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Health inequalities and health equity challenges for victims of modern slavery

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Abstract

Background. Modern slavery is a serious organised crime, with severe consequences for the physical and mental health of victims, and so has public health implications. Anecdotally many victims of sex slavery experience difficulties accessing healthcare. Public Health England recently articulated the importance of health engagement to address modern slavery but little is known about the experiences of the survivors.

Methods. We conducted in depth interviews with Albanian female survivors of sex slavery who all displayed significant and complex health needs. Interviews were conducted between July 2017 and January 2018. Thematic analysis identified four primary themes, i) barriers to access, ii) negotiating access, iii) health needs and care received, and iv) overall experience of primary care.

Results: Survivors experienced repeated challenges accessing healthcare, for themselves and their children, and initially could not access GP services. When accompanied by an advocate they reported qualitatively and quantitatively improved experiences resulting in improved permeability. Confusion surrounding eligibility criteria and a lack of understanding of modern slavery emerged as the primary barriers, fuelling biased adjudications.

Conclusions. The importance of advocates, enabling rights-based approaches, improving understanding about access to health services for vulnerable groups, and a need for education across health service settings are discussed.

Introduction.

Psychological abuse, coercion, and mental manipulation force modern slaves to work in a variety of industries using (1; 2; 3; 4). Gauging the prevalence of modern slavery in the UK is challenging because psychological abuse and manipulation is easy to conceal (1; 4; 5), but many estimate there are ‘tens of thousands’ of victims in the UK, and that modern slavery is far more prevalent than previously thought (6). Indeed, the National Referral Mechanism, the framework for identifying victims of modern slavery, has seen the number of referrals increase year-on-year since it was introduced in 2009, as have the other two main sources of data - the number of modern slavery crimes reported to police, and referrals under the ‘duty to notify’ provision of the Modern Slavery Act, 2015 (7).

Modern slavery is a transnational organized crime that violates human rights with severe and diverse consequences for the physical and mental health of victims and survivors, and so has public health implications (8; 9; 10). Even when appropriately treated, the consequences of the abuse experienced by victims and survivors can endure for decades, none more so than for victims of sex trafficking (11; 12), one type of modern slavery that brings with it a high prevalence of sexually transmitted infections, pregnancy, physical injury, and serious mental distress (13; 14; 15)¹.

Although there is little published research on the experiences of victims and survivors of sex trafficking, researchers in North America have reported that the healthcare system often fails victims and survivors of modern slavery *per se* (9; 16). Victims are often not recognised when being treated, and so are returned to their abusers, and survivors can

¹ It is important to understand the distinction between sex trafficking and sex worker. In the case of the former, victims are forced to take part in the sale of sex through threat, violence, abduction and psychological coercion. Sex work, on the other hand, is typically a consensual transaction between adults, where the act of selling or buying sexual services is not a violation of human rights as is the case with sex trafficking.

face persistent healthcare barriers when seeking treatment, which can prolong the physical and mental illnesses and injuries incurred while enslaved (16; 17). It is the healthcare experiences of survivors of sex trafficking that is the primary focus of this research – where victims have escaped criminal captivity and are seeking healthcare either for themselves or their children.

Given the marked differences in healthcare practices, procedures and legislation between the USA and UK it is appropriate that UK centric research be undertaken. We report the findings of qualitative research investigating the experiences of Albanian female survivors of sex trafficking in the West Midlands of England. As far as we are aware this is the first of its kind to be conducted with this group of vulnerable, hard to access survivors of organised crime, and as such no theoretical predictions are offered. Rather, we employed an inductive data-driven approach. However, the theoretical framework of ‘candidacy’ offers one method for understanding the lived experiences of individual’s healthcare experiences, and as such it is entirely possible that the experiences of these survivors may mirror those of other vulnerable groups (18; 19).

This research is timely because the National Referral Mechanism (NRM) data reveals an enduring pattern of referrals whereby Albania, a transitional country in the Western Balkans, has topped the table of source countries for potential adult victims since 2012. Indeed, the most recent figures for 2017 again highlight that Albania heads the ‘nationality of potential victims’ for England, with over 30% more adult victims than the next highest nationality (Vietnam) in the last quarter of 2017. Further, of the Albanian adults referred to the NRM in the last quarter of 2017 alone, almost 75% were believed to be victims of sexual exploitation, approaching double the number from the next highest source country (20).

