analysis; Smith, 1996) to gain a deeper understanding of the partner notification process. Two higher order domains emerged from the fifteen participants' transcripts; (1) Sexually transmitted infections (STIs) that are perceived as easy to cure are also seen as less threatening and stigmatising. This may encourage clinic attendance and notification to partners, but may reduce vigilance concerning infection risk, and (2) Diagnosis of an STI produces emotional reactions that affect the form, and possibly the effectiveness of partner notification. Most participants were able to inform their partners about their diagnosis, and described feeling a social responsibility to do so

These results are related to the wider body of knowledge represented by traditional health psychology research, and discussed in terms of the wider literature. In the final section, the method used to gather and analyse the data are critiqued, and research opportunities and clinical implications from this study are outlined.

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Finally, this research would not have been possible without the help and interest of participants who provided stimulating and rich data. I hope this project is useful to them and their peers in some way.

# Chapter 1: Introduction

## The Rising Prevalence of Sexually Transmitted Infections in the UK

In this opening section, I will describe the extent of sexually transmitted infections in the UK today. I will highlight the particular risk groups that bear a disproportionate burden of chlamydia and gonorrhoea infection, and describe the strategy of partner notification that is a major tool in public health efforts to intervene the transmission of these infections.

There has been a rapid increase in the levels of sexually transmitted infection (STI) in the UK, since the mid-1980's. More recently, the rise has been so rapid, that demand for services now threatens to outstrip the resources available to meet it (Adler, 2003).

According to the Public Health Laboratory Service (PHLS, 2002[1]), between 1991 and 2001, new episodes seen at GUM clinics in England, Wales and Northern Ireland rose from 669,291 to 1,332,910. This represents a clinic workload increase of 155%. Diagnoses over the same period increased by 61%. In particular, genital chlamydia infection increased by 122%, uncomplicated gonorrhoea increased by 35%, and infectious syphilis increased by 207%. Recent increases are illustrated in more detail in Table 1.

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[1] All statistical information presented is extracted from the published PHLS data at www.phls.co.uk

| | 2001 | % Change | |
|---|---|---|---|
| | | 2000-2001 | 1996-2001 |
| Chlamydia | 71,225 | 10% | 108% |
| Genital Warts | 67,672 | 2% | 14% |
| Gonorrhoea | 22,697 | 7% | 87% |
| Genital Herpes | 17,850 | 5% | 12% |
| Syphilis | 715 | 119% | 486% |

Table 1: New diagnoses of selected STIs in GUM clinics, England, Wales, and Northern

Ireland: 2001

Although the greatest rise in STIs was seen in cases of syphilis, absolute numbers remain relatively low. Taking both absolute numbers and proportionate increases into account, there have been alarming rises in the rates of both genital chlamydia (108%) and uncomplicated gonorrhoea infections (87%), between 1995 and 2001. This section focuses on the impact of the recent increases in rates of these two diagnoses.

Taking a shorter time frame (between 2000 and 2001), new episodes of chlamydia and gonorrhoea seen at GUM clinics in England, Wales and Northern Ireland rose from 1,195,641 to 1,332,910.

The burden of STIs falls unequally in the population, with young heterosexuals, men who have sex with men (MSM) and minority ethnic groups at increased risk. The figures from the PHLS show that 42% of females with gonorrhoea and 36% of females with genital chlamydia were under 20 years of age. Furthermore, 22% of diagnoses of gonorrhoea were in MSM, 53% of which were diagnosed in London. The PHLS conclude that the rapid raise in bacterial STIs probably reflects a general deterioration in the sexual health of young people and MSM, although increases in testing and improved test sensitivity may also play a part.

*The Rapid Rise of Chlamydia*

In 2001, a bacterial STI became the most commonly diagnosed STI for the first time in three decades. Chlamydia[2] became the most common STI seen in GUM clinics in 2001, with 71,225 cases. Although this may be explained through increased prevalence, increased case finding and awareness may also have a role to play (Thin, 2000).

If we look more closely at the variations in prevalence according to gender of the patient, genital chlamydia rose by 9% in males, and 10% in females between 2000 and 2001. Furthermore, it seems that younger men and women are most acutely affected. During 2001 in England, Wales and Northern Ireland, rates in males were highest in those aged 20-24 years (670/100,000), whereas in females, they were highest in the 16-19 year olds (1034/100,000). This means that over 1% of 16-19 year old females had a diagnosis of chlamydia in a GUM clinic in 2001.

If we consider regional variations in the 16-19 year old group, rates of genital chlamydia infection are considerably higher for females than males. In females, the highest rates are seen in London (1629/100,000). A similar distribution pattern is reproduced for the 20-24 year old age group. Furthermore, data from the Programme of Enhanced Surveillance of STIs (progrESS) indicates that in London, rates of diagnoses of genital chlamydia are

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[2] Common symptoms of chlamydia are described in Appendix I

considerably higher in black ethnic minorities than in any other ethnic group (PHLS, 2002).

Further evidence of the increase in the prevalence of chlamydia comes from the report from one of the pilot screening projects in the Department of Health's chlamydia screening programme (PHLS, 2002). This programme aims to screen thousands of women between 16 and 24 years of age for chlamydia. The research team tested over 14,700 urine samples for the presence of chlamydia (93% for women), over a 12-month period at multiple health care sites in the Portsmouth area. Those screened included men and women aged from 16 to 24 years, as well as under 16s who had changed their sexual partner after being screened previously. Overall, around 10% of samples were positive for chlamydia infection. The highest prevalence of chlamydia was in men attending GUM clinics (16%), followed by female GUM clinic attendees (13.4%), and those attending young person clinics (12.1%).

*Gonorrhoea cases increase dramatically*

Taking a historical view, diagnoses of gonorrhoea in GUM clinics rose steadily during the 1960s and 1970s and remained high until 1985. At this point, numbers began to decrease sharply, and during the 1990s, the number of diagnoses fell to their lowest levels since recording began. This decline in the incidence of gonorrhoea between 1985 and 1988 may reflect changes in sexual behaviour brought about in response to the spread of HIV. However, since 1994, diagnoses of gonorrhoea have risen considerably. These subsequent

rises suggest that the behavioural modifications in response to the spread of HIV have not been maintained, or encouraged in the generation that has become sexually active since 1994.

There were 22,697 new cases of gonorrhoea [3] in 2001. This represents an increase of 8% in men (compared against 2000 rates), and a rise of 6% in the number of female cases. If we look at the breakdown in more details, some interesting trends are revealed.

Between 1995 and 2001, the highest rates of infection of gonorrhoea for both men and women were seen in England[4] (63 and 26/100,000 for males and females respectively in 2001). This considerably higher rate of infection for men partly reflects infections through sex between men (a 20% increase in number of cases from 2000 to 2001), and may also reflect the increased likelihood of symptomatic infection in men. Like other STIs, young people are disproportionately affected by gonorrhoea. During 2001 in England, Wales and Northern Ireland, 42% of females diagnosed with gonorrhoea were under 20 years old. In males, the highest rates were in the 20-24 age group (256/100,000); a 16% increase since 2000. Even higher increases in infection were seen in this age group for men having sex with men (29% increase in 2001).

Rates of diagnoses of gonorrhoea showed marked regional variation in 2001. For both males and females, the highest rates of infection were seen in London (181 and 74/100,000), where they are twice more than any other region. For both males and

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[3] Common symptoms of gonorrhoea are described in Appendix I

females 16-19 year olds, the rates of infection were highest in London (447 and 649/100,000), and the same pattern held for 20-24 year olds (559 and 273/100,000).

From the trends described above, it is clear that there has been a recent rapid increase in bacterial STIs, especially gonorrhoea and chlamydia. This rise has affected the population disproportionately, with the greatest burden falling upon young male and female heterosexuals, and young men who have sex with men, with risk of infection being particularly high in London.

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[4] Compared to available figures for Wales and Northern Ireland for the same time period

**Intervening to Tackle the Spread of STIs**

*"It is no exaggeration that we now face a public health crisis in relation to sexual health"*

Professor Michael Adler, Editorial, Sexually Transmitted Infections, April 2003

*"We must both improve and modernise services and also seek to change individual's behaviour, drawing on the evidence of what works in achieving this"*

Department of Health Spokesman, responding to Professor Michael Adler's comments, quoted in The Guardian, April 15, 2003

These quotes illustrate the clear recognition of the scale of the problem that now faces public health services by those that fund and direct these resources, together with a commitment to understanding these changes and designing suitable evidence-based interventions.

*Partner Notification*

One of the methods used by GUM clinics in attempting to control the spread of STIs is partner notification. This process aims to break the chain of transmission of infection by

identifying, counselling, and screening sexual partners of individuals with a STI. Treatment is then offered if appropriate (Cowan et al, 1996). Three approaches to partner notification are commonly used; (a) patient referral – when the index patient is encouraged to notify partner(s) of their possible infection without direct involvement of health care providers, and encourages them to seek appropriate medical advice, (b) provider referral – where health care providers trace and notify partner(s) of the index patient without naming the patient concerned, and (c) contract referral – where health care providers obtain the partner(s) name from the index patient, but the patient is 'contracted' to notify the partners themselves, within a certain time period (Milson et al, 1994).

In their survey of partner notification practices for STDs in GUM clinics in England and Wales, Stokes and Schober (1999) found that the most popular method of partner notification was patient referral, although a minority of clinics used contract referral as their method of first choice. Descriptive research is required to ascertain perceived problems associated with the partner notification process, and it's overall impact, both positive and negative.

*Evaluating the Consequences of Partner Notification*

A systematic review of partner notification conducted by Oxman et al, (1994) found it difficult to make comparisons between studies due to differences in methodology, cultural factors, and health care systems. A more recent review by Mathews et al, (2002) came to similar conclusions. First, the authors noted that although there was a large

literature on partner notification for STDs, few randomized control trials had been conducted. Second, the methodological weaknesses of the studies did not allow reliable conclusions to be made. Third, the variability in study designs and differences in diseases complicated the identification of effective partner notification strategies. Finally, they pointed out how cultural issues may influence results and make comparisons between studies misleading and meaningless.

In addition, Mathews et al, (2002) highlight the paucity of literature on the potential negative consequences of partner notification. The authors highlight some anecdotal evidence suggesting that fears of domestic violence, loss of partners, or community isolation may lie behind decisions by index patients not to inform sexual partners of possible infection.

These potential social and psychological harms may not only be located in consequences to the patient in their interactions with others, but also in how the patient may think and feel about themselves. In considering the *process* of partner notification, there is a body of evidence indicating that cognitive and emotional experiences of stigma and shame are crucial in shaping individual and interpersonal responses in coping with the diagnosis of an STI (e.g. Cunningham et al, 2002; Dixon-Woods et al, 2001). Therefore, in order to understand the process of partner notification, it is necessary to define and understand the concepts of stigma and shame, and how they may influence people's experience of STIs, and coping with their illness.

**Sigma, Shame and STIs**

This section outlines the how stigma and shame are important in considering the reactions to a diagnosis of an STI, and how they may relate to coping with the problems that may be associated with this diagnosis.

*Why are Stigma and Shame important?*

Recent findings show that stigma and shame are important barriers to appropriate diagnostic and treatment services, in STI care (Fortenberry et al, 2002; Leenars et al, 1993). Stigma and shame can also affect identity, and how the patient perceives the care setting (Dixon-Woods et al, 2001; Scoular at al, 2001). It can affect how and what patients disclose about their sexual behaviour to doctors and nurses (Cunningham et al, 2002). Furthermore, it may be associated with a range of coping strategies that patients may use (Baker et al, 2001), and their anxieties about partner notification (Duncan et al, 2001).

*What are Stigma and Shame?*

The concept of stigma has been defined as any attribute or feature of a person that marks an individual as being unacceptably different from "normal" people in the rest of society (Goffman, 1963; Lewis, 1999). Sontag (1977) has argued that different diseases arouse

particular feelings of dread or repulsion through fear of personal consequences or social sanctions during different eras (e.g. cancer has replaced tuberculosis in this respect). More recently, the concept has evolved such that stigma is typically associated with disorders for which people are considered culpable - i.e. achieved rather than ascribed stigma (Albrecht, Walker and Levy, 1982). STIs fit into this category (e.g. Scoular et al, 2001).

The experience of stigma can vary. Goffman differentiates between those with disorders that cannot be hidden, and those that with conditions that allow people to "pass as normal". In these cases, it may be useful to employ a distinction between enacted stigma and felt stigma (Scrambler, 1998). Enacted stigma refers to actual discrimination and rejection through the words and actions of others whereas felt stigma refers to the fear of such discrimination, and a person's internal negative thoughts about the impact of a condition. Originally used to study reactions to a diagnosis of epilepsy, the model predicts that adults with epilepsy may typically develop an acute sense of felt stigma before any exposure to enacted stigma. Second, as a consequence of felt stigma, it was proposed that people tend to adopt a strategy of non-disclosure and concealment of their seizures and diagnosis. Third, because few people are aware of people's seizures and epilepsy, the instances of enacted stigma would be few. Finally, Scrambler predicts that as a function of successful concealment, felt stigma would disrupt people's lives more than enacted stigma. Essentially, the argument is that the fear of discrimination leads to a strategy of self-concealment. This self-concealment poses threats to self-esteem, security, identities and life chances for those with certain diseases and symptoms, and can prove difficult for

care providers to work with. This model of enacted and felt stigma has been applied to the diagnosis of an STI (see Scoular et al, 2001).

Shame can be defined as an intense negative emotion that stems from a person experiencing failure in relation to meeting their personal or other people's standards, feeling responsible for that failure, and believing that this failure represents a defective self (Lewis, 1995). Shame is sometimes referred to as "self-stigmatisation", signalling a person's acceptance of the negative aspects of stigma (Corrigan, 1999). For people who have conditions that are not visibly stigmatising (e.g. having an STI), avoiding situations where they fear enacted stigma may be a way of avoiding experiencing intense feelings of shame. However, the felt stigma may continue to be a corrosive threat to self-esteem, identity and help-seeking behaviour.

*Stigma, Shame, and STIs*

Members of the public often report negative experiences about attendance at GUM clinics (Scoular et al, 2001). These are often characterized by notions about the type of person who acquires STIs, the association with lack of personal hygiene, with certain types of sexual activities, and fears of humiliation and painful examinations (Kinghorn, 2001; Scoular et al, 2001). Kinghorn argues that the stigmatisation of GUM patients has long been institutionalised within hospitals and their staff, which has a potentially negative effect upon patients, who may not be afforded the same respect as those attending other services. If clinic staff has beliefs that the cause of the disease is controllable and

avoidable, and that the patient should bear some personal responsibility (Albrecht, Walker and Levy, 1982), this may contribute to their stigmatisation.

Dixon-Woods et al (2001) provide evidence in their qualitative study of 37 screened for chlamydia that women have concerns that their feelings of stigma and embarrassment will not be managed properly within services. Several women feared judgmental attitudes from their GPs, and reported friends being shouted at and being accused of promiscuity by GPs. Some women who were friendly with their GP nevertheless opted for the anonymity of the clinic setting as their preferred choice. A key priority for women attending the clinic specialist services was a non-judgmental attitude of clinic staff, routine management of STIs. Given that many of the women in this study adopted the role of "ambassadors" of the service to their contacts, it is very important that services address these issues and priorities if they are to encourage repeat use of the service and further lay referrals. This concern is not limited to patients' opinions. In a survey of Glasgow healthcare workers, 86% of the 101 people surveyed perceived GUM services as stigmatising to patients, and regarded this as a significant barrier to referral (MacClean, Reid and Scoular, 1995).

In a questionnaire-based study of 142 African-American adolescents between the ages of 13-19 years in a depressed urban area in the USA, Cunningham et al (2002) hypothesised that concealment of stigma through non-attendance at clinics is a way of avoiding shame feelings. This ties in with Scrambler's (1998) ideas about non-disclosure as a consequence of felt stigma. They predicted that those who do not anticipate negative

evaluation upon the disclosure of their sexual activities to clinic staff are more likely to seek care for STIs, even in the face of perceived stigma and shame. The sample was not limited to those already attending STI clinic settings – these were sampled from households in the local area, including adolescents who might not usually seek health care. The study found that 48% experienced high levels of stigma (e.g. if you had an STD, would people think you were unclean?), 69% reported high levels of shame (e.g. If you had an STD, how ashamed would you feel?), and 38% expected a negative reaction when disclosing their sexual behaviour to a nurse or doctor. For women, there was an expectation of isolation and negative social judgment associated with STIs that was related to perceptions of disclosure. This suggests that perceived stigma about STIs might be an important influence on adolescents' decisions as to whether or not to reveal their sexual activity to clinic staff. High levels of STI associated stigma negatively related to the decreased likelihood of women to have sought STI related care in the past year. This has important implications: adolescent women may avoid social interactions and disclosure (i.e. talking with clinic staff) necessary for effective STI care as a way of managing current or feared future feelings of stigma and shame. This study's findings were consistent with other research that "shame is part of the experience of seeking STD related care but stigma may be a more powerful barrier to STD related care" (Fortenberry et al, 2002).

*Stigma, STIs, and beliefs about other people*

Seeking STI care has been shown to be associated with the perception of stigma by health professionals in health care settings. Another perspective on stigma and seeking STI care is the perception of other attendees at clinics for STI care.

Scoular et al's, (2001) study of the nature of stigma as reported in interviews with 17 women (18-29 years old) recently diagnosed with chlamydia found that STIs were often viewed as a problem for other people. Women reacted with a mixture of shock and disbelief, as a diagnosis of a STI was seen as morally unacceptable in a cultural sense. This reaction was in contrast with their previous view of themselves as invulnerable to conditions associated with a stereotypically polluted image (Leenars et al, 1993). These women experienced feelings of isolation because of their fear of public disclosure and disapproval. Their anxieties were increased by a perception of a low level of knowledge in the community about STIs, increasing their feelings of isolation. Furthermore, women expressed some fears about "guilt by association" in that they feared public disclosure in waiting rooms, and censure by clinic staff. Interestingly, women preferred to attend Family Planning Clinics, allowing them an opportunity to distance themselves from the model of health care that a GUM clinic may represent, and from the negative associations of an STI. Finally, women reported an experience of normalization through attending the clinic, which served to decrease (but not remove) feelings of stigma. This came about through a realisation that other attendees did not conform to stereotype, and through the active efforts of staff to treat patients with STIs routinely, that they would have a

therapeutic experience. In these ways, although attending the clinic was seen as stressful, it did not correspond to the patients' worse fears. The authors contend that the patients' experience "felt" stigma, rather than "enacted" stigma. They go on to argue that felt stigma may act as a barrier to the dissemination of their relatively positive experiences of attending a GUM clinic to their wider peer group. In turn, this may lead to continuing fear of GUM clinics.

Further experiences of stigma are described in Duncan et al's (2001) study of 17 women (aged 18-29 years) attending clinics for chlamydia testing in Glasgow, using interpretative phenomenological analysis (IPA) to capture the meaning of each participant statement to produce emergent themes. As a result of this analysis, three themes were identified: (a) perception of stigma associated with STI, (b) uncertainty about reproductive health after a diagnosis, and (c) anxieties about partners' reaction to diagnosis. As in Scoular et al's study (2001), women perceived themselves as relatively invulnerable to infection. STIs were associated with notions of delinquency and contamination. They distanced themselves from the type of person that would normally be expected to contract an STI, which led them to believe that chlamydia and other STIs were not personally relevant. Therefore, the diagnosis came as a shock, and all women reported feelings ranging from mild self-disgust to distress. Also of interest was the expressed anxiety about male partners' reactions to the diagnosis. Despite the reported norm of serial monogamy among the participants, and their partners, feelings of guilt, regret and "dirtiness" were reported, and fear of partners' reactions was a tangible worry. Informing a partner was perceived as difficult, especially when a relationship had ended badly. Although some

women chose not to inform partners, the authors hypothesise that such a decision could

lead to feelings of guilt and perceived "irresponsibility".

