Abstract

The first UK prosecution for Genital Herpes Simplex Virus (HSV) transmission in 2011 attracted strong criticism from medical experts. To address the dearth of research on the topic, this study aimed to explore the nature of advice given to patients by the multidisciplinary team (MDT) in the West of Scotland on HSV disclosure to partners. Ten semi-structured interviews with members of the MDT were conducted and the interviews were analysed using Burnard's Thematic Content Analysis. Four themes emerged which explored practitioners' knowledge of HSV and their feelings regarding the emotional aspects of the diagnosis on clients including the challenges of discussing disclosure. Within this framework, participants' attitudes to the legal prosecution were also surveyed. This study revealed that participants had good knowledge about HSV. Furthermore, participants believed disclosure to be the patient's choice and had not altered their practice to advise disclosure to all partners in accordance with local protocol. However, there was a general consensus that disclosure was not required due to the prevalence of HSV and prevalence was used to dissipate emotional reactions to HSV diagnosis.

Key words: HSV (Herpes Simplex Virus), Diagnosis, Europe, Prevention.

Background:

Genital herpes simplex virus (HSV) has been recognised as the leading cause of genital ulcerative disease[1]. ~~In the UK, approximately 25% of the sexually active population have genital HSV~~The prevalence of genital HSV has continued to rise, with over 30,000 first episodes diagnosed in England in 2015[2]. In 2011 David Golding was sentenced to 14 months in jail after he pleaded guilty to a charge of '~~*Intentional*~~ *Grievous Bodily Harm'* for reckless transmission of an incurable sexually transmitted infection (STI) – genital HSV. This verdict attracted strong criticism by ~~sexual health charities and~~ medical experts~~.~~[3] ~~The case was appealed in 2014 and the verdict upheld~~ The case was appealed in 2014 and the verdict upheld~~.~~[4]. This ~~case~~ has raised questions in terms of its impact on current clinical practice with HSV patients and whether clinical guidance would require alteration to incorporate the 'legal issue' of disclosure to partners.

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HSV has been identified as a stigmatised condition[5] that creates significant emotional distress and psychological morbidity[6,7]. Furthermore, along with the stigma, there are challenges and complications involved in disclosing this information[8, 9,10.] For example, the associated stigma has been shown to affect how partners interpreted the infection. Patients feared assumptions that they were sexually promiscuous while fear of rejection was associated with non-disclosure. For these reasons, genital HSV is often concealed and not disclosed[7]. Disclosure of HSV status was also linked to the value of the relationship, with the likelihood of disclosure decreasing with casual rather than regular partners[8,9]. One study exploring factors determining whether and when disclosure about genital HSV to sexual partners would occur found that the duration and nature of the relationship were significant[11]. The lived experience of patients diagnosed with genital HSV suggests that their STI affected their sexual behaviour, such as significantly decreasing the number of sexual experiences or ceasing all sexual contact[12,] or deterred them from entering a relationship[11]., In terms of disclosing about having an STI, research suggests participants express feelings of depression, anxiety and fear[8-10,] with some either not disclosing it or ending relationships to avoid disclosure[12].

Within the literature there is a recognition that healthcare workers have a central role to play in counselling about HSV and disclosure[8,11,12,13]. One study evaluating the quality, accuracy and differences in advice given by the Multi-disciplinary Team (MDT) in sexual health clinics to a patient presenting with genital HSV, found that some staff confused HSV-1 and HSV-2, and frequently declined to give prognostic information[14]. The Sexual Health Advisor (SHA) consultations were sometimes rated as being less acceptable than the nurse-led consultations. Another study found staff underestimated the risk of transmission, and gave participants inaccurate information[11]. These findings support earlier studies which demonstrated that patients received confusing or conflicting advice from healthcare staff on HSV transmission[15] while the general knowledge of doctors about the risk of transmission was unsatisfactory[16,17].

It has been argued that healthcare staff must provide clear guidance regarding disclosure[10,11,18] since the manner in which HSV is disclosed has been found to impact on the reaction of the patient and may potentially mitigate negative responses[7]. Despite this, there is limited literature that focuses specifically on disclosure and what patients are advised by the MDT. This study aimed to address this by exploring the nature of advice given to patients by the MDT regarding HSV disclosure to partners.