Albania is a non-EEA country, which does not have a reciprocal healthcare agreement with the UK (21). However, there are a number of healthcare services free to all, irrespective

of status. These include treatment for the most infectious diseases including sexually transmitted infections, and treatment for a mental or physical condition caused by torture and sexual violence. In addition, those seeking asylum, or temporary or humanitarian protection can access free healthcare, until the application (including appeal) is decided. Likewise, those formally identified, or *suspected* of being a victim of modern slavery and/or sexual exploitation from Non-EEA source countries, including the victim's spouse or civil partner and any children under 18, as long as they are lawfully present in the UK (22).

Some Albanian survivors of modern slavery do seek asylum in the UK, which provides evidence of their status and entitlement. However, others do not because they may be too traumatized, suffering from poor mental health, language barriers can result in poor understanding, fear for the safety of family still resident in their home country, and difficulties with trust and disclosure (23). An NRM reasonable/conclusive grounds decision also offers evidence to indicate there are reasonable grounds to believe a person is a potential victim, or that the person is more likely than not a victim of modern slavery. Again, some Albanian survivors consent to be entered into the NRM, others do not. Adults can only be accepted into the NRM with consent. Reasons why victims decline are numerous. They often distrust authorities/officials, or simply wish to return home, may not fully understand the NRM process, or may be too traumatized and frightened of repercussions from the perpetrators in England, and in their home country (24; 25)

Given the various exemptions, rules and regulations it may be that deciding whether non-EEA citizens are entitled to free healthcare challenges many of the organizations that survivors come into contact with (26; 27). Indeed, evidence suggests there is some uncertainty surrounding eligibility to access health care for some of the poorest groups from non-EEA countries (28). In the case of non-EEA survivors who have not consented to be entered into the NRM and have not sought asylum, they have no documentation nor evidence

of their status when accessing healthcare. The corollary being, survivors *may* not seek healthcare in the first instance, *may* be turned away and/or *may* be asked to pay for healthcare (28). This might also be the case even when in possession of the relevant documentation those making triage access decisions may concern themselves with EEA status in the first instance, resulting in sub-optimal decisions.

A review of the published academic and practitioner literature reveals that little known about the healthcare experiences of Albanian survivors of sex trafficking, and so the barriers and/or enablers for this specific group are not clear. Their experiences may mirror those of other vulnerable groups, or they may not. Indeed, there is some evidence to indicate Albanian survivors face unique challenges because i) of their non-EEA status and the associated confusion that arises between immigration and victim/survivor status (1), ii) prejudice toward immigrants resulting in victim-blaming attitudes (28; 29; 30), iii) a lack of knowledge about modern slavery *per se*, and its long term health consequences (31), iv) misunderstandings at first point of contact where common decision-making biases result in suboptimal decisions concerning who should and should not be allowed to access healthcare (32), amplified by increasing demands on GP practices (33).

Methods.

Ethical approval for this research was granted by the University of Westminster Psychology Ethics Committee and was completed in accordance with the Health and Care Practitioner Council codes of ethical conduct. Participation was on a voluntary basis, and informed consent was gained from all participants, both in writing, and again verbally at the start of each interview (digitally recorded). Participants were aware that they could stop the interview at any point, without explanation, and that even after the interview had finished they could withdraw until the point of publication. To protect their identity, each participant was assigned a number, and a pseudonym, and all identifying information was removed from the

transcriptions of the audio data. Once the data had been transcribed (verbatim), analysis was conducted using the transcribed data.

Using purposeful sampling, seven female survivors of modern slavery and sexual exploitation were recruited between July 2017 and January 2018, referred to the researchers via one government organisation, and two charities. All participants were female, born in Albania². The mean age of participants was 24.7 years, ranging from 21 to 29 years. Six participants reported having between one and three children, and all reported i) a positive National Referral Mechanism outcome³ and ii) that they were currently seeking asylum in the UK⁴. This research reports participant's experiences since 2014 onwards.

