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**Citation for published version:**

Palattiyil, G & Sidhva, D 2015, 'Caught in a web of multiple jeopardy: Post-traumatic stress disorder and HIV-positive asylum seekers in Scotland', *Clinical Social Work Journal*, vol. 43, no. 4, pp. 362-374.  
<https://doi.org/10.1007/s10615-015-0542-5>

**Digital Object Identifier (DOI):**

[10.1007/s10615-015-0542-5](https://doi.org/10.1007/s10615-015-0542-5)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

Clinical Social Work Journal

**Publisher Rights Statement:**

This is a post-peer-review, pre-copyedit version of an article published in Clinical Social Work Journal. The final authenticated version is available online at: <https://doi.org/10.1007/s10615-015-0542-5>

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**Title: Caught in a web of multiple jeopardy: Post-traumatic stress disorder and HIV-positive asylum seekers in Scotland**

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**Acknowledgement of sources of funding:** This research was made possible by funding from the British Academy Grant Number: SG-52166

## **Caught in a web of multiple jeopardy: Post-traumatic stress disorder and HIV-positive asylum seekers in Scotland**

### **Abstract**

Many HIV-positive asylum seekers have experienced multiple traumas and human rights violations—circumstances that engender posttraumatic stress disorder (PTSD). This qualitative study examines the impact of PTSD symptoms among HIV-positive asylum seekers in Scotland. Data were collected from 19 participants, using open-ended interviews, and narrative analysis was used to develop significant themes. All respondents had significant traumatic experiences, such as physical and sexual assault, witnessing the beating and death of a loved one, and being forced to participate in the sex trade. Many experienced multiple symptoms of PTSD, including re-experiencing of intrusive thoughts, flashbacks, avoidance, and arousal. These symptoms met the duration and impairment requirements for DSM-5 diagnosis of PTSD. Their symptoms impacted their ability to tell their stories convincingly when interviewed by immigration officials. Legal processes for asylum seeking require individuals to tell their stories but ignore the impact of trauma on their ability to do so, thus increasing the likelihood of their applications being rejected. The findings indicate the need for asylum seekers to have routine assessment and treatment for PTSD and the provision of appropriate therapeutic and advocacy services.

**Key words:** HIV and AIDS, asylum seekers, human rights, post-traumatic stress disorder, multiple jeopardy

## Introduction

Asylum seekers constitute a uniquely vulnerable group in the United Kingdom. The 1951 United Nations Convention Relating to the Status of Refugees defines asylum as protection provided for those who are unable to return to their country because of a well-founded fear of persecution on grounds of race, religion, nationality, membership of a particular social group, or political opinion. An asylum seeker is often defined as any individual who has applied for asylum under the Geneva Convention, while waiting for the application to be considered for refugee status. These individuals have left their home countries to seek protection as refugees in another country, and in order to achieve protected refugee status, they must prove that they have migrated to escape persecution, war, or violence (United Nations High Commissioner for Refugees [UNHCR], 2011). Yet the very issues that have led many asylum seekers to seek asylum also make it difficult for them to advocate for themselves.

By definition, asylum seekers are people in limbo. Sales (2002, p.456) argued that U.K. immigration policy “has increasingly dichotomised two sets of arrivals—the deserving refugee and the undeserving asylum seeker”. In the United Kingdom, the asylum process commences with an application to the United Kingdom Border Agency (UKBA<sup>1</sup>; Pitman, 2010), that conducts an initial screening and issues a registration card. Subsequently, a case worker carries out an interview with the applicant and then considers the evidence gathered at interviews and makes a decision. Those whose asylum applications are refused are expected to return home voluntarily, or they will be forcefully deported by the UKBA officials. Those applicants whose claims are successful are granted refugee status, with temporary leave to remain for an initial 5 years. In some cases discretionary leave to remain may be granted for up to 3 years (UKBA, 2012). Although the average timeframe for a decision on an application is 6 months, evidence suggests that seldom has this timeframe been achieved, due to appeals or errors in recording information, or instances where further information is required (Jain, 2010; Pitman, 2010).

A considerable number of asylum seekers have come to the United Kingdom during the past few years, although successive government policies have attempted to cut the overall number. For example, the United Kingdom received 262,400 asylum seekers during the period from 2002 to 2006 (UNHCR, 2007). The Joint Committee on Human Rights (2007) stated that asylum applications within the United Kingdom increased from 32,505 in 1997 to 84,130 in 2002. Aspinall and Watters (2010) highlighted that in 2008, there were 25,930 applications for asylum with 19,400 initial

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<sup>1</sup> This agency has been recently renamed as the UK Visas and Immigration (UKVI), but the older term will be used in this paper because it was in use when data were collected and references were obtained.

decisions made (11% fewer than in 2007). According to the UNHCR (2015), there were 23,070 pending asylum cases and 205 stateless persons in the UK at the end of 2013. Those seeking asylum are often fleeing from countries that experience higher rates of HIV, and many asylum seekers are HIV positive themselves.

The HIV/AIDS pandemic is a global concern that has left an indelible mark on the health and social fabric of almost every country in the world. A recent report estimates that globally 35.3 (32.2–38.8) million people are living with HIV (UNAIDS, 2013). The incidence of HIV in the United Kingdom continues to rise, with over 86,500 people living with HIV in 2009 (Health Protection Agency, 2010). In 2010, there were 6,136 new diagnoses of HIV, and as of December 2010, there have been 26,791 diagnoses of AIDS (Avert, 2010), with the diagnosis rate for Black Africans being three times higher than that of the general population (National AIDS Trust, 2008).