*Adolescents' responses to STI diagnosis*

The studies reviewed thus far show how institutionalised stigma, and patients' views of

stigma and shame might affect how they use health care services. More specifically, it is

important to understand the nature of responses of young people infected with STIs, as

this group has been identified in the earlier sections as a group particularly at risk for

contracting STIs. Understanding adolescent coping styles from a developmental

perspective may provide some information as to how they may react to the diagnosis of

an STI. In terms of their general coping styles, Recklitis & Noam (1999) found that

problem solving and interpersonal strategies in adolescents were associated with fewer

psychological symptoms and higher levels of development. Significant gender differences

were found, with girls using more interpersonal coping and boys using more physically

active strategies. In terms of physical health, active coping strategies have been associated

with better metabolic control in adolescent diabetic patients (e.g. Delamater et al, 1978),

while denial of worry has been associated with less well adapted response to medical

procedures (e.g. Knight et al, 1979).

Although adolescents are thought to use coping styles that may be related to their

developmental stage, it is important to consider if cognitive and emotional reactions to

the diagnosis of an STI may be a particular barrier to partner notification in this group.

Baker et al (2001) considered whether coping strategies used for diagnosis of an STI were similar to those used in coping with stresses associated with a friendship. They surveyed 67 girls (aged 12-15) – all had an STI history. When comparing the strategies used for coping with an STI (compared to coping with a friendship problem), they found that, (a) there was significantly less use of cognitive restructuring (e.g. finding something positive in acquiring an STI), (b) they were less likely to use distraction strategies, and (c) they were less likely to have an emotional outburst. Moreover, the results indicated an increased endorsement of self-blame coping statements, and decreased endorsement of problem solving strategies. The authors suggest that the girls' sense of stigma and self-blame regarding STI acquisition was a barrier to seeking help with their problem solving (e.g. getting more facts and information by talking to others).

It is clear that stigma and shame can act as barriers to accessing services, and are personally distressing experiences that can affect self-image, coping efforts, and interpersonal communications.

**Disclosure of Personal Information**

The evidence reviewed shows that when receiving a diagnosis of an STI, people often feel shock, a sense of disbelief and dirtiness, and other features of felt stigma and shame. As GUM clinics request that patients communicate this diagnosis to current and previous sex partners, it is likely these feelings may act as a barrier to this communication. The

literature about the disclosure of secret, intimate personal information to others may inform our understanding of disclosure difficulties.

*What are the consequences of revealing secret information about oneself?*

When a person is told new information that may have negative consequences for their health, they are faced with a decision as to whether to keep that information to themselves, or to disclose it to others. Keeping has been found to be stressful in that it depletes cognitive resources to hiding information from others (e.g. Wegner, 1989, 1992, 1994). Furthermore, it seems that there is evidence that the harder one works at inhibiting information, the higher the likelihood of psychological and physical problems (Kelly and McKillop, 1996; Pennebaker, 1990).

Disclosing negative health information to others is a potentially risky task that may involve several consequences, including the possibility of being rejected by the listener (Lehman, Ellard and Wortman, 1986). When reviewing the literature on the consequences of revealing personal secrets, Kelly and McKillop (1996) contend that;

"... when a person does reveal a personal secret, the real or perceived reactions of the *confidant* are critical in determining whether the person will benefit from the revealing" (*ibid.* p.450, italics in original text).

On a more positive note, it has been argued that sharing secrets with others may lead to insights regarding the meaning of those secrets, and help people to develop a sense of mastery and control over their lives (Pennebaker, 1989, 1990, Tait & Silver, 1989). Revealing secrets may also reduce shame and guilt or states of negative arousal (Derlega et al., 1993, Stice, 1992). It has been suggested that, "the act of not discussing or confiding the event with another may be more damaging than having experienced the event itself *per se*" (Pennebaker, 1985, p.82). The victims may tell themselves that because they have hidden the experience from other people, the event must indeed be very shameful, and they may consequently develop feelings of lowered self-worth (Derlega et al, 1993

Central to the problem of damaging secrets is the idea that people may form their identities through interacting with others (e.g. Goffman, 1959). It is argued that people incorporate real or imagined feedback from others about their behaviour to construct their self-image (e.g. Schlenker and Weigold, 1992). However, receiving real or imagined negative feedback from others presents us with a problem. Since people tend to prefer to construct beneficial self-images, and to avoid negative ones (Schlenker and Weigold, 1992), people may avoid revealing information to others where they perceive that this information may be received badly and may have negative consequences that may be damaging to their self-image. Indeed, public expressions have been shown to influence private beliefs about a number of personal attributes e.g. depression (Kelly, McKillop and Neimeyer, 1991), sociability (McKillop, Berzonsky and Schlenker, 1992), and global self-esteem (Rhodewalt and Agustsdottir, 1986).

By confiding a personal secret to another, there is a possibility that people may relieve themselves of the self-stigmatisation through fear of negative evaluation by others, and to prevent these feelings of lowered self-worth and shame. However, whether this possibility is realised depends upon how the confidant reacts to the self-disclosure.

There are several characteristics that have been identified in those whom secret-keepers might benefit from disclosing to (Kelly and McGillop, 1996). These include, persons who are perceived to be (a) discreet and can be trusted not to reveal a secret, (b) non-judgmental, and (c) able to offer new insights into the secret. A consistent finding is that the mere presence of a marital or romantic partner is not a sufficient asset for those going through a stressful event. Instead, it is the quality of the relationship that is important for the individual's well being (Kennedy, Kiecolt-Glaser and Glaser, 1990).

*What are the consequences of revealing information about an STI diagnosis?*

There is relatively little research available upon how self-disclosure of an STI to partners is received. However, when overviewing the STI literature (gonorrhoea and chlamydia), it seems clear that even though there are negative feelings associated with receiving a diagnosis of an STI, most people do tell their partners about it (e.g. Catchpole, 2001).

Lim and Coupey (2001) conducted a small questionnaire-based study on a sample of 30 female patients at a medical centre in the USA (aged 10-21 years), with positive

chlamydia test results. 83% of the sample reported informing at least one of their sex partners about the infection. From an array of 6 possible choices, the two most commonly endorsed reasons for partner notification were, (a) "I did not want my sex partner to give the infection back to me" (15/30), and (b) "I wanted to let my sex partner know he had given me the infection" (11/30). From 8 possible partner reactions, the two most common were, (a) "My sex partner accepted the news well" (16/30), and (b) "My sex partner got upset" (7/30). Of the 7 possible choices for not notifying their partners, the two most common were, (a) I knew my sex partner would be very upset (2/5), and (b) "I was afraid my sex partner would physically hurt me". Although this is a small study, it is clear that in line with other evidence, most patients did manage to tell their partners about their infection. Those who did not notify their partners anticipated negative consequences if they disclosed.

Chacko et al (2000), found that a minority of young women feared possible negative consequences when telling their male partners about an STI. This was a cross-sectional qualitative study of 54 women, aged from 13-20 years old. They all had positive tests for either gonorrhoea or chlamydia. Fifty seven percent of the sample reported telling at least one sex partner about the infection; 43% did not inform any partners. Fifty two percent disclosed this information face-to-face, whereas 45% did this on the telephone. A direct style of communication (factual information stated in a matter of fact way) was used by 48% and 32% used a combination of this direct style with a more sensitive style, suggesting a non-threatening joint-partner approach to the problem. The remaining 20% used an angry and accusatory style, accusing the partner of being the source of infection.

Ninety percent of those who told their partner reported no barrier to notification. Identified barriers included discomfort, fear, guilt, hassle, and lack of trust.

Other studies also point to reasons why adolescents (in particular) may not notify a partner. Rosenthal et al (1995, cited in Chacko et al, 2000) reports the three most common reasons given by adolescents for not notifying a partner as, (a) the patient fears she will no longer be involved with the partner, (b) they expect a negative emotional response from the partner, or (c) the patient blames the partner for the infection. Furthermore, they described the three most common experiences described by adolescents who notified a partner as (a) negative emotional response from the partner, (b) a focus on blame, and (c) a positive emotional response. It is clear then that adolescents fears about disclosure are not unrealistic, although partner reactions are not wholly negative.

It is apparent from this review of selected literature that although disclosure of diagnosis is uncomfortable, it is relatively manageable for most patients. For a minority of patients, disclosure of diagnosis may be accompanied by fears of rejection, or negative emotional response from the partner, and a focus on blame regarding acquisition of the STI.

It is interesting to note that although the concepts of stigma and shame are important, not all people diagnosed with an STI report these experiences. Indeed, most people seem able to notify their partners with few problems. This may mean that these people may not experience stigma or shame to a distressing extent, or perhaps that they find a way of overcoming it. The process of partner notification seems likely to be more of an obstacle

for those who develop acute feelings of felt stigma and shame. This makes it difficult for these people to disclose their diagnosis to their partners, particularly if they perceive their reaction to be rejecting, hostile, or otherwise unhelpful.

## Understanding Representations of Illness

In this section I will describe how an established health psychology model accounts for how people make sense of illness threats, and how they cope with them. I will briefly review the evidence for this model, and then describe its relevance to STIs and how it may help develop a deeper understanding of the partner notification process.

The Common Sense Model of illness representations (CSM; Leventhal, 1990) proposes that people create mental representations of their illness based on the abstract and concrete information available to them, in order to make sense of, and manage their problem effectively. The model is divided into three stages; (a) interpretation – making sense of the problem, (b) coping – dealing with the problem, and (c) appraisal – assessing how effective the coping has been. This discussion will focus upon the first two stages, which are most relevant to this study.

Individuals are thought to make sense of their illness by drawing upon information from three sources. The first source is a general pool of lay information, generated from previous specific knowledge and general cultural knowledge about the illness. Second, individuals may access information from others in their social environment (e.g.

authoritative sources, such as health care staff). Third, the individual takes their experience of illness (signs and symptoms) into account.

This interpretation of information helps to form a representation of the illness that gives meaning to the illness experience (Leventhal, 1990). It is argued that there are five dimensions that form a person's cognitive representation of their; cause, consequences, identity, timeline, and cure / controllability. The cause dimension refers to beliefs relating to causes underlying the illness. Examples of the types of causes that have been reported in the literature include biological causes (e.g. Heijmans, 1998) and emotional causes (e.g. Moss-Morris et al., 1996). The consequences dimension represents beliefs about the impact of an illness on overall quality of life or functioning. Illness identity refers to the beliefs about the illness label and knowledge about its symptoms. Timeline refers to beliefs about the course of an illness and the time scale of their symptoms. Finally, cure / controllability refers to the belief that actions that might be taken will have an influence over the illness.

The CSM is argued to be a parallel-processing model, in that people simultaneously make cognitive and emotional representations of their illness, which may be important in determining both problem and emotion-focused coping strategies. However, these emotional representations of illness have been under-researched compared with the evidence that has accumulated concerning cognitive representations of illness. Indeed, one of the widest used measures in this field of research – the Illness Perception

Questionnaire (Weinman et al, 1996) – was designed to investigate only the cognitive components of illness representation.

In sum, illness representations act as an interpretive schema for the information about an illness, and guide actions in response to an illness threat i.e. the illness cognitions affect coping behaviours in proportion to the perceived severity of the illness. The following sections summarise the evidence about the links between illness representations and coping efforts.

*The Common Sense Model and Coping Strategies*

Hagger and Orbell's (2003) meta-analytic review found strong evidence that these cognitive representations are linked to how people cope with their illness. Their analysis suggested that perceived controllability was associated with active coping and cognitive re-appraisal strategies. For example, Moss-Morris et al. (1996) found that identity and cure / control dimensions were significantly related to active coping, seeking social support, and behavioural engagement, in their study of patients with chronic fatigue syndrome. Furthermore, patients who perceived that their illness had serious consequences were more likely to use denial and behavioural disengagement coping strategies. The data from the meta-analysis also suggested that if patients see their illness as controllable, they tend to change their appraisal of their illness. Looking at other ways of coping, they found that strong illness identity was associated with avoidance and emotion expression.

Although the evidence for the CSM model of illness representation is largely supportive, several caveats have been identified. These include the lack of prospective longitudinal evidence, the lack of knowledge about the emotional representation of illness, and the concentration of research efforts on chronic disease.

In Hagger and Orbell's review, only one study was identified that did not focus on a chronic disease (the common cold; Lau et al, 1989). It is therefore unknown how well the evidence base of the CSM model for chronic illness may be applied to illnesses of a more acute nature e.g. STIs. Although Moss-Morris et al's (2002) study of patients with multiple sclerosis indicated that emotional representations were largely unrelated to severity of illness, relatively little is known about how these representations may be linked to coping style.

**Chapter Summary and Rationale for the Study**

This chapter has described how there has been a sharp increase in the incidence of STIs in the UK, particularly for chlamydia and gonorrhoea infections. The burden falls especially upon young heterosexual men and women under 25 years old, and young men who have sex with men. In attempting to break the chains in the transmissions if STIs, sexual health services have used partner notification as one of their main tools. The most commonly used for of partner notification is patient referral, where the patient is encouraged to notify their partner(s) of their possible infection without direct involvement of health care

providers. Although partner notification is widely used, there is relatively little evidence to date on the potential consequences of notification for the patient who discloses information about their infection to others. In terms of public health policy priorities, the National Strategy for Sexual Health and HIV Action Point 24 states an aim to "tackle stigma and discrimination (p. 16 *ibid.*). Further more, Action Point 27 encourages efforts to develop the evidence base, and prioritises research to improve the effectiveness of partner notification within clinics and the community. The forthcoming Health Development Agency review (2003) highlights how the potential hazards that patients face as a result of partner notification have been poorly investigated.

The chapter has given an overview of the stigma and shame that is often associated with STIs in many contexts, and how they may often act as a barrier to disclosure. I also summarise the existing literature on the potential consequences of revealing secret information, and relate this to the finding that most partners manage to notify their partners despite the barriers of potential stigma and shame.

Given the paucity of literature on the consequences of partner notification, and the significant public health concerns about recent rises in the incidence of STIs, this study aims to elaborate our understanding of the experience of screening and partner notification through the use of a qualitative approach. I aim to explore how patients recently diagnosed with chlamydia and / or gonorrhoea react to the news of their diagnosis by using interpretative phenomenological analysis (IPA) (Smith, 1996) to provide a rich and detailed picture of the process in a small sample of young people

attending sexual health services. This study also attempts to integrate the finding with a broader pool of knowledge represented by the social cognitive understanding of health that dominate health psychology. The CSM has been used successfully with other types of disease to predict how certain illness representations may be associated with certain styles of coping and illness outcomes. This study aims to explore how well this model maps on to the experiences of the participants involved.

Specifically, this qualitative study addresses three aims:

1) To develop a deeper understanding of the emotional reactions and cognitive beliefs associated with the diagnosis of chlamydia and / or gonorrhoea.

2) To investigate whether participants intended to tell, or told their partners about their diagnosis.

3) To elaborate upon the consequences of the STI testing and partner notification process for participants

# Chapter 2: Method

*Why use a Qualitative Approach?*

As this is an area of interest that has not been studied in great detail before, the approach used to collect and access the data requires careful consideration. Quantitative approaches to design, analysis and interpretation of data are appropriate where the topic being investigated is already established in certain contexts. The goal of quantitative approaches is to integrate and generalise the information of research findings with knowledge that already exists, through the use of methods such as random sampling and standardized measurement. However, many qualitative researchers see their work as an endeavour of theory building. Researchers will often require in-depth accounts of a person's experience in order to understand the significance that a particular health event has on a person's everyday lived experience. Through the use of a qualitative approach, there is an explicit acceptance that the context of the research is of fundamental importance, and that these approaches espouse a focus upon the particular situations and experiences of individuals participating in the research. Central significance is given to the nature of the interaction between the participant and the investigator, and the personal and ethical issues that may arise from the potential for mutual influence.

There is a considerable diversity in qualitative approaches that may be used, each with their own subset of methods. These approaches include Case Studies, Grounded Theory, Discursive Psychology, and Interpretative Phenomenological Analysis (IPA). Each of

these approaches are embedded within certain epistemological positions. Madill et al (2000) argued that these positions are not discrete, but can be viewed as positions on a continuum, with naïve realism at one end, and radical anti-realism on the other. Realist approaches (e.g. case studies, realist Grounded Theory) take a discovery-oriented position, whereas radical constructionists (e.g. discursive psychology) challenge the very notion of representation itself (Willig, 2001). Somewhere midway between these poles of the continuum lays a series of approaches known as 'contextual constructionist' research. This approach is based upon the assumption that all knowledge is contextual and situation dependent. Different perspectives will generate different insights into the same phenomenon. As a result, this kind of research is concerned with completeness or representations, rather than accuracy. Using Madill et al's classification system, IPA can be described as taking this contextual constructionist approach.

It is not impossible to use a quantitative approach in an empathic and exploratory way, paying attention to issues of language, culture, and meanings. However, qualitative approaches are especially well suited for such objectives.

*What is Interpretative Phenomenological Analysis?*

Within this broad range of qualitative approaches, Interpretative Phenomenological Analysis seems an appropriate set of methods to use to explore this research topic. IPA is derived from broader phenomenological approaches and shares their aims in capturing the quality and nuances of individual experiences. However, IPA also explicitly

recognises that such experience is never directly available to the researcher. It's founder, Jonathan Smith characterizes IPA as:

"an attempt to unravel the meanings contained in ... accounts through a process of interpretative engagement with the texts and transcripts" (Smith, 1997, p.189)

There is a fundamental assumption in IPA that a person is a cognitive, linguistic, affective and physical entity. Theoretically, it takes the stance that there is a chain of connections between the language that people use in their talk, and their thinking and emotional state. IPA also acknowledges that this connection may not be straightforward. People may struggle to express what they think and feel, or there may be reasons why they may wish not to self-disclose (see introduction for particular reasons why this may be in this context). As a result, IPA argues that the researcher has to interpret the person's mental and emotional state from what they say. According to these assumptions, IPA seems to be a two stage process in that the participant is trying to make sense of their world, and the researcher is trying to make sense of the participant's sense-making (Smith, 1997).

IPA is a relevant means of analysis if a research project is focused upon the exploration of experiences of individuals. It requires a qualitative method of data-collection, such as semi-structured interviews, focus groups, participants' diaries etc. in order to produce a detailed account of the phenomenon in question. It also requires an active contribution from the researcher, including a familiarisation with the data i.e. revealing the themes that

are addressed by the participants, and a 'making sense' of the data, through establishing a series of analytic codes that reflect the nature of the participants' experiences to provide answers to the research questions (Shaw, 2001). Within this framework, IPA aims to provide an in-depth understanding of both the idiosyncratic and shared cultural understandings of a person's experience of the world. One of the greatest assets of the IPA approach is its ability to reveal unanticipated phenomena (Shaw, 2001) in that the methods used are flexible enough allowing the participants to discuss aspects of their experiences not anticipated by the researcher.

The interpretative work of the researcher is an integral part of IPA. Chamberlain (2001) argues that qualitative research *must* be interpretative if it is to contribute understandings of value. It is not enough to identify themes – often these contribute nothing more than self-evident labels, and offer little conceptual insight or theoretical interest. The level of identifying themes evident in the transcript provides little understanding of why they talk this way. Richards (1998) argues against this 'garden path analysis', or confining ourselves to the detail of the data. She argues that not only does the researcher need to get into the data, but they also need to get out again. Chamberlain offers a strong role to the researcher as interpreter:

"not … merely offering a descriptive account of the major themes of what was said in an interview, but offering some insights into the meanings behind it." (Chamberlain, 2001, p.19)

*Why use Interpretative Phenomenological Analysis instead of another Qualitative Approach?*

IPA has several advantages over other qualitative approaches to text / language analysis. The analytic methods associated with IPA are systematic in nature, and there are well founded, detailed descriptions of the process of analysis (e.g. Flowers et al, 1997). Furthermore, sexual health and well-being has become the focus of a significant body of IPA research (see Duncan, 2001). IPA is an attractive research approach for psychologists working in this field of research, particularly one such as myself who is relatively inexperienced in the use of qualitative approaches. By adopting IPA and it's connection between the account and cognition, I hope to facilitate a dialogue with other areas of clinical health psychology and social psychology, as well as adding to the significant body of IPA research in sexual health.

*Why not use Grounded Theory instead?*

Although Grounded Theory can be construed as taking either a realist or contextual constructionist approach depending upon how it is used, there are important differences between IPA and Grounded Theory. Grounded Theory (realist version) takes a position that the data generated truly reflects the experience of the participant. The way in which this version of Grounded Theory is evaluated concentrates upon the objectivity and reliability of the knowledge that the approach has generated. The theory is built from the ground up, taking the data at face value. IPA goes beyond this in extrapolating from the

face value of data, through a careful consideration of the personal and situational contexts of both the participant and the researcher. Quality in this case is assessed by triangulation (or researchers and / or other methods) to show how different perspectives converge and confirm or disconfirm one's observations and interpretative work (see section on assessing quality below). Although Grounded Theory (constructionist version) shares the contextual constructionist position of IPA, it lets categories emerge from the data. IPA approaches seek to develop the meaning within such categories through interpreting the data actively by using and acknowledging the researcher's declared perspective.