Methods:

A qualitative descriptive study was conducted in a large sexual and reproductive health clinic in the West of Scotland. Ethical approval was obtained from NHS Research and Development Management and the University where the study was based (Project No: 200130050). A semi-structured interview template was developed and piloted for use. Questions elicited knowledge about HSV and experiences of giving a diagnosis of HSV as well as views on the Golding case. Data were collected over a three-week period in March 2014, using a stratified convenience sample of ten members of the MDT (see Table 1).

*************************************insert Table 1 **

All interviews were recorded and transcribed verbatim. Analysis was conducted using Burnard's thematic content analysis[19] from which four key themes were established. '*HSV–The Facts'*, reviewed the medical aspects of the infection; '*Stigma and Psychological Aspects of HSV*', explored participants’ experiences of the emotional aspects of a HSV diagnosis; ‘*The Challenge of Disclosure’*, examined participants’ views and experiences of discussing disclosure; and ‘*Revenge not Justice*’ analysed the motivation of legal action.

Findings:

‘*HSV–The Facts’*, surveyed the advice given to patients in managing HSV as well as drug treatment and dealing with the herpatic ulceration. All participants provided practical advice on symptom management, pain relief and treatment of HSV and were found to have accurate knowledge.

> *‘I would talk about the immediate symptomatic relief and treatment to reduce the severity and duration of her lesions.’* (Participant 9)

During consultations facts about HSV were used to de-stigmatize and clarify any myth and/or misinformation about HSV, thus confirming or challenging what participants knew and what they had ‘googled*’*. The key message conveyed to clients was that HSV was a manageable infection that most people were unaware of.

> ‘*I talk about the prevalence of asymptomatic herpes simplex infection…this is to try and normalise the fact that many of us carry viral infections without knowing it.*’ (Participant 8)

Half the participants compared genital HSV to ‘cold sores’, believing this helped to normalize and de-stigmitise the infection.

‘Stigma and ~~p~~Psychological ~~a~~Aspects of HSV’ explored the participants’ perceptions of the emotional and psychological responses of patients regarding their HSV diagnosis. Most participants revealed that these were often their most challenging consultations, describing patients as being ‘devastated’ and ‘anxious’ when given their diagnosis.

> *‘It is definitely the one that brings the most tears’.* (Participant 4)

This was often because the patients described feeling unclean and embarrassed.

> *‘They feel dirty’.* (Participant 7)

Consultations were patient-centred in their approach and tended to focus on the psychological aspects of the HSV diagnosis to negate potential psychological harm. This was because patients were concerned about future relationships or how they would manage the condition given the lifelong nature of HSV.

> *‘What to expect in the future in terms of when this heals up. Will it happen again? How often is that likely to be?’* (Participant 2)

> *'They become concerned about the future and if they will ever~~y~~ have a sexual partner again 'cause they don't want to transmit it to somebody else*.' (Participant 6)

Within the conversations, four participants had experience of patients who avoided sex due to their diagnosis and concerns over transmitting it. Anxiety about fidelity and 'f*ear* of rejection' were also noted.

> '*If they are in an established relationship then there is that uncertainty about fidelity or that they have been unfaithful'. (Participant 10)*

This led to the theme '*The Challenge of Disclosure'* which explored the participants' current practice and feelings regarding advice on disclosure. Whether or not a patient disclosed to a partner was seen as the patient's choice by participants. Participants acknowledged that their role was to provide patients with facts, but that the final decision on disclosure was the patient's.

> '*Ultimately it is up to them. If patients choose not to tell their partners that is up to them.'* (Participant 3)

The majority of participants described disclosure as challenging and used dialogue, supported by written information, when discussing 'disclosure'. Only one participant advised patients to disclose, whilst another participant said they 'devolved' this to a SHA. Despite not specifically advising disclosure, four participants encouraged it from the perspective of being honest and open with partners, whilst two others discussed treating partners in the same way they would wish to be treated themselves.