A 2011 report by Health Protection Scotland (2011) estimated that there are currently 4,033 HIV-positive people living in Scotland, which includes a number of asylum seekers with uncertain immigration status, who since the introduction of the dispersal policy in 2000 (Creighton, Sethi, Edwards, & Miller, 2004; Johnson, 2003), have been relocated to Scotland. Research indicates that, in comparison to any other group within the United Kingdom, African men are at a greater risk of contracting HIV (Health Protection Agency, 2008). Within a Scottish context, the highest prevalence of HIV in both sexes is among those who have risked exposure in sub-Saharan Africa. A Health Protection Agency (2010) weekly report suggested that most cases of HIV infection among non-drug using heterosexual individuals in Scotland were to be found among individuals moving to Scotland from countries where there is a high prevalence of HIV, particularly sub-Saharan Africa; however the actual number of asylum seekers who are HIV positive remains unclear.

Current research on HIV-positive asylum seekers and refugees in Scotland is sparse. Tallis (2002, p.18) argued that programs designed to tackle HIV/AIDS must include the “lived realities” of those affected and ensure they are involved in both defining the problem and reaching a resolution. Yet there remains a significant absence of empirical research that examines the experiences of asylum seekers in Scotland (Bowes, Ferguson, & Sim, 2009). Despite a growing awareness of the need to understand issues that affect this marginalized and vulnerable group, both qualitative and quantitative data remain limited.

### **Background and Context**

HIV disproportionately affects marginalized groups, and the risk of HIV transmission is known to be greater in situations of poverty and inequality (Cherfas, 2006). Large numbers of asylum seekers travel from poorer countries where there is a high prevalence of HIV/AIDS, and they also have individual experiences of persecution, conflict, and human

rights violations. Consequently, they are at a greater risk of contracting HIV. The instability and destitution many experience upon entering a new country heightens risks and increases their vulnerability.

Policies which lead to poverty and insecurity place significant amounts of stress on asylum seekers and impact their physical and emotional well-being (Crawley, Hemmings, & Price, 2011). This stress, compounded with previous experiences of loss, grief, and trauma, makes asylum seekers more vulnerable to physical and mental health issues and exploitation (Sinyemu & Baillie, 2005).

Many asylum seekers are fleeing areas where there are few legal protections of individual rights and where conflict, violence, and abuse are all too commonplace. Experiences of extreme violence, torture, and threat are very often a part of the asylum seekers' experience; consequently they are at an increased risk of experiencing mental health problems, such as depression and posttraumatic stress disorder (PTSD; Aspinall & Watters, 2010). PTSD is a disorder that involves particular clusters of psychological symptoms that occur in response to the experience of an intensely traumatic event (Young, 2011). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) these symptom clusters include intrusive re-experiencing the trauma, avoidance of stimuli that are related to the trauma, alterations of cognition or mood, and alterations in arousal (American Psychiatric Association, 2013).

Evidence from a number of sources indicates that PTSD has a very high incidence among asylum seekers and refugees. Nuttman-Shwartz, Dekel, and Tuval-Mashiach (2011) found that asylum seekers and refugees who fled conflict in the Gaza Strip experienced a high degree of psychological distress both pre- and post-migration. They noted PTSD symptoms including re-experiencing of trauma via dreams and flashbacks, avoidance of stimuli that reminded them of the trauma, detachment, and a heightened sense of arousal. Fazel, Wheeler, and Danesh (2005) reviewed a number of studies in this area and concluded that refugees were 10 times more likely to have PTSD in comparison to citizens within their host country. Bernardes, Wright, Edwards, Tomkins, Difo, and Livingstone (2010) reported that 76% of respondents in their study of asylum seekers were found to meet the criteria for a PTSD diagnosis. Toar, O'Brien, and Fahey (2009) found that asylum seekers reported a higher level of PTSD symptoms than individuals who had achieved refugee status, and noted that the conditions that surround the process of seeking asylum seem to contribute to PTSD symptoms.

Asylum seekers who are also HIV positive are even more vulnerable. The conditions that have led to their status as asylum seekers, such as conflict, poverty, trauma, and powerlessness (Haour-Knipe, 2003) are also conditions that foster the spread of HIV. Asylum seekers, particularly women, often report experiencing acts of sexual violence, and such violence may result in HIV infection as well as PTSD. A number of studies suggest that experiences of trauma are common in HIV-positive patients in general (Gore-Felton, Butler, & Koopman, 2001; Gore-Felton & Koopman, 2002; Kimerling,

Armistead, & Forehand 1999; Smith, Winkel, & Jacobson 2002). A recent meta-analysis of 29 studies from the United States (Machtinger, Wilson, Haberer, & Weiss, 2012) found disproportionate rates of both trauma exposure and PTSD in HIV-positive women.

Asylum seekers who are HIV positive may be reluctant to reveal their medical history in the course of the immigration process, because they fear stigmatization and discrimination. They also face the risk of their asylum claims being rejected because their health status may be perceived as the real reason for seeking asylum. Moreover, research indicates that asylum seekers can be reluctant to be screened for HIV for fear of deportation (Clarke & Mytton, 2007). This circumstance is potentially life-threatening, because it prevents early diagnosis and treatment. Crawley et al. (2011) drew attention to the destitution experienced by failed asylum seekers and the coping strategies they used in order to survive. Furthermore, their uncertain status as asylum seekers may add to the hardship of being HIV positive and may compromise their ability to obtain appropriate medical care, nutrition, and support. Many are unaware that they are entitled to free primary healthcare and are prevented from accessing any form of support for fear of deportation. Thus, social relationships become central to existence. This includes forming sexual relationships with local people and selling sex in exchange for cash, goods, and/or shelter (Cherfas, 2006; Crawley, 2010). These relationships can be exploitative and disempowering for asylum seekers and can increase the risk of HIV infection.