*Establishing Quality in Interpretative Phenomenological Analysis*

Qualitative research is concerned with meaning in context. The role of the IPA researcher in particular requires an active engagement with the data, to which the researcher brings their own standpoint. This means that the qualitative research process acknowledges a subjective element (Willig, 2001). How can we ensure that this qualitative work is done in a rigorous way, such that we can have some notion as to the process through which qualitative research findings are derived, so that the reader can make their own judgments about the meanings, and the contexts in which they are located?

Quantitative approaches have established criteria against which to benchmark the quality of research (e.g. reliability, objectivity, generalisability, power, validity). However, they are not meaningfully applicable to qualitative research in their current form. Several different methodological traditions have emerged with separate conventions and criteria

for evaluation. Although this can be seen as healthy pluralism, it may also lead to fragmented and rigid research groupings. As a result, qualitative researchers have engaged in debate as to how the production of their efforts ought to be evaluated more effectively and flexibly.

Several authors have attempted to identify criteria for judging the quality of qualitative research in psychology. For example, Elliot et al (1999) identified their own guidelines for evaluating qualitative research. However, Salmon, (2003) argues that establishing criteria for qualitative research as a checklist against which to benchmark research is to fall into the same error of 'methodologism' of which quantitative research often stands accused. Salmon reasons that "methodologism is a limited epistemology" (p.24), in that it is an error to think that quality can be verified simply through following procedures. Such an approach serves only to assert rather than justify a particular approach. Instead, Salmon contends that rather than establishing another checklist of truths to describe what research should be about, researchers should seek to develop an analysis that 'works'. In this, he means that the research should be high in coherence and organisation, so that it empowers the reader or the participants. The data should indeed be analysed, not merely meticulously recorded and reported. Furthermore, he urges researchers to be clear about what the research is intended to achieve, such as 'to describe' or 'to convey a more elaborate understanding of …'. Finally, he argues that the work should matter to others, and not just the researcher.

Bearing this critique in mind in trying not to follow procedures laid down for IPA in a blind fashion, it is useful to consider what criteria might be useful in establishing quality in research of this kind. Willig (2001) gives a convincing account of the factors that should be considered as important in evaluating IPA. She argues that IPA's main concern is with different insights into the same phenomena. Therefore, such research is concerned with the completeness rather than accuracy of representations. Willig argues that good interpretative phenomenological analyses should be grounded in the conditions in which they were produced, both for the participant's accounts, and the researcher's interpretations. This *reflexivity* is the prime criteria by which IPA should be evaluated.

Developing these reflexivity ideas further, Yardley (2000) proposed several useful criteria including sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. She also emphasises the flexible interpretation in the use of these guidelines.

Sensitivity to context refers to the context of the theory and understanding created by previous investigators who have employed similar methods or who have analysed similar topics. It also includes respect and attention to unexpected findings in the transcripts that should be fully investigated and accounted for. Furthermore, there should be reflexivity in the interpretation of language, in the context of the personhood of the participant, and the situational context of the interview. The relationship between the patient and the participant should also be attended to.

The standards of commitment and rigour advocate a prolonged engagement with the topic, in terms of competence in the use of research skills, and immersion in the data. A completeness of data collection and analysis should be evident, as well as an adequacy of the sample to supply the information required for a complete analysis. The interpretation of the data should be complete, taking into account the variation and complexity involved.

Transparency refers to the degree to which all aspects of the research process are disclosed, and the detail to which each aspect of the rules used to code data are described. Ideally, the researcher should present excerpts of the data so the reader can discern patterns identified by the analysis. Once again, the issue of reflexivity is touched upon here. The fit between the theory and the methods used to approach the topic should be good. Furthermore, a consideration of how the work was influenced by external constraints should be in evidence in the analysis.

Lastly, good qualitative research should be characterized by an enriched understanding of the phenomenon in question, and should be judged as useful by those who will use it (e.g. participants, patients, clinicians, the research community etc.). Indeed, a desirable outcome, although not necessary, is action research – research that originally seeks to explain existing problems, which creates new solutions.

*Method*

The project proposal was developed with the lead staff at the clinics in which participants were to be recruited. At this point, the project outline and proposal was submitted for Local Area Ethics Committee approval, which was granted, subject to some re-wording on the participant information and consent sheets (see Appendix II).

The specific procedures of the study were developed during further meetings and communications with lead clinic staff, and a consultation with the wider clinic staff, in order to take on board the views of those for whom the research may have service implications. These meetings were productive in terms of refining the final protocols for interviews.

Criteria for inclusion in the study included;

(i)    Recent diagnosis (within the last 12 weeks) of chlamydia, gonorrhoea, or both.

(ii)   Aged under 25 years (as this age group is most at risk of contracting an STI), and able to understand the information given to them orally and or in written form (according to British Medical Association Guidelines; see references for website address).

(iii)  Permission given by the potential participant for researcher to interview them

In order to preserve the confidentiality and respect for the personhood of the participant, the interviewer did not approach the participant in any public area, as this may mark them out as being a person with a positive diagnosis for an STI. Instead, Health Advisors were asked to mention the study, and to give the information sheet to the patient during their routine consultation following a positive diagnosis. If the patient was willing to explore the option further, they became potential participants in the study and I spoke with them about the aims of the study, and went through the information sheet with them. Participants were asked to sign the relevant consent forms and were given a contact telephone number should they have any questions about the study after the interview. They were also assured that any personal identifiers, or those of other named persons in mentioned during the interview transcribed interviews would be removed in the transcription of the interview. When the interview ended, I also checked the participants' their current emotional well-being, in case issues had been raised during the interview that had left them feeling distressed. No participants indicated that they had been distressed by the interview – although procedures and access to support staff were available should this had been the case. The participant was given a final opportunity to add any further reflections and comments, and were then thanked and compensated with £5 for the time spent in the interview. Participants were also given a copy of their consent form, information sheet, and contact telephone number in case they had any questions about the research once they had left the premises.

Initially, the study took place in one young person's sexual health clinic in North London. However, due to concerns about speed of recruitment to the study, this was later extended

to two further clinics – a young gay man's clinic, and a young woman's clinic, both at a different site in Central London. Ethical approval was sought for these extensions, and was obtained (see Appendix II). At the end of the study, 15 participants had been recruited from two out of these three clinics. A table giving an overview of participants' characteristics is presented overleaf.

Originally, the study was aiming to interview people both before and after they had been through the clinic partner notification process. However, due to the difficulty of getting appointments at the clinic, and / or difficulty in attending appointments that were scheduled, this did not happen in a formal way. Instead, a purposive sample was obtained, who met minimum criteria for inclusion in the study.

*Individual Interviews*

Much of the approach in this study has been derived from the methods described by Smith et al (1996, 1997). This study employed individual, in-depth, semi-structured interviews. I developed the interview through a process of examining issues highlighted in the relevant literature, and theoretical areas of significance highlighted by clinical health and social psychological research. I also took clinic staff views and suggestions fully into account. Through this process, I finalised a schedule that addressed research goals and also respected the personhood of the participants.

| Participant* | Ethnicity | Age | Sexuality | Diagnosis |
|---|---|---|---|---|
| F1 | Black-Caribbean | 18 | Heterosexual | Chlamydia & Trichomonis Vaginalis |
| F2 | Mixed White and Asian | 15 | Heterosexual | Chlamydia |
| F3 | Black-Caribbean | 17 | Heterosexual | Chlamydia |
| F4 | White British | 20 | Heterosexual | Chlamydia |
| F5 | Latino | 20 | Heterosexual | Gonorrhoea & Chlamydia |
| F6 | Black-Caribbean | 19 | Heterosexual | Gonorrhoea & Chlamydia |
| F7 | Greek-Ghanaian | 17 | Heterosexual | Chlamydia |
| M1 | British-Black | 20 | Heterosexual | Chlamydia |
| M2 | Black-Caribbean | 22 | Heterosexual | Chlamydia |
| M3 | Black-Caribbean | 17 | Heterosexual | Gonorrhoea |
| M4 | White Irish | 22 | Gay | Gonorrhoea |
| M5 | Black-Caribbean | 18 | Gay | Chlamydia & Non-Specific Urethritis |
| M6 | White Spanish | 25 | Gay | Gonorrhoea |
| M7 | Black-Caribbean | 19 | Heterosexual | Chlamydia |
| M8 | Black-Caribbean | 20 | Heterosexual | Gonorrhoea & Chlamydia |

*F denotes female, M denotes male

Table 3: Characteristics of Participants

The focus of the interview was to elicit the participants' views on their diagnosis with chlamydia or gonorrhoea, the process of telling (or not telling) their partners, and the consequences of these events. The interview schedule used was to provide a framework for me to structure the interview, but was flexible enough for me to request more detailed information, questioning the participants' understanding of the process and meaning of the diagnosis of the STI and the meaning of telling this to a partner. The structure of the interviews fell into three broad categories; (a) causes, consequences, susceptibility, social meanings; (b) partner issues; and (c) self-efficacy in coping with the consequences of STI. Slightly different versions of the schedule were used according to whether the participant had just been told their diagnosis and had not yet had an opportunity to notify their partner, or whether they had returned for a STI treatment check, and had an opportunity to tell partners. The questions most meaningful for this analysis were; "How do you think you got your infection", "How do (did) you feel, getting the diagnosis?", "Do you intend to tell you partner(s)?", and "How do you think they will (would) react?" or "How did they react?" The questions asked were open in style, but closed questions were also used when trying to ascertain certain details or clarifications during the interviews.

The sampling procedures used in this study were designed to recruit a relatively diverse set of young people that maybe at risk, rather than a strictly representative sample. This recruitment strategy of this study aimed for a reasonable diverse sample of young people attending the sexual health clinics, that roughly corresponded to the major risk groups for STIs, as described in Chapter 1. In this way, the study was aiming to achieve a

completeness of description, rather than a truly representative sample. Although IPA lends itself to a strategy of attempting to recruit a heterogeneous sample within a relatively homogenous stratum of the population (in this case, young people), it is acknowledged that the final sample probably did not reflect the full diversity of the population of young people throughout England. The sample can therefore be thought of as purposive.

Initially, this study aimed to interview a greater number of participants both before and after partner notification, and some participants at both time points in order to access a longitudinal perspective on the process. However, recruitment to the study proved more difficult than first anticipated. Out of 19 possible participants referred to me for interview, 3 declined to take the process any further. I terminated one further interview (for confidentiality concerns) when it became apparent that the interviewee was the partner of someone who had already attended for interview that day, and was still on the premises. 15 participants therefore completed interviews and their interviews were transcribed for analysis. It is not known how many other participants were approached by Health Advisors to take part in the project, but refused. Informal feedback indicated that the number of people who responded in this way was low.

The interviews were recorded on to minidisk and subsequently transcribed verbatim, and then anonymised. All interviews were conducted in dedicated comfortable and confidential settings, in the premises of the sexual health clinics.

*Analysis*

The object of the analysis was to identify themes emerging from the data to develop the understanding of how the participants make sense of the process of diagnosis with an STI, disclosure of this STI to sex partners, and the consequences of the diagnosis and disclosure.

Using the manual IPA strategy as described by Smith et al. (1997), the transcripts were analysed for recurring themes through a sustained engagement with the data. Themes emerged both within individual interviews and across interviews. Repetitions of emergent themes across individual transcripts were taken as indicative of their status as recurrent themes that reflected shared understandings.

Although the themes presented in the results are selected as they reflect the emerging themes from the data, it is important to remember that this selection process involves interpretative work on the part of the researcher. Although this researcher is attempting to capture the meaning of the events to the participant, this necessarily involves interpretative engagement with the text (Smith, 1996). Extracts presented here are selected because they capture the essential nature of the recurrent themes, or because they represent particularly articulate expressions of the underlying themes or contexts. For detailed description of the analytic procedure, please see Smith et al (1997).

Following these recommendations, I engaged with a case that was selected for the relative richness of content and potential themes contained within. The selection of this case already represents the judgments and interpretations that I made with the participants' transcripts. The analytic procedure was followed in detail for this first engagement with the transcript. This included initial annotation of the text, followed by transformation of these notes into theme statements for the whole text. These initial statements were then re-framed as emergent themes. Following this, the emergent themes were noted on a separate sheet of paper, and connections were made between them. These clustered themes were checked back against the original text and annotations to make sure that the connections worked for the primary source material. From these clustered themes, a table of super-ordinate themes was produced. A number of themes not well supported in the text were dropped at this point. Each theme in this table was appended with the sections in the text that related to it. This process continued in an iterative fashion throughout the drafting of the final report.

The author carried out this part of the analysis alone, engaging with the text, and with the research methodology literature, and previous studies using the IPA approach. These stages of the analysis and the final list of themes were then circulated to two colleague psychologists (both acting as supervisors to the research). One colleague had good knowledge of the IPA approach, and how it related to other qualitative methods. This colleague provided helpful feedback on the further abstraction of the themes to a higher level than the original themes. The second colleague had good knowledge of the service and clinical context in which the research was situated. This colleague suggested a

number of helpful changes in the wording of themes and the relationship of these themes

to the text.

These modifications were checked back with the original primary source material to see

if they still worked in a coherent way. No attempt was made to take this analysis back to

the participants. This refined table of themes and original transcript was then circulated

amongst peer psychologists. As a result of feedback, only minor refinements were made

to the thematic structure.

Following this intensive analysis of the first case, I followed the strategy suggested by

Smith and Osborn (1997) for analyses with more than 10 participants. The master theme

list from the first case was applied to the second interview, looking for more instances of

the themes that were identified in the first transcript, and identifying any new ones that

arise. There followed a process in which new themes emerging in subsequent transcripts

were tested against earlier transcripts, aiming to respect convergences and divergences in

the data. I took care to take adequate time over this process, so that important themes did

not get missed, or over-included. Finally, a master list of themes for the group was

obtained. An excerpt of a transcript and the process of annotation and theme generation

can be viewed in Appendix IV.

*Researcher's Perspective*

It is worth being transparent and explicit about the experiences and training that I bring to this research process. My previous training has mainly been in using quantitative approaches to research, employing social cognitive models of health behaviour. I chose to focus on a topic that was relatively new and uncharted because I wished to develop my understanding and skills in the use of qualitative approaches. The project topic was also chosen to intersect with my clinical interests – sexual health and working with adolescents - and my final placement of clinical training was partly based in one of the clinics in which the research took place. As such, I had to manage dual roles in this clinic – the role of both trainee clinician and researcher. In practical terms, this was managed through only conducting research in this clinic during one session of the week. I also negotiated with other clinic staff and supervisors about the appropriateness of seeing clinical referrals from this clinic. In terms of my engagement in the project, and the experiences of the participants, I decided early on to attend a sexual health clinic as a patient in a different area of London. This experience proved extremely valuable to me in terms of gaining some insights into the challenges and strains of attending such a service, from a user perspective. It is notable that the topic of STIs and young people received a fair amount of press coverage during the data collection and analysis phase of the project. This was challenging in that it required me to be aware of the possible impact that this press coverage was having upon participants and their decision to attend clinics, and my own sense of how I was analysing their data.

## Chapter 3: Results

*Background Information*

Fifteen participants completed the interviews, including 7 women and 8 men. The age range of the participants was 15 - 25 years for women, and 17 – 25 for men. The participants were recruited from 2 different clinics: 12 participants were recruited from a Young Persons Sexual Health Clinic, and 3 were recruited from a Young Gay Men's Clinic. Twelve participants identified themselves as heterosexual, and 3 men identified themselves as gay. In terms of ethnicity and cultural background, 8 participants described themselves as Black Caribbean, 1 as British Black, 1 as Latino, 1 as White Spanish, 1 as White Irish, 1 as White British, 1 as mixed-race White and Asian, and 1 as Greek – Ghanaian.

Seven participants were interviewed at the time of diagnosis of their STI at the clinic, and another 7 were interviewed when they re-attended at the clinic for follow-up after they had an opportunity to inform partners. One participant had been diagnosed with an STI, and had informed their partner. However, at time of clinic follow-up (and interview), they received a diagnosis of another STI, which they had yet to tell their partner about. No participants were interviewed more than once.

Nine of the participants were diagnosed with chlamydia (5 women and 4 men). Three participants were diagnosed with gonorrhoea (all men). Three participants were co-

infected with both gonorrhoea and chlamydia. One participant was co-infected with both chlamydia and trichomonas vaginalis, and another received an initial diagnosis of non-specific urethritis, but received a further diagnosis of chlamydia on return to the clinic for a follow-up appointment.

None of the men were attending the clinic because a partner had informed them that they should present for screening. However, 4 of the women interviewed attended the clinic because partners had told them that there was a risk that they had come into contact with an STI.

*Qualitative data*

This study seeks to elaborate our understanding of participants' cognitive and emotional representations in relation to a diagnosis of chlamydia or gonorrhoea. Through analysing participants' accounts, this study attempts to describe and develop a deeper understanding of the partner notification process for people attending a young person's sexual health clinic.

The analysis identified several themes and sub-themes that explored young persons' beliefs about testing and partner notification. These were organised into two higher ordered, relatively independent domains:

(1) STIs that are perceived as easy to cure are also seen as less threatening and stigmatising. This may encourage clinic attendance and notification to partners, but may reduce vigilance concerning infection risk.

(2) Diagnosis of an STI produces emotional reactions that affect the form, and possibly the effectiveness of partner notification.

These domains, the themes and sub-themes, and how they relate to each other are shown in Tables 3 and 4 below. In describing the results, I will only present those themes that directly address the relationship between attending for STI testing, the process of notifying partners, and the consequences of the notification process. Although other

themes were identified, they are not directly relevant to the research questions, and are omitted from this presentation. In describing these themes, extracts are presented as the most articulate examples of the recurrent themes and sub-themes. The extracts used are also selected to show the nuances in the themes that were extracted from the participants' accounts.

In the excerpts from these transcripts, a convention of M or F is used to denote whether the participant talking is male or female. The number following this letter designation uniquely identifies each participant. Each theme and sub-theme are labelled throughout this results section following the numbering convention used within the tables above. For example, the section referring to the sub-theme of 'responsibility to disclose to partners' is labelled 2.1.1.

| Higher Order Themes | Themes | Sub-themes |
|---|---|---|
| 1. STIs that are perceived as easy to cure are also seen as less threatening and stigmatising. This may encourage clinic attendance and notification to partners, but may reduce vigilance concerning infection risk. | 1. Some women ignore minor symptoms and peer groups use avoidance widely. Notification by partner and / or serious symptoms can encourage attendance at clinics. | 1. Minimisation of symptoms by some women<br><br>2. Avoidance coping by peers<br><br>3. Serious symptoms prompt information seeking<br><br>4. Sharing information with peers<br><br>5. Difficulties accessing care |
|  | 2. Emotional reactions to diagnosis are linked to beliefs about STI severity, vulnerability, and treatment options | 1. Emotional reactions to diagnosis: shame and stigma<br><br>2. Fertility implications are worrying for some women<br><br>3. Men and women report feeling invulnerable to STIs<br><br>4. For men, avoiding unwanted pregnancy is a greater concern that STIs<br><br>5. Low frequency of stigma as believe treatment is simple, and relief STI diagnosis not as serious as HIV<br><br>6. Health care staff are reassuring and can help reduce stigma |

Table 3: Themes and sub-themes encapsulated by the first higher order domain

| Higher Order Themes | Themes | Sub-themes |
|---|---|---|
| 2. Diagnosis of an STI produces emotional reactions that affect the form, and possibly the effectiveness of partner notification. | 1. Shame and stigma are not experienced acutely enough to prevent notification of STI status to partners | 1. Responsibility to disclose to partners<br><br>2. Low stigma associated with matter-of-fact notification style<br><br>3. Shock, upset, shame and stigma associated with more difficulties in notification |
| | 2. The consequences of notification are uncomfortable, but manageable and sometimes positive | 1. Trust, blame and regret<br><br>2. Fears of negative response are managed through choice of how information is disclosed<br><br>3. Women developing a sense of mastery<br><br>4. Women report a positive reappraisal of testing and relationships after notification<br><br>5. Testing is seen as an opportunity for behaviour change for some men |

Table 4: Themes and sub-themes encapsulated by the second higher order domain

## 1.1 Some women ignore minor symptoms, and peer groups use avoidance widely. Notification by partner and / or serious symptoms can encourage attendance at clinics.