> *'I sometimes throw it round the other way, how would you feel if your partner had herpes and didn't tell you.'* (Participant 10)

Discussions about disclosure raised issues about oral versus genital herpes.

> *'If someone is diagnosed with HSV-1 on their lips they are not automatically told they have to tell future sexual partners that they can transmit that virus. So why, when it is a similar virus, are patients in the position where they have to disclose that they have been diagnosed with genital herpes?'* (Participant 4)

Irrespective of their own views, practitioners recognised the stigma surrounding HSV.

> '*I think that it is unreasonable for us to expect people to disclose it to every future sexual partner because of the stigma, [it] arouses.'* (Participant 5)

The majority of participants felt that that the value of the relationship would determine the likelihood of disclosure.

> '*I think it is up to you to gauge each relationship…..Obviously if it is casual sex….I think it is much less likely that someone will be willing to do that.*' (Participant 5)

This raised the issue about a lack of professional guidance in relation to disclosure since discussions with patients were generally based on their own opinion. This difficulty in knowing what to discuss led to some clinicians feeling there was a need for clearer guidance on disclosure.

> '*I think we need some clear guidance as to what should form part of the consultation about the partner notification aspects of HSV.'*
> (Participant 10)

The final theme '*Revenge not Justice'* described participants' feelings about the legal prosecution for HSV transmission in the UK. All participants when asked were aware of the case and felt it to be damaging and ridiculous. The majority strongly believed that the verdict should be overturned because of the difficulty about how a prosecution could be proved in the case of HSV.

> *'Makes no sense to me given the prevalence of herpes. How could they prove it was him?'* (Participant 7)

Participants raised numerous concerns about the implications of legal cases for them as practitioners, but also the impact on patients accessing services. Many believed that it would reinforce the stigma surrounding HSV. Furthermore, if the guilty verdict was not overturned, participants recognised it might have implications for other infections.

> *'It seems bizarre because there are so many things that people could potentially pass on and where do you draw the line?'*
> (Participant 2)

Despite the Golding verdict, all but one participant stated they would not change their practice relating to the advice offered to patients regarding disclosure. This was because in some cases, legal prosecutions for sexual transmission of infection could relate to revenge and not justice.

> *'I just wonder whether some of these cases are driven more by revenge than justice.'* (Participant 10)

Consequently they left it up to the patient to decide.

Discussion:

In this study, the post-diagnosis consultation was a key component in normalizing and de-stigmitizing HSV whilst ensuring that the medical aspects of the infection were conveyed. Unlike previous studies, the information imparted by participants about HSV was found to be consistent and accurate[11,14,15,16,17]. Furthermore, it complied with the information contained in the local protocol as well as British Association of Sexual Health and HIV (~~BASSH~~BASHH) national guidance on the management of HSV[20,21]. However, cognisance must be taken of the small number of participants who were all from the same clinical area and likely to have been exposed to similar training. Moreover, they volunteered to participate so may have had a specialist interest in the topic or studied it prior to the interview.

In their consultations, participants focused on dealing with the psychological aspects of the HSV diagnosis which concurs with previous work in the area[6,7,8,9,]. However, participants in this study employed prevalence of HSV as a mechanism for reassurance when discussing HSV with patients. Previous research only reported prevalence being discussed in relation to managing the infection or in encouraging disclosure[13]. As with earlier studies, participants reported clients feeling upset, damaged and dirty on being diagnosed[6,7,8,9,10,12]. However, considering prevalence in this context was found to dilute some of the emotional aspects of a HSV diagnosis and offered a means to manage the distress within the consultation. This is pertinent as the care and advice received following diagnosis have been found to have considerable influence on psychological reaction to HSV in the long term[10,18] and the distress this incurs is acknowledged in national guidance[20]. In this study the severity and misconceptions surrounding HSV found one patient avoiding sex for five years due to HSV. This example is perhaps extreme but abstention from sexual intercourse is common[8,11,12]. This case emphasises the potential for psychological morbidity following diagnosis, and the necessity for clinicians to address and support the patient to deal with the 'distressing nature of symptoms and the stigma associated with HSV' (p.9)[20]. Thus discussing prevalence may help to address this. Following diagnosis, patients' fears about the future, in terms of how the infection would affect them, the risk of transmitting the infection to partners and fear of rejection were noted. These findings concur with previous work[9,10,11,16].