The combination of trauma exposure, PTSD, and HIV infection among asylum seekers creates a situation in which vulnerable individuals are faced with the daunting challenge of advocating for themselves with immigration authorities. Asylum seekers who are suffering from PTSD may have particular difficulty in providing the kind of evidence that they need in order to achieve refugee status. Blunting of affect, difficulty recalling aspects of the experience, and feelings of detachment are all characteristic of PTSD (American Psychiatric Association, 2013), and these characteristics can make it difficult for asylum seekers to tell their stories in a convincing way. Fear of authorities and language barriers may further impair their efforts to advocate for themselves.

This paper uses qualitative methodology to examine the experiences of HIV-positive asylum seekers to the United Kingdom who are struggling to manage the process of seeking asylum along with the challenges of living with HIV and AIDS. We initially adopted an exploratory approach, but as the interviews progressed, it became apparent that the majority of the participants had suffered significant trauma and were having difficulties characteristic of PTSD. We also noted the reticence and anxiety that the participants had in relating their histories. We sought to understand the difficulties that these individuals had in telling their stories, and to link these difficulties to their experiences of trauma and PTSD. Their experiences are laid against the DSM-5 template of diagnostic criteria for PTSD (American Psychiatric Association, 2013),

in order to evaluate the evidence for PTSD and to discuss the implications of this evidence for the fair treatment of asylum seekers.

## **Research Design and Methodology**

### **Research Design**

Many HIV-positive asylum seekers—and in particular those whose applications have been refused—are reluctant to engage with people outside of their known support systems. For this reason, we needed to approach the participants on their own terms and allow them to tell their stories in their own ways. We thus adopted a qualitative research design that helped us to construct a narrative of the lived experience of the participants. To understand the complexity and uncertainty that marked the lives of HIV-positive asylum seekers, we chose research methods that would be inclusive and participatory, allowing flexibility and openness for participants to tell their stories. The methodology helped us to explore the perspectives and experiences of the respondents in their own words and encouraged an exploratory and descriptive analysis that stressed the importance of context, setting, and the respondents' frame of reference (Marshall & Rossman, 1995; Mason, 2002).

### **Sample**

Given the sensitivity of the study, identifying participants was challenging and time consuming. We began by contacting a number of voluntary organizations in Scotland that worked with people living with HIV. The large majority of the sample came from the Waverley Care's African Health Project in Glasgow, which provides support to HIV-positive people, the majority of whom originate from sub-Saharan Africa. All participants lived in Glasgow and received support from the above project; some of them were also service users at another voluntary organization in Glasgow—the Terrence Higgins Trust.

The participants in this study included 19 HIV-positive Black African asylum seekers (15 women and 4 men). The nationalities of the participants varied; however, a significant number came from Zimbabwe (8,  $N = 19$ ), others were from the Ivory Coast, Burundi, Ethiopia, Malawi, South Africa, Nigeria, Tanzania, and Kenya. The field work for collecting data was complex, often fraught with uncertainties that marked the lives of the asylum seekers; with interviews cancelled at very short notice on several occasions.

### **Data Collection**

Using an open-ended interview guide, in-depth interviews were held with the participants, most of which took place in the premise of the African Health Project. A few interviews were held in more unconventional venues, such as the



researcher's own automobile or in a café, as the participants felt most safe in such environments. Interviews were audio-recorded with consent of the participants and lasted between an hour-and-a-half to 3 hours; some of the interviews extended over multiple sessions.

### **Ethical Concerns**

Ethical issues of informed consent, confidentiality, voluntary participation, and anonymity were central to the research, and ethical approval for conducting the research was obtained from the Research Committee of the university where the researchers were based, before commencing the interviews. Participants were informed that they could discontinue the interview at any point that they felt necessary and that they were not obliged to answer anything they felt uncomfortable with or did not choose to answer. In fact there were a few occasions where participants felt totally overtaken by their emotions and the researcher had to terminate the interviews immediately. After a pause, and if requested by the participants, these interviews were resumed, with a few of them being rescheduled to another date. It was very evident from the outset of the study how difficult it was to gain access to this otherwise very hard-to-reach population, as some of the failed asylum seekers lived essentially as fugitives, fearing deportation. Therefore, ensuring anonymity and protecting the identity of the participants were central to the research process.

It is important to acknowledge that the interview did have elements of a therapeutic interview (Birch & Miller 2000): participants were invited by the researcher to share their thoughts by eliciting their core emotions, and by listening to them (Weiss, 1994). When a respondent became very disturbed while recollecting traumatic experiences from the past, he or she was supported to be calmed down, and the researcher reiterated that the participant was free to stop the interview, at the same time, assuring the participant of support if he or she chose to continue (Massey, 1996); thus we aimed to develop an "emotional middle distance" (Weiss 1994, p.123).