1.1.1 Many of the young women interviewed reported experiencing minor symptoms that they tended to minimise, and even ignore. These participants often expressed regret in not seeking professional care before they did:

SJ:     *How long ago was that when you noticed the discharge and the pains?*
F7:     *About early April (6 weeks prior to interview)– but I didn't really take any notice cos I didn't know about them – about the different types ... so, I didn't really take any notice – I thought it would just go ...*

SJ:     *Can you tell me what brought you to the clinic today?*
F4:     *Today, to get my results, but last week ... just because, I've now been having pain and discharge and bleeding and everything else for so long that you can't ignore it after a while (laughs)*
SJ:     *Yes ...*
F4:     *And I kind of wish I hadn't ignored it for so long now*
SJ:     *OK ... so it got to a point where it got too much ...*
F4:     *Yes, much too much ... it gets in the way after a while ... that's the thing – of you're your regular life, when it starts infringing on that you can't ignore it any more*

           *...*
F4:     *I think it depends she said, on how far on it is ... she said that because I didn't feel any pain when she touched my stomach and that ... that it's not affected any of my fertility like my fallopian tubes, which is all I was worried about really ... so I think it's fairly easy if you catch it early on ... but, that's why I'm annoyed at myself for having left it ...*

Although minimisation of symptoms was a common response, some participants indicated that they sought treatment promptly, including most of the young men. These participants tended to have previous knowledge and / or experience of STIs.

1.1.2   Many participants described a pattern of an absence of symptoms, minimisation, or an ignoring of minor symptoms with a hope they would go away spontaneously that was common amongst their peers:

*F1:*   *People can have things and don't know about it ... or just take no notice of what, and don't even care or don't get checked up or nothing ... so they just class it as I ain't got nothing ... I feel that certain people are in denial and can't come to here ... they know they might have something, but they prefer to be like, in denial about it*

*M7:*   *... because some of them they completely ignore it, they probably think, well if they go and get treated, the other person doesn't need to...*
*SJ:*   *Yeah*
*M7:*   *So, he probably got himself treated, yet still slept with that same person – the other girl probably went, no I don't want go the clinic neither – I ain't got nothing blah blah blah ...*

1.1.3   When symptoms became more noticeable and they began to impinge upon the participants' daily lives, participants described trying to find out more about what might be happening to them. For many of the participants, they chose to find further information from their peers or other sources of information before seeking professional health care:

*M3:*   *I did kind of like ... Well, when I first got symptoms, I was wondering what it was so I checked on the internet for what I thought it might be ... and I wasn't sure. I thought it was either chlamydia or gonorrhoea so I already had quite an idea ...*

*M8:*   *I was speaking to him (a friend) a couple of days before hand – and I told him, and he was telling me yeah, it was the same thing that happened to him – he told me what it could be, but it might not be so ... you know, just go to a doctor's and find out*

1.1.4   Some participants also indicated that they shared the knowledge that they had gained about STIs with their peers, so they could make a decision as to whether to attend for screening or not:

*F6:*   *Erm Oh! It helped me a little bit because one of my friends had had it before ... One of my friends that I told about – she's an older friend – she had it before so ... it was you know, talking to her, she was just re-confirming like you know its nothing bad ... the other friend, I was more talking to her at a preaching level*
*SJ:*   *Uh-huh ...*
*F6:*   *You know like ... get yourself checked because you don't know ... you wouldn't know ...*

However, some participants described how their peers would not come in for testing. In an excerpt from M1's account, he describes how a young man would not attend, even though M1 had tried to persuade him to attend for testing:

*M1:*   *Yes, I do tell you the truth ... but trying to get him in here is like trying to drag a bull by its tail (laughs)*
*SJ:*   *Yes ... it's hard ...*
*M1:*   *Its not funny, I shouldn't even laugh ... he don't listen to me ...*
*SJ:*   *Is it just one guy or one girl you've got in mind or more than one?*

*M1:*     *No, just one guy ... everyone else I know who has ... who does get it has come to terms with it and deals with it ... it's only one friend I've got who's reluctant to go and do it*

*SJ:*     *And ... what do they tell you when you talk to them about it?*

*M1:*     *Sometimes, it's like he can't be bothered ... he can't be bothered, he's scared... that's it really – he can't be bothered and he's scared*

*SJ:*     *Sometimes he can't be bothered and sometimes he's scared....*

*M1:*     *Yes ...*

*SJ:*     *Do you know what he's scared of ... has he said anything to you about that?*

*M1:*     *Well, a few words about the treatment ... it's only like a half a second treatment ... going in and then coming out ... but some boys just don't like it (laughs)*

*SJ:*     *Yes ...*

*M1:*     *He's heard a lot of bad stories about it so ... he doesn't want to ...*


*F1:*     *I'm the only one I know that comes to clinic to get checked up. Everyone else I know is too scared to come to clinic, or like don't really want to know the results ... silly things like that*


*M7:*     *Yeah, most of the times we see each other ... its this girl's got blah blah blah or something's like, down there ... we might have information that they don't know, so its basically just sharing it ... so, I might like turn to him ... "you've probably got chlamydia or something", he goes "no, do you think so?" – and I was like "probably because I've read up about the symptoms you might get", and he was like "oh", and I said, "so, are you gonna get yourself treated?" and he was like "yeah yeah yeah I'm gonna go but I don't wanna go yet", so ...*


It seems that although the participants in this study are able to attend for testing at the clinic, the idea of coming to a sexual health clinic provokes fear and / or avoidance for many of their peers.


1.1.5     Once participants had decided they wanted to consult a health care professional, through a process of peer consultation and information gathering, and / or the development of more serious symptoms, they often described difficulties in accessing the appropriate care:

*M3:*    *Because it's really hard to like ... well, I'm not at college now, I was in college then. In college time, it's hard to get appointments. I got to college quite far away, and around college there's not many of these places ... and none of them are open at weekends.*

*SJ:*    *Yes...*

*M3:*    *So it's hard to get ... But ... yes, first I went to my GP, and the GP said they can't do anything about it ...*

*SJ:*    *Yes ...*

*M3:*    *And, they told me to come here, phone here ... and then you can't phone here because the line is always busy ...*

*SJ:*    *Yes ...*

*M3:*    *And then so ... I ended up going to ... it got really bad, so I ended up going to A & E at (Hospital), and they told me to come here the next Monday, so I ended up taking time off*

*SJ:*    *... and what brought you to the clinic in the first place?*

*F6:*    *... I was having problems urinating ... I was urinating blood ... and I went to the doctor and they didn't know what it was ... and I took about 3 urine tests and they couldn't ... every week I would go back and take it and they couldn't find out what it was*

*SJ:*    *Was that at your doctor's?*

*F6:*    *This was at my regular GP*

*SJ:*    *Uh-huh ...*

*F6:*    *And then my GP got a bit worried because I was still urinating blood, and they couldn't understand why, so then ... she just ... they put me on to medication but they couldn't find what's wrong so they just referred ... they took a gonorrhoea and syphilis and something else test ... but it all came back negative, but she told me to come along ... to the health clinic*

This section has described how some women reported minimising their symptoms and employing avoidance-type coping strategies. Both men and women also described how this avoidance was a common strategy amongst their peers. When symptoms became more noticeable, participants described a process of information seeking and sharing. Indeed, some participants described talking to others about their experiences at sexual health clinics and their knowledge about STIs, in order to encourage others to attend for

screening. This encouragement was not always successful. Once the decision to attend for screening had been taken, participants described several barriers in accessing appropriate health care, including diagnostic problems at a primary care level, and difficulties in being able to get appointments at a sexual health clinic.

## 1.2 Emotional reactions to diagnosis are linked to beliefs about STI severity, vulnerability, and simple treatment options

1.2.1 Participants had various responses to the diagnosis of either chlamydia or gonorrhoea at the clinic or being notified by a sex partner to attend the clinic for screening. Women who had been notified by a partner described feeling surprised and shocked:

*SJ: Right. And how did you react when you were told?*
*F5: Well, I was shocked. I thought well, I didn't give you that! I couldn't have! Unless ... I've had it from my ex, but I've been with my boyfriend for a year now ... almost a year so ... unless it was someone that I was with before but I don't know if you can have that for that long ...*

For those given a diagnosis at the clinic, participants reported experiencing shock, and anger at themselves and their partners. Both men and women experienced feelings of stigma and shame when diagnosed, although these experiences were not universal:

*M2: A bit of anger really ... more so at myself for allowing myself to be in this position ... because I came here a long time ago – about a year and a half ago ... and I had the test – the test to see if you have any of these kinds of infections ... its not the nicest of tests and I did promise myself that I'd never come back ...*

SJ:     *Right ... I'm thinking about how did it feel when they told you that you had gonorrhoea and chlamydia – what did it feel like?*

M8:     *I felt dirty ...*


SJ:     *So what was that like when you got that phone call?*

F6:     *What was it like?*

SJ:     *Yes ...*

F6:     *I was hurt*

SJ:     *Uh-huh ...*

F6:     *I was hurt ... I felt, I don't know ... you just feel a bit dirty ...*

SJ:     *Can you tell me a bit more about what that was feeling like ... what that experience was like?*

F6:     *What was it like ... woooo ... I felt ... I felt dirty ... and it was like, because I've got high standards of myself ... so if you hear that you've got two things ... I think, I've heard about these things but I've never been associated with anything like that*

        *...*

F6:     *Do you understand, I haven't been doing stuff – I still don't do things like that ... do you understand, so that's why it did affect me. If I was a dirty girl, dirty as in to say been around ... you know ... had sex with a lot of men ... well maybe then I would have said, oh, well I should have expected this to happen, something like that, but ... If you understand what I mean*


1.2.2   Some women had concerns over their fertility, and how it may be affected by

chlamydia:


SJ:     *Yes ... OK... How do you feel today, getting the diagnosis and receiving the news?*

F4:     *Mixed ... because I was really worried because they said to me last week, you know, that most of it came back negative because they can tell you most of it straight away, and that panicked me because the idea that I wouldn't know what it was, that it wouldn't be treatable ... because like I said, it has begun to infringe on my life ... now ... the idea that I would have to deal with it (laughs) ... that was .. I didn't want that at all ... but on the other hand I didn't want chlamydia because I know chlamydia's one of the ones that can lead to infertility... I know that and I didn't want that ...*

*F2:*     *Well, I was told that all I have to do is take the antibiotics. But the things is I've heard lots about all them people who've had it for lots of years, and can't get rid of it, and it's affected their fertility and that ... so I'm not quite sure*

1.2.3     Both men and women reported beliefs of invulnerability to infection. Before they were diagnosed, they believed that contracting an STI was the kind of event that happened to other people.

*F6:*     *Woooo! ... what's the consequences ... I've lost my trust in him, I don't really trust him. Really, I mean he tells me ... I think, I really do think that he was thinking on the same level as me ... thinking that he couldn't get caught with anything, or she won't have anything or, he won't have anything ... I think that's like how he was thinking ... that's why he actually ... when he did get caught with something, it kind of shocked him ... do you understand, because we have spoken about it, and the way he speaks I don't think he thought it could happen to him either...and now it has, it has changed him, because I think in a way, another reason I haven't left him is that now I know that – obviously there are so many things that – I was aware of it before but, I just really didn't pay attention to it but, I mean obviously you're now more aware of the amount of diseases that are out there so you wouldn't really want to sleep about with any and everybody*

*M2:*     *When I ... I received a letter through the post ... when I received that letter ... I was actually quite upset ... because, I don't know if everyone thinks this, but I thought this would never happen to me, type thing...*

*SJ:*     *Yes ... have you ever had conversations about this topic with your friends or brothers or sisters or anyone?*

*M2:*     *Friends, yes ... you know you watch programmes on television ... there's quite a few nowadays that talk about sexually transmitted disease, and like I said, you never think, oh I'm going to get one of them but ... it can happen and it has*

1.2.4    In relation to these beliefs about invulnerability to STIs, some men also reported

that they tended to think more the about risk of unwanted pregnancy rather that risk of

contracting an STI:

SJ:     *Was there anything else you felt when you knew you had a diagnosis of*
        *gonorrhoea?*
M3:     *Oh yeah, there was like a definite feeling that I will like use condoms forever!*
        *(laughs) And, yes ... just relief .. and a kind of wake up call.*
SJ:     *Yes ... Can you tell me a bit more about 'a wake up call' ... what do you mean by*
        *that?*
M3:     *It's just ... you kind of use them sometimes ... but when you're having sex you're*
        *really thinking about pregnancy. You care about STDs but you don't think it's*
        *going to happen to you ... so as long as when you ejaculate you're not inside ...*
        *you're like, you feel like you're fine with that. But, it like after this, it's no, no way*
        *... condoms all the time ...*

1.2.5    Some participants reported a low incidence of negative feelings at diagnosis, even

if it was their second or third episode of infection. For these participants, there seemed to

be associations between an absence of reported stigma, and the knowledge that treatment

was simple and effective:

SJ:     *How easy do you think it is to get treatment for the infection you had before?*
F1:     *You just come down to the clinic (laughs)*
SJ:     *You just come down to the clinic ...*
F1:     *You just come down to the clinic and they give you a treatment – that's it.*

M1:     *Even though she didn't know if it was, she might have given it to me ... she*
        *doesn't know that for a fact ... but she'd be shouting at me for giving it to her ...*
        *she go round and tell every single person that she knows ... (Name) gave me this*
        *and this ... that's wrong (laughs) ... that went the wrong way (laughs)*
SJ:     *She was telling everyone that you gave it to her*
M1:     *Yes ...*
SJ:     *And how did that make you feel?*

*Ml:*    *To tell you the truth it didn't make me feel nothing really ... because as I said chlamydia ... well, it's only chlamydia ... go to the clinic and get it checked out*

        *...*

*Ml:*    *I think I was about 18 ... but I can't really remember that one ... by that time ... I think there were so many people that had chlamydia that I know ... it just doesn't seem like something big any more ... like something shocking ... it wasn't something scary ... it was like caught chlamydia, call into the clinic and get it sorted ... so that time it was, and that's what it feels like this time as well ... because it doesn't really bother me to tell you the truth ... when it should, it should bother me*

*SJ:*    *How come it should bother you ... what do you think?*

*Ml:*    *Because its ... I could damage myself ... I could damage myself*

In the excerpt above, the participant reports how he is not really affected by the diagnosis of chlamydia and his opinion that the infection is common, no longer 'something shocking' or 'something scary', and is easily treated. The participant also expresses some concern about the effects that chlamydia could have, but is relatively ambivalent about this. This complex set of beliefs may partly reflect the context in which the interview is taking place – in a sexual health clinic where the participant is seeking treatment for his STI. To a certain extent, the participant may feel obliged to express concern for his health in order to gain treatment. This social desirability issue is developed further in the discussion section.

Once they suspected that they may have contracted an STI, some participants also described experiencing a sense of relief as they received the diagnosis of chlamydia or gonorrhoea, as they feared that they might be receiving news about more a serious infection:

SJ:     *You just wanted to get the treatment ... yeah ... what did they tell you about treatment?*

M7:     *They said that I had to take some pills twice a day, and for a week, and that it would clear up – and that I couldn't have sex for a week*

SJ:     *Yeah ...*

M7:     *Which obviously was hard but if you want to get rid of it then that's the sacrifice ... so ... but it was all right, I didn't really take it bad, only if anything was obviously, I was thinking if I had AIDS or something*


This excerpt implies the low level of seriousness that is ascribed to chlamydia by this participant, compared with AIDS.


1.2.6   Finally, participants accessing care at the clinic described experiencing staff as reassuring and helpful in reducing their worries about treatment and feelings of stigma:


SJ:     *So what sort of things were you interested in ...*

F6:     *Side effects ... is it everlasting? ... will it go away? ... you know, can it be treated? ... the regular ones (laughs)*

SJ:     *Did that make you feel less shocked? .... How did that feeling of shock affect you?*

F6:     *Its still ... At certain times, I do still think about it ... I still can't believe it but ... I don't know ... the doctor made me feel alright because she explained to me that its not something that will single you out, its ... it's a common sexually transmitted disease*


M1:     *But it was only when I said it to a friend ... he's already had it, he told me what it was ... and he told me about this place so I come up here ... got checked out*

SJ:     *And what did they say?*

M1:     *Well, to tell you the truth, I think I had chlamydia and gonorrhoea ... at the same time*

SJ:     *Right ...*

M1:     *And I was a bit worried about it but they told me it was nothing to worry about ... get it cleared up, and just use the condoms ... but ... I'm not too great at using those*

Although some participants found attendance at the clinic and the waiting room environment unpleasant, it did not emerge as a dominant theme.

This section details the range of participants' responses to receiving the news of an STI. Both men and women reported feelings of shock, shame and stigma, although these were not universal experiences. Women also expressed concerns about the effects that chlamydia infection may have upon their future fertility. Both men and women expressed surprise that they had been diagnosed with an STI. They described beliefs of invulnerability to infection, and some men reported being more concerned with reducing the risk of unwanted pregnancy, rather than focusing on susceptibility to STIs. Reports of stigma and shame were low for those men and women who saw treatment for the STI as a simple and straightforward process. Some participants also expressed relief that the infection diagnosed was not as serious as they feared. Several participants found that information and reassurance from clinic staff was helpful and reduced their feelings of worry and stigma.

## 2.1     Shame and stigma are not experienced acutely enough to prevent notification of STI status to partners

Despite the wide variety of emotional reactions in response to the discovery of an STI, including stigma and shame, the participants showed remarkable consistency in their behaviour with regards to partner notification. Whether the participants' were interviewed just after diagnosis prior to telling their partner, or some time after diagnosis,

14 out of the 15 participants reported telling or intending to tell their partners about their infection. The remaining participant started the interview reporting that she would not tell her partner, but became more ambivalent as the interview progressed.

