

'BENEFICIAL BUT TRIGGERING': EXPERIENCES AND SUPPORT OF SURVIVOR SPEAKERS IN THE UK



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‘Beneficial but triggering’: Experiences and support of survivor speakers in the UK

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Executive Summary

This report and related recommendations should be considered vital to any organisation seeking to engage victims, survivors and people with experience of all different types of abuse, oppression, health and illness, loss, distress, and trauma.

With many organisations now moving towards, or aspiring to trauma informed approaches and philosophies, now is the time to explore whether asking children and adults to retell their traumas repeatedly, is still needed or indeed, whether it was ever ethical at all.

We are grateful to the 58 survivor speakers from across the UK who took part anonymously. Their experiences show that despite many of them retelling their traumas more than 25 times each, only 9% of them had ever been paid, or had their expenses reimbursed. Further to the financial exploitation of these roles, only 7% of survivor speakers in our study said that they had ever been offered psychological support, counselling, debriefing or emotional support after retelling their experiences.

These findings are somewhat concerning given that most survivor speakers are approached by the charities, services or authorities that helped them, and report feeling obliged to give back by becoming a speaker.

In their experiences of public speaking, over two thirds of the survivor speakers said that they had been subjected to offensive, inappropriate, or hurtful comments and questions from the audience. Around half of them said that retelling their experiences had impacted them negatively and had led to them blaming themselves for being abused, feeling belittled, commodified and triggered.

We do not want this report to be received as a message against anyone who wants to share their experiences of abuse and trauma, as we agree that hearing from people who have lived those experiences is vital to us challenging poor practice, changing policy, informing research and empowering others. There were many survivor speakers who felt that despite not being paid or receiving any support, they still felt that they were making an important

contribution to others, to society, and to professional practice. Some reported that it was an important part of their own journey.

Some participants said that using their distressing and traumatic experiences to help others had given them a sense of worth and purpose that cannot be ignored.

We do however feel that the results of our small study have shown that most survivor speakers and experts by experience are not being paid, are not being supported, are not being safeguarded against vicarious trauma or retraumatisation, and instead, are sometimes being exploited by professionals and institutions to carry out difficult and complex unpaid work.

If any message can be taken from this report, and the experiences you will read about in this document, it is that whilst retelling is the choice of the person subjected to the trauma or abuse – we must not ignore our duty to protect them from harm, pay them properly as professional speakers, support them with their trauma responses, and ensure that they never feel pressure or obliged to disclose to anyone.

I would like to thank each person who took part in this study. Your experiences, views, and ideas have been vital in developing our understanding of what it is like to be invited to talk about traumatic events and experiences.

We hope that the recommendations go some way to supporting a more ethical and trauma-informed approach to working with speakers.

Dr Jessica Taylor

Director

VictimFocus

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Introduction

This report explores the impact of retelling serious traumas in a professional setting and explores whether survivor speakers are being supported and treated ethically when providing organisations, agencies and professionals with their experiences and expertise. Individuals who retell their experience of trauma to influence the work of organisations, agencies and professionals are often referred to as an expert by experience. Curran, et al (2015) state that individuals often want to become experts by experience out of a personal drive to challenge and change the organisations that they have been involved with, due to futile experiences of the services that they provide.

Throughout the literature search that was conducted for the purpose of this report, it became apparent that there was no research surrounding how experts by experience are treated by those that they provide their expertise to. There was also very little research surrounding the support that they receive, and how retelling their trauma had impacted them. From this, it appears that there is a gap in the literature and little insight into this complex topic. This report will consider the experiences of 58 survivors and victims who give talks, speeches and provide training based on their own disclosures of abuse, trauma and violence, in order to provide that insight.

Literature

The literature search for this study was conducted with an aim to discover if there was any existing literature surrounding the retelling of serious traumas as a survivor speaker or an expert by experience and the effect this has on the person. The authors also searched for literature surrounding the ethical treatment of experts by experience and the support available for experts by experience. The authors used the below keywords and phrases in their literature search.

Academic library

Keywords or Phrase	Results	Relevant Sources	Results
Expert by Experience/ Survivor Speaker	7	0	N/A
Retelling trauma as an Expert by Experience	2	0	N/A
Support for Experts by Experience	21,462	3	<p>Leadership as Experts by Experience in Professional Education Authors: Tillie Curran, Ruth Sayers and Barry Percy-Smith. Journal: <i>Social and Behavioural Sciences</i> (2015) Vol.186</p> <p>Experts by Experience: Peer Support and its Use with the Homeless. Authors: Stephanie L. Barker, Nick Maguire. Journal: <i>Community Mental Health Journal</i> (2017) Vol.58</p> <p>They are a Different Breed aren't They? Exploring how Experts by Experience Influence Students through Mental Health Education. Authors: Brenda Happell, Aine O'Donovan, Julie Sharrock Terri Warner, Sarah Gordon. Journal:</p>

			<i>International Journal of Mental Health Nursing (2021)</i>
The ethics surrounding Experts by Experience	23	0	N/A
Triggering Experts by Experience	158	0	N/A
Paying Experts by Experience	354	0	N/A

Of the six key phrases that were searched during this section of the literature review, only three studies were found surrounding support. One study in particular mentioned support for Survivors/ experts by experience, the other studies that were found focused on the support that an expert by experience could provide to others. Though this was not relevant to the search directly, the authors felt as though this was relevant to the wider study as this shows that there is more of a fixation in academia on how experts by experience can support others but very little interest surrounding the support that an expert by experience should receive. The authors were interested mostly in the emotional support provided for experts by experience, of which there are currently no found studies.

Support for experts by experience

In 2015, Curran et al., shared the learning from a new course designed for experts by experience involved in shaping health and social care to explore and develop leadership practice. A knowledge cafe was used to provide opportunities for participants to explore and reflect together on shared experiences of what it means to be an expert by experience. A knowledge cafe is a process that brings a group of people together to share experiences in a topic of mutual interest. Within this study Curran, et al. (2015) state that they heard how

crisis situations had been a significant force for becoming an expert by experience and they learned the importance of the expert by experience role in supporting others in critical situations. As a result of this they concluded that professional leadership should include the involvement of experts by experience in critical situations. Curran, et al. (2015) raise the issue of the lack of learning opportunities available to experts by experience and suggest that higher education and service providers should strengthen opportunities and provide support to them.

In 2017, Barker and Maguire conducted a study with an aim to assess the effectiveness of experts by experience as an intervention with young adults and adult homeless persons. They state that accessing peer support has significant positive impacts on quality of life, drug/alcohol use, and social support. Shared experiences, role modelling, and social support are suggested to be vital aspects of peer support and in supporting homeless clients. Within their study, Barker and Maguire (2017) found experts by experience can have a positive impact on outcomes for homeless people. They do state that more research is needed to ascertain clearly defined peer interventions and their impact on the homeless population. The treatment of, and support for the experts by experience were not considered within this study. Nor was the impact on the expert by experience when retelling their experience of homelessness to others who were currently homeless.

Happell, et al. (2021) conducted a study aimed to explore the implementation of expert by experience roles in academic settings and the impact of expert by experience led education on students. They interviewed 16 participants who were described as allies experienced in facilitating the establishment of expert by experience roles in academia. Happell, et al.

(2021) found the impact that experts by experience had on students to be positive. They explain that the participants observed changes in the students, the students became critical of their own practice and that they were not afraid of the service users, the participants state that the students were more open and accepting as a result of the experts by experience being present. Happell, et al. (2021) found that the challenging nature of some expert by experience sessions suggested that students needed support and possibly greater preparation before being exposed to the experiences of some experts by experience. Again, the treatment of or support of experts by experience is not the focal point of this study, the study is aimed to look at how experts by experience can support and enrich the learning experience of students.

This study is of interest, as it raises several issues and assumptions made about survivor speakers and experts by experience. The first appears to be that students were afraid of the speakers (service users) before they met them, suggesting that they had preconceived ideas about what or who they would be like.

The second appears to be that the authors considered greater support and preparation of the university students before 'exposing them' to the experiences of the speakers but did not consider greater support or preparation for the speakers themselves.

In this example then, the potential for distress and trauma seems focussed on the students, instead of the speaker who is publicly disclosing traumatic events.

There were no studies found surrounding the way in which survivor speakers or experts by experience are impacted when retelling their trauma to a wider audience, there were also no studies surrounding the way in which experts by experience are supported emotionally

when sharing their experiences and expertise. Because of this the literature search was broadened to consider the effects of retelling trauma and the impact of public speaking.