### **Data Analysis**

Analysis began with the transcription of interviews. We then used narrative analysis (Riessman, 1993) to understand the participants' everyday experiences and the way they perceived the world. Each transcript was read and analyzed for its significant content, which was classified into categories that recurred across participant accounts or were unique to a particular participant's account. These categories were then developed into themes that described the lived experiences of the participants. The data analysis was designed to portray the participants' experiences as accurately as possible and to preserve the richness and uniqueness of the data, enabling improved understanding of the particular phenomenon being explored (McLeod, 2000).

## Findings

### Traumatic Experiences

The first DSM-5 criterion for PTSD requires that the person has experienced a traumatic event, which may take the form of actual or threatened death, serious injury, or sexual violence. Almost all the respondents in the study (17,  $N = 19$ ) came from backgrounds that were affected by poverty, war, and conflict and had life experiences that included violence and powerlessness, particularly powerlessness of women. Three-quarters of respondents (15,  $N = 19$ ) recalled extremely violent, traumatic events, including being beaten up, being raped or gang-raped, having a child witness the gang-rape, and seeing a family member violently attacked and killed in front of them. Three of these respondents spoke about persistent, traumatic, and inhumane domestic abuse. And one woman described her ordeal of exploitation and abuse through human trafficking. Thus, 15 of our 19 respondents gave evidence of experiencing events that are outside the range of normal human experience and are readily recognisable as traumatic.

The experiences of the participants provoked alterations in cognition and mood as described in the DSM-5 criteria (PTSD Diagnostic Criteria, Group D; American Psychiatric Association, 2013). One woman spoke about the continuing dread that she has lived through after she was violently beaten and raped in front of her teenage son by the supporters of the ruling party, which she did not support. She spoke about the indignity, humiliation, and deep hurt of being gang-raped in front of her child:

*I remember how my son was drenched in blood...they hit him and knocked his two teeth out... crying silent tears trying to help his half-naked mother. Can you imagine he was covering my dirty, bloodied body and telling me not to cry? How could I continue to live there after my 16 year old son had seen me like that?*

A woman who was shot in her leg and gang-raped by members of the ruling party started shaking and crying as she showed her gunshot marks to the researcher. This was the third time that the researcher had spent over an hour with her as she struggled to tell her story. On the earlier two occasions she complained of nausea and dizziness as soon as she began to recall what happened to her, so the interviews had to be stopped immediately. She said,

*I feel very scared when the days get dark here; it was very dark when they dumped me on the roadside and me I was just lying there... I just lay there for hours unconscious before someone took me to the hospital, I do not know who took me there... I was very confused, I was in coma, so I don't remember everything that I went through.*

Another woman spoke about her helplessness when her brother, who had voiced his displeasure with the despotic regime, was murdered in front of her. She said,

*They pushed the door in, we were sitting and eating and they tied my brother's hands behind him. Two men held him and another held a gun to his head and forced him to open his mouth or he would kill us all...my brother was forced to drink poison and he was killed that way...I thought I was going to die. I still see his eyes as he was coughing, choking, choking, not breathing...I was screaming because I could not help him, I felt so helpless...I still see him shaking.*

One younger woman spoke about the pain and helplessness she felt when she recalled the beatings and violence from her husband because she failed to become pregnant. Her pastor helped her to get a visitor's visa to the United Kingdom, when her husband chased her out of the house completely naked. She said,

*He would say many times in a day, let's try to conceive and then if I did not accept to do it he would beat me really hardly...my ribs were so hurt I was crying asking God to take me...I have left that living hell but it has followed me in my head...*

One young woman, who was trafficked into the United Kingdom, was tearful and agitated and used terms such as *utterly horrible, unbelievably terrible, and such horridness* to describe her situation. She thought she was escaping a forced marriage to a much older man and migrating in expectation of a well-paid nanny's job, only to find herself forced into sex work under exploitative conditions. She spoke about her revulsion, misery, and suffering as a 17-year-old who was compelled into sex work in a country where she was a stranger. She said,

*When I came to the UK, I was an innocent girl...with many dreams, but that was the hardest, most difficult terrible time of my life...I still shake every time I think of the terribleness.*

### **Re-experiencing**

The second cluster of DSM-5 symptoms requires evidence of intrusive symptoms related to the traumatic event. These symptoms can take a number of forms, including recurrent, involuntary and intrusive distressing memories of the traumatic event, recurrent distressing dreams, dissociative reactions (e.g., flashbacks), intense or prolonged psychological distress, and marked physiological reactions to the internal or external cues that symbolize or resemble an aspect of the traumatic event.

Eight participants spoke about flashbacks and disturbing memories. Two women spoke about having nightmares and flashbacks before visits to the UKBA, where they were required to sign up for payments and also to report their whereabouts. Both women had children and were terrified at the thought of being deported. The fact that the UKBA wanted them to come in with their children was daunting, because it meant that they could be sent off to detention and onwards to be deported back to their countries, from which both women had fled because of the toxic combination of violence, lawlessness and abuse. One woman said,

*I could not sleep for years after I was raped...I would drink a lot of wine to try and sleep. Six years later I still have nightmares every time I have to go to the UKBA, [nightmares] of the pain and bleeding on the street.*

Another woman described reliving the trauma of being thrown out of her in-laws' home along with her children when they discovered she was HIV-positive. She recalled that every week when she needed to sign up, she would have flashbacks of that day when she became homeless. She said,

*Sometimes when I go to the Home Office, I am not sure whether I am going to come back or they are going to take me in...ever since they have asked me to come with the kids, I wonder are they going to send me to detention...I get so scared...I shiver with fright...I keep seeing my torn dress and my mother-in-law kicking me and the children out...I feel like throwing up and my stomach churns.*

One man, who fled his home and country after his uncle and brother were murdered in front of him, broke down three times during the interview. He said that he was “plagued” by the memory every night as he lay down. He said,

*I hear my brother crying out 'help me, help me', I keep seeing his body on the floor the blood just going and going...I just can't stop seeing that picture in my eyes.*

### **Avoidance**

The third cluster of DSM-5 symptoms requires evidence of persistent avoidance of stimuli associated with the trauma, beginning after the traumatic event. This evidence can take a number of forms, including avoidance of or efforts to avoid distressing memories, thoughts, or feelings about or closely associated with the traumatic event and or avoidance of or efforts to avoid external reminders that arouse distressing memories, thoughts, or feelings about or closely associated with the traumatic event.