2.1.1   Many participants talked about a responsibility to disclose the infection to sex partners, even though they acknowledged that this might raise some uncomfortable issues for them, and their relationships with others:

*F2:*    *If you respect somebody then you will tell them*

*SJ:*    *Yes ... is this the only person you're having sexual contact with?*
*F4:*    *Yes, yes... has been for 11 months*
*SJ:*    *Yes ... and do you intend to tell your partner?*
*F4:*    *Yes ... definitely, I'm going to have to tell all of them (laughs)*
         *...*
*F4:*    *And then with my partner, and I haven't been with anyone else since my partner*
         *... but then on the other hand if it was my partner who gave it to me? ... he's*
         *going to have to go back to his ex ...*
*SJ:*    *Right...*
*F4:*    *Which is ... this is the thing that I'm not happy about ...*
*SJ:*    *What, the fact that he's going to have to go back to his ex?*
*F4:*    *I don't want him ... I don't want any ... it was a one night stand ... but she was*
         *like a two time one night stand ... it's something I've never been comfortable with*
         *... because everyone knows about it ... its like a common knowledge thing ... and*
         *I really don't, we just kind of ignore the fact that it happened, like block it out*
         *because I don't like it and he's going to have to go and SPEAK to her about the*
         *fact that he had sex now ...*
*SJ:*    *Right...*
*F4:*    *Which I wish he didn't have to do ... but he's going to have to*
*SJ:*    *So, do you intend on telling one or more of these people?*
*F4:*    *Yes, all of them ...*

*SJ:*    *OK ... Did you tell the guy who you think you might have got this sexual infection*
         *from?*
*M4:*    *I did, yes...*
*SJ:*    *How did that conversation go?*

*M4:*    *Well, I phoned up my friend to tell him just for a bit of support ...it's like a mutual friend ... and he was the one who said oh no it's not Alan it's the other one ... so I had to defend Alan because (participant) was saying he's passed this onto him it was the other one ... I ended up kind of defending myself almost kind of saying ... if it wasn't him that gave it to me then obviously if I got it from somebody else, then I could have given it to him so ... my friend then put a lot of pressure on me saying, you've got to tell him, you've got to tell him now, so I said well ... I knew I had to tell him. I was going to tell him from the point of view that you've given me this, you know you should have had the symptoms sort of thing ...*

2.1.2   Participants who reported being only being mildly troubled by the diagnosis of an

STI used a matter-of-fact style to inform their partners. These participants also reported

being able to notify previous sex partners, as well as their current main sex partner:

*SJ:*    *Do you plan on telling your main girlfriend?*
*M7:*    *Yeah*
*SJ:*    *You do*
*M7:*    *I already have*
*SJ:*    *You have ... you told her today?*
*M7:*    *I already told her last week, cos they gave me the tablets last week. They said that we think you may have chlamydia, so they gave me that. So, my thing's gone now.*
*SJ:*    *Uh-huh ...*
*M7:*    *So, I already told her – she was like – Oh! ... I'm going to go to the clinic tomorrow then – it wasn't that hard, I just told her straight away*
*SJ:*    *Did you tell her ... How did you tell her?*
*M7:*    *I've got chlamydia, and you've probably got it as well (laughs). That was it.*

*SJ:*    *Yes ... when you had the first 2 episodes of chlamydia, were you seeing anyone at those times?*
*M1:*    *I was seeing everybody*
*SJ:*    *You were seeing everybody ... were there people that you told that you had chlamydia and gonorrhoea*
*M1:*    *Yes ... anyone who I could reach*
*SJ:*    *Anyone who you could reach ... who you had had sexual contact with ...*
*M1:*    *Yes ...*
*SJ:*    *How did that go ... having that conversation with people?*
*M1:*    *Some cases, not too good ... some girls took it the wrong way ... and some other girls were straightforward about it and knew what they had to do*

2.1.3    Other participants who reacted to the diagnosis of an STI with shock or upset

feelings, or shame and stigma, reported experiencing more hostile thoughts when

planning how to notify their partners. In the excerpt from the F6's account quoted below,

she recounts notifying her partner in a manner where she struggles to control her temper:

*F6:*    *... first of all, I don't know, I know it's quite like ... well what I wanted to do was just shout my head off at him, I just wanted to scream at him but then ... I was like, it's not going to change anything, you get me, because, I've got it already*

*...*

*F6:*    *So it had to be him! ... When I spoke to him, I had to choose the right time, I had to word my words, but as you know you just think what you're going to say but it never comes out the way its supposed to come out (laughs) ... so I just phoned him and I said ... what did I say ... I said, I think you need to go to the clinic, that's what I said to him, I said I think you need to go to the doctors, and he said what...he was asleep just woken up, yeah ... he said what, what? ... I said, I think you need to go to the doctors, I've just come from the clinic and they're telling me that I've got chlamydia and gonorrhoea ... but I was trying to talk low (laughs) yeah, and he was just disbelief saying what, what, you've got what? ... and I said, are you listening I've got chlamydia AND gonorrhoea*

*F3:*    *I'm not telling him ha! ... He should have been with me when I was in hospital ... he should have been with me so it will serve him right if he doesn't know then he can give it to all the others ha! ... Even if I did tell him ... how  ...how do you do that ... I'm not sure ... maybe I ... maybe I should tell him ... but it'll just come back to me*

*SJ:*    *I'm wondering if you could tell me a bit more about what went through your mind when you were told you tested positive for chlamydia?*

*F7:*    *Kill the boy*

*SJ:*    *Kill the boy?*

*F7:*    *I want to hurt him*

*SJ:*    *Yeah ... you feel that quite strongly*

*F7:*    *Yeah ...*

*SJ:*    *What are your feelings towards him?*

*F7:*    *(SIGHS) ... I don't know, cos I love him, but I wanna hurt him ... and I'm just confused ...*

...

*F7:*   *I'll tell him ... that I have it ... I don't know ... I don't know what I'm going to say to him ...*

*SJ:*   *Do you know how you might tell him? Or have you thought about that?*

*F7:*   *Not really ... I'm most probably going to shout or ... say it in an abusive way ... or aggressive way, something like that*

In summary, although both men and women experience a variety of negative emotions in response to the diagnosis of chlamydia and / or gonorrhoea, participants reported that they were able to inform their partners about the infection, and indeed felt a responsibility to do so. If the participant viewed the infection as relatively benign and easy to treat, the information was communicated to partners in a matter-of-fact style. However, if the participant was experiencing feelings of shame or stigma, they were more likely to have angry feelings towards their partners, which may affect their style of notification.

## 2.2   The consequences of notification are uncomfortable, but manageable, and sometimes positive

For 6 out of the 7 women, interviews took place before they notified their partners. However, 4 of these women were attending the clinic because they had received notification of an STI from their partner. For 6 out of the 8 men, interviews took place after they had notified their partners. None of these men were attending the clinic as a result of being notified of a positive result for an STI by a partner. It is a complex task to attempt to compare the expectations and actual experiences of those participants interviewed before and after partner notification. However, some general themes did seem to emerge.

2.2.1    In talking about telling a partner about their infection, some participants expressed

fears about how the news would be received. In addition, issues of trust, blame, and

regret were raised:


*SJ:*    *OK ... do you intend to tell you partner about your diagnosis?*
*M2:*    *Yes, I don't really know how but ... I suppose you just have to say it ...*
*SJ:*    *How do you think that conversation's going to go?*
*M2:*    *Er ... moments of long silence...*
*SJ:*    *Uh-huh ...*
*M2:*    *It's going to be quite difficult really ... sort of like a sense of disbelief ...*
*SJ:*    *On whose part?*
*M2:*    *On hers ... because she's obviously caught it from somewhere else ...*
*SJ:*    *Uh-huh...*
*M2:*    *I don't know, maybe it puts doubt in my mind now ... about our relationship and*
         *where it's going ... and where it can go ...*
*SJ:*    *Yes ... what are the scenarios going through your head about what might happen*
         *when you think about this conversation ...*
*M2:*    *I think its about an idea of blame ... in there, this idea ... because when I first got*
         *here, I walked into the advisors room as she said, you've got chlamydia ...*
         *immediately she said, you've obviously caught it from someone else ... I thought*
         *... this other person has given this to me ... you know and they've not ... really*
         *thought about ... what they was doing before ...*


*SJ:*    *I'm wondering about his reaction, and how that conversation was ...*
*M4:*    *He's quite easy-going and he says ... he said, oh its fine and I'll get myself tested*
         *... but was kind of like he didn't think it was him... he didn't think he was*
         *responsible for it ... then he eventually got tested and he was clear and they gave*
         *him some tablets just in case ... yes, so ... I think he thinks we can go back to*
         *being friends, but I find it a bit strained you know – the whole atmosphere now ...*
         *I don't find it very easy now... it's still in my mind after everything that's*
         *happened ... and I wish I could turn the clock back and pretend like nothing*
         *happened, you know?*


2.2.2    Some men reported expecting an overwhelmingly negative reaction from the

partner. They reported disclosing their infection using less direct communication

methods, such as mobile phone text messaging, or through a brief telephone conversation

in preference to face-to-face notification. These men reported receiving reactions that

were not as bad as they had feared:

SJ:     *Tell me a bit more about what was difficult about telling her ... and about how you came to the decision to send it by text message ...*

M3:     *It's kind of like an accusation (laughs) ... It's kind of like an accusation ... and there was always ... what if she didn't have it, but I'm trying to wonder how I could have got it ... and there would be that, if she were to ask me about that ...*

SJ:     *Yes ...*

M3:     *Yes ... when I first asked her – when I told her she was like, are you sure and stuff ... are you sure it's from me, because she hadn't actually had any symptoms ...*

SJ:     *Yes ...*

M3:     *So ... it's just a hard thing to bring up. And to know when to and how to do*

SJ:     *Yes ... so, you sent her a text message*

M3:     *Yes*

SJ:     *And then what happened after the text message. What did the message say?*

M3:     *Because I hadn't come down in a while ... and I just told her the reason was ... this gonorrhoea ...and you've got it but don't worry because they can just give you pills and this sort of this, so it's nothing really to worry about.*

SJ:     *Yes ...*

M3:     *She was like, are you sure, and then we ended up speaking on the phone, so ...*

SJ:     *So, she texted you back?*

M3:     *Yes...*

SJ:     *Then, you ended up speaking on the phone ...*

M3:     *Yes...*
        *PAUSE*

M3:     *But ... it wasn't as hard as I thought it would be, it's just hard to do it in the first place. But the actual doing it isn't bad.*

SJ:     *What reaction were you expecting maybe?*

M3:     *I don't know ... I thought I might just not get one (laughs) ... not speak to me again or something ... I was expecting her not to be happy with it or ... I don't know ... It's just an embarrassing horrible thing to talk about...*

2.2.3   A strong theme emerged for some women about assertiveness in their

relationships, and a sense of agency or mastery. These engagement-type coping strategies

were manifested in the way they managed telling their partners about their diagnosis, and

how this information would be passed on to other sex partners. It was also evident in the

way these women managed further testing of themselves and their partners.

F6:     *He was just shocked. He was just what, what, and I said I think you need to go,*
        *and he said when did I find out and I said they phoned me today and told me*
        *because that was the night after I got the medication and everything ... and then*
        *he said, oh, and I said sort your shit out. Goodbye. And I put down the phone.*
SJ:     *Uh-huh ... so what was that, kind of like end of story?*
F6:     *That was ... basically ... that kind of put the ball in his court ... I mean, I knew to*
        *myself I wasn't going to contact him no more ... to me it was finished but to him, I*
        *don't know, it obviously wasn't finished for him... do you understand. That put*
        *the ball in his court, which actually did end up happening – he phoned me – he*
        *ended up phoning me and discussing it, another time. He phoned me ... actually,*
        *because I phoned him the Tuesday night because I found out on Tuesday – I*
        *phoned him the Tuesday night ... and he phoned me something like Saturday or*
        *Sunday the following week, no the same week ... and told me he had just gone the*
        *Friday ... so...*

SJ:     *Uh-huh ... what's do you think's going to happen if he doesn't want to come in for*
        *testing?*
F4:     *He IS going to come in for testing ... (laughs) ... he will ...*

SJ:     *And so he told you, and then you came here?*
F2:     *No – I brought him here, and I got checked out that day as well, and I got him*
        *checked out.*
SJ:     *Right, OK ... So, you both came at the same time*
F2:     *Mmmm*
SJ:     *What made you come along?*
F2:     *Because he was saying how he thoughts he had symptoms, and I was a bit unsure*
        *about his previous relationships ... and what he'd been up to ... so, better to be*
        *safe than sorry (laughs). So I thought I'll come to clinic and I told him to come as*
        *well, even though he was a bit reluctant (laughs)*

SJ:     *Right ... And how do you think that conversation is going to go with this guy*
        *you're going out with at the moment?*
F1:     *I think he's going to take it well ... Yes, I think he'll take it well.*
SJ:     *What do you think he'll do?*
F1:     *Come down and get checked up.*

SJ:     *Yes...*

F1:     *I'll make him come down and get checked up.*

SJ:     *Uh-huh ... How do you think he's going to react ... you say he's going to take it well ... can you tell me a bit more about what you mean?*

F1:     *... he might be like ... like what? Chlamydia? ... what? you got chlamydia? He might make a little scene ... or whatever ... but then it'll die down, and he'll know what he has to do – come down to the clinic to get checked up to see if he's got anything*

2.2.4    Some women talked about the experience of coming in for testing, and how conversations about the experience with their partners had the effect of making their relationships stronger:

F6:     *So, the way I see it I don't know who has, who hasn't got this so ... stick with somebody who I know who hasn't (laughs) ... because he got rid of it ... so it was like ... we dealt with it together ... we dealt with it together*

        *...*

SJ:     *So you think that this experience has had a result of making your relationship different?*

F6:     *It's changed it because its definitely put an experience that we've had to deal with ... it gave us something big that we had to overcome because I think a lot of people would break up over something like that ... I mean, it could either make you or break you (laughs) ... do you know what I mean*

SJ:     *Yeah ...*

F6:     *A lot of people would have broken up over it but ... we kind of stuck together, and it think it makes us a little bit stronger now ... because we've been through things together... and we worked at it, you know*

2.2.5    After telling their partners, some men talked about the notification process as an opportunity for them to change their behaviour and reduce their risk of subsequent STIs:

M8:     *I don't know ... it's not about just sleeping with anyone really, but ... I'm with my girlfriend now – stay with her ... see what happens ... I ain't really hoping to get it, but you never know what can happen ... don't know what the future is ... all you can do is just take protection, be precautious ... that's it – I can't tell if I'm*

*going to get it again... hopefully not ... I don't really want to come back here again*

M7:   *I think it's just like a circle of people anyway... I mean, I probably have slept with someone that my friend has slept with, and so on ... and so on and so on, so it's like a big circuit like ... you've caught it off someone, and given it to someone and blah blah blah ... so I don't know, just wanna get myself out of that loop so I don't have to worry*

SJ:   *Yeah*

M7:   *I'm not really concerned with that – until now – it never happened to me, so I could be ignorant to it, so ... now it's happened to me, I can realise that it can always happen to me again so ... I'm going to take steps to make sure it doesn't happen again ... probably get myself checked in a couple of months time just to see it's all cool anyway*

SJ:   *You'll come back just to make sure you're clear?*

M7:   *Yeah ... I think before there was some kind of stigma or embarrassment about coming to this place, but there's no embarrassment – when I came in I saw quite a few people that I knew anyway*

SJ:   *Yeah*

M7:   *And everyone was just joking and stuff like ... so it's not like when you see people going to the sex clinic they're going urgh, you've got some blah blah blah blah blah blah ... I dunno maybe I've matured or something, I've changed as a person, so they don't threaten me so I'm not even bothered  ... I mean, I even told my mum – it didn't feel too bad to me*

SJ:   *You told your mum*

M7:   *Yeah ... I didn't feel like ... cos I knew it was something I could get cleared up so ... it's like a cold or something ... I was alright with it, so ... I didn't feel like an embarrassment about it, or whatever*

This last section shows how this participant feels little stigma associated with the diagnosis of an STI. For him, it is simple to treat and easy to deal with, even though others may see attendance at a sexual health clinic as a threatening experience. Perhaps the diagnosis provides an opportunity for him to reflect upon his behaviour, after realising that his previous belief of invulnerability was not true. In many ways, this final excerpt illustrates many of the themes presented within this domain: perceived invulnerability to STIs until diagnosed, low incidence of shame in relation to the diagnosis of an STI, and a belief that treatment for an STI is relatively simple. The

participant also talks about how he feels little embarrassment in coming to the clinic, although he implies that there once may have been a time when he did experience such feelings.

In summary, this section has described how notifying a partner is experienced as an uncomfortable, but manageable process for almost all participants interviewed, in that all but one participant reported either telling or intending to tell their main partners about their infection. Common issues around notification included regret, blame, and issues around trust. Although there was some expectation that partner reactions to notification would be negative, reactions were usually not as bad as participants feared. A strong theme concerning assertiveness and the development of a sense of mastery in relationships emerged from the transcripts of several women. Furthermore, some women perceived testing and notification as a process that could make their relationships stronger, whereas men tended to view the notification process as an opportunity for behaviour change to reduce risk of further infection.

# Chapter 4: Discussion

This study had three specific aims:

1)   To develop a deeper understanding of the emotional reactions and cognitive

beliefs associated with the diagnosis of chlamydia and / or gonorrhoea.

2)   To investigate whether participants intended to tell, or told their partners about

their diagnosis.

3)   To elaborate upon the consequences of the STI testing and partner notification

process for participants

This study also aims to explore how well an established social cognitive model of illness

representations (The Common Sense Model; Leventhal, 1990) maps on to an area of

health in which it has not yet been applied.

The interpretative phenomenological analysis of the participants' generated 4 major

themes that were encapsulated by two higher order domains:

- STIs that are perceived as easy to cure are also seen as less threatening and

stigmatising. This may encourage clinic attendance and notification to partners,

but may reduce vigilance concerning infection risk.

- Diagnosis of an STI produces emotional reactions that affect the form, and possibly the effectiveness of partner notification.

In this section, I discuss how the issues identified in each higher order domain and themes relate to, and extend upon the existing research literature. I consider the effectiveness of the Common Sense Model (CSM; Leventhal, 1990) and Taylor and colleagues' (1983, 1984) coping adaptation model as ways to integrate the themes. Following this, I present a methodological critique of the study, including an assessment of the quality of the analysis, the strengths and weaknesses of the design of the study, and opportunities for further research. Finally, I discuss clinical implications and recommendations from the findings of this study, followed by my concluding remarks.

*Discussion of Emerging Higher Order Domains and Themes*

This study aimed to deepen the understanding of the partner notification process and it's consequences for patients by using an interpretative phenomenological approach to analyse participants' accounts of testing for either chlamydia and / or gonorrhoea at a sexual health clinic. These participants were interviewed either before or after they had the opportunity to tell their partners about an infection. The analysis paid particular attention to the emotional and cognitive representations participants' of the STI testing and the partner notification process.

*First higher order domain*

The first higher order domain contends that STIs that are perceived as easy to cure are also seen as less threatening and stigmatising. This may encourage clinic attendance and notification to partners, but may reduce vigilance concerning infection risk. Within this domain, the first theme extracted from the transcripts relates to young women minimising or avoiding symptoms until they could no longer be ignored. The theme also identifies avoidance of symptoms and clinic attendance as a coping strategy that is used widely by this participant group's peers.

The minimisation of symptoms, or failure to follow up on initial consultations may represent the consequences of 'felt stigma' (Scrambler, 1998). Felt stigma represents a person's internal thoughts about the impact of a particular condition. Scrambler argues that non-disclosure or self-concealment as a result of felt stigma reduces self-esteem, security, and help seeking behaviour. Cunningham et al (2002) also suggested that concealment of stigma through non-attendance at clinics is a way of avoiding shame feelings.

Scoular et al, (2001) argued that felt stigma may act as a barrier to the dissemination of positive help seeking experiences to a wider peer group. The evidence presented here indicates that some participants both received and disseminated information to their peer group about STIs and avenues for treatment. However, the results of this dissemination were not always positive. Some participants described how their peers had heard stories

about bad experiences at clinics. Whether these reports of bad experiences were based in reality or not, the reported experience seems to be that as these stories are passed around the community, they may have the effect of discouraging people from attending sexual health clinics until symptoms become so serious, they cannot be ignored.

In relation to this non-presentation for screening, Banikarim et al's (2003) study found that although young women recognised the importance of screening for STIs, they were not being currently tested when at risk for STIs. They linked this finding to the Transtheoretical Model (Prochaska & Velicer, 1997), which views individual behaviour change as a gradual process that occurs through the stages of change. These stages are precontemplation, contemplation, preparation, action, and maintenance. Another construct of the model is decisional balance, which refers to an individual's weighting of factors in favour of 'pros' and 'cons' of changing or acquiring behaviour. Banikarim and colleagues found that the pros for STI screening increased across the stages of change for their sample of young women, when there was a change of partner, or unprotected sex with a main partner. However, they found that there was no decrease in 'cons' across the stages of change associated with a change of sexual partner, suggesting that cons exist regardless of the stage of change. We might speculate that this rigidity of the 'cons' might explain the continued avoidance of STI screening as described by the participants in the present study when talking about their peer group. The 'pros' for screening may only outweigh the 'cons' when key events occur, such as the development of more serious symptoms.

The second theme in this domain refers to the emotional reactions to STIs, and how they relate to perceived severity, vulnerability and treatment options. The reactions of shock, regret, anger, shame and stigma found here correspond with previously existing literature (e.g. Scoular, 2001, Duncan et al, 2001). Reactions of worry and regret were typical for those who saw the STI as having more long-lasting consequences, e.g. the fertility consequences of chlamydia infection.

What is novel in this study are the emerging associations between the knowledge that treatment options are simple and effective, the belief that the STI is relatively benign and common, and an absence of stigma. Related to this, some participants described feelings of relief upon diagnosis of chlamydia or gonorrhoea if their initial fears were of an infection with more serious consequences (HIV). It seems that if an STI has a simple and effective treatment, participants believe that infection with the STI is not a serious matter.

This theme seems linked to the idea that until their actual diagnosis with an STI, some participants reported perceiving their risk of infection as low, in their belief that contracting an STI was an event that happened to other people. This is reflected in the way that some men reported their main concern as the avoidance of unwanted pregnancy, rather than reducing the risk of infection.

In considering these findings, it may be helpful to refer to Taylor and colleagues (e.g. Taylor. 1983, Taylor et al, 1984) work on alternate models of coping. They examined

ways in which people attempt to adjust to threatening events, including illness. Based on their work with women who had been raped, and cardiac and cancer patients, they suggested that coping with threatening events consists of three processes; (1) a search for meaning, (2) a search for mastery, and (3) a process of self-enhancement. They argue that these processes lead to the development of cognitive illusions, which are central to the process of cognitive adaptation to threatening events.