The impact of public speaking

We know that experts by experience often speak publicly about the trauma that they were subjected to. On their webpage titled 'Survivor Voices: Expert by Experience', Women's aid (2020)., state that after living through domestic abuse, many women wish to speak out, tell others about their experiences and use their expertise to create change, they go on to state that although this can be incredibly powerful, healing and positive it is also important to recognise that speaking out can leave women feeling exposed, and can bring about 'unexpected consequences', they state that sharing your story will inspire many. But there are still many harmful attitudes about domestic abuse, for example victim blaming, disbelief and judgement, which can be tough to deal with.

When researching the literature surrounding the impact of public speaking, one common theme occurred in the sense of fear or anxiety. Stein, et al. (1996) conducted a study surrounding the prevalence of and impact of public speaking fears. They state that Anxious cognitions about public speaking included the following fears: doing or saying something embarrassing (64%), one's mind going blank (74%), being unable to continue talking (63%), saying foolish things or not making sense (59%), and trembling, shaking, or showing other signs of anxiety (80%). The study concludes that public speaking anxiety may have a detrimental impact on the lives of many individuals. Though this study is somewhat dated, the theme of anxiety and fear surrounding public speaking is still present in more contemporary literature. Raja (2017) conducted a study with the aim of analysing the

reasons behind the high levels of anxiety experienced by students surrounding public speaking. What is interesting with this study is that again, support is key to the treatment of public speaking anxiety. 95% of participants agreed that if support was available, the fear could be overcome. From this it is clear to see that it can be unnerving to speak publicly, even when the topic is not related to an experience of trauma. It can be considered fundamental for experts by experience to receive the proper support before during and after speaking publicly about what it is they were subjected to.

The effects of retelling trauma

We know that experts by experience often disclose the abuse or trauma that they were subject to, to a wider audience. One charity, called Surviving Economic Abuse, explain that their expert by experience group is a group of survivors of economic abuse who generously give their time and insights to influence their work, they go on to state that the expert by experience speaks openly and honestly about what they have been through so that they can be a force for change (Surviving Economic Abuse, 2021).

When researching the effects of retelling trauma, two common themes occurred. The first theme surrounded retraumatisation, the second theme surrounded support. Katirai (2020) conducted a study surrounding how the court system re-traumatises victims of intimate partner violence. Within the study they state that the legal system subjects survivors to the trauma of reliving what they were subjected to through the retelling of the abuse. Katirai (2020) goes on to state that expanding trauma-informed support services can better prepare clients for the retelling of the trauma that they were subjected to whilst in court.

Brouneus (2008) conducted a study surrounding the impact of retelling serious trauma in relation to genocide in the form of testifying. They aimed to discover if the participants found the retelling healing or retraumatising. Brouneus (2008), state within their findings that there has been an assumption that testifying in truth and reconciliation commissions will be a healing experience for survivors, they state that healing has been a central concept in the general reconciliation literature and in political rhetoric around truth commissions. However, they argue that there may be risks involved concerning the psychological health of women survivors who give testimony. These risks would be due to the short-term exposure that the retelling of trauma involves. For all the women interviewed, giving testimony caused intense psychological suffering. They state that five participants could not continue their testimonies due to trauma and several participants re-experienced their traumas of the genocide so strongly that they felt as though it was happening again. Again, within the conclusion of this study, Brouneus (2008), state that support is needed for the survivors before, during, and after the retelling of the trauma. They also state that there is reason to cease stating that the truth heals. From this it is clear to see that when a survivor speaker or expert by experience retells their experience of trauma for the purpose of educating individuals within an organisation or charity, this can be damaging and triggering and can lead to the retraumatisation of the expert by experience. It is also clear to see from the literature that adequate trauma informed support is imperative for individuals who retell the trauma that they were subjected to.

The literature reviewed for this study suggests that there is currently a gap in evidence when considering the ethical treatment of, and support provided to experts by experience. Our study provides the view of the experts by experience and considers the ethical

treatment and the support provided to them and whether this is currently effective. It is commonly suggested within the literature that experts by experience are beneficial to organisations and students as they provide lived experience that can help shape future practice, this is relevant to our study as we know from this that experts by experience provide organisations with a unique insight into their experience, we suggest that because of this experts by experience should be treated ethically, they should be paid in accordance with the professionals they work with and train. We considered the impact of public speaking and the impact of retelling trauma; this is relevant to our study as all the participants that were interviewed had lived experience of publicly speaking about their trauma on several occasions, from the literature we learnt that public speaking can be frightening and can cause anxiety, we also learnt that retelling trauma can be re-traumatising for an individual. The treatment suggested for both public speaking anxiety and retraumatisation is trauma informed support, before during and after the retelling of trauma and public speaking; from this we suggest that experts by experience should receive adequate trauma informed support for the work they do.

Methodology

This study was an anonymous, online questionnaire combining qualitative questions and scenarios with quantitative items. The purpose of the study was to explore the impact of retelling serious traumas in a professional setting as a survivor speaker or expert by experience. Further to this, the study aimed to explore if there is adequate support available for experts by experience, and if they are treated ethically by those who they provide their time to.

Between 15th January 2019 and 2nd February 2019 an anonymous questionnaire was posted on Facebook, Twitter, and LinkedIn. Users were encouraged to share the study and call for participants.

Participants for this study were all over the age of 18 years old, could read and write English and lived in the UK; participants must have shared their experiences publicly as an expert by experience or survivor speaker, surrounding any relevant topic. There were no other participant requirements.

Participants

This study engaged 58 participants, all of which reside in the UK. Participants in this study were mainly female (93%), 7% being male. The age range of the respondents was 18-75 years old. 12% were 18-30, 40% were 31-45, 41% were 46-60, 7% were 61-75%, there were no participants aged 75 and over. All participants currently deliver speeches, talks, presentations or training based on their own experiences of violence, abuse, harm, trauma or exploitation.

Participants gave regular personal talks and disclosures on a range of topics including:

- Sexual violence and abuse
- Mental health and trauma from abuse

- CSE and CSA
- Domestic violence
- Ritual abuse
- Trafficking and prostitution
- Criminal exploitation
- Revenge porn
- Racism and oppression

Ethical Considerations

The study began with a detailed explanation of what the questions would ask of participants and an accessible easy-read section about consent, withdrawal, and anonymity and data protection. All participants remained anonymous and were discouraged from disclosing personal details including names, locations, areas, venues, schools or any other identifying information of themselves or others during the study. This study had the potential to be traumatic or distressing for participants and may have attracted people who already had personal experience or an interest in the topic. Therefore, the study also began with a list of organisations, helplines and services that could support people subjected to sexual violence, abuse, trafficking and domestic violence. The study was conducted using the principles set out by the British Psychological Society Code of Human Research Ethics and the anonymous data was stored and licensed securely. Data from the quantitative section was analysed using the questionnaire software as it only sought basic frequencies and proportions. Qualitative data was analysed with two coders utilising thematic analysis.

Findings

As aforementioned, this was a mixed methods study, participants were asked a series of quantitative multiple-choice questions, to explore what it is that Survivor Speakers or experts by experience discuss how often they do this and who they provide their time to. It was also considered if participants receive any payment or support for the time that they provide.

1. I have personal experience of... (Participants had the option to select multiple answers depending on what was relevant to them)

Answers	Percentage
Mental Health or Trauma	71%
Child Sexual abuse	64%
Child Sexual Exploitation	21%
Female Genital Mutilation (FGM)	0%
Domestic Abuse	62%
Forced Marriage	0%
Rape or Sexual Assault	66%
Criminal Exploitation	5%
Sexual Harassment	29%
Trafficking	9%
Ritual Abuse	7%
Revenge Porn or Image Based Abuse	14%
Other (Specified below)	16%

Participants had the opportunity to specify 'other' in a free text box. Other experiences included racism, bullying, modern slavery, financial abuse, prostitution, threats to kill, adult grooming, addiction, child homelessness and the murder of a family member.

2. When you give talks or training, which of your experiences do you talk about?

Most participants advised that they give talks about domestic abuse and coercive control, the second most common answer was rape and sexual abuse. Mental health, trauma and child sexual abuse were then visibly prevalent in the participant response. Other responses

included the journey through the criminal justice system as a victim and personal experiences of catfishing.

3. How many times have you shared your experience as part of a talk, speech, training, or lesson?

Answers	Percentage
Once	5%
Up to 5 times	19%
Up to 10 times	22%
Up to 25 times	10%
Up to 50 times	14%
More than 50 times	12%
I do this regularly (Weekly or many times per month)	17%

From this it is apparent that many of the participants who took part in this study would regularly retell their trauma, which from the literature we know can be re-traumatising.