One man's narration clearly reflected the element of avoiding external reminders that evoked the memory of the trauma. He said,

*“I can never bear to wear anything red, because I was in a red T-shirt on the day when they banged open the door of my house and killed my family...even when I see another man in red, I can't bear to see”.*

Another woman recalled distressing memories of her being attacked and raped by a gang of ruling party members as she walked home from work. She said,

*“I panic and dread when I see any group of people or a crowd...I don't go out alone now, I take my friend with me even when I go to see my doctor”.*

### **Alterations in Cognition and Mood**

The fourth cluster of DSM-5 symptoms includes a number of symptoms of altered cognitive and emotional functioning related to the traumatic event. Such alteration could be manifested by phenomena such as detachment and flattened affect (referred to in the previous version of DSM as *numbing*; American Psychiatric Association, 2000), which we observed in a number of our participants as they began to recount their histories. Clinical experience teaches us that persons with PTSD experience extremes of recall regarding traumatic circumstances—either intrusive memories of the

event (i.e., hypermnesia) or lack of recall of thoughts and feelings related to the event (i.e., amnesia) (Gil, Caspi, Ben-Ari, & Klein, 2006 ; Birrera, Michaelb, & Munsch, 2007; Greenberg, Brooks, & Dunn, 2015).

During the interviews two participants said that they could not talk because their minds had gone blank. Other participants displayed avoidance in more indirect ways. The researcher observed during many interviews that respondents initially spoke in a very matter-of-fact, limited way and reported difficulty remembering some experiences. It almost appeared as though they were unwilling to fully engage. This reaction is similar to reactions reported in the accounts of torture victims. Talking about their memories to the researcher seemed to be the first stage of triggering traumatic re-experiencing. Avoidance of distressing memories is an understandable coping mechanism. Why would one want to go there? The very nature of traumatization makes it difficult to recall, but also to verbally access the issues of the traumatization. When the respondents talked dispassionately, they did not have to access this pain; it was hard for them to express themselves in a verbally accessible way. The pain appeared to be held at arm's length.

One woman, who fled her country because her husband was brutally injured and left to die when he did not attend a political rally, said that she found it difficult to remember exactly what had happened. She said,

*It is a blank now what happened on that day, I was in such a shock for so many months and when I told that to the Immigration Officer in London he said 'Lady so you telling me you can't remember what happened to your own husband even though you were with him,' ... You see he was so surprised; he did not believe me, but I say honest to God I cannot remember.*

### **Persistent Arousal**

The fifth cluster of DSM-5 symptoms requires evidence of persistent alterations in arousal and reactivity, such as sleep difficulties, trouble concentrating, hypervigilance, irritability, and an exaggerated startle reaction. A consistent observation that the interviewer made following seven interviews was the extent to which respondents displayed symptoms of physiological arousal, such as sweating, shaking (particularly the head), shivering, complaints of dry mouth and wanting to drink water, breathlessness, and quavering of the voice. Typically these symptoms came to the fore 20-30 minutes after the interview had begun, when respondents recalled their life experiences prior to leaving for the United Kingdom. For two women, this was followed by breaking down and crying. In five others, these symptoms of arousal were accompanied with an exceedingly low mood and emotion and a remarkably flat presentation. This was usually the point when the researcher gave participants an opportunity to stop the interview and set another date when they could be reinterviewed.

In four of our respondents, arousal disturbance was manifested by sleep disturbance and difficulty concentrating. One man whose family members had been killed because of their political loyalties spoke about the suffering and anguish he had experienced after he fled his home 3 days after their murder. He said that the ordeal had affected his ability to sleep

and to eat. He had lost over 20 kilos in weight over the period of 14 months and likened his life to living on the edge of a cliff. His distress about his prior experiences was compounded by the uncertainty of his asylum status. He explained,

*It is a very difficult time for me; I feel every time worry and thinking all the time; I cannot stop thinking, this and that. I am worrying about me, what about my life in this country? What the Home Office is going to do with me; how is my future going to be? As if I am at the end of a high mountain and can be fallen down at any moment.*

### **Duration**

The DSM-5 duration criterion requires that the duration of the disturbance is greater than 1 month. All 15 respondents who reported experiencing some major trauma in their past had experienced this disturbance for well over a year. The significant majority (10,  $N = 19$ ) had experienced disturbance for over 3 years, and one woman had experienced the disturbance for 6 years. Thus it would be appropriate to suggest that the respondents suffered from what DSM-IV-TR referred to as chronic PTSD, in which the symptoms last for 3 months or longer (American Psychiatric Association, 2000, p.465).