All participants spoke English as a second language, with Albanian as a first language. All interviews were conducted in English. Participants were provided with an information sheet by the referring organisation (in English and Albanian, as appropriate). Once the participant had agreed to take part in the research, participants met with the researcher face-to-face. Three interviews took place with a support worker/advocate present. The remainder were conducted by the researcher with the survivor, alone.

Interviews were between 60 and 80 minutes in duration. Interviews were digitally audio recorded and all took place either on the premises of the referring organisation, or in a private room in a large public library in the West Midlands of England. A semi-structured interview schedule was developed with reference to our research questions, previous research in this domain, and in collaboration with Public Health England and West Midlands Anti-Slavery Network. Questions were mainly open-ended invitations. When responding,

² Proof of country of birth was not requested. However, of the 7 participants, 4 volunteered documentary proof. The country of birth of the remainder was self-reported.

³ Proof of NRM outcome was not requested. However, of the 7 participants, 3 volunteered documentary proof of conclusive grounds decision. The NRM status of the remainder was verbally confirmed by the referring organization as having either a conclusive grounds or reasonable grounds decision.

⁴ Proof of immigration/asylum status was not requested. However, of the 7 participants, the status of 3 was confirmed by the relevant referring organization. The remainder self-reported their immigration/asylum status, which we did not question.

participants were uninterrupted, and allowed unlimited time to answer/describe their experiences. Where appropriate, additional probing questions were asked to further understand specific elements of participant's experiences relevant to this research. All questions concerned participant's objective and subjective experiences of accessing healthcare in England and were conducted by the first author. All participants answered every question posed. No questions were asked regarding their past experiences, although all volunteered some details of their abuse to provide context in terms of why they were seeking medical aid and to emphasise their victim status.

Interviews were analysed using data-driven thematic analysis, a qualitative method for identifying, analyzing, and reporting patterns (themes) within data. From listening to the audiotaped interviews and then reading the transcripts, initial themes or codes were identified, which were grouped together, and then checked for emerging patterns, variability and consistency. Initial analysis was carried out on a single case by JM, then subsequent cases by CD. These themes (or codes) were then rechecked against the transcripts and discussed and checked for consistency between co-authors.

Findings

Four key themes emerged, which are illustrated below by verbatim data extracts. The themes are: Barriers to access; Negotiating access; Healthcare needs and care received; Overall experiences of primary care.

Barriers to access.

Participants all reported several initially unsuccessful attempts to access a General Practitioner (GP) in the West Midlands of England. All reported being turned away by practice receptionists or administrators on numerous occasions, and so were prevented from registering *per se*, or that practice receptionists and administrators used delay techniques. For example, providing registration documents and general information, but not allowing

participants to complete them on the premises, not helping participants to understand what was required to register, and warning participants that they would have to wait a considerable amount of time, in some cases over 3 months to access a GP or practice nurse and so should seek an alternative GP who could see them more quickly.

Six participants reported visiting numerous practices within their local area prior to successfully accessing a GP. At the time of this research, one participant had still not been able to register with a GP in the West Midlands. Of the seven participants, three had moved from asylum accommodation in London, to asylum accommodation in the West Midlands of England, and so had previously been seen by a GP in London/admitted to hospital and diagnosed with a number of long term illnesses/conditions. Having been successful in registering with a GP, four participants then reported having to ask to see an alternative GP within a multi GP practice because of extended periods of delay between asking for an appointment and being given an appointment, or because they believed they were not being properly treated. Of these four, all of their requests were initially refused.