4. Who do you give talks, speeches, or training to? (Participants had the option to select multiple answers depending on what was relevant to them)

Answers	Percentage
Other Survivors	52%
NHS/ Health Workers	52%
Large Conferences	41%
Charities	40%
Mental Health Workers	36%
General Public	36%
University Students	34%
Social Workers	33%
Police Forces	28%
Other (Specified below)	26%
Teachers and Educational Staff	21%
Secondary School Children	9%
Probation	7%
Youth Offending Services	7%
Primary School Children	2%

Participants had the opportunity to specify 'other' in a free text box. Other answers included the CPS, hard to reach communities, academics, mainstream media, TV, researchers, forums and blogs.

5. Are you reimbursed for what you do?

Answers	Percentage
I have never asked for payment and never received any payment	41%
I have received expenses only (train fare, accommodation) but I have never been paid a fee for speaking	17%
I am occasionally paid a fee but usually I am asked to do it for free	17%
I am usually paid a fee but sometimes I am asked to do it for free	3%
I have asked for a fee, but I have always been told there is no budget, so I did it for free to help others	0%
I am always paid a fee for what I do, I do not speak for free	9%
Other (Specified below)	12%

Participants had the opportunity to specify 'other' in a free text box. Others answers mostly reflected that it was a part of their role.

Most participants had never been paid for providing their expertise and had never asked for payment. As previously stated, Surviving Economic Abuse (2021) state, an expert by experience speaks about what they have been through to create change. It is also accepted within academia that experts by experience can be beneficial for organisations as they can support others experiencing what they have been subjected to (Barker and Maguire, 2017). Experts by experience have lived experience that can help shape effective practice. Professionals can theorise what might work for survivors, but the survivor can provide knowledge from first-hand experience. It can be considered exploitive for organisations not to pay individuals who are providing their expertise and time when this benefits the organisation. Conservation Careers (2021), state that exploitation exists when somebody has an experience which gives far less return on their investment of time and/or money, than they should expect. This is the case when experts by experience are not paid in line with others doing work of a similar nature.

6. If you do get paid for sharing your experiences or training, how much is the fee?

Participants had the opportunity to answer this question with free text. The answers range from £11 to £500.

One Participant wrote: "I used to get £45 per session as a service user consultant by the NHS. I worked with them for 8 years, most of the time full time, but we were seen as 'volunteers' on expenses. I have had to wait up to 9 months for expenses but was expected to do the same things as my NHS colleagues."

This response is interesting as it suggests that there is a hierarchy where experts by experience are considered lesser than their NHS colleagues.

Another Participant wrote: "Due to expenses which are typically uncompensated, this has created personal hardship and I have recently needed to refrain from engagement."

Again, this response reinforces the argument of exploitation. Many experts by experience give their time to create change (Curran et al., 2015) and in turn to help others. As aforementioned organisations are aware that this change is beneficial for them, as it helps shape effective practice. It can be considered exploitive for an organisation to allow an individual to provide their time and expertise without return, to the extent that has this has resulted in personal hardship.

7. Do you receive any support for sharing your experiences to audiences?

Answers	Percentage
The organisation who commissions me to speak about my experience provides support for me	7%
I access my own support or supervision independently	28%
I use my peer network and friends for support	26%
I don't have access to any support after I shared my experiences	10%
I don't feel like I need any support after I share my experiences	22%
Other (Specified below)	7%

Participants had the opportunity to specify 'other' in a free text box.

One participant wrote: *"I have had to be inventive over self-care."*

Only 7% of participants have received support following sharing their experience. Most participants were giving talks, training or speeches on domestic abuse which is widely acknowledged as traumatic (Kozłowska, 2020). The second most common subject that the participants provide talks and training on was rape and sexual assault, also widely acknowledged as traumatic. We know that retelling such trauma can be triggering for some time before, during and after the retelling (Katirai, 2020). Organisations should provide support to experts by experience as standard. We also know that the majority of participants had never received a payment for sharing their experience meaning that those who accessed their own support would have done so at their own expense. It is acknowledged that those who retell their trauma should receive support when doing so (Katirai, 2020); therefore, the fact that many participants must fund their own support is objectionable.

8. How did you start sharing your experiences? How did it come about?

Key theme frequencies

I was asked/ Invited	25
Through writing about my experience	5
Myth busting and making a change	17
Raise awareness	2

I was asked/ invited

This theme was made up of 25 participants who discussed being asked to share their experience. Participants explained that they were asked usually by a service provider that they had used following being subjected to a traumatic event.

“I was asked by the charity that supported me with therapy”

Participants could potentially feel obliged to give back when approached by a charity that has supported them, creating a power imbalance, therefore this could be considered unethical.

“Through patient involvement and being approached by the charity I use services from”

“I started being asked to get involved in public speaking by my mental health social worker”

As being asked/ invited was the most common theme analysed from the participant responses, many people become involved in work as an expert by experience through being approached by organisations or charities who see the benefit that these experiences can bring to their organisation/charity, this ties in with what was found in the literature review that was conducted for the purpose of this report. It appears that there is a fixation on the support that an expert by experience can provide to others and less consideration for the support that an expert by experience may require.

Myth busting and creating change

The second most common theme was surrounding myth busting and creating change. This theme was made up of 17 participants who wrote that they had started sharing their experience through a need to bust any myths that there are surrounding their experience and to create change to the current system.

“By chance to be fair, I wanted to blow away the myths and share what happened to me, I wanted mental health workers to be truly informed and stop drugging people who in fact need to talk”

“I felt let down by the police and other agencies greatly but felt that complaining would not change anything, so I decided I wanted to help these services by sharing my story and highlighting what worked and what did not. I sent an email to the police and was then contacted to take part in domestic abuse research. I ended up being part of the stewing group and from that; I and another survivor (and friend) started sharing our experiences at meetings, conferences, training etc.”

One participant wrote that they started sharing their experience through a desire to support the rights of others.

“Seeing other people suffering in the same situation, who have no idea about the system. I wanted to support their rights.”

The majority of participants who advised that they felt the need to make a change or help to bust myths had had a negative experience of an organisation or charity that they had used and wrote about not wanting others to have the same experience. These comments are important as they show that these individuals felt somewhat responsible for creating change within systems that are/were ineffective, to prevent others from being subjected to the same negative experience at the hand of the organisation.

One participant wrote –

“Initially I was afraid of publicly speaking about traumatic experiences, but I noticed far too many others face similar issues and I felt I needed to become vocal. Then, I faced legal threats which thankfully did not go any further as I had ample evidence to support the truth. After this, I was repeatedly called upon to share”.

Stein, et al (1996), state that public speaking may have a detrimental impact on the lives of many individuals. Katirai (2020) states that retelling serious trauma, contributes to retraumatisation. This participant overcame the impact of both public speaking and retelling their trauma to create change within an organisation. This again highlights the need for adequate support for experts by experience and the need to provide payment for the expertise that they provide.

9. What does it feel like to disclose distressing parts of your life to professionals and strangers?

Key theme frequencies

Mixed feelings	32
A negative experience	14
Meaningful and helpful	9

Mixed feelings

This theme was made up of 32 participants who wrote that disclosing distressing parts of their lives to professionals and strangers had both negative and positive aspects. Many participants felt that this was beneficial to others but triggering or exhausting for them. This is in line with the ‘myth busting and creating change’ theme found within the response to question 8. Many participants felt that although it is harmful for them to discuss their trauma, it is helping create change which in turn feels empowering.

Participants wrote –

“I ultimately find it empowering. Retelling my story and owning my trauma helps me to feel in control and it helps me to weaponise my trauma against the status quo which subjugates women. It makes me feel like a small bit of good could come out of my awful experiences. Sometimes I feel detached/dissociated, which later on tends to lead to flashbacks, nightmares and distressing trauma symptoms. But overall, I find it empowering to finally have a voice when I grew up voiceless”

“Triggers me in the lead up to it, thinking about it, and afterwards. But I do it to raise awareness to hopefully prevent it happening to somebody else”

This comment is interesting as this participant was retelling their trauma to prevent something similar happening to somebody else, a victim should not feel responsible for ensuring that others do not experience the same trauma. There is often the expectation from organisations and local authorities for victims and survivors to share their knowledge and experience to protect other victims, this can lead to victim blaming. If the victim is responsible for preventing further abuse and/or trauma then the perpetrator is excused. Victims of abuse do not have the power to prevent other people from becoming victims, only the perpetrator has that power (Taylor, 2020). The responsibility of ensuring the physical and emotional safety of potential victims lies with the perpetrator and the organisations working with the perpetrator.

“Embarrassing but empowering, sad but positive. Gives me a sense of pride to be able to enlighten student social workers. Feeling that I am repaying the charity’s support”

This comment solidifies the idea that experts by experience may feel obliged to give back to the charity that helps them, creating a power imbalance where the expert by experience repays the charity or organisation for the service they have provided.