Once a diagnosis has been given, practitioners have to tackle disclosure. As with earlier studies, participants in this study found this challenging, especially in dealing with feelings of fear and anxiety which surface in patients around disclosing to partners[8,9,10,12]. This challenge was compounded by the paucity of guidance on what to advise patients regarding disclosure. In this study all but one participant discussed the issue, aside from one (a consultant) preferring to defer the responsibility to a SHA. People diagnosed with HSV have tended to disclose in the context of a regular relationship[8,11,13], although one paper reported the majority of their respondents would tell all sexual partners, regardless of whether it was a regular or casual partner[12]. It is noteworthy that in this study the majority of participants reported patients would be less likely to disclose their HSV status to casual partners. However, participants believed that patients would be more likely to disclose as commitment to the relationship increased, which reflects previous findings[8,9,11]. Participants noted that patients who were in a regular relationship and given a diagnosis of HSV raised concerns about fidelity. This has not been reported previously and reinforces the need for imparting accurate information.

The local protocol regarding disclosure states that all patients should be advised to inform all partners due to the Golding verdict[21]. Most participants had not altered their practice to advise disclosure to all partners, believing disclosure to be the patient's choice. Again, in direct contrast to local protocol, there was a general consensus from participants that disclosure was not required due to the prevalence of HSV. As with previous work, several participants reported encouraging disclosure as the 'right' course of action from the perspective of being open and honest with partners[12,13]. Only one participant fully followed the local guidelines, advising disclosure to all patients. Several participants mentioned there was a lack of professional guidance relating to disclosure which led to the discussion being based on their own opinion and welcomed clearer guidance on disclosure. Admittedly the ~~BASSH~~BASHH guidance on the management of HSV at the time of the study did not provide direct advice on what to advise patients but advocated disclosure as a means of identifying partners with undiagnosed disease[20]. Since completion of this study the ~~BASSH~~BASHH guidance has been reviewed and now states: 'it is important that the clinician raises this issue and advises the patient that disclosure is advised in all relationships' [23]. It would be interesting to ascertain if participants had altered their practice to comply with the change in guidance. Additionally, the views of these participants reflect arguments put forward in The Law Commission's consultation on the Crimes Against the Person Act which closed in February 2015. Findings have yet to be released, but decisions about disclosure or whether minor infections should be criminalised or be removed this from the draft Bill and made a specialised offence are eagerly awaited.

The lack of compliance with the local protocol may have reflected participants' feelings about the prosecution in the Golding case. They saw it as damaging and ridiculous, which reflects published views[3]. Several felt that legal prosecutions for transmitting STIs created stigma, and were possibly related to revenge, not justice. Wider arguments within the literature noted that the criminalisation of transmitting STIs produces consequences that are detrimental to public policy aims for sexual health and morally unjustifiable[3,22]. This perhaps explains why all but one participant stated they would not be altering their practice regarding disclosure following the Golding verdict, irrespective of opposing the local clinical protocol on HSV management[21]. *The author is currently involved in a large audit of practice in relation to HSV first diagnosis. Moreover, a working group has been established to review local practice and ensure clinicians are aware of the change in BASHH guidance and address any variations in practice/advice being given to clients.*

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Conclusion

This study challenged a key finding from the literature that healthcare providers were providing inaccurate information about HSV. It also revealed that participants believed disclosure to be the patient's choice and was not always required due to the prevalence of HSV. Consequently, participants had not altered their practice to advise disclosure to all partners in accordance with local protocol. The prevalence of HSV was deployed by participants in an attempt to normalise and de-stigm~~i~~atize the infection, and was seen as a means of managing the patient's emotions when a diagnosis of HSV was made. Widening the research across the UK is required to ascertain if these findings have general applicability and are not specific to this clinical area.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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