In this context, we might speculate that if STIs such as chlamydia and gonorrhoea are seen as easy to treat and low in severity, people are easily able to adapt to the diagnosis of an infection, experiencing little negative emotion and able to proceed with screening and treatment. The diagnosis of an STI may have different meanings according to an individual's beliefs about the severity of the illness and treatment options available.

If illness severity is believed to be high, and treatment options are difficult, the illness threatens the *status quo*, and the cognitive adaptation model predicts that the person will engage in a search for different meanings and avenues of control and self-enhancement to cope with the new illness threat. In the example presented in the thematic analysis, the news that the diagnosis is chlamydia, and not HIV, is greeted with relief.

However, if the illness severity is perceived as low and / or treatment options are simple (as identified in the transcripts earlier), illness threat is believed to be low, and little adaptation to the illness threat is needed. If this is the case, we might speculate that these beliefs are likely to be associated with the maintenance of existing behaviour concerning

risk or exposure to STIs, i.e. there is low vigilance for STI risk or motivation for changing sexual risk behaviour. Indeed, in the final theme, it is only after diagnosis of an STI that some men perceive the illness threat as sufficient to engage in a search for mastery, through talk about changing their behaviour. This hypothesis has important clinical implications that are be outlined later in this discussion.

*Second higher order domain*

The second higher order domain proposes that the diagnosis of an STI produces emotional reactions that affect the form, and possibly the effectiveness of partner notification. Within this domain, the third theme suggests that although there is a range of emotional reactions to the diagnosis of an STI, these do not act as significant barriers to informing partners of the possible risk of infection. Fourteen of the 15 participants either intended to, or had already informed their partners. Although shame and stigma were experienced, these feelings did not act as barriers to informing partners. These findings concur with Catchpole's (2001) report that even though there are negative feelings associated with receiving a diagnosis of an STI, most people will tell their partners about it (see also Chacko et al, 2000). This study further elaborates upon this argument in that participants do not seem to inform partners simply because the clinic procedure requires them to do so. Rather, the participants describe feeling a social responsibility to tell partners of the risk of infection.

In relation to the literature relating to the positive effects of disclosure, Pennebaker (1989, 1990) has argued that sharing secrets with others help people to develop a sense of mastery and control over their lives. Furthermore, revealing secrets may help to reduce shame and guilt (Derlega et al., 1993; Stice, 1992). In this study, the motives that people give for telling their partners are taken at face value, but may be influenced by the context of the interview. This matter is discussed further in the methodological issues section.

A majority of participants in the study by Chacko and colleagues (2000) used a direct, matter-of-fact style of communication when disclosing an infection to their partners. However, a fifth of their sample used an angry and accusatory style of communication. The present study found that many participants who saw the infection as benign and easy to treat used a matter-of-fact, (perhaps even off-hand) way of communicating with sexual partners. However, if the participant viewed the infection as having potentially serious consequences, or were experiencing feelings or shame or stigma, they reported experiencing more hostile thoughts when planning on how to notify their partners. Although the extent to which these participants actually expressed their anger or accusations in notifying their partners is not known, we might speculate that information received in a conversation that is angry and accusatory in tone may be experienced as threatening (provoking, for example, denial or angry emotions in the recipient). As a result, recipients of such information may engage in avoidance-type coping, in order to avoid the threat (Leventhal, 1990). Indeed, news received in a way that is blaming or stigmatising may block attempts at problem-solving coping (Baker et al, 2001). We may

speculate that information that is received during a matter-of-fact conversation may be more likely to be attended to, and acted upon. This may result in increased levels of information seeking, and possible attendance for STI screening. These issues will be discussed further in the clinical implications section.

The fourth theme indicates how the consequences of notification sometimes had positive benefits. Lim and Coupy (2001) found that women disclosed to their partners because they wished to let their partner know that they had given them the infection, and because they did not want to receive the infection back again. This corresponds to the self-protective behaviour and assertiveness that emerged as a strong theme for women in the present study. We might speculate that women seek a sense of mastery over the illness (e.g. Taylor. 1983, Taylor et al, 1984) in an interpersonal context, through managing the disclosure and testing process of themselves and of their main partner. For men, mastery could be seen as the intent to change behaviour so that the infection and the process of partner notification do not occur again. For both women and men, the process of increasing their sense of mastery helps them to adapt to the diagnosis of their infection. Of course, this is only necessary if the infection is seen a sufficient threat. If it is not seen as a threat, then little adaptation is necessary.

Contrary to the findings by Baker et al (2001), some women in this study talked about how their relationships became stronger as a result of the partner notifications process. We might hypothesise that this relates to the process of self-enhancement, as proposed by Taylor et al (1984), where individuals attempt to build their own self-esteem through a

process of positive appraisal. Taylor's theory suggests that this positive appraisal and sense of mastery both contribute to the participants' cognitive adjustment to their diagnosis, and the process of partner notification. It is noteworthy that women indicated coping with the illness threat by using an interpersonal style of relationship management, whereas men tended to talk about changing their sexual risk behaviour – a more activity-based style of coping.

*The common sense model of illness representations*

Although the themes from the data are presented in 4 discrete blocks, it is clear that there are shared theoretical issues (e.g. the cognitive adaptation model; Taylor, 1983). The Common Sense Model (CSM; Leventhal, 1990) provides another useful framework within which to overview and integrate these themes for a more holistic understanding of how people deal with the diagnosis of chlamydia or gonorrhea. It also represents an attempt to offer some dialogue between the complex reactions to diagnosis with a STI and traditional health psychology theory.

The CSM identifies 5 cognitive components of a person's illness representation including cause, consequences, identity, timeline, and cure / controllability. There are also emotional representations of illness that may also be related to these cognitive components. It proposes that these illness representations (cognitive and emotional) act as an interpretative schema for information about an illness, which guides actions in response to an illness threat. This information is drawn from a cultural pool of

information, information from the social environment (e.g. peers or health care professionals), and personal experience of illness. In a recent meta-analytic review, Haggar and Orbell (2003) provided extensive evidence that perceived controllability is associated with active coping and cognitive re-appraisal strategies in coping with illness. Furthermore, patients who perceived their illness as having serious consequences were more likely to use denial and behavioural disengagement strategies.

One of the aims of this study was to explore how well the CSM maps on to the findings of this study. Although the themes emerging from the present study do not represent a full specification of the components of the CSM (e.g. cause and illness coherence are not represented), some of the predictions from the CSM seem to be supported.

In relation to coping outcomes, the CSM literature suggests that perceived controllability is associated with active coping and cognitive reappraisal strategies. The findings of this study indicate that those participants who see the consequences of illness as relatively benign and easy to treat gave accounts about attendance for screening and treatment at the clinic, and talking to their partners about infection in a matter-of-fact way. Furthermore, the CSM predicts that an increase in controllability of the illness is associated with a change in appraisal of the illness. This can be related to the reaction of women to the diagnosis of the STI in their search for mastery over the illness, and positive reappraisal of the process of seeking treatment, and the quality of their relationships. A increase in control over the impact that the infection has on these participants' relationships and bodies is associated with a positive appraisal about seeking

treatment, and the effect that the process has had on their relationship. Although the evidence does not indicate that this connection is causal, it is worthy of further investigation.

The CSM also proposes that people who perceive that their illness has serious consequences are more likely to use denial and behavioural disengagement strategies. In the context of the present study, a theme emerged that linked a suspicion of infection with reports of worry, fear, stigma and shame, and avoidance coping and minimisation of symptoms by participants and their peers. In this formulation, the emotional representations of the STI can be viewed as a parallel process (alongside cognitive representations of illness) that act as influences on behaviour.

Although this commentary on how the CSM corresponds with themes emerging from the accounts of these participants is simplistic and speculative, it serves as a useful narrative and theoretical framework. In addition to the parallels drawn above, participants talk about how information about the illness is drawn from their own illness experience, general lay beliefs, and specific information from authoritative sources. Moreover, they describe the emotional representations associated with STI diagnosis. This correspondence provides reasonable evidence that work with the CSM could be extended into the area of STIs to explore how the cognitive and emotional representations of STIs (including cognitions of cause, identity and coherence of illness) affect coping responses in more detail.

*Levels of explanation*

The findings described in this study should be tempered with a consideration of the type of knowledge that phenomenological approaches produce. IPA focuses on *perceptions*. While such an approach is able to generate rich accounts of situations and events, these accounts do not increase our understanding of *why* such experiences are reported. It describes the experience of participants, but it does not explain it (Willig, 2001).

One strength of this study is the attempt to make sense of why certain associations and variations emerge by establishing some dialogue with more traditional health psychology, based on theories of social cognition (Leventhal, 1990; Taylor, 1983). However, a major limitation of this group of models as a whole is their focus on the individual (e.g. Pitts, 1996). No matter how many more variables are added to these models, they all still assume the individual as the central focus. Another critique levelled at models focusing upon this level of explanation is their neglect of routine, or non-cognitively mediated health behaviours, and that much health behaviour happens routinely, without need for a rational decision making process (Bennett et al, 1995). Bennett et al. offer as a contrast to social cognition model something that might be called a social-contextual model, where the wider contexts in which health behaviours are occurring are emphasised. As Ground (1995) puts it:

"If we took into account that … people are pretty complicated, then we could be more effective. We have to see that people are neither just rational decision makers, not just

black boxes responding to external stimuli but are a bit of both with a whole lot more complicated, and more important stuff thrown in too." (Ground, *ibid*, p.25.)

In terms of considering the data in this study, several levels of explanation are possible. Taking one step above the level of intra-psychic explanation, Abraham & Sheeran (1993) argued that as sex is intrinsically an interactive behaviour, social cognition models should be expanded to include interpersonal and situational variables described by the literature on contraception use. In particular, they argue that relationship factors such as duration, intimacy, quality of communication and status (e.g. casual *vs.* regular) are important. Gold et al (1991) attempted to place individual cognitions within a broader social context in their study of condom use in gay men. They conclude that it is the thoughts and beliefs that occur during the sexual encounters themselves which are more relevant than those described in the 'cold light of day'.

Beliefs, emotions, and cognitions about STIs do not just exist within individuals. They exist within a much broader context, such as the form and influence of sex education, the social meanings, expectations and norms that are developed and presented through the media, and the wider world of gender, power, and inequality (Ogden, 1996).

The present study has touched upon how information about STIs comes from an individual's social world in term's of partners and peers. Holland et al (1990a) argued that the process of learning about sex happens in the context of a many different sources of information. In attending to these sources, the resulting knowledge not only shapes an

individual's own knowledge and beliefs, but also creates their sexuality. They identified the following five sources; school, peers, parents, magazines, and partners and relationships. Holland et al. argued that through these different sources, individuals learn about sex and sexuality. Although women were presented with messages of passive sexuality, they did not simply passively accept this version of sexuality, but were constantly involved in a process of negotiating and re-negotiating the meaning that others give to their behaviour. This analysis may help us to explain why women in the present study took an assertive role in their management of testing, in that they were attempting to re-negotiate the meaning of the diagnosis and information about the STI in the context of their relationships with their partners and their social worlds. This also relates to how sex is constructed in a context of gender and power (Holland et al, 1990b). Although this is not analysed in detail in this study, we may speculate that gender and power contexts have an effect upon how the diagnosis of an STI may be received (e.g. reproductive health and choices), that relate to relationship history, intimacy with current partner, and broader cultural understanding about what it means to be a young man or a young woman with an STI.

Wider cultural discourses also exist about the meaning of sex and the spread of STIs in the younger end of the population spectrum, and the media response to this as a moral panic (Weeks, 1985).

Why did this study not attempt to collect data that might relate more to these wider levels of explanation? Part of the answer to this question involves practicality. In piloting the

study, it was clear that the combination of clinic procedures and routines, and clients'

limits about the acceptability of the research interview meant that it would be difficult to

talk with participants for more than 30 minutes at a time. It was also difficult to guarantee

that participants would attend for follow-up appointments. This meant that although the

interviews were loosely structured and flexible, the amount of material that could be

collected in this time was limited. Therefore, a decision was made to collect data

pertaining to the research questions in a way that met with the need for the participants to

leave the clinic as soon as possible. Although this ensured a good match between

research demand and participants' needs, it somewhat limited the amount and type of

data that could be collected. An interesting variation would have been to try to interview

participants in small groups to see what common themes and discourses about sex, STI

testing, partner notification, and relationships emerged. However, the clinic has recently

experienced difficulty in its attempts to recruit users to focus groups to discuss aspects of

the service (Curran, *personal communication*, 2003), indicating how difficult it is to

recruit from this user group.

*Methodological Issues*

In the following sections, I consider the methodological strengths and issues of the study. First, I discuss the characteristics of the sample, and the extent to which the people who took part may be representative of the wider population of young people that may use sexual health clinics. I then consider issues that may have affected the quality of the data, and how this study has addressed some widely accepted principles of good practice in qualitative research.

*The sample*

The participants in this study were drawn from relatively narrow strata of the population known to be at particular risk of chlamydia and gonorrhoeal infection. Recent data indicate that the greatest burden of infection falls upon young heterosexual men and women, and young men who have sex with men, with the risk of infection being particularly high in London. The criteria for invitation to participate in the study were set out in order to recruit solely from these risk groups.

The 15 participants recruited to the study reflected these groups reasonably well, in terms of age profile, and declared sexual orientation. In terms of ethnicity, informal consultations with clinic staff indicate that the sample is reasonably representative of the overall profile of patients attending for treatment at the clinics. The relatively large proportion of Black-Caribbean participants also reflects the wider data about infection

risk, although this study did not specifically find any trends with respect to ethnicity in the emerging themes.

There may be some issues as to whether the issues that concern young gay men with respect to STIS are the same as those that affect young heterosexual men and women. Indeed, the data generated in this study indicates that the issues that concern young heterosexual men and women are not necessarily the same. It is also unlikely that the transcripts of 3 gay men are characteristic of the range of opinions that may be expressed by the population of young gay men in general. In this respect, the heterogeneity of the sample may be a limitation of this study. Nevertheless, the variations that emerged between men and women indicate are a relatively novel feature of this study that merits further investigation.

*Recruitment difficulties*

The original plan for this study was to recruit a greater number of participants, and to try to interview some participants both before and after they informed their partners. However, it proved difficult to recruit volunteers for the study. Feedback from NHS colleagues who were helping with recruitment indicated that they had not been able to identify many people who fit the criteria for inclusion in the study. Moreover, those that had been given information had often left the premises by the time staff was available to talk to them about the study. One of the highest priorities of service users attending the young persons sexual health clinic was to leave the premises in the quickest possible

time, as they often had friends waiting for them close by, or in the clinic itself. As the research interview meant that users would have to spend extra time in the building, it is unsurprising perhaps that recruitment to the study was so difficult.

The sample that did opt to participate in this study was self-selected. Recruitment to the study was not a random process. As such, this selected sample may not represent the wider community of young people at risk of infection. These participants volunteered to talk in an open way about a topic that to others may have been regarded as stigmatising. In this way, they demonstrated their ability to engage with their diagnoses and their consequences. At the same time, these participants described how many in their peer group used avoidance-type coping strategies with regards to the possibility of sexual infection. Moreover, this is an articulate group of young people, able to speak about their emotional and physical experiences, within the constraints and demands of a research interview.

In sum, it could be argued that this self-selected sample may be atypical in being socially skilled and have come to terms with their diagnoses and the process of partner notification. Their views may not be representative of other young people who did not volunteer for the research project, or even present at a clinic for testing.

*The quality of the data*

In assessing the quality of the knowledge generated by this study, Willig (2001) argues that the reflexivity is the key concern. Yardley suggests the flexible use of 4 criteria against which to gauge the quality of phenomenological research. The study was designed and carried out with these criteria in mind, but also acknowledging Salmon's (2003) notion that blind adherence to benchmark criteria should be avoided. Instead, an account that research should 'work', in that it should be high in coherence and organisation.

The first criterion refers to sensitivity to context. Language and the context in which it is generated and analysed in phenomenological research requires careful consideration. Interview transcripts tend to provide more information about how participants *talk* about the experience of attending the clinic and the partner notification process, rather then offering direct access to the experiences themselves. At several points in the interviews, I noticed how participants sometimes stopped in mid-sentence as if to censor or correct their own speech (e.g. mid-way through swearing). Participants were aware that in the context of the interview they were being recorded, and this may have altered not only the way they talked about their experiences, but the content too.

The consultation procedure at the clinics meant that the research interview with the participants took place when they were attending for screening and initial treatment, or test of cure. The type of talk in these medical care consultations was quite different to the

research interview. In the consultations with clinic staff, the style of talk was weighted

towards closed-style questioning and included an explicit focus upon the patient's need to

be able to ask questions about their infection. In my research interview, the balance was

in favour of more open-style questions, with the researcher asking the questions, and the

participant answering them. Several participants commented upon the difference in style

and agendas between the clinical and research interviews. This may have affected what

they chose to reveal in their research interviews. The effects of my personal

characteristics (Asian ethnicity, male, and perhaps viewed as a member of clinic staff) are

also relevant in considering how the interviews turned out. Different participant groups

may have identified with different aspects of my persona, and this may have affected the

extent to which they revealed their thoughts and feelings during the interview, and the

type of language in which they chose to do so.


Social desirability bias may have affected what and how participants talked about in the

interviews. Research indicates that the nature of the topic that is being talked about can

affect how people may respond. For instance, Holtgraves, Eck & Laskey (1997) noted

differences between socially desirable knowledge, socially undesirable behaviour and

socially desirable behaviour. If the person judges that there is a risk of being evaluated

negatively as a result of what they might say, they may choose to modify their response

to produce answers that are socially acceptable. In this study, participants may have been

tempted to give the responses that conformed to what they believe the researcher wanted

to hear, rather than describe what they actually think, believe or do. In this respect, the

finding that 14 out of 15 participants intended to tell, or had told their partners about their

infection is taken at face value. However, there is a possibility that the participants were giving socially desirable responses to this, and other parts of the interview.

There are issues concerning the extent to which participants' accounts are suitable for phenomenological analysis. Willig (2001) argues that participants' need to be able to communicate the rich texture of their experience, and to be able to use language to capture the nuances of their physical and emotional experiences. If participants are not able to articulate them in a sophisticated manner, phenomenological research methods may not be suitable. Although some participants sometimes struggled to articulate their experiences in words at their first attempt, I was careful to provide subsequent opportunities to re-visit descriptions of experience throughout the loosely structured interview. In general, it seems that the majority of participants were able to recount their experiences at an adequate level for phenomenological analysis.

Examples of the data are presented so that the reader can assess the extent to which the data support's the investigator's interpretation of the data presented as examples of the themes, and also be in a position to consider alternative possible readings (Elliott et al, 1999). With this aim in mind, the themes are extensively supported by extracts from the participants' accounts.

The second criterion suggested by Yardley refers to standards of commitment and rigour, in terms of competence in research skills and immersion in the data. I took care to design the study with the co-operation of clinic staff and supervisors. The process of analysing

the data was painstaking, following established procedures described by Smith and Osborn (1997). As a novice researcher using the IPA approach, I made particular efforts to better understand the scope of the participants' experiences through my own attendance as a client requiring screening and testing at a sexual health clinic in a different area of London. I believe that my experience in going through the testing process, and experiencing the clinical protocol, the waiting room area, and general environment of the clinic from a user perspective helped me to engage with the participants' accounts in a deeper way than would otherwise have been achieved.

*Influence of the researcher's perspective*

Yardley's third criterion refers to transparency, i.e. the degree to which all aspects of the research process are disclosed. Part of this is the consideration of the perspective of the researcher and how this may impact upon the interpretative process.

The interpretative work on my part is influenced by personal assumptions, and understandings of related cultural and academic / clinical material. It is also shaped by my previous experience of research, in which in which social cognition and individual differences were my chief interpretative framework. This is reflected in the way that I have attempted to relate the themes emerging from the transcripts into higher order domains that offer a dialogue with mainstream health psychology models (much of which is based on social-cognitive understandings of behaviour). My previous research training and personal beliefs make it possible that I would have been more receptive to the aspects

of the testing and notification process that had qualities which matched those that I identify with most strongly. Thus, it could be argued that I would have been more likely to attend to issues concerning social-cognitive aspects of the phenomenon during the planning of the interview and during the interview itself. Moreover, these may have been the themes I was most likely to emphasise in analysing and organising the data.