“If they are mothers going through the same then it’s helpful and has made me feel less isolated and that I am doing something to help them cope, and to try to raise awareness when we are all being silenced. For others it can be difficult for them to understand the horror and accept it is happening in a ‘civilised’ country. It can be triggering and upsetting, makes feel helpless knowing that children are being sent to court and ordered contact/residence and I’m unable to help. I do need to take a break.”

A negative experience

The second most common theme was made up of 14 participants, who wrote that disclosing distressing parts of their lives to professionals and strangers was a negative experience.

Participants wrote –

“It is isolating and tokenistic. I know it’s my job to appeal to their emotional response and that otherwise; the plight of survivors may be disbelieved or dismissed. I often found it was when I didn’t speak with emotion or disclose details that were more powerful. If I spoke factually there was doubt, so I had to dig at painful old wounds to ensure I was taken seriously. It was painful and eventually I had to stop, though, I am in a better place now and know I’d go about it differently if I was to do that work again”

The participant discussed feeling the need to expose the most distressing experience in order to be believed by individuals from the organisation they were retelling their trauma to, this ultimately led to the participant having to stop sharing their experience. This could have occurred due to what is called the ideal victim theory. (Larcombe, 2002) states that somebody who does not scream for help when being attacked is likely to have their credibility questioned and are likely not be seen as vulnerable or the ideal victim, the victim is then likely not believed or blamed for what they have been subject to.

Randall (2010), states that the ideal victim theory undermines the credibility of women, who are seen to deviate from the stereotypical notion of an authentic victim. If the expert by experience is not emotional enough or does not act like a victim is expected to, then they may be viewed as not credible. This response again highlights the need for experts by experience to receive adequate support when in this line of work, it also highlights the need for audiences to be briefed prior to the public speaking.

Retelling trauma can be retraumatising, so to then not be believed depending on the severity of the trauma that is shared, creates pressure to discuss the most severe experience and ultimately guarantees that the expert by experience will be retraumatised.

“I used to feel positive and liberating – now it feels like sharing part of one’s soul with people who often have little empathy. You are the entertainment for many.”

From this comment, it appears that the participant felt that sharing their experience was initially positive, though over time the work had become tokenistic, as though they were entertainment. This suggests that organisations must ensure that effective support must be in place for experts by experience and they must brief audiences before an expert by experience speaks. If little change is occurring from the insight that an expert by experience is providing, then over time they may feel that they are retelling their trauma for the entertainment of professionals as opposed to retelling their trauma to create change and help others.

“I feel exhausted afterwards and on occasion have felt distressed hours later”

“Tiring, conflicting. Remaining professional while blocking out flashbacks and protecting your mental health”

Again, these comments suggest that support must be in place for experts by experience. It is exploitive to subject experts by experience to this level of distress with no support available and often without any return on their time. Within this theme participants discussed how talking about their trauma was triggering and that the intensity of this outweighed any potential benefits.

Meaningful and Helpful

The final theme, made up of the response from 9 participants, was that disclosing distressing parts of their lives to professionals and strangers was for them meaningful and helpful.

Participants wrote –

“I find it helps me on my journey and knowing that I am helping others is my mission”

“I find talking about it helps me and others”

“I am not ashamed of my experience and I’m glad that I can use it to help others”

Again, in line with the myth busting and creating change theme found within the response to question 8. These participants felt that talking about their experience was positive due to the potential change that could be brought from doing so. It appears that these participants felt empowered by the notion that they were helping others.

Brouneus (2008) state that there is an assumption that testifying in truth and reconciliation commissions will be a healing experience, however, they argue that there may be risks involved concerning the psychological wellbeing of survivors who give testimony, and those risks are associated with the short-term exposure that retelling trauma involves. Over time experts by experience may become retraumatised due to the continuous exposure.

10. Have you ever had inappropriate questions or offensive comments made after you shared your experience?

Participants mostly answered this question with a ‘yes’ or a ‘no’, others provided context.

Yes	10
No	19

Key theme frequencies

Online	6
Insensitive and Inappropriate	10
Comments made by the organisation	4

There were more participants that had been asked inappropriate or offensive comments than those who had not.

Insensitive and inappropriate

Ten participants wrote that they had been asked insensitive or inappropriate questions after sharing their experience.

Participants wrote –

“From time to time, professionals say I am generalising from personal experience. I guess they just haven’t listened to what I actually said. Others say they feel hurt because I use harsh language and they have good intentions and really want to help. Well, when ‘treatment’ is in fact torture to the person being restrained and forcefully medicated, it does not help that their intentions are good. They just won’t see their part. I am always the problem to them”

“Insensitive is probably a better word. Some people have been quite defensive if I have described a situation where I was let down by services, but I’ve never felt offended”

The above comments suggest that organisations often invite experts by experience to speak publicly and provide their insight into what the failings are within their organisation, only to react insensitively when the experience is shared. The organisation is subjecting the expert by experience to retraumatisation, only to dismiss their insight and their feelings. It can be suggested that this mirrors the actions of an abuser. It is considered why an organisation would use an expert by experience at all if they were going to be dismissive when learning the experience of the survivor.

“One person at a focus group was very inappropriate as she kept deviating from the topic”

“Yes, I have been asked about my sexual relationships after CSE”

Becker- Blease and Freyd (2006) state that for research purposes, it is important to ask participants about past trauma, they go on to state that although there may be harm in not asking participants about abuse for learning purposes, the way in which survivors are treated when they do disclose is crucially important. The participants’ well-being, and

whether they tell anyone else about the abuse, depends on how researchers respond when they disclose. Researchers must not ask about abuse without planning, ideally with clinicians, trauma survivors, and advocates, ways in which to respond that are empowering and compassionate. It is important that inappropriate questions are not asked of experts by experience; organisations must put measures in place before an expert by experience speaks about their trauma and must offer support following the retelling of their trauma.

Online

Six participants wrote that they had inappropriate or offensive comments made to them after sharing their experience online

Participants wrote –

“Yes, many times over, but the most prominent that comes to mind is a comment on my blog (which is anonymous and so must have come from someone who made the connection between me and the blog) which used my name and said I was too ugly to have been a whore so I must be lying. Nobody would ever pay to sleep with me”

“Yes, many online, from fathers who are nasty and abusive, and from solicitors who can be out of control and/or in denial. In person they can be disbelieving and patronising but less aggressive”

It appears that the intensity of the offensive comments is amplified online as opposed to in person. This could be due to aggressive individuals often having the advantage of anonymity online.

Comments made by the organisation

Four participants wrote that organisations often made insensitive, inappropriate or offensive comments after they shared their experience.

Participants wrote –

“Only off a local authority social worker, CAFCASS, but domestic abuse doesn’t exist in their world”

“Only from the police, someone asked if I had a chip on my shoulder”

From the participants response it appears that the police were the most prevalent in making offensive comments to participants. This could be due to stigma surrounding the expert by experience.

Victims and trauma survivors often face stigma surrounding what they were subjected to. Happell, et al (2021) wrote that the use of experts by experience meant that students became critical of their own work and were no longer afraid of service users. Suggesting that experts by experience are seen as different to others, somebody to be feared and that there is stigma surrounding experts by experience. Ahmedani (2011)., states that that stigma is “an attribute that is deeply discrediting” that reduces someone “from a whole and usual person to a tainted, discounted one” The stigmatized, thus, are perceived as having a “spoiled identity”.

Thornberg (2015), explains that being negatively labelled as different becomes the dominant feature of the victim’s social identity. Therefore, the victim or expert by experience is perceived as different and not-credible, organisations must ensure that they treat experts by experience as professionals, through adequate payment and support in line with what other professionals receive for doing the same work, this is to end the stigma that experts by experience face.

11. How do you think sharing your experiences in this way has impacted you?

Key theme frequencies

It has impacted me positively	25
Mixed feelings	18
It has impacted me negatively	13

Participants discussed mostly that sharing their experience had a positive impact on them, again with the notion that they were making a difference and helping others who are or have been subjected to trauma of a similar nature. The second most common theme was 'Mixed feelings'. Many participants wrote that they felt that they were helping others, and this made them feel good, this being said it was at the cost of them being triggered or retraumatised through retelling their trauma. The remaining participants wrote that they had been impacted negatively by sharing their experience, that it was triggering, that a lack of change was frustrating and that they had been bullied for doing so.

It has impacted me positively

Participants who wrote that sharing their experience impacted them positively wrote about how they felt positively about helping others, they also discussed being able to make sense of and reflect on their experience through talking about it, others wrote about how it had affected them positively as they were removing the shame and stigma surrounding their experience through talking about it.