Table 1. *Exemplar quotes for barriers to accessing primary healthcare.*

Barriers to Access

'I try many, many times. First GP I go and try and register but nobody let me, the lady at the front said 'I cannot understand what you want'. I can speak good English, and I had all my papers with me... I said I have my address, I have my papers saying I am seeking asylum, but the woman just keep saying 'I don't know what you want' but she knew' (Maria 1)

'I ask them to see a doctor for my hepatitis, they say no, they said you are in hostel and it will take more than 3 months maybe you not here then... hepatitis is I don't know in English, in my language hepatitis is aggressive and if I wait 4 months 5 month I get worse. I don't understand, so I try another doctor' (Mariela 6)

'I try to see the GP but at the counter she said, where you from. I say Albanian, but it doesn't matter, I need to see doctor, I have right because I am waiting to live in England, and I have papers, here I show you. She said 'no I cannot help you, you will have to find another doctor or go to hospital, you are not from the E.U.' so I try others (Maria 6)'

'When I see GP with my baby, she did not look at him, she asked where I am from. I say look at him, she said go home and give him paracetamol from chemist. I complain, they try and get me to leave practice...My baby sick. I know he sick. I call ambulance to hospital. They see him, and he very sick, almost died with bad chest infection and asthma' (Maria 1)

'One lady when I go first time said she only let me see GP if I say what happened to me and I would not see GP and could not pass this door if I not say what happened' (Esta 5)

Documents included proof a child's place of birth, proof of address, proof they were seeking asylum, and/or that they were a victim of modern slavery. Participants also described how they had sought assistance from advocates, charities and non-government organisations, and in one case asking a more experienced/older acquaintance to accompany her when returning to a GP practice after having been turned away on several occasions.

Negotiating access

All participants described having to negotiate/leverage access to a GP. They described their experiences, explaining they were eventually successful only after having learned what to do following a series of earlier unsuccessful attempts.

Table 2. Exemplar quotes for negotiating access to primary healthcare.

| Negotiating Access |
|---|
| <p><i>At the XXXX this lady came to help, and I spoke to her and told her everything, and I said this is what has happened. and then she came with me next time, and she complain and she say to them why you talk to her like this... she needs help. She was very good. Then GP examined my breast, and then referred me to the hospital, but took nearly a year for her to examine me.’ (Rina 6)</i></p> |
| <p><i>‘I say why you not treat me? I am ill you treat me otherwise you call police, I am not a criminal, I am ill. I come here to this country, was not my choice’ (Marjeta 4)</i></p> |
| <p><i>‘I wanted to go and speak to someone about what was going on in my head, but GP would not see me. The lady eep asking about my background, but I couldn’t tell because I just can’t it’s too bad and I try to forget. I go somewhere else. I went to see XXXX , they helped me XXXX came with me to the GP, and then the GP was different. The GP say ‘oh hello XXXX how are you today’ she never speak to me like that before... even the receptionist say hello how can I help you’ she never never, never say that to me.’ (Maria 1)</i></p> |
| <p><i>‘Not one time, many many times, and they sent me away. After that there was an older lady I knew from Albania, and she helped me a lot about this one. We went again together and then they let me in, but not before.’ (Ariana 1)</i></p> |
| <p><i>‘Well I come back with my son’s book, his baby book, and I showed it and then I did get some help, at last. He born in UK, he deserves to be treated. He was very ill. My daughters, they born in this county, they all got books’ (Maria 1).</i></p> |

Negotiation/leverage included making multiple daily visits to demand access to a GP, making official complaints to surgery managers, and bringing numerous documents to the surgery.

Healthcare needs and care received

Without exception all experienced what they believed to be poor or inappropriate healthcare exemplified by unacceptable delays prior to an initial appointment, and/or having to waiting to see the GP for hours despite having appointment times. Five survivors never saw a GP, rather they were seen by a student GP, or a practice nurse, having been told the GP was too busy despite having an appointment. All reported their symptoms were often not taken seriously and advised to use over the counter medicine, which they believed was inappropriate given their symptoms.