At the time of interviews and analysis of the transcripts, there was a large amount of media coverage of the increase in diagnosis rates of STIs in England and Wales. Most of these reports were quite alarmist in their content, and although the likelihood is low, this may have had an impact on the willingness of participants to participate in the study. Moreover, it may have affected the content of what was said during the interviews. It is more likely that the media reports may have had an effect upon the way in I analysed and organised the themes, in that I connected and attended to aspects of the interviews that most disconfirmed the alarmist content of these media reports. To a certain extent, it is a social and political decision on my part to provide a voice for a sector of the population that has had much negative attention and social commentary in recent times.

To summarise, it is widely acknowledged amongst qualitative researchers that there is no one 'true' reading of the data. However, by equipping the reader with information about the researcher's perspective, they are better able to make sense of this researcher's interpretation and decide whether or not he or she agrees.

The final criterion against which to measure the success of phenomenological research is the degree to which the findings are characterized by an enriched understanding of the phenomenon in question. This also refers to the level of coherence and structure achieved by the analyses (Salmon, 2003; Yardley, 2000). This study organises the data into two higher order domains, each comprising two themes, in an attempt to provide an integrated and coherent structure. The variations and nuances in the data were preserved through the presentation of a further layer of sub-themes, which were grounded in examples from the transcripts.

*Suggestions for further research*

Research on this topic is currently at an early stage, in that there is a paucity of literature looking at the consequences of partner notification, particularly in this risk group of young people under 25 years of age. Further research on the current topic, addressing some of the limitations of this study could explore a similar range of issues, interviewing a larger number of participants both before and after partner notification. Including the interview protocol as a part of the standard clinic procedure, on a random group of attendees at the young person's clinic would help to eliminate the self-selection bias inherent in the present study.

A second line of research could explore the way that people at the receiving end of the partner notification react to this process. Although four of the participants in the present study attended the clinic as they had been notified themselves, the difference between

their accounts and the other transcripts was not analysed. A number of mainstream
theoretical models could be used to conceptualise and analyse the phenomenon. The
Common Sense Model (Leventhal, 1990) would predict that the way this illness threat
information is received would produce different coping responses according to the
person's emotional and cognitive representations. The Transtheoretical Model (Prochaska
& Velicer, 1997) would take the decision balance and stage of change into account. For
example, it is possible that the 'pros' of screening' would outweigh the 'cons' to
screening, and the person would present for screening at a sexual health clinic (Banikarim
et al, 2003). The coping adaptation model would predict that if the information about the
infection were perceived as a threat, the person would engage in a search for meaning,
mastery, and self-enhancement in order to cope with the illness threat.

Although this study provides a useful starting point, a deeper understanding and
elaboration of the relationship and wider social contexts in which the participants
interpret and communicate the information about their diagnosis would be a potentially
useful extension of the present analysis. Although the current study indicates that
recruitment of participants can be difficult, perseverance shows that the results of such
research can be illuminating in its own right, and as a bridge to different ways and
traditions of conceptualising the same behaviour.

*Clinical implications*

Rates of chlamydia and gonorrhoea in this group of people (young heterosexuals, and young men who have sex with men) have risen sharply in the last few years. In this study of participants that conform to this profile, chlamydia and gonorrhoea were seen as STIs that were relatively benign, and easy to treat, unless concerns were expressed about the potential fertility consequences of chlamydia infection. Many of those who saw chlamydia and gonorrhoea infection as non-serious and easy to treat also reported a lack of stigma associated with these infections. Some participants commented upon how the clinic staff was helpful in terms of pointing out the ease of treatment for such infections, and how common they were in the wider population.

It could be argued that attending for treatment at an STI clinic represents something of a 'double-edged sword'. The infection is de-stigmatised through the wider social discourse about STIs, and through the reassurance of health care staff. Furthermore, illness threat is minimised through the ease of treatment for the infection. Although these factors may result in the decrease of avoidance type coping with STIs in this risk group, there is a risk that it will reduce vigilance for STIs in subsequent sexual relationships and encounters. If the infection is no longer seen as a threat, either cognitively, or emotionally, there is little benefit in changing behaviour in order to negate a benign threat. Although the sample involved in this study is small and self-selected, some men gave accounts of how their main focus for risk reduction was unwanted pregnancy rather than exposure to STIs. If the consequences of STI infection are seen as minimal, there is little motivation for

changing established, routine behaviours such as the use of condoms to protect against pregnancy rather than STIs. Thus, if men are having sex in a context where they believe the risk of pregnancy is minimal (e.g. a participant's account of using withdrawal as a method of contraception), and they already believe that the consequences of STIs are minimal, little behaviour change will occur. This has the result of placing these men at risk for subsequent, and possibly more serious infections.

This is a significant challenge for STI services. Although they may be able to increase the numbers treated in clinics (theoretically, if not practically), and indeed notified by partners, if the infections are seen as having minimal consequences, the cycle of infection may continue unabated.

However, if the consequences of infection are seen as harmful (e.g. participants' accounts of fertility worries), then this may provide the impetus to establish regular screening and safer sex behaviours. This might be evidenced in increased attempts to gain mastery over the illness threat, through the screening of all partners in a relationship, and through increasing vigilance and self-protective behaviour (e.g. Lim & Coupey, 2001).

Although there is a risk that a reduction in stigma combined with a belief that the STI has few harmful consequences and is easy to treat seems like a potentially risky combination, there is good evidence that a reduction in stigma associated with STIs is desirable (e.g. Dixon-Woods et al, 2001) in order to increase partner notification and lay referrals. The ideas of lay referral and peer education were raised in this study where participants gave

accounts of how they shared information about STIs and their experiences of using clinic services with their friends. However, the participants also described how some of their peers still avoided coming in to the clinic, even though they had the information, and an apparent infection. The use of peer educators is recognised at a policy and strategy level in planning effective sexual health services. A forthcoming Health Development Agency review (2003) reports that there is evidence that peer-led educations is more likely to be effective than sex education programmes, particularly with adolescents. However, the report also indicates that the evidence thus far is somewhat equivocal. The recruitment of peer educators may be an important way in which sexual health services can try to get a two-fold message of illness threat and treatment options into the wider community work in a context of wider relationship and interpersonal issues. Nevertheless, it is a tricky message to get across.

Finally, access to care continues to be a significant barrier this sector of the population. Some participants described difficulty in accessing appropriate diagnosis and treatment at their GP, and further problems in obtaining an appointment at a sexual health clinic, until symptoms became dangerously extreme. Aside from the effects of untreated symptomatic STIs on the personal health of individuals, there are public health implications as the infection continues to be spread (as long as the individual remains sexually active in the community before they manage to get treatment.) Feedback from NHS colleagues and the House of Commons Health Committee Report on Sexual Health (2003) indicates that sexual health services are already operating at maximum capacity:

"We have been appalled by the crisis in sexual health we have heard about and witnessed during our inquiry. We do not use the word 'crisis' lightly, but in this case it is appropriate. This is a major public health issue and the problems identified in this report must be addressed immediately".

House of Commons Health Committee Report on Sexual Health (*ibid*, p.6)

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APPENDIX I


Symptoms of chlamydia and gonorrhoea

*Chlamydia*

Men often do not get symptoms when infected with chlamydia, but they can include inflammation of the urethra, discharge from the penis and itchiness around the opening, and tenderness in the testicles. In women, symptoms often do not appear, but the disease can cause pelvic inflammation and a range of abdominal problems. The first line of direct treatment is usually a course of antibiotics. If untreated, chlamydia can lead to infertility in women, or cause life-threatening ectopic pregnancy. It is estimated the infection causes up to a third of all infertility cases in the UK.

*Gonorrhoea*

In men, gonorrhoea can cause pain while urinating and penile discharge. In women, there can often be no symptoms. However, if the infection spreads to the fallopian tubes, it can cause pelvic inflammatory disease, leading to fever, pelvic pain, and pain during sex. Antibiotics can lead to a complete cure, although there is evidence of increasing resistance to routine gonorrhoea treatments. If untreated, gonorrhoea can cause conjunctivitis and septicaemia in adults and babies born to an infected mother.

All descriptions provided by the Public Health Laboratory Service (www.phls.co.uk).

APPENDIX II


Information sheets, consent forms and example of Interview Schedule

Research Project:
Service users beliefs about the partner notification process in a young
person's sexual health clinic

## An Invitation

You are being asked to take part in a research study. Before you decide, it's important for you to understand why the research is being done, and what it will involve. Please take time to read this information carefully, and discuss it with friends, a member of staff, or me if you wish. Ask us if there is anything not clear, or if you would like to know more. Take time to decide whether you want to take part or not.

We are inviting about 30 people who attend the clinic over the next few weeks to take part. We would like to talk to you today if possible.

**In this research, we are talking to young people with a diagnosis of Chlamydia and/or Gonorrhea, about their approach to telling their partner(s) about this diagnosis.**

- *The conversation should take about 15-20 minutes*

- *To thank you taking part in the project, I can offer you a £5 Woolworths voucher*

If you would like to carry on taking part in this project, there will be another opportunity to talk to me again about your thoughts in a few weeks time. I will record the conversations, but you remain anonymous on tape, and in the write-up of the project. What you say will be treated confidentially, and you (or anyone else you talk about) will not be identified personally in any written material to do with the project. The tapes will be destroyed at the end of the project.

If you do agree to participate, you will help us to provide a better service for young people like you, attending clinics like this one. You can come back to the clinic in September for a leaflet to find out more about what we found in the project, and how it will help the clinic provide a better service.

If you would like to take part, please sign the consent form on the next page. Remember, if you're not sure, you can try and take part if you like, and you're free to withdraw at any time you like, without giving a reason.
If you decide not to take part, that's OK too. This decision will not affect the treatment you receive at this clinic.

Thanks for reading this information sheet. If you have any questions at any point, you can contact me on 07905 943654.

Sarb Johal
Trainee Clinical Psychologist
Archway Sexual Health Clinic

<u>Please note:</u>

The Camden & Islington Local Research Ethics Committee has approved this research. Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

**If you become upset at any point during this research, or you find yourself becoming upset after the interview, please contact a member of staff at the clinic, where someone will be able to help you.**

## Research Project:
## Service users beliefs about the partner notification process in a young person's sexual health clinic

## An Invitation

You are being asked to take part in a research study. Before you decide, it's important for you to understand why the research is being done, and what it will involve. Please take time to read this information carefully, and discuss it with friends, a member of staff, or me if you wish. Ask us if there is anything not clear, or if you would like to know more. Take time to decide whether you want to take part or not.

We are inviting about 10 people who attend the clinic over the next few weeks to take part. We would like to talk to you today if possible.

**In this research, we would like to talk to you about what has happened since the last time you visited this clinic.**

- *The conversation should take about 30-40 minutes*

- *To thank you taking part in the project, I can offer you a £5 Woolworths voucher*

If you would like to carry on taking part in this project, there will be another opportunity to talk to me again about your thoughts in a few weeks time. I will record the conversations, but you remain anonymous on tape, and in the write-up of the project. What you say will be treated confidentially, and you (or anyone else you talk about) will not be identified personally in any written material to do with the project. The tapes will be destroyed at the end of the project.

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Sarb Johal
Trainee Clinical Psychologist
Archway Sexual Health Clinic

Information Sheet 2, March, 2003

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**If you become upset at any point during this research, or you find yourself becoming upset after the interview, please contact a member of staff at the clinic, where someone will be able to help you.**

Patient Identification Number for this trial:

# CONSENT FORM

**Title of Project:**     **Service users beliefs about the partner notification process in a young person's sexual health clinic**

Name of Researcher:    Sarb Johal (Tel: 07905 943654)

**Please initial box**

1.  I confirm that I have read and understand the information sheet (dated March 2003)    ☐
    for the above study and have had the opportunity to ask questions.

2.  I understand that my participation is voluntary and that I am free to withdraw at any time,    ☐
    without giving any reason, without my medical care or legal rights being affected.

3.  I understand that sections of any of my medical notes may be looked at by responsible    ☐
    individuals from regulatory authorities where it is relevant to my taking part in research.
    I give permission for these individuals to have access to my records.

4.  I agree to take part in the above study.    ☐

---

Name of Patient          Date          Signature

---

Name of Person taking consent     Date          Signature
(if different from researcher)

---

Researcher          Date          Signature

1 for patient;  1 for researcher;  1 to be kept with hospital notes

<u>Returning Interview prompts</u>

Duration = 20 to 30 minutes

Thank you for agreeing to take part in this research. I'd like to talk to you for 20 minutes or so today. I understand you have received a diagnosis of a sexually transmitted infection?

*<u>Causes, consequences, susceptibility, social meanings</u>*

Can you tell me about your diagnosis?
Have you received treatment for this diagnosis?
Did you manage to complete the medication, and do what the advisors asked you to do as far you they advised you on your treatment?

Now that it has been some time since your initial diagnosis, what do you think about getting this diagnosis?
How does it make you feel about yourself?

Do you know anyone else with this diagnosis?
Have you talked to them about it?
What did they tell you?

Do you think you are at risk of getting this infection again in the future?
If not, why not? If yes, why so? Where do you think you might get infection from? How do you think you might get it?

*<u>Partner issues</u>*

Do you have a sexual partner(s) at the moment?
Are you seeing anyone who you are having any kind of sexual contact with?
Did you tell your partner about your diagnosis?
(follow up with reasons why this did or did not happen, and what might be difficult)
What happened when you told your partner?
What do you think will happen next?

*<u>Efficacy</u>*

What do you think you will do now you have been told you have this infection?
Do you think you will change anything about your behaviours?
Do you think you'll be able to maintain this change?
Can you see anything that might be difficult about this change?
What do you think might help you make a change?

Thank for participating, and record payment. Photocopy consent form and give to participant as their own copy.

APPENDIX III


Example of transcript and table of themes

F004

P:
I understand you've just received …

*P:       Great news! Yeah...*

Could you tell me what your diagnosis is?

*P:       Chlamydia*

Chlamydia … OK … Can you tell me what brought you to the clinic today?

*P:       Today, to get my results, but last week … just because, I've now been having pain and discharge and bleeding and everything else for so long that you can't ignore it after a while (laughs)*

Yes …

*P:       And I kind of wish I hadn't ignored it for so long now*

How long had you ignored it?

*P:       About 10 months … I've ignored it for – well, not ignored it even … because I went to my doctor … and she told me I probably had thrush … and just gave me something that didn't clear it up but, I didn't follow it up, I've just sort of left it be*

OK … so it got to a point where it got too much …

*P:       Yes, much too much … it gets in the way after a while … that's the thing – of you're your regular life, when it starts infringing on that you can't ignore it any more*

Yes … OK … how do you think you go your infection?

LAUGHS

*P:       I've been sitting here trying to work that one out – I don't know – it depends … I've only been … I've had … sex with three – no, yes – three people … in total … one of them was a girl and I don't think we had enough actual sexual contact to have managed that*

Uh-huh …

*P:*       *But ... then oral with a guy – and I don't know where I've got it from! Thankfully, God thankfully, I'm friends with all these people ... so ... I can work it out, it'll be like a little mystery*

OK ...

*P:*       *I've just been thinking about the fact that because everyone's friends with everyone and everyone's got an ex in the group, and stuff like this it's going to be a nightmare, it's going to be the whole lot of them, it's going to be like dominos*

Uh-huh...OK ... we'll come on to that topic of partners and what do you do and how do you tell them in a sec ... we'll just stick with you for the moment

*P:*       *OK ...*

Do you think it's easy to get chlamydia or ...

*P:*       *Easy, because apparently you can get it from oral which I didn't know at all ... and I tell you something, most people don't know that, and that's a definite thing ... because that's something I would have been a LOT more careful about when I was younger ... if I'd have known that ... because you're kind of told that you can't really get anything from oral ... I mean chlamydia is a pretty big thing, most people know about chlamydia ... but I don't think anyone I knows knows you can get it through that at all*

Yes ... so you think it's relatively easy...

*P:*       *Yes, really easy ...*

OK ... what about treating chlamydia – do you think that's hard, easy – somewhere in between?

PAUSE

*P:*       *I think it depends she said, on how far on it is ... she said that because I didn't feel any pain when she touched my stomach and that ... that it's not affected any of my fertility like my fallopian tubes, which is all I was worried about really ... so I think it's fairly easy if you catch it early on ... but, that's why I'm annoyed at myself for having left it ...*

Yes ...

*P:*       *Because I would rather I'd have just caught it and it not led to other things ...*

Could you tell me a bit about what was going on, why you left it, I know you talked about it a bit at the beginning ...

*P:      You just don't have time ... you don't ... I worked in a bar ... and ... you finish late and you get up late – my boyfriend works nights, and ... the cycle of your life, I've got, and I've been good, I've got myself a job – I'm in a 9 to 5 job now, and its different its very different... and I had time to ring up and do it, and everything else but ... your social life? ... when you're working in a place like that it doesn't allow time for anything else except your social life – I know that sounds odd, but when your local pub's the one you're working in – you're always with friends, you finish work and they say sit and have a drink and you sit, and you have a drink and then its 11 o'clock at night and you just don't get time to do anything*

Yes ...

*P:      And I kept thinking it's alright I'll do it next week or the week after and it just never happened ...*

Yes ... OK... How do you feel today, getting the diagnosis and receiving the news?

*P:      Mixed ... because I was really worried because they said to me last week, you know that most of it came back negative because they can tell you most of it straight away, and that panicked me because the idea that I wouldn't know what it was, that it wouldn't be treatable ... because like I said, it has begun to infringe on my life ... now ... the idea that I would have to deal with it (laughs) ... that was .. I didn't want that at all ... but on the other hand I didn't want chlamydia because I know chlamydia's one of the one's that can lead to infertility... I know that and I didn't want that ... but she says that's unlikely so...*

And what are you feelings about getting chlamydia – I know there's the fear about fertility ...

*P:      That's the main one to be honest ... I think most people at the end of the day end up catching something or other now, be it thrush which is a really simple one but ... most girls end up with it at some point ... very few girls or blokes stay completely clean id they're sexually active, I mean, I know sexually active can mean you have one partner, and you know, that's all you ever have, but most people aren't like that, most people maybe do have the odd one-night occasionally, or ... and I think, certainly nowadays, its not the stigma attached to it that it used to be ... that doesn't bother me at all...*

Uh-huh ...

*P:      It's only the idea that I could have actually damaged myself with it ... to be honest is the only thing ... I'm just glad I know what it is ... and I can take something for it now*

You were saying that it was more of a worry because it started to impinge upon your life ... can you tell me what you mean by that?

*P:      You can't (laughs) ... I know it's stupid and I know it's probably really petty and selfish but you can't go home and ... you know ... you can't sit down and fool around with your boyfriend ... because you have to go, you have to wash, and it's really silly, but I don't ... I'm washing like 10 times a night or 10 times a day or whatever ... and it gets to a point where its silly ... and like at work I'm always worried that people are going to notice ... and like I said, it did just get where I couldn't ignore it*

Yes... OK ... do you know anybody else with this diagnosis?

*P:      Not chlamydia ... no I don't think so ... probably, but (laughs) no*

OK ... thinking about partners, do you have a sexual partner at the moment?

*P:      Yes, my boyfriend*

Yes ... is this the only person you're having sexual contact with?

*P:      Yes, yes... has been for 11 months*

Yes ... and do you intend to tell your partner?

*P:      Yes ... definitely, I'm going to have to tell all of them (laughs)*

You're going to have to tell all of them ... can you tell me a bit more about that?

LAUGHS

*P:      Right ... OK ...*

PAUSE

*P:      You see I'm going to sound bad now and I really don't want to, but basically there was a ... I was a virgin up until 12 months ago*

Uh-huh ...

*P:      I'd had sexual contact all over the shop – don't get me wrong, but I'd somehow managed to maintain my virginity and I don't know how I'd done it, because I was in a four year relationship and everything, but somehow it just worked out that way*

Uh-huh ...