Participants wrote –

"It has given me a voice that I never had, and it has enabled me to help others both directly and indirectly. I feel strong, confident and empowered to continue sharing my story as it has helped me on my healing journey"

"Positive validation, empowering, reduced the shame, met others in the same situation, great to raise awareness of this unspoken uncomfortable subject, got involved in charities to help raise awareness"

“It made me use those experiences for something other than sadness, self-harm or therapy. It helped me own them and feel they were worth something as they can help others”

“It has helped me reflect on my own situation and feelings rather than ignoring it and dealing with my emotions”

“I think it is necessary as it shines a light on what is often regarded as a dirty little secret”

“Positively mostly, I feel I am helping to reduce the shame culture around sexual assault”

The above comments from participants suggest that experts by experience consider their work to have had a positive impact on them as it has helped reduce the shame that they felt surrounding what they were subjected to and has educated others about their experience or created awareness. This is somewhat positive, however, experts by experience should not have to initially feel shame surrounding what they were subjected to, this highlights a wider issue in the fact that victims have been made to feel ashamed of what the perpetrator has subjected them to. This suggests that violence committed against women and girls, is trivialised and excused, to the extent that victims of abuse and oppression feel ashamed of what they have been subjected to and the perpetrator is excused from feeling shame.

Mixed Feelings

Many participants wrote about how, although there were some positive elements surrounding sharing their experience, it had impacted them negatively through being triggered when sharing their experience. Others discussed how it became frustrating retelling their story when this resulted in very little change.

Participants wrote -

“Sometimes in a positive way, sometimes it has really triggered me”

“Largely beneficial, occasionally triggering. I have been well prepared in how to share appropriately for me”

“It has made me stronger but also more vulnerable”

“A feeling of helping, but also frustration that so little is being done to improve the situation. It has caused triggers and upset so I need to take time off to ‘lick my wounds’”

This comment is important as we know that experts by experience are often retraumatised from the retelling of their trauma (Brouneus, 2008), this comment suggests that retraumatisation sometimes occurs and little is done to improve the ineffective practice; many participants have stated that they find being an expert by experience beneficial but triggering. Beneficial because they can create change and help others, therefore, in some cases individuals are being re-traumatised unwarrantedly.

It has impacted me negatively

Many participants discussed being impacted negatively from sharing their experience. Those who expressed that they were impacted negatively generally spoke of feeling vulnerable and exposed, they also discussed being triggered and retraumatised by retelling their story and mentioned not being able to move forward. One participant spoke of the bullying being relentless and that they had attempted suicide as a result of this.

Participants wrote –

“For a long time, I thought it was helping me. A kind of purging toxicity and a healing through being heard and potentially making a difference to others. But eventually, I realised it was hurting me and I was letting in a different kind of toxicity in, one that felt eerily similar to being used”

This comment suggests that the participant felt retraumatised because of repeatedly retelling their trauma, and that the organisation they were providing their insight to was not supporting the participant. This highlights the damage caused by retelling trauma and highlights the need for effective trauma informed support when sharing an experience of trauma.

“Initially it led to Post Traumatic Stress type symptoms”

“To expose your deepest emotional pain in a public space steals a bit of your spirit, increasingly the more you do it”

“I found it empowering at first and positive that it was making a change. After doing it for several years it became draining, and it felt as though it was stopping me from moving forward. I was always only a survivor of CSE, it was my whole identity, and I didn’t like it. After a while, I found the sympathy belittling. I didn’t do it for sympathy; I did it to change the system”

“Difficult to recover from and creates difficulty to recover from for some time after”

“I now blame myself; I feel judged”

“It made me leave work after a suicide attempt. The reality was the bullying was relentless and it didn’t stop even after a suicide attempt”

Again, the above comments highlight the impact of retelling trauma, in line with the literature found for this study it can be argued that retelling trauma can over time lead to retraumatisation, again highlighting the need for effective support, and baring the question, is it ethical at all to use experts by experience, when this is the impact that the work has on participants.

12. What do you feel you get from sharing your experiences with these groups? Are there any benefits for you?

Key theme frequencies

It helps others	30
It helps me	19
I don't feel that this is beneficial	4

Most participants discussed that what they get from sharing their experiences is the feeling that they have helped others. Participants stated that they feel they have helped others through educating organisations and charities, others feel they have helped others directly. The second most common theme was 'it helps me'; participants explained that sharing their experience has helped them as they have learnt new skills and connected with others, some participants explained that it had helped them in their healing journey. The final theme established was 'I don't feel that this is beneficial', these participants state that no change has occurred from sharing their story.

It helps others

As aforementioned many participants felt that what they get from sharing their experience is the benefit of helping others. Participants advised that they do it for others, not for themselves and that they want to give a voice to other survivors in systems that ignore or disregard the voices of victims. Included in this theme are the participants who stated that feel that they help other survivors indirectly through educating organisations whose systems are oppressive.

Participants wrote –

"Helping others and preventing the abuse of others"

"I don't do it for me, I do it because I don't want anyone else to suffer what I did, and I want services to understand how they can help victims who find themselves through the CJS and make their experience as smooth as possible"

The comments above are again important as they suggest that the participants felt responsible for preventing others from becoming victims of abuse, organisations should not hold victims of abuse responsible for preventing other people from becoming victims of abuse. The responsibility lies with the perpetrator (Taylor, 2020)

“Knowing that I am helping them reconfigure their idea of who and what a survivor can be. For example, articulate, strong, good interpersonal skills. Shame to have to correct such a damning image, but important”

This comment highlights the current stigma that exists surrounding victims. As previously stated Happell, et al (2021) wrote that the use of experts by experience meant that students became critical of their own work and were no longer afraid of service users. Suggesting that experts by experience are seen as different to others, somebody to be feared and that there is stigma surrounding experts by experience. Ahmedani (2011)., states that that stigma is “an attribute that is deeply discrediting” that reduces someone “from a whole and usual person to a tainted, discounted one” The stigmatized, thus, are perceived as having a “spoiled identity”. Stigma is damaging to an expert by experience and is ultimately the reason experts by experience are discriminated against and considered lesser than the professionals they work alongside. An expert by experience should not have to correct such a damaging image as stated by this participant. This comment also suggests that the victim must be seen as the ‘ideal victim’ in order to be considered credible.

“Just the hope that I can stop this happening to somebody else.”

This comment is important, as it suggests that this participant felt personal responsibility to prevent what happened to them, happening to somebody else. This is again a wider societal issue where a victim is made to feel responsible for ensuring the safety of future victims. This excuses the perpetrator and places the responsibility onto the victim. Only the perpetrator and the organisations working with the perpetrator can ensure the safety of future victims. Victims should not be made to feel as though this is their responsibility.

“It is a comfort to know that I have helped someone, so that what I suffered was not done in vain”

“By speaking up about it, I realise that many women think they’re alone in experiencing this. When I endured several years of the most humiliating and degrading sexual coercion, I felt disgusted, dirty and worthless, being able to help others realise that the shame rests with the abuser is not only liberating but the ultimate form of surviving. It gives the abuser less places to hide”

“The hope that sharing my experience can help others, both other professionals who are survivors and the people they help”

“Hopefully providing a better understanding so organisations can change policies to improve their response/ service to victims, however, when you see no changes occurring it can have a negative effect”

As aforementioned participants state that it becomes tokenistic when no change is occurring because of the insight that they are providing. In which case it is concerning that these organisations are using experts by experience at all. We know that retelling trauma can be retraumatising, for an expert by experience to see no changes in practice after being subjected to retraumatisation it can be considered exploitative and abusive.

“Good to know that my experiences can help shape responses from professionals in future. On a small scale it makes me feel resentful that I had no intervention”

Most of these participants felt that it was beneficial for them to educate organisations that have been/are ineffective in order to protect future victims. Though it is positive that change is sometimes occurring within these organisations, the survivors who were failed previously should not be responsible for exposing those failings at the risk of being triggered because of retelling their trauma. Some participants have stated that they haven’t seen any change occurring; therefore, those survivors are at risk of being triggered with no positive outcomes and often without payment or support.

It helps me

Many participants discussed how sharing their experience had been beneficial as it had helped them. Some participants explained that it had helped them feel heard; some participants explained that it had helped them no longer feel like a victim. Others explained that they had connected with others and learned new skills from publicly speaking about their experience that had helped them get into paid work.

Participants wrote –

“I have developed a lot of skills and experience that have been great to put on my CV, which helped me to actually find paid work. Like conference speaking, organising sessions, developing training etc.”