### **Impairment**

The final DSM-5 criterion requires that the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning. It must be noted that because the respondents were asylum seekers, they are automatically precluded from being involved in any sort of gainful employment or carrying out a role in which they could function on a day-to-day basis. It is noteworthy that several respondents spoke about the anguish they experienced because they were not allowed to work. Six of them had been employed as professionals in their home country, but were now forced to live on benefits and charity. Several respondents (9,  $N = 19$ ) expressed frustration, a sense of hopelessness and a deep desire to be able to support themselves and their families. One woman who had studied in a Scottish University, but was currently an asylum seeker, said,

*I'm very frustrated because I cannot work even though I really want to, I have the qualification from their country...I want to earn for myself and my daughter. Why can't the Home Office at least give us some dignity?*

For most of our respondents, being unable to work reinforced a feeling of futility and illness. As one man put it,

*For us Africans, work is too important. It means you can improve your life, but also your family's life...it gives us a reason to live, not just plain sitting. Back home we are always working so hard. Here I can only keep thinking of being sick because I am not working, so my mind keeps going back to being sick.*

Perhaps the most important way in which our participants are not functioning well is their inability to advocate for themselves. The accounts of the majority of participants (14,  $N = 19$ ) point to the problems they had in recounting their difficult life experiences to immigration officials. For these participants, striving to achieve refugee status involves retelling

the story of the traumatic experiences that led them to leave their homes in the first place; doing so would force them to relive the horrendous trauma to authorities who are often insensitive to their suffering.

The narratives of two failed asylum seekers are particularly poignant. Both women were gang-raped in their countries because of their husbands' political allegiance. The modus operandi for both had been similar; each woman was shot and demobilised, and then raped. The Home Office's investigations appear to have concluded that their stories were a fabrication, yet both women showed the interviewer prominent scars on the legs and chest that were consistent with their accounts. One woman, a professional in the finance sector, spoke poignantly about the horrific pain that she experienced. She said,

*I have experienced so much pain, can you imagine being raped and my leg almost being amputated because they left me there just to die...after such a severe trauma I could not remember any dates...I do forget my dates. I showed them my scars but they did not bother to see...they don't believe me...I feel so bad that I want to kill myself..*

Another woman's narrative nearly echoed this account. She repeatedly pointed to the gunshot marks on her leg as she spoke. She said,

*You can see how raw my skin is even after so many years, it still really hurts when it gets dry in this weather. I wanted to show the man all my hurts (pointing to her chest and leg) but he just kept staring and asking me to describe what happened exactly. I told him I'm sorry I cannot exactly remember and he kept saying 'so what day was it, what time was it, give me an approximate time, surely you must remember the time, how do you expect me to believe that you don't remember such a big thing in your life.'*

### **Discussion**

Our findings demonstrate considerable evidence of PTSD among these asylum seekers, a finding that has been demonstrated in a number of other studies of this population (Bernardes et al. 2010; Fazel et al. 2005; Nuttman-Shwartz et al. 2011; Toar et al., 2009) and its impact on claiming asylum.

These findings reveal a fundamental problem with the process of evaluating the claims of asylum seekers who have been exposed to trauma—the difficulty of verifying the trauma in people whose ability to tell their stories is blunted. As the accounts of our participants demonstrate, traumatic experiences and resulting symptoms of PTSD are all too common among asylum seekers. However, such stories are extremely difficult to tell, especially in circumstances in which they are dealing with a feared and unsympathetic authority figure.

It took the interviewer, who is an experienced researcher, much time, patience and skill to get respondents to open up and tell their stories. They were at first very reluctant to reveal anything about themselves even though they had volunteered to take part in the study, and what they did reveal was presented in a matter-of-fact way with little detail. When they did begin to open up, there was a hugely palpable sense of their trauma—the flood gates opened and the more the

researcher supported them, by holding their hands, giving them a hug, giving them time and space—the more validated they seemed to feel. It was only then that they began to reveal the full scope and impact of their stories. Once they felt that they trusted the interviewer, they spoke articulately, fluently, and with great emphasis about their lives and about the trauma they had experienced. The rapport and relationship the researchers built with the participants provided an open space for participants to share their stories. The researchers were sensitive to the participants and always spent time for debriefing after the interviews. All participants received support (counselling, group therapy, legal support for claiming asylum, etc.) from the voluntary social work agencies and were encouraged to speak to their caseworker after the interview. The researchers also went on to help in setting up an advocacy program for these asylum seekers, the details of which will be discussed in a forthcoming paper on this topic.

The cruellest irony is that the respondents who are most badly affected by trauma are the ones whose symptoms make it even harder for them to achieve refugee status. Two of the three female asylum seekers who showed the researcher their gunshot scars became failed asylum seekers, because the UKBA determined (they both showed their letters to the researcher), that their stories were baseless and that the investigations indicated that they were cheating the system. The fact that their accounts were not only not accepted but also thrown out as baseless lies has had a huge psychological impact on these women. As individuals, they feel invalidated, humiliated and quashed.

It is telling that the researcher initially had questions about the veracity of their narratives, because of the form that their presentations took. Given this reaction by a sensitive and motivated researcher who has their interest at heart, one might imagine the impact their narratives had on officials. What chance do traumatized asylum seekers really stand with officials who begin with a premise of wanting to screen them out, instead of screening them in? In a way this is the double jeopardy that they suffer: to get credibility as an asylum seeker it is necessary to give a detailed account; however, the ability to tell a credible story is limited by symptoms of PTSD, and this inability to give credible details has a vicious effect on the asylum claim.