*P:      And then I decided that I didn't really want my virginity any more ... and I had a bit of an odd weekend, and I slept with my friend Luke. Unfortunately, Luke is not ... the most ... he gets about ...*

Uh-huh…

P:      But, I did use a condom and everything … but if you can get it from oral then I didn't so … yes, Luke's been about … and he's still getting about which is something that does worry me … because if he has got it he's just spreading it … everywhere … then I slept with Luke and my friend … as well … because it was her birthday, and we were all a bit drunk and it was just something that happened … I have to admit it's not something I regret or anything … it's kind of a bit of a group joke and everything … and it's odd yeas, it happened, how bizarre! … but … same thing it was all protected everything, but … oral you don't think about … then I had just oral sex with a friend of mine called Alec who I'm going to have to tell …

Uh-huh …

P:      And then with my partner, and I haven't been with anyone else since my partner … but then on the other hand if it was my partner who gave it to me? … he's going to have to go back to his ex …

Right…

P:      Which is … this is the thing that I'm not happy about …

What, the fact that he's going to have to go back to his ex?

P:      I don't want him … I don't want any … it was a one night stand … but she was like a two time one night stand … it's something I've never been comfortable with … because everyone knows about it … its like a common knowledge thing … and I really don't, we just kind of ignore the fact that it happened, like block it out because I don't like it and he's going to have to go and SPEAK to her about the fact that he had sex now …

Right…

P:      Which I wish he didn't have to do … but he's going to have to

So, do you intend on telling one or more of these people?

P:      Yes, all of them …

All of them … how do you think these conversations are going to go?

P:      Honestly? … my best friend is going to smack me around the head and that'll be the extent of it … well, she's just going to go, well, you're stupid … but I think she's been checked out since … I'm pretty sure she's been … because I know that three of my friends went when I was at work, and they all went together … and, so I think she's been checked out, so she's probably fine …

Uh-huh…

P:     Luke … I'm going to have to phone up … that'll go OK, because he's, he is very, very sexually active, I'll be able to talk to him fine … about it, actually … it's going to be quite odd talking to Alec … because we don't really talk about the fact that it happened … we'll be alright once we…

This is your partner?

P:     No, no … this is the guy I just had the oral with…

Right, yes…

P:     I sound awful by the way (laughs) … he'll be alright once we get past the fact that … well, we're really good mates now (laughs) … and we just don't think about it, you know we just hang around and sit up drinking beer and stuff … and once we get past the fact that we have to actually acknowledge the fact that it happened … its should be fine – all my friends are quite grown up – they're quite … I'm not going to say this, and they're going to get all funny on me

Uh-huh …

P:     My boyfriend is not going to like it – he's not going to want to come in for testing … at all. I'm not sure he's going to tell his ex … I will say that, I'm not sure … I think he's going to turn round and say, oh no, it was a long while ago, no I'm not going to bother … because I don't think he's … he wouldn't see it the way I did, I don't think he feels the responsibility…

Uh-huh … what's do you think's going to happen if he doesn't want to come in for testing?

P:     He IS going to come in for testing … (laughs) … he will … no, he was really good … he came with me … and sat with me, because I've got an absolutely petrifying fear of blood tests … I don't like … and obviously I didn't want my internal examination, and he sat with me through the whole thing … and they said to him are you going to get tested and he said, no not today … and what he basically said to me was, I don't want it done, but if there's something wrong with you then I know I'm going to have to – so he'll come in … but he's going to hate it … he's going to absolutlely hate it .. but the woman was really good, and she showed me the little thing they use on guys, so I can go home and tell him

(I laugh)

P:     Yes, I can find something that looks vaguely like it in the house and go, here look!

Yes ... OK ... I guess there's a few people to tell, although it sounds like your boyfriend maybe the most difficult one?

P:      *Only because of his ex's ... I'm not bothered, between me and him, he knows I've got something wrong with me, he's known for a long while, he's been pushing me to come here more than I've been pushing myself ... but I think in terms of his ex's, he's not going to want to know ... as far as they're concerned, which I think is going to be difficult, because I'm going to tell him he should (laughs) – as much as I might not want him to...*

Yes ... is there anything you think that might get in the way of telling your boyfriend or anyone else?

P:      *The only thing that would get in the way of me telling luke is that I don't really get to see him much at the moment ... I don't even know if he still lives where he used to live ... I haven't seen him in a couple of months, but ... I will get in contact with him, someone will have his number ...*

So, just two or three more questions ... just thinking about what happens next? Now that you've been told you've got chlamydia, what do you think you'll do next?

P:      *I've got to take the pills that she's going to prescribe for me... I don't know if she's going to prescribe them now for me, I don't actually understand what's happening there ... I've forgotten what she said to me! But yes, I've got to take the pills, he's got to come in, he's got to take the pills, we're not allowed any sexual contact until we've both taken the pills (laughs) ... and . . I think that's it, wait and see if ... I had a kidney infection about 5 months ago ... and my doctor said she couldn't work out why I had it and stuff ... and I'm just wondering if maybe the bacteria, I don't know ... but that's something maybe ... to look into, to see if it's done anything else basically ... biut wait for it to clear up and go away and I can go backto being normal with it really...*

OK ... so you've got to take the pills, boyfriend's got to come in, get checked, take the pills, and got to stop having sex for a while until you've both been checked out as being clear – is there anything that's going to be difficult about that?

P:      *Yes – the not having sex will be really difficult – purely because we live together, and ... it's not like, you know, its going to drive us crazy, it's just going to be really sad ... to be honest ... because it's going to be about a month probably, if you think about it ... once he comes in, and then he completes his course, and we're both checked out, it probably is going to be about a month... that's a long while ...*

PAUSE

P:      *But you've got to do it – but ... that is a long while*

It does feel like it's going to be difficult ...

*P:      Yes, definitely, very difficult*

Is there anything that you think might help you along that path?

PAUSE

*P:      No (laughs), not really – you've just got to ... you've just got to do it... and just make sure we talk ... about it, because what does worry me ... is that we've actually been having a big issue about the fact that we're not having enough sex at the moment, and we really don't know why it is – it's just because we've been tired through work and everything else, and what I'm kind of thinking is that it's not good that we're now not going to have it for a month. But it might work, it might work the opposite way, and not having it at all might mean, you know that ... it improves when we do start having it, I don't know – no idea (laughs)*

Thanks for answering the questions … is there anything you'd like to add?

*P:      No ... only that it is something ... I think that probably on a relationship level ... the fact that you're going to have to talk about people you've been with ... to people you've been with about what happened ... I think that's odd ... that's going to be odd for my partner ... that I've got to ring up these people and say hmmm, look we had sex and discuss it with them ... pretty much in a relationship, you don't really acknowledge what happened with other people and now you've got to ... because I don't want to acknowledge what happened with him and other people at all, even though I have to now ... that's my first instinct with it, and it's probably going to be his as well*

Re-organisation of themes and labeling for F004 transcript

*Control, Illness identity, and Consequences of STIs*

Illness Identity and Coherence

| | |
|---|---|
| Overwhelming symptoms | p1, line 6; 'pain and discharge'<br>P2, line 16; 'chlamydia's a big thing' |
| Symptoms as prompt for seeking treatment | p4, line 4; 'washing like 10 times' |
| Unclear symptoms | p7, line 22; 'maybe the bacteria' |
| Unclear diagnosis | p1, line 13; 'probably has thrush' |

Control over STI

| | |
|---|---|
| Untreatable STI fear | p3, line17; 'wouldn't be treatable' |
| Understanding treatment | p7, line 18; 'take the pills' |
| Commitment to treatment | p7, line 34, 'got to do it' |

Consequences of STI

| | |
|---|---|
| Personal life and STIs | p1, line 17; 'it starts infringing' |
| Worry about STI symptoms and consequences | p2, line24; 'affected my fertility' |
| Fear of consequences of chlamydia | p3, line 20; 'lead to infertility' |
| Damage of self – consequences of STI | p3, line 32; 'actually damaged' |
| Interferes with sex life | p4, line2; 'fool around' |
| Treatment consequences – lack of sex | p8, line 8; 'not going to have it'<br>p7, line 29; 'really sad' |

*Susceptibility to STI*

| | |
|---|---|
| Ease of transmission | p2, line 5; 'everyone's friends' |
| Commonality of STIs | p3, line 25; 'few girls stay clean' |
| Spread of STIs | p2, line 7; 'like dominos' |
| Type of sex leading to transmission | p2, line 10; 'get it from oral'<br>p6, line; 'had the oral with'<br>p5, line 9 ; 'just oral sex' |

| | |
|---|---|
| Lack of knowledge | p2, line 10; 'I didn't know that'<br>p2, line11; 'most people don't' |
| Questioning source of infection | p5, line 14; 'my partner gave it' |

*Control and consequences of partner notification process*

| | |
|---|---|
| Notification of partner and past sex partners | p4, line 14; 'yes ... definitely'<br>p5, line 26; 'yes, all of them' |
| Discomfort over disclosure of STI | p5, line 22; 'SPEAK to her' |
| Control over disclosure | p5, line 19; 'I don't want him'<br>p6, line17; 'I'm not sure'<br>p6, line ; 'feels the responsibility'<br>p7, line 12; 'I will get in contact'<br>p7, line 7; 'I'm going to tell him' |
| Consequences of disclosure | p5, line 14; 'back to his ex'<br>P5, line 28; 'Honestly?...'<br>P6, line 2; 'that'll go OK'<br>P6, line 12; 'it should be fine'<br>P6, line 16; 'not going to like it'<br>P7, line 3; 'between me and him'<br>P8, line 5; 'what does worry me' |

*Reactions to STI diagnosis*

| | |
|---|---|
| Panic and fear | p3, line17; 'that panicked me' |
| Shameful self | p4, line19, 'I'm going to sound bad' |
| Fear of judgment | p6, line9; 'I sound awful'<br>p3, line22;' don't get me wrong' |
| Lack of stigma | p3, line 30; 'not the stigma' |

*Coping with an STI*

<u>Avoidance</u>

| | |
|---|---|
| Avoidance – ignoring | p1, line 8; 'can't ignore it' |

Avoidance                                         p1, line 10; 'wish I hadn't ignored'
                                                  p3, line 11 'I'll do it next week'
Annoyed with self and avoidance                   p2, line 26; 'why I'm annoyed'
Avoidance coping by partner                        p6, line 28; 'I don't want it'
Personal demands of life                           p2, line 9; 'don't get the time'

Other types of coping

Negotiation and safe sex skills                    p3, line 24; 'four year relationship'
Stopping avoidance coping                          p3, line 20; 'I didn't want that'
Cognitive restructuring of treatment – positive    p8, line 9; 'it might work'
                                                   p2, line 2; 'like a little mystery'


Support and mutual understanding

Supportive partner                                 p6, line 26; 'sat with me'
                                                   p7, line 4; 'he's been pushing me'
Understanding partner's reactions                  p8, line 20; 'going to be his as well'



*Health care professionals*

Supportive clinic staff                            p6, line 31; 'woman was really good'

APPENDIX IV


Ethical Approval for the Study

# Camden & Islington Community Health Service
# LOCAL RESEARCH ETHICS COMMITTEE

3 March 2003

Dr Sarbjit Johal
The Garden Flat
5 Lessing St
London
SE23 1DS

Dear Dr Johal

<u>LREC Ref</u>: 02/145 (please quote in all further correspondence)
**Title: Service users beliefs about the partner notification process in a young person's sexual health clinic**

Thank you for submitting the above project for ethical review. The Committee gave careful consideration to your proposal at its meeting on Monday 24 February 2003, and it was agreed that before a favourable opinion could be offered the following points would need to be addressed.

1. The Committee was concerned that the proposal does not state whether only participants with a certain sexually transmitted infection would be recruited. It was suggested that as chlamydia and gonorrhoea are most common STIs in this age group, it might be best to restrict the inclusion criteria to young people with this diagnosis. This would ensure that the results are not confounded by a 'mix-bag' of STIs.

2. The actual project title should appear on the patient information sheet, as the current title on the information sheet does not mention STIs and this may be construed as misleading.

3. Your own contact details should also be included on the information sheet.

4. The Committee expressed concerns that the current consent form is not very user-friendly. It was suggested that instead something along the lines of the LREC's standard consent form could be used, and I enclose a copy of this example consent form.

5. The Committee understood the need for confidentiality in a study of this nature, and hence it can appreciate why participants under 16 years of age should not, in this instance, be asked to obtain their parents consent to participate. The Committee however felt that you should refer explicitly to the Gillick principle, which allows children of any age to consent to treatment if they have "sufficient understanding". Although your explanation of why you only intend to obtain the child's consent does rely implicitly on the Gillick principle, the Committee felt the proposal needed to refer to it categorically.

Please forward any requested additional material/amendments regarding your study to the Ethics Committee Administrator or the Chair at the above address.

**PLEASE NOTE THAT THIS PROJECT SHOULD <u>NOT</u> PROCEED UNTIL THIS ETHICS COMMITTEE HAS CONFIRMED IT HAS NO ETHICAL OBJECTIONS TO THE STUDY *AND* THE NHS BODY/ORGANISATIONS HOSTING THE RESEARCH HAVE, IN WRITING, GIVEN THEIR APPROVAL TO COMMENCE THIS STUDY.**

If you have any queries, please do not hesitate to contact the Local Research Ethics Administrator at the address above.

Yours sincerely

Stephanie Ellis
**Ethics Committee Chair**

# Camden and Islington Community Health Service
# LOCAL RESEARCH ETHICS COMMITTEE

Research & Development Unit, 3<sup>rd</sup> Floor, West Wing, St. Pancras Conference Centre
St Pancras Hospital, London NWI OPE
tel: 020 7530 3376   fax: 020 7530 3235
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Chair: *Stephanie Ellis*   Administrator: *Kate Theodore*

6 March 2003

Dr Sabjit Johal
The Garden Flat
5 Lessing St
London
SE23 1DS

Dear Dr Johal

**LREC Ref: 02/145** (please quote in all further correspondence)
**Title: Service users beliefs about the partner notification process in a young person's sexual health clinic**

Thank you for your letter dated 4 March 2003, which contained amendments to the above project as requested by the Ethics Committee at their meeting on Monday 24 February 2003. I am pleased to inform you that after careful consideration the Local Research Ethics Committee has no ethical objections to your project proceeding.

Please note the following:

*   The Committee suggested that you could think about amending the information sheet to make it more explicit with regard to what the study is actually investigating. That is you may wish to state on the information sheet that you are talking to young people with a diagnosis of STI (just those with a diagnosis of Chlamydia and/or Gonnorhea) about their approach to partner notification.

This opinion has also been communicated to the North Central London Community Research Consortium.

**PLEASE NOTE THAT THIS OPINION ALONE DOES NOT ENTITLE YOU TO BEGIN RESEARCH.**

Camden and Islington Community Health Service LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility to decide whether or not the project should go ahead, taking into account the ethical advice of the LREC[1]. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management, who will need to be assured that the researcher holds an appropriate NHS contract, and that indemnity issues have been adequately addressed.

**N.B.** Camden and Islington Community Health Service LREC is an independent body providing advice to the North Central London Community Research Consortium.  A favourable opinion from the LREC and approval from the Trust to commence research on Trust premises or patients are **NOT** one and the same. Trust approval is notified through the Research & Development Unit.

**The following conditions apply to this project:**

*   You must write and inform the Committee of the start date of your project. The Committee (via the Local Research Ethics Committee Administrator or the Chair at the above address) must also receive notification:

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[1] Governance Arrangements for NHS Research Ethics Committees, *July 2001 (known as GAFREC)*

a) when the study commences;
b) when the study is complete;
c) if it fails to start or is abandoned;
d) if the investigator/s change and
e) if any amendments to the study are made.

- The Committee <u>must</u> receive immediate notification of any adverse or unforeseen circumstances arising out of the project.

- It is the responsibility of the investigators to ensure that all associated staff, including nursing staff, are informed of research projects and are told that they have the approval of the Ethics Committee and management approval from the body hosting the research.

- The Committee will require a copy of the report on completion of the project and may request details of the progress of the research project periodically (i.e. annually for longer projects).

- If data is to be stored on a computer in such a way as to make it possible to identify individuals, then the project must be registered under the Data Protection Act 1998. Please consult your department data protection officer for advice.

- Failure to adhere to these conditions set out above will result in the invalidation of this letter of no objection.

**Please forward any additional information/amendments regarding your study to the Local Research Ethics Committee Administrator or the Chair at the above address.**

Yours sincerely

Stephanie Ellis
Chair, LREC

**North Central London
Community Research Consortium**

Dr Paul Fox
Research & Development Unit
3rd Floor West Wing
St Pancras Hospital
London
NW1 0PE

E-mail Paul.Fox@camdenpct.nhs.uk

Phone 020 7530 5375
Fax 020 7530 3235

17 March 2003

Dr Sabjit Johal
The Garden Flat
5 Lessing Street
London
SE23 1DS

Dear Dr Johal

LREC Ref: 02/145
Title: Service users beliefs about the partner notification process in young persons sexual health clinic

I am pleased to note that the Local Research Ethics Committee has recommended to the Trust that there are no ethical reasons why your study should not proceed.

Projects are registered with the North London Community Research Consortium if they utilise patients, staff, records, facilities or other resources of Camden Primary Care Trust, Islington Primary Care Trust or the Camden & Islington Mental Health and Social Care Trust. On the basis of the documentation supplied to us, your study has the support of the clinical service manager/assistant locality director of the service in which it will be based.

The Camden Primary Care Trust therefore grants approval to begin research based on the proposal reviewed by the ethics committee and subject to any conditions set out in their letter of 6 March 2003. Should you fail to adhere to these conditions or deviate from the protocol reviewed by the ethics committee, then this approval would become void. The approval is also subject to your consent for information to be extracted from your project registration form for inclusion in NHS project registration/management databases and, where appropriate, the National Research Register and the UCL Clinical Research Network register.

Permission to conduct research is also conditional on the research being conducted in accordance with the Department of Health Research Governance Framework for Health and Social Care:

- Appendix A to this letter outlines responsibilities of principal investigators;

- Appendix B details the research governance responsibilities for other researchers. It also outlines the duties of all researchers under the Health and Safety at Work Act

1974. Principal investigators should disseminate the contents of Appendix B to all those in their research teams.

Further information on the research governance framework for health and social care can be found on the DH web pages at http://www.doh.gov.uk/research/
Staff working within trusts covered by the research consortium can also find the information on the Trust Intranet.

Researchers are also reminded that personally identifiable information on living persons must be collected, stored, processed and disclosed in accordance with the Data Protection Act 1998. Such data may be in the form of electronic files, paper files, voice recordings or photographs/scans/X-rays. Further information on the Data Protection Act is available from your organisations Data Protection Officer or from the Consortium R&D Unit. The Medical Research Council also publishes the guidance booklet 'Personal Information in Medical Research' which is available from http://www.mrc.ac.uk/pdf-pimr.pdf

Except in the case of commercially funded research projects, the following acknowledgement and disclaimer MUST appear on all publications arising from your work.
*"This work was undertaken with the support of Camden Primary Care Trust, who received [\*\*\*insert "funding" or a "proportion of funding" \*\*\*]\* from the NHS Executive; the views expressed in this publication are those of the authors and not necessarily those of the NHS Executive".*

\* *"a proportion of funding" where the research is also supported by an external funding body; "funding" where no external funding has been obtained.*

This is a requirement of the contract between the Trust and the NHS Executive in which the Trust receives funding to cover the infrastructure costs associated with performing non-commercial research.

Please make all members of the research team aware of the contents of this approval. I wish you every success with your research.

Yours sincerely,

Dr Paul Fox
Assistant Director of Research and Development

# Camden & Islington Community Health Services
# LOCAL RESEARCH ETHICS COMMITTEE

Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
St Pancras Hospital, London NWI OPE
tel: 020 7530 3799   fax: 020 7530 3235
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Chair: *Stephanie Ellis*   Administrator: *Kate Theodore*

25 April 2003

Dr Sarbjit Johal
The Garden Flat
5 Lessing Street
London
SE22 1DS

Dear Dr Johal

**LREC Ref: 02/145**
**Title:** **Service users beliefs about the partner notification process in young persons sexual health clinic**

Thank you for informing the Committee that you wish to extend the above project to include recruitment at Mortimer Market Centre in addition to Archway Young Persons Sexual Health Clinic.

I can also confirm receipt of your service manager's approval letter dated 24 April 2003.

I am pleased to inform you that the Committee has no ethical objections to the extension of your recruitment. However, please note that the conditions set out in our letter dated 6 March 2003 still apply.

Please forward any additional material to the Ethics Committee Administrator at the above address.


Yours sincerely



Stephanie Ellis
**Committee Chair**