Curran, et al (2015)., state that there is a lack of learning opportunities for experts by experience and that higher education providers and service providers should support experts by experience by strengthening learning opportunities, the above comment suggests that this participant learnt a lot from working as an expert by experience. In line with what Curran, et al (2015) argue, it would be beneficial for organisations to offer learning opportunities for this line of work, in terms of recognised qualifications and/or certificates.

“It has helped me get through terror and grief when sharing with other mothers. I get the sense that I am doing something useful instead of dying in pain alone, also that I am not the only one and it wasn’t my fault, but the systems fault and my ex’s fault”

“It’s good to know you’re not alone and to meet brave and inspiring survivors and those who help them”

“I feel empowered, useful and no longer feel like a victim”

“Acceptance, social connectedness, agency, control, an opportunity to understand and be understood”

Many participants mentioned that they felt that speaking about their experience was beneficial for them as it enabled them to connect with others with other survivors. The fact that survivors are feeling isolated prior to this highlights a lack of support provided by organisations in terms of support networks.

I don't feel that this is beneficial

Some participants discussed feeling as though sharing their experience was not beneficial to them or others. Participants wrote that they felt like entertainment, others wrote that the system needs a total overhaul and that they were not actually successful in creating change within the organisations that were/ are ineffective.

Participants wrote –

“At first it was empowering, and I felt like I was changing something, later I realised it's not the people who need to understand, the whole system needs an overhaul. Frontline staff have their hands tied”

“Initially it felt like you were changing minds, bringing reality to people. Now I feel survivors easily become the ‘freak’ show which is brought in to entertain the audience and allow box-ticking for the organisation”

As previously stated, the above comments suggest that over time many participants have felt that there is no change occurring as a result of sharing their insight, the work then becomes tokenistic and voyeuristic, it can be suggested that organisations should not be using experts by experience at all if they are not able to create effective change. The participants concluded that they were being retraumatised with no positive outcomes. It is imperative for organisations to offer aftercare if they feel it necessary to use experts by experience; supervision would be beneficial to the participants in this instance so that they could openly discuss their frustration with the lack of positive change.

Learning from Scenarios

In this section of the questionnaire participants were asked to read four scenarios and respond with their thoughts on the scenario presented. All scenarios put forward a real situation surrounding expert by experience speaking at events and providing training to organisations.

SCENARIO 1

Mandy was recently speaking at a large conference about sexual and domestic abuse. She was speaking amongst professors, doctoral researchers, a couple of CEOs of rape centres and even a local MP. In the afternoon she gave her speech about what it was like to be trafficked and raped in the Midlands. After the conference, she found out that all the speakers were all paid £250, except her, as she was a survivor speaker.

Key findings – Scenario 1
What do you think of this scenario? What are your opinions?
<ul style="list-style-type: none">• “This is abhorrent. The other speakers are professionals and academics therefore detached. The person with the most expertise and understanding was the survivor and so they should receive a higher fee. This is exploitation all over again”• “Disgusting and completely exploitative”• “I think that it is wrong that she wasn’t given a fee. She should not have to ask. The value of a survivor’s testimony is immense and should be treated with respect. Nothing can repay the damage that abuse causes, but being respectfully

reimbursed, making life a little more comfortable for the survivor, is a positive outcome”

- “Typical, Survivors expect nothing and believe they are worth nothing, so they are far more likely to be exploited as they are far less likely to ask for or expect anything from anyone”
- “Due to my own low self-worth, I wouldn’t expect any different if I were the speaker because I have a feeling about myself that I am less valuable than other people who are better trained (and better waged) than me. But this discrepancy between pay of course worsens this feeling of self-worth. I think Mandy should be paid for speaking as she is an expert in her experiences and obviously has valuable contributions to the talk”
- “It makes me extremely angry. I cannot even imagine what was in the minds of the organisers to do this. It seems totally unethical and exploitative and places no value on her contribution. Maybe they would argue that paying would mean that someone who is not ready to share their story would take part because they needed money, but I don’t buy this argument at all. There are other ways of ensuring people are not harmed by taking part and, once someone agrees to take part, they should be recognised equally with other speakers”
- “It is simply wrong to exploit others, particularly those who have already suffered significant harm. Many victims/ survivors live in poverty since their trauma does not allow them paid full-time employment”

- “Shows a lack of respect for experts by experience. Academics have trained and worked hard but they need survivors to best shape their practice otherwise responses will continue to be inappropriate”
- “I would be very angry and upset. It seems deeply unfair and exploitative. If anything, it’s the professionals who should waive a fee. I’d feel unappreciated and used like I have been in the past. It’s re-traumatising to be used and treated as less. I feel our desire to want to help is used and I still feel like I should do it, to try and help others. This is exploited too often”

A common theme in the participant’s response to this scenario is exploitation. Many participants discussed how this was exploitive. Conference organisers can learn from this response, as participants felt that there was a lack of respect for Mandy and that Mandy was being exploited all over again. Participants explained that Mandy should not have to ask for a payment from the conference organisers and that this should be standard. Participants discussed how they can feel less valuable than others due to the trauma they have been subjected to and that not offering a payment for their knowledge and expertise can solidify this notion.

Within the participants response it was clear to see that they could identify the exploitation of others, despite them being exploited themselves by organisations and charities through a lack of payment and support.

SCENARIO 2

Dan has been invited to deliver a speech about his experiences of being abused in a care home at a new survivor's event for professionals. The event is in London and the tickets are £356 each. The event organiser tells Dan that none of the survivors are being paid to talk as the event is about raising awareness. Dan doesn't feel confident enough to ask for payment, but he feels he should be paid if the event organiser is profiting from the event with such expensive tickets.

Key findings – Scenario 2
What do you think of this scenario? What are your opinions?
<ul style="list-style-type: none">• “Again, this is purely exploitation if a profit is being made. If the profit isn't being donated to charities, then this is not for the benefit of survivors at all. He deserves payment”• “Again, this is wrong they are learning from his painful experiences and regard their knowledge more worthy of payment than the person who has suffered and does it because he wants other people to be treated in a better way than he was by the people who should have done. Also, they are picking the vulnerable because of his life experiences and they know he hasn't the courage to ask”• “Absolutely right, Dan should get a good speaker fee. I am continually told that “there's no funding” but the income from the tickets must be going somewhere. It

almost feels sometimes like we are being abused again. I hate having to ask. You shouldn't have to"

- "As described above, I think our (survivors') low sense of self-worth or low-confidence is one thing that stops us asking about pay. As described above, I believe he should be being paid. Particularly with such a high-ticket price!"
- "As mentioned, this is a very real concern. Sometimes we need to help ourselves first or we cannot be well enough to be available to others. "No" is empowering"
- "Survivors can be intimidated to ask for their own needs to be met. This gets taken advantage of. We like to give back and help change things, but this is mostly expected to be free"
- "I understand the reluctance to speak up. Again re-exploiting. He's not a product to be sold. He's not a freak in a circus"
- "Again, that is exploiting a survivor"
- "As above. Exploitation of already exploited people"

Participants discussed the idea that survivors can be intimidated or have low self-esteem or self-worth because of what they have been subjected to, and that conference organisers/ organisations can as previously stated; solidify these feelings due to the exploitation of survivors when they discuss their experience. Organisations and conference organisers can learn from this scenario, by acknowledging that this feels to survivors like they are being abused all over again.

SCENARIO 3

For the last year, Rita has been delivering training to local police forces from her perspective as a victim of FGM and abuse. She goes into the police force and delivers a 2-hour session to police officers to raise awareness and to tell them her story. She has been doing this every month for about a year and is beginning to wonder if she should charge the police forces and why they have never offered to pay her. Her feedback is always great, and they always invite her back, she feels weird about asking them for money.