Chantler (2011) argued that international human rights policy instruments and national policy processes for determining refugee status present particular challenges for female asylum seekers who have experienced sexual assault. Legal processes for those seeking asylum require individuals to share their story but ignore the power structures and interplay between race, gender, culture and ethnicity. In determining the credibility of asylum seekers' applications, most officials rely on the applicants being able to share their story (due to a lack of concrete evidence), yet psychological and cultural barriers can impact on perceived credibility of stories (Melloy, 2007). For example, research indicates many women have difficulty with detailed disclosure and are more likely to experience shame and PTSD symptoms, and may attempt to



protect themselves through disassociation (Baillot, Cowan, & Munro, 2009, Chantler, 2011; Melloy, 2007). It is common for someone suffering from PTSD to appear “withdrawn, uninterested and detached” and to block/forget painful experiences (Melloy, 2007, p. 653).

The intimidating and hostile environment and the experience of being in a new country can also limit the applicants’ capacity to recount events of their journey (Melloy, 2007). For instance, Chantler (2011) noted that women may associate male authority figures with their abusers and therefore be more fearful and less able to disclose information. As a result, judgments are often based on perceived inconsistencies in information, late disclosures, and applicant demeanour (Baillot et al. 2009; Melloy, 2007). Moreover, decisions require subjective interpretation by interviewers who are not adequately trained or equipped to deal appropriately with people suffering from mental health issues (Chantler, 2011).

Thus, gathering evidence of the journey of asylum seekers premigration is particularly problematic, as it expects people to describe traumatic experiences in one interview (Chantler, 2011). As Baillot et al. (2009, p.208) asserted, “You cannot expect someone who’s been here a month to go into a hostile interview environment and disclose everything, it’s crazy.” Further, encouraging people to discuss traumatic experiences too early or at a point in their life when they are not prepared to deal with them can be psychologically damaging (Rosenthal, 2003). Application decisions continue to be made without taking account of the impact of PTSD and the influence of postmigration factors (Chantler, 2011; Melloy, 2007). Thus, one of the main issues for asylum seekers is that legal processes often establish “truths that do not take into consideration the whole story” (Melloy, 2007, p.675).

### **Implications for Policy and Practice**

**PTSD and its implications for asylum claims.** Research indicates that asylum seekers are more likely than accepted refugees to display symptoms associated with PTSD (Crumlish & O’Rourke, 2010; Toar et al., 2009). Bernardes et al. (2010, p.8), found 64% of the asylum seekers they interviewed in the United Kingdom had experienced physical assault, 52% imprisonment, and 52% torture. Nevertheless, Jain (2010) pointed out that there is a lack of adequate mental health screening for asylum seekers arriving in a new country. As a result, many asylum seekers who suffer from PTSD are not treated, and significant numbers of PTSD cases appear to be left undiagnosed. For those who are diagnosed with symptoms associated with PTSD, emphasis appears to be more on an individualized medical model of treatment rather than a social model which focuses on their surrounding environment (Bernardes et al., 2010; Chantler, 2011). Additionally, research suggests that symptoms associated with PTSD are compounded by punitive policies within the United Kingdom (Crumlish & O’Rourke, 2010); for instance, lack of adequate social and financial support, lengthy and complicated processes in the

application process, stigma associated with asylum seeking status and detention (Bernardes et al., 2010; Jain, 2010; Robjant, Robbins, & Senior, 2010).

There is also a need to change the interview process, provide more time, and include a competent evaluation for PTSD. This is poignantly reported by a clinician who spoke about the difficulties meeting the needs of individuals who had experienced torture, who said: “*We have no specialist torture counsellors. [It is] traumatic to go through history again. [Asylum seekers] often don’t speak English [and it is] traumatic for interpreters.*” (National Aids Trust, 2008, p.13).

**Importance of sensitive interviewing.** The participants in this study lived through some most horrific experiences and had some painful stories to tell. Many of them felt they contracted HIV as a result of sexual assault. These traumatic experiences have left them in a state of limbo, exposing them to PTSD. Anxiety, worry, feeling of terror, sleeplessness, and uncertainty about their immigration status are part of their lives. They are unable to tell their life story coherently, their conversation is very flat and dry, and their affect is very low.

Seeking asylum in the UK involves telling their lived experiences in a convincing and coherent way, so that the immigration officials are able to believe their story—the threat to their safety, well-being and human rights. However due to their PTSD, they become rather unable to tell their story in a coherent and convincing manner. For the immigration authorities, their stories need to be strong and based on evidence; the absence of which increases the likelihood of their claims being rejected.

Reflecting on interviewing asylum seekers, Melloy (2007, p.653) pointed out that many suffer from PTSD and in these instances it is common for these asylum seekers to appear “withdrawn, uninterested and detached” and block/forget painful experiences. Thus application decisions can be made without an awareness of the impact of PTSD. Whittaker, Hardy, Lewis, and Buchan (2005) asserted that services that enabled asylum seekers to share their stories promoted psychological well-being and “someone to talk to” was sometimes all that was needed for some people (p.184). Being able to share stories has the potential for reducing vulnerability, building resilience and increasing well-being.

When McKenzie-Mohr and Lafrance (2011) explored the experience of women coming to terms with being raped and/or suffering depression, they found that the women appeared to be conscious of the potential for their stories to be misunderstood and would often search for alternative words to describe their experiences. Cole (2010) argued that while storytelling can be therapeutic and have beneficial outcomes for some, they can have a negative impact for others, especially if they are used as a political tool. Consequently, if power differences are ignored and stories are used inappropriately they can be harmful. Leonard and Ellen (2008) drew attention to the power structures at play and highlight the dangers in ignoring other significant factors such as economic resources.