Table 3. Exemplar quotes for healthcare needs and care received.

| Healthcare Needs and Care Received |
|---|
| <i>'She had infection ... she got this from me, but she not even look at her. She say give paracetamol from chemist. I say but she baby, she need medicine' (Esta 5)</i> |
| <i>'First GP when I went there I say I have a lump in my breast they say go away there is nothing here, and when I say about stress in my head, they say just go away and take paracetamol, and drink water...second GP told me to lie in bed'. (Maria 1)</i> |
| <i>'I went for my son, and not for me. I give up for me, this was my baby son, and she not look at him. She did not look at my child, the first thing she said was where are you from, where is your husband, why you not stay in your country. She not look at my baby' (Rina 6)</i> |
| <i>'They told me no, I start crying and sometimes when I am really bad I think better to die because what to do if you sick and no one help ... no one for me to call to say I need help because I have brain problem. They gave me tissues and headache pill' (Ariana 2)</i> |
| <i>'I never got to see GP, only a nurse who told me GP busy. But I wait seven hours. I have bad illness and infection below, I know not right, but I never got help. Doctor just keep giving nurse paper for antibiotics – this not normal to take antibiotics for 6 months' (Mirela 7)</i> |

In two cases participants had been moved from other areas of the country having already been diagnosed with significant mental and physical illnesses that required ongoing treatment yet they too were advised to visit a chemist. In some instances, these experiences also extended to healthcare for their children.

Overall experiences of primary care

All reported negative psychological consequences of their healthcare experiences, which appeared to further compound the mental health consequences emanating from their enslavement.

Table 4. Exemplar quotes for overall experiences of primary healthcare

| Overall Experiences of Primary Care |
|--|
| <p>'After one year I giving up going to GP, I come here to XXXX where I see councilor who say I have mental illness, I cannot remember, but it is bad, and it keeps me awake. GP does not care. Looks at me and not what is wrong with me. She treat me like bad meat, just like before, but I have to keep going for my children.' (Ariana 2)</p> |
| <p><i>'She not like my baby because I am not married and there is no father. It is not her fault, she is just a baby and she was ill and needed help – GP hard, and not care, and I cry and cry until I could not breath' (Maria 1)</i></p> |
| <p><i>'I understand its stress and depression I know I have this, I know this new problem is not because of my own stress, no no, this because I cannot get help with my body, I could die I am not coming here for fun I come here because I need help, I wish I wake up one day and everything wiped. it better you don't know what happened to me' (Mirela 7)</i></p> |
| <p><i>'If someone comes for help, it is not about me or my situation, it is about my health. I don't want to explain my situation, but I just want help with my health. I do not want money. I have babies and it is about my health – I worry, worry, worry, worry until I will die of worry and no sleep.' (Rina 6)</i></p> |
| <p><i>'I felt alone and very scared about what happens to me if I die, and what about my children they have no one just me, my girls get taken like me' (Elisa 2)</i></p> |

Despite attempting to manage their health, and the health of their children, this group of survivors' healthcare needs appear not to have been met. They perceived their healthcare experiences as negative, frustrating, unfair, and unprofessional, from the very start when attempting to access healthcare in the first instance, through to the treatment that they and their children received. All survivors reported feeling helpless, and alone. Those with children expressed significant recurrent concerns regarding the welfare of their children resulting from their own ill health, which increased their anxiety and appeared to exacerbate pre-existing mental health trauma. Three survivors reported barriers to accessing healthcare

for their children, which they found particularly disturbing believing their children were being punished.

Discussion

Main findings of the study.

This research provides novel understanding of the healthcare experiences of Albanian female survivors of sex trafficking in the West Midlands of England, and some insight into the impact of their experiences. Our findings reveal a consistent pattern whereby *all* reported being turned away from GP practices on numerous occasions by receptionists/administrators in the first instance – typically not being ‘allowed’ to register because they were non-EEA citizens. Persistence was often met with delay tactics and where survivors did eventually access a GP/practice nurse all reported perceiving their care/treatment, and on occasions their children’s care/treatment, to be inappropriate. When returning to medical practices that had initially turned them away, if accompanied by more experienced peers or advocates every survivor reported being treated differently – more respectfully, more professionally, and their illnesses taken seriously. All reported feeling that their experiences exacerbated their already fragile mental health, typically making them more anxious, disrupting their sleep, and increasing concerns regarding their future health and their ability to care for their children.

One way of understanding these findings is with reference to the construct of candidacy, which describes how people’s eligibility is negotiated between themselves and the relevant health services. Candidacy is a dynamic construct subject to multiple influences arising from people and their social contexts on allocation of resources and configuration of services (18; 19; 34) and highlights the complexity of accessing healthcare. The candidacy model comprises seven broad challenges (dimensions). As has been reported with other vulnerable groups (19; 34), our survivors also experienced several challenges. Identification of candidacy for themselves and/or children did appear to occur at points of health crises.