Key findings – Scenario 3
What do you think of this scenario? What are your opinions?
<ul style="list-style-type: none">• “The police routinely pay for training so they're obviously undervaluing her as an expert. She's not a professional, she's a normal everyday person. I firmly believe survivors doing this work should declare themselves freelance facilitators and have a fee, we deserve to be paid for our time even if we aren't academics or professionals”• “The police need training around how they could be re-traumatising Rita by exploiting her like this. There should be someone at police end responsible for ensuring ethics of these things”

- “Again, a survivor is giving valuable education and information why do they think is ok not to pay if they had employed a company in, they would have to pay automatically. That person is being used, they are all learning and being paid for that why not the person who is educating”
- “The professionals should understand a survivor’s mentality and should have a standard payment system in place”
- “It is incredibly hard to ask for money. And when the organisation you’re speaking for are a bit intimidating (in my opinion!) like the police, I’d be terrified to ask. But if she’s been speaking regularly, she should definitely get paid. I believe the onus should be on the police (in this instance) to offer pay. There should be best practice guidelines for NHS and police that says survivors/experts by experience should be paid. To motivate them, this could be something CQC and similar inspection bodies check when inspecting services”
- “This is a huge amount of unpaid work. It’s also potentially extremely stressful and distressing. She should be paid and shouldn’t have to ask. She would be absolutely justified in saying that she can’t continue to do it for free and to ask if other speakers get paid. It would probably be helpful to have allies who can support her, so it’s not just left to her. But really, she shouldn’t have to do this. The police should discuss payment with her at the outset. They should also consider emotional support for her”
- “This is the position I am in. I do it because I would rather they get it for free than not at all. But it costs a lot and uses up my time to develop and drive. My local force was adamant that I claimed all expenses when I was unsure about it, as it

was my time and they said I should be. So, I am aware it is not always those 'lower down' the chain making those decisions”

- “Further exploitation. Money is there but the organisations choose not to share it. It devalues the work of the survivor and is exploitative”

Participants discussed that it may be hard to ask for money as a survivor of abuse and that experts by experience should not have to ask an organisation for money for the knowledge and expertise that they are providing, one participant explained that they would rather do it for free than not at all, due to the current ineffective practice. Participants discussed that not being offered payment devalues the work of an expert by experience. Organisations can learn from this scenario. As one participant mentioned it would be beneficial for organisations to have a standard payment system in place, so that experts by experience are not further exploited.

SCENARIO 4

Lana and Goran are brother and sister whose mother was murdered by their father. They have been invited to give many speeches about their experiences over the years, and they have sometimes been paid and sometimes done it for free. However, as the years have passed, Lana is beginning to wonder whether the constant retelling of their mother's murder by their father is affecting their own mental health. They are still traumatised and when they get off the stage or drive home after the speeches or appearances, they are often quiet and stressed. Goran has also started wondering whether the retelling of their story is stopping him from recovering from the trauma. They support each other, but no one has ever offered them emotional support for retelling their traumas to audiences

Key findings – Scenario 4
What do you think of this scenario? What are your opinions?
<ul style="list-style-type: none">“I have come to believe that this work both needs us to have healed from our own traumas and also not. To get the emotional impact audiences crave, we still need to be in the midst of our trauma. For us to be able to do it without further harm, we have to have worked on processing our trauma ourselves”

- “I do feel that counselling and therapy can help with that processing and that we can do the work afterwards from a more stable place, but I feel that audiences want to see that real, raw emotion”
- “Again, they have been systemically completely let down. It is exploitative and there should be some kind of body or agency that supports survivors to tell these stories”
- “It's the reality in my experience Organisers need to not only pay survivors but also have proper professional protocols for debriefing them following speaking - they would want no less for themselves”
- “They are being used by voyeuristic people. They are being abused and taken advantage of”
- “All organisations which hire expert by experience/survivor speakers should have a best practice guide which should prioritise the mental health of the speaker. They should be assigned a contact in the organisation with whom to debrief or to give them advice and guidance. Charities and organisations like NHS and police will obviously have someone qualified to do this. It should be a must to provide speakers with a contact trained in counselling/AIG”
- “I wish that they could have some proper clinical / therapeutic support around the retelling, so that they can debrief after speaking. However, I also identify with the feeling of being re-traumatised by the retelling, as that is sometime true for me, and it can feel like you are only living in the difficulties and become defined by them, and I to have questioned its usefulness for myself and others. Only they will

know if they feel it is time to stop 'telling their story', but they should be receiving support whilst they do”

- “It is totally understandable that they would feel like this. Constant retelling can be re-traumatising. Those who engage them should consider this and offer support. They should not feel that they have to keep on doing it. I feel really strongly that we need to think about HOW survivors contribute to training. It doesn’t have to be about telling your story. it can involve sharing your expertise without having to relive the trauma”
- “Talking about your experiences can be re traumatising. Supervision is a helpful space to talk about this. I use peer support/supervision. If I feel as though I need to take a break from "speaking" "training" I take time out for me. There is a personal cost from speaking about our "trauma" it’s important to know how to look after yourself. I think it takes time to learn this. A lot of people are eager to speak and "give" back but don't look after themselves in the process”

Some participants discussed how audiences crave an emotional impact and that audiences want the raw emotion that somebody who is traumatised can offer. This is extremely insensitive. Experts by experience should not have to provide ‘entertainment’; this is apparent exploitation. Organisations can learn from this response. It would be beneficial for organisations to brief the audience beforehand and offer support for an expert by experience before and after they have spoken. One participant wrote that organisations would want not less for themselves. Happell et al (2021)., explained that some of the students from their study found that the challenging nature of some expert by experience sessions suggested that students needed support and greater preparation before being exposed to the experiences of some of the experts by experience. If it is noticed that those being exposed to the experiences of an expert by experience need preparation and support,

then organisations must acknowledge that the expert by experience required preparation and support for retelling their own trauma.

Discussion

The response to this study has presented information from participants that can influence the way that organisations and charities treat and support experts by experience moving forward. Using thematic analysis this study found that there are a variety of areas that must be addressed surrounding how experts by experience or survivor speakers feel they are treated. The six key themes established from the findings are exploitation and lack of payment, retraumatisation and support, creating change and helping others, voyeurism and entertainment, feeling obliged and mixed impact and feelings.

Exploitation and lack of payment

Organisations appear to be underpaying and undervaluing experts by experience, despite them giving talks and training about the most distressing times of their lives. Participants were mostly paid nothing or very little for sharing their trauma. 41% of participants stated that they have never received any form of payment from those that they provide their time to. A further 17% of participants stated that had only ever received expenses and further 17% of participants stated that they are occasionally paid a fee but are usually asked to provide their time for free. As previously stated, Conservation Careers (2021) explain that exploitation exists when someone has an experience which gives far less return on their investment, of time and/or money than they should expect. It could be argued that the

'return' that participants received for sharing their trauma is the notion that change will occur and other survivors will not be subjected to what they were subjected to, in terms of the treatment they received from the organisations or charities that they wish to reform. Some participants explained that they became extremely frustrated over time because no change was occurring, as well as this, it can be argued that it should not be the responsibility of survivors to reform ineffective organisations for free. If an individual is providing their time and expertise to create change then they should be paid and treated the same way as academic or professional speakers. From the response to the questions asked, and the response to the scenarios presented to participants it appears that survivor speakers are becoming more aware of unethical and exploitative practice. Organisations that initially supported the victim went onto encourage them to share their stories of trauma, creating a power dynamic where the victim may feel obliged to "give back".

Retraumatism and support

The findings from this study suggest that many participants feel triggered by sharing their trauma. As Katirai (2020) state, the legal system subject's survivors to the trauma of reliving what they were subjected to through the retelling of the abuse. This is the same for experts by experience. Experts by experience are often impacted by sharing their trauma in the sense that they are retraumatized, as they keep reliving their experience when they retell the story time and time again. As experts by experience are often retraumatized or triggered because of sharing their experience, they should receive trauma informed support (Katirai, 2020). Many speakers were not offered support of any kind after they had disclosed their experiences. Only 7% of participants stated that the organisation that they were rendering their time to, provided support. 28% of participants accessed their own support, 26% of participants looked to get support from their friends and family and 10% of participants did not have access to support at all. This shows that many participants felt that they did need support after sharing their experience, predictably as we are aware that sharing and talking about a traumatic experience can be retraumatizing (Brouneus, 2008). What is interesting is that many organisations either offered no payment at all to participants for sharing their experience, or very little payment; therefore, it appears that many participants had to source their own support by their own means. Many participants expressed feeling triggered during, or after sharing their experience, as several participants

are sharing their experience for the benefit of the organisation, it can be argued that the organisation should provide emotional support for the survivor. Another theme surrounding support that was uncovered was that many participants found that they benefitted from sharing their experience as they met others who had been subjected to similar trauma. This suggests that organisations could do more to support all survivors in terms of setting up support groups. It could be beneficial for organisations to provide support by initiating events where survivors are not expected to share their trauma but where they can meet with other individuals who understand their experience, without the added pressure of giving back to the organisation. Another way that organisations can support experts by experience is by means of offering learning opportunities as suggested by Curran, et al (2015), in terms of certificates or recognised qualifications.