It is therefore vital that asylum seekers should be offered assessment and treatment for PTSD as a matter of course. Immigration officials should develop a partnership with social work and other counselling/mental health services to create an enabling environment that empowers asylum seekers to tell their stories. Practitioners working with asylum seekers need to be flexible in their approach, sensitive and non-judgemental, appropriately trained, and able to actively listen (Baillot et al., 2009), besides being aware of the intense emotions storytelling can invoke. Thus an empathetic approach is crucial (Rosenthal, 2003) which aims to develop culturally sensitive story-telling tools/practices, reflecting the ethnic and cultural diversity of the asylum seekers. Practitioners need to be prepared to recognize that stories are more than words alone and involve a complex mixture of verbal, nonverbal, and symbolic interactions when searching for meaning (McKenzie-Mohr & Lafrance, 2011).

**Collective voice from the medical consultants.** Many HIV-positive asylum seekers in the study reported on the support and care received from clinical consultants and other allied health professionals at the clinic they attended on an individual basis. This was, however, limited to their care and treatment. There was a strong message that consultants should act as advocates for these patients. Medical consultants could campaign and advocate for these vulnerable individuals with their local politicians and raise the profile at the central government level by lodging complaints and supporting campaigns to help asylum seekers, such that their voices inform policy decisions.

**Advocacy services.** A majority of the participants reported life-threatening issues that forced them to seek asylum. Almost all of them showed symptoms of PTSD which, coupled with dispersal, made them more isolated and depressed as they found themselves in a strange place, away from their family and friends. It was evident that they lacked the knowledge and skills for dealing with bureaucracy. It is therefore vital that special advocates are appointed for each applicant at the time of first application, so that each asylum seeker will have a person who can guide him or her through the entire process and who will have sufficient sensitivity to understand his or her needs and their limitations. There is a clear need to engage counselling and psychological services from early on to deal with the trauma and stress experienced by asylum seekers.

## Conclusion

Forced migration is known to impact the well-being of those seeking asylum. Evidence indicates that asylum seekers are particularly vulnerable to PTSD due to experiences of pre-migration trauma (Bernardes et al., 2010; Crumlish & O'Rourke, 2010; Jain, 2010; Robjant et al., 2009), and having to seek asylum in a county hitherto unknown to them increases their vulnerabilities further. This combined with being HIV-positive and experiencing varied discrimination makes their lives particularly difficult. Thus, our respondents found themselves caught in a web of multiple jeopardy.

The majority of their narratives bear testament to traumatic life events, beyond the realms of normality, borne by them and the resultant PTSD that they live with. Anxiety, worry, feeling of terror, sleeplessness, coupled with hopelessness and helplessness, being HIV-positive and a pervasive sense of uncertainty about their immigration status all mark their lives. So painful and distressing are their life experiences that they were initially only able to present in a flat, unconvincing, detached manner. With building of trust, time, and patience, their narratives emerged as extremely moving, heart-rending and powerful accounts. However, seeking asylum in the UK involves telling their lived experiences coherently in the very first meeting, so that the immigration officials are able to make a judgement. Blanch (2008) asserted that refugee status is determined by meeting the criterion of a well-founded fear of being persecuted. To be considered as reliable, the asylum seeker's official personal story must fit with some larger socially accepted account of what is happening to persons of a particular background from a particular part of the world. Thus the asylum seeker's story is not just his or her own, but inevitably "invokes the voices of others," with especially real implications for the person's future (Kirmayer, Lemelson, & Barad, 2007). Thus the paradox here is that due to PTSD and the immigration procedures, the depth of their stories is difficult to reach, thus increasing the likelihood of their claims being prolonged and rejected—binding them even more inextricably in a web of multiple jeopardy.

For several of our respondents, telling their stories was difficult and they needed time to develop trust with the researchers before they could open up and tell their real stories. As highlighted earlier, some interviews had to be done over multiple sessions and intervening time helped to establish trust and relationship. Recent research by Smith et al. (2012) found that clients become increasingly able to express their views as trust develops between them and professionals.

Many respondents said that telling their stories had helped them to feel good about themselves. Telling their story to a sympathetic listener is therapeutic (Palattiyil & Sidhva, 2011) and ultimately healing (Sidhva, 2004). Rosenthal (2003) found that a listener who is able to acknowledge/recognise the suffering of another person can help bridge the gap between repressed feeling and being able to communicate these. It can also pass control to the person telling the story and help people understand themselves, make sense of the present and support them in reorganising their thought process, thus promoting a positive sense of self. Melloy (2007, p.652) argued that "asylum seekers are storytellers." Therefore, providing an environment where asylum seekers feel able to tell their story can be pivotal in them being granted refugee status. For some, this can be a matter of life or death. However in our research, this was almost the polar opposite where asylum seekers reported that their stories were rejected as baseless.

The narratives of HIV-positive asylum seekers in this study bear out a complex relationship between HIV and PTSD. Living with PTSD had a significant impact on the ability of asylum-seekers to tell their stories convincingly. Legal

processes for asylum applications require individuals to tell their story; the findings from this study underscore the importance of appreciating the power structures and interplay among race, gender, culture, and ethnicity in enabling asylum seekers to do so effectively. If the health needs of asylum seekers are to be met, greater attention needs to be given to the influence of PTSD on this vulnerable group. A commitment to focusing on psychosocial needs as well as medical needs is imperative.

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