That is, participants typically waited some while before seeking healthcare hoping their symptoms would ease, waiting until crisis point before seeking help although this was not the case for all. Physically navigating access was effortful (required numerous visits) and costly (often incurring travel costs). The services they approached were clearly less permeable, and ‘adjudications’ made at first point of contact with practice staff and medical professionals indicated that the manner in which these survivors were categorized and subsequently turned away, referred or treated was heavily influenced by their non-EEA status and/or misunderstandings regarding the nature of sex trafficking.

What is already known on this topic.

As far as we are aware no empirical research has been conducted with survivors of modern slavery for sexual exploitation in the UK, but research conducted in North America, and elsewhere in Europe indicates victims and survivors of modern slavery consistently experience barriers to healthcare. Our research supports the enduring anecdotal reports concerning the difficulties experienced when accessing healthcare in the UK, despite legal and regulatory entitlements (27; 22).

What this study adds.

Modern slavery is a serious organised crime and a major global public health concern. Sex work and sex trafficking are all too often conflated, yet they differ significantly (36; 37) and the latter is rarely in public view. Hence, the challenges of navigating healthcare services for this group are not understood. Here, all seven survivors report being turned away when seeking treatment for a health crisis. Their Non-EEA status was the primary excuse for denying healthcare in the first instance whereby those making triage decisions apparently ‘seize and freeze’ on this information, disregarding legal entitlement, the nature of the illnesses and injuries survivors presented with, and without allowing survivors to show relevant documentation. Frontline staff are typically the first port of call for survivors, yet

they often the least trained, and their role is under researched (33). Our data also indicates the primary enabler was the presence of an advocate, which qualitatively and quantitatively improved their healthcare experiences – access was ‘allowed’, it was quicker and more frequent, and referrals to relevant specialists were immediately instigated. Finally, some practice managers/receptionists, GPs and practice nurses appeared uninformed regarding the nature of Modern Slavery for sexual exploitation and appeared not to be cognizant of the contractual rules or regulatory requirements in respect of patient registration, resulting in inequitable, and psychological stressful experiences for survivors.

Limitations.

The primary limitation of this timely research is the small sample size, albeit it is in line with similar in-depth qualitative research of this nature (38; 39). Our survivors were unknown to each other, and so given the consistency and prevalence of the emergent key themes we believe our findings are robust. Nonetheless, future research should extend and expand the population sample to other victim/survivor groups, including men and those from EEA countries. The second limitation is that survivors provided retrospective accounts of their experiences, which did not necessarily preclude perceptions. Accordingly, their accounts may have been biased and/or subject to memory failures/interference. The psychological impact of their experiences while enslaved may also have affected their memory for events (40; 41).

Conclusions and recommendations

Our findings indicate that training in modern slavery, with an emphasis on access to healthcare, is required for staff at GP practices in some areas of the West Midlands.

Importantly, this training should include reception staff and practice administrators, who are ‘gate keepers’ in the first instance, which may go some way to increase permeability and reduce the adjudication biases that were evident in these data. This training should also emphasize the rights of the individual, possibly alongside an extension of the ‘rights to

access healthcare' cards currently used in London to help homeless individuals to overcome barriers to primary healthcare (42). In their recent briefing on modern slavery Public Health England reinforced the importance of health engagement, pointing out that the public health community have considerable knowledge and experience of addressing cognate complex areas, such as intimate partner and sexual violence, from which good practice could be developed and applied to other vulnerable groups (42; 43).

GPs and practice staff cannot be expected to have in-depth knowledge of modern slavery and UK Immigration legislation, and so advocacy is also important. Here, being accompanied by an advocate with the appropriate knowledge of survivor's legal rights and health needs was fundamental to gaining access in the first instance and ensuring the appropriate specialist care was quickly instigated. Staff need to better understand rights and entitlements of victims/survivors to enable appropriate and timely access to healthcare services and support (43). Advocates appear important for driving this agenda.

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