Creating change and helping others

Most participants stated that they shared their experience because they wanted to help others, either directly or indirectly by way of creating change within organisations and systems that they felt had somewhat failed them. Some speakers reported that they did not feel they got anything positive from disclosing but felt they should do it to protect others or raise awareness. As aforementioned, it should not be the responsibility of survivors to create change within organisations to help others, when they are often not paid to do this, or paid very little and also not supported for doing this. If an expert by experience is providing content that can create change and better the way that an ineffective organisation provides services for future survivors, then the expert by experience should be treated fairly for doing this. They should be paid accordingly for the knowledge and expertise that they bring, and they should be treated as professionals if the work they are doing is supporting the overhaul of ineffective services. Again, they should have access to the same support as paid professionals, as the work they do not only affects them because they are in an environment discussing traumatic experiences, but they are also affected because they are discussing their own personal traumatic experience.

Voyeurism and entertainment

Many participants discussed that being an expert by experience had over time become tokenistic, that they felt that they had become entertainment for the organisations that

they were providing their knowledge and expertise to. They usually felt this way when no change had occurred following sharing their trauma. One participant wrote ***“Initially it felt like you were changing minds, bringing reality to people. Now I feel survivors easily become the ‘freak’ show which is brought in to entertain the audience and allow box-ticking for the organisation”***. It is argued that organisations should not be using experts by experience at all when they are not willing to listen to their experience and create change because of their experience. We know that it is retraumatising for experts by experience to retell their trauma, for an organisation to then dismiss their insight to the extent that the expert by experience feels as though they are merely entertainment for the organisation, is abusive and exploitative.

Feeling obliged

Some participants discussed feeling obliged to give back to the organisation that had supported them throughout their trauma. When an organisation approaches and asks an individual to be an expert by experience they must acknowledge that this creates a power imbalance where the individual may feel obliged to give back.

This power imbalance cannot be understated.

Many participants were retelling their traumas 50-100 times for organisations that helped them when they were in crisis, as they felt they had to.

Organisations may need to make it clear that they do not need their clients to repay them in any way. They may also need to consider how a client may feel if they are approached to become a speaker or trainer, right after accessing services themselves.

If the organisation feels strongly that they would be the right person for a role, they should follow ethical and equal employment processes to ensure the person is not exploited or harmed by a feeling of obligation towards free labour.

Mixed impact and feelings

Most participants expressed that being an expert by experience was beneficial but triggering. They explained that they wanted to help others and create change because of the experience of the organisation that they had, because it was usually an ineffective experience, but this was often triggering or retraumatising for them. The responsibility of creating change should ultimately not be the responsibility of an expert by experience if an

individual wants to provide their time and knowledge to an organisation to create effective change then they should be sourced ethically, they must be paid in accordance with other professionals and they must be supported before, during and after sharing their most traumatic 'experiences'. Organisations must acknowledge how heavy this type of work is for the individual, and they must treat the individual providing their expertise ethically.

Recommendations

The authors have made some recommendations surrounding the initial invitation that the expert by experience receives, the payment that they receive and the support that they receive. The notion that victims cannot be professionals has also been discussed. The participant's requests surrounding being an expert by experience are highlighted following this. First, the authors' note that organisations and charities should acknowledge the value of the survivor speaker. Survivor speakers offer an immense opportunity for reflective development to organisations, and they have first-hand experience of the impact of the current practice that can help shape effective practice in future. This feedback cannot be underestimated.

Initial invitation

The initial invitation provided to potential experts by experience should be one that recognises that a survivor may be agreeing to partake in any events, because the organisation has helped them prior to being invited. Participants may feel obliged to agree. If the organisation has previously been connected with the individual they are inviting through helping them as a victim, then it is unethical to ask, considering the authority imbalance.

Payment

Experts by experience should be paid for their time and their contribution. This should also include expenses if applicable. It should not cost an expert by experience time and money to provide an organisation with their expertise, as previously stated, Conversation Careers (2021) explain that exploitation exists when someone has an experience which gives far less

return on their investment, of time and/or money than they should expect. Many experts by experience want to create change for others and for the organisation that they are providing their services to. Therefore, it is exploitative to expect an expert by experience to provide their expertise for free when the organisation and their clients benefit from this. Experts by experience should be paid at the same rate as other speakers.

Support

It should be acknowledged that experts by experience often share an experience in their life that was traumatic and that this is difficult, emotionally exhausting, and often retraumatises the individual. Sharing this experience can impact the expert by experience for some time after the retelling (Brouneus, 2008). Mental health and wellbeing provisions are limited in availability (Centre for Mental Health, 2021). Therefore, many individuals must seek these provisions privately which is costly. This makes it difficult for experts by experience to access these services. It is suggested that organisations and charities are to provide experts by experience with trauma informed intervention as standard. Again, it is exploitive to expect an expert by experience to seek and pay for these services themselves when they are not often paid for their time.

Victims and Professionals

When an expert by experience is using their lived experience to provide organisations and charities with knowledge and training to create change within/ improve their services, they should be treated accordingly. In essence an expert by experience often trains the professionals, and therefore should be treated as a professional. Professionals are paid for their valuable time and expertise and are offered supervision and debriefing.

Why use them at all?

Some participants discussed feeling as though sharing their experience felt tokenistic, that change was not occurring because of the insight that they were providing, and that they were being dismissed by those they were educating, or insensitive comments were made to them about their experience in which case it should be considered by an organisation why they would use an expert by experience at all. It is retraumatising for an expert by

experience to continually retell their trauma, this is only amplified by a lack of understanding and compassion from organisations and charities inviting an expert by experience to speak. When an expert by experience is dismissed or spoken to insensitively this mirrors the abuse that they were subjected to and when this occurs it can be considered unethical, exploitive and also abusive to invite an expert by experience to speak for your organisation.

Final Notes from the Participants

13. This study is about the wellbeing and experiences of being asked as a survivor or victim to retell your story to professionals. There is very little guidance written on this topic and VictimFocus aims to use your answers to build a set of good practice guidelines to make sure you are looked after, respected, protected, and reimbursed for the time and expertise you offer to the field. Do you have any other comments you would like to make about any of these topics that we could share with organisations and professionals?

Participants wrote -

- “I feel that you need people with lived experience to learn from. They have been abused to get that lived experience don't re abuse them by treating them like a second-class citizen”
- “As stated earlier, there is no benchmarking or Quality Control of Survivors who speak. Also, there is no central register of individuals who have specific skill sets or areas of expertise. Often, I will see that there is a conference arranged and have had no contact from the organisers although it is on a subject for which I have superb knowledge. It is frustrating that most of this is about word-of-mouth recommendations. Perhaps we can have some sort of register that people can access? What comes with bigger speaker fees comes a system of regulation and a guarantee that the conference organiser will get an impactful, well presented, presenter”

- “I would like to see organisations who hire you offer the survivor speaker references (i.e., for jobs). For me, speaking at Samaritans was the first experience of ‘working’ after a 2-year break from work due to sexual assault and long hospitalisation. I desperately needed referees to prove to employers I could work, despite my long break. This wouldn’t be suitable for all survivor speakers, but it would be useful for someone from the organisation to offer to be a reference or to write a little paragraph about what you did for them to help with CVs”
- “I think it's vital there is support. You are talking about your life and something very painful and raw. I had support and had therapy and was in a good place to talk about it. Not everybody is and although it helps sometimes there comes a time when you need to close the chapter on your life and move on”
- “Thanks for doing this. I have witnessed survivors being exploited in the organisation I work for. I get angry, so thanks for doing this really important work”
- “We need proper support / supervision whilst doing this work. There needs to be a proper understanding of both the psychological costs and benefits of the work undertaken by peers by the people who are asking them to share their experiences. Peer trainers and those with lived experience should be properly and fully remunerated for the work they do, in line with all other experts and professionals”
- “Much of the sector is very toxic. This isn’t talked about enough and it really needs to be as there are so many people who are being exploited and there is so much nastiness that gets overlooked because, at the end of the day, the

priority is protecting against reputational damage and not the wellbeing and welfare of people and that's not right"

- "Giving these talks is difficult but fulfilling, however they take time out of your life and sometimes your work and you should be paid accordingly, and treated courteously and kindly"
- "Victims should be offered therapy due to the triggering caused by retelling the story over and over. The professionals should have proper training which is often not the case especially in child protection and family courts systems. The victim is often accused of 'failing to protect' or being vindictive or too anxious if fearing for their children if left alone with an abuser"
- "Lack of reimbursement either, in kind or financial, is draining and re-traumatising. Although it is not the reason I am no longer in this line of work, lack of support, sudden withdrawal of support and feelings of exploitation make it unlikely that I would pursue this work in future. I would love to get back into it but currently have no viable avenue"
- "The long-term cost of revisiting our traumas is not always apparent. If we have received good support or inadequate support, we may push ourselves to give too much of ourselves out of feelings of gratitude or compassion, respectively. This can lead us to expose unhealed traumas by talking about experiences we know we don't want to, or to work to the detriment of our own wellbeing or finances"

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