Madness’ after the war in Bosnia and Herzegovina – challenging dominant understandings of distress


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‘Madness’ after the war in Bosnia and Herzegovina – challenging dominant understandings of distress

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Abstract
This article reports on the findings from a small-scale co-produced qualitative study on experiences of distress caused by the war in Bosnia and Herzegovina (BiH). Inspired by the emerging interdisciplinary field of Mad Studies, the study is novel and unique in two ways. First, it prioritises social understanding and interpretation of madness and distress. Second, an emphasis is placed on experiential knowledge. Beyond interviews with 20 people who experienced distress due to political conflict, this included contextualisation of the study in the knowledge generated through survivor research and within the field of Mad Studies. Study findings highlight the social causes and consequences of distress caused by conflict, such as war-related violence, gender-based violence, experiences of poverty and corruption. Participants stressed the importance of safety and support within their own home, mutual and supportive relationships with their families, friends, other people who experienced distress, the broader community and opportunities to do everyday activities they enjoy. In terms of professional support,
the findings suggest that poverty alleviation and protection of people’s right to self-determination through access to human rights advocacy and representation may be as relevant as non-coercive community-based services. This indicates that support for distress caused by political conflict need not be different from any other support for people who experience distress. Emphasis should be placed on survivor-run initiatives and non-coercive, community-based support which addresses social causes of distress and enables people to exercise self-determination.

**Keywords**

experiencing illness and narratives, mental health, narrative analysis, Organisation of health services, sociology of health in developing countries

**Introduction**

This article reports on the findings from a small-scale qualitative study on experiences of distress caused by the war in Bosnia and Herzegovina (BiH in further text). Inspired by the field of Mad Studies (Beresford and Russo, 2021; LeFrançois et al., 2013; Russo and Sweeney, 2016), the study is unique in two ways. First, the objective was to explore how people understand and interpret their distress, rather than professional interpretations or assessments of such experiences. Second, the study was co-produced by social science researchers and co-researchers who themselves experienced distress due to the war in BiH. As highlighted by Russo (2016: 60): ‘Madness can be researched in many different ways and from many different perspectives. It has, however, rarely been studied from the perspectives of those labelled mad, and even less often from the standpoint of their shared knowledge’.

On a related note, the potential to be ‘disqualified as a legitimate knower’ (Liegghio, 2013: 123) extends beyond experiences of distress. Post-conflict countries are frequently subject to development policy and practice. Such international involvement can include ‘nothing short of the managed reorganisation of state and society’ (Mosse, 2004: 3). This study, funded by the Independent Social Research Foundation, was conceived, and led by people whose languages and histories are part of BiH. Hence, both in relation to distress and the study context, the findings emerge from ‘within the reality it seeks to understand [as] first-person knowledge [which has] different grounding and enables different epistemology than knowledge coming from any third person, outside perspective (Russo, 2021a: 25, author’s emphasis).

The first section covers the study background and context in relation to the post-war reform of mental health services in BiH and dominant (medical) understanding of distress caused by political conflict. This is followed by a brief overview of the study in relation to the field of Mad Studies. A section on methodology explains the process of research co-production and the methods used for this small-scale qualitative study. Both Mad Studies and survivor research in mental health centralise experiential knowledge of distress (Sweeney, 2016a). Hence, our findings are written up in dialogue with the literature on experiential knowledge. In the conclusion, we consider the implications of the findings for further activism and research within the field of Mad Studies.
Note on language

Language used in the article varies, both in relation to the context of its use and/or the translation required from Bosnian, Serbian or Croatian. These choices are led by the primacy given to experiential knowledge and understanding. Experiential learning and knowing is referred to as ‘survivor research’ and ‘Mad Studies’ (Sweeney, 2016a). Breslow (2019: 59) refers to professional knowledge and mental health services as the ‘troubled persons industry’. Their terminology is used in the article when, for example, discussing the reform of mental health services in BiH or if used by the study participants. While not native to Bosnian, Serbian or Croatian languages, terms such as madness and Mad Studies translated well (ludost) and spoke to the experiences of study co-researchers and participants. Practices which may be referred to as ‘peer initiatives in mental health’ in Western European and North American contexts (Faulkner, 2017) are referred to as ‘mutual support’ initiatives. This offers a more accurate conceptual, cultural and practical insight into how such support is organised in BiH.

Study background and context

This section provides a brief critical overview of common understanding of distress caused by political conflict, mental health services in Bosnia and Herzegovina, and how this study was inspired by the emerging field of Mad Studies.

Understanding distress caused by political conflict

Knowledge about distress caused by political conflicts is rooted in Western and medical understanding of distress. This applies to children’s experiences as civilians (e.g. Attanayake et al., 2009) or soldiers (Betancourt et al., 2013), experiences of adult civilians (Johnson and Thompson, 2008; Musisi and Kinyanda, 2020) or military (Hom et al., 2017; Nematshahi et al., 2020), as well as broad understanding of mental health consequences of war (Murthy and Lakshminarayana, 2006). Even studies which aim to develop culturally relevant new understanding of war-induced suffering rely on concepts, diagnostic tools and research methods associated with medical understanding of distress, such as Post-Traumatic Stress Disorder (see, e.g. Barber et al., 2016).

Beyond counting and categorising medical understanding of distress, studies also mainly focus on people’s experience of mental health services. This reflects the experiences and practices in our research team, too. Despite a commitment to experiential understanding of distress, our previous research focused on people’s experiences of Community Mental Health Centres (CMHCs) established after the war (HNI and SWEBIH, 2003). Research questions included, for example, ‘what is your experience of your local CMHC? Which of their services do you use? What works well in it and what can be improved?’ These studies were conducted to assess the progress of the reform of mental health services. Reflections on these experiences are included in a more detailed critique of dominant understanding of distress caused by political conflict (see Maglajlic, 2021).
Support for mental distress in the post-war Bosnia and Herzegovina

Before the war, support for any experience of distress was primarily organised through psychiatric departments in general hospitals and/or large, long-stay, hospitals. Many of such institutions in BiH were damaged and destroyed during the war. Following the war, a decision was made not to rebuild such institutions. Instead, Community Mental Health Centres (CMHCs) were created within the community primary health care centres\(^1\) (Kucukalic et al., 2005; Racetovic et al., 2017). This reform was supported by the World Health Organisation, funded by the European Commission, and implemented by the Ministry of Health of the Federation of BiH.\(^2\) It was later rolled out across the country. Each CMHC is supposed to be staffed by a psychiatrist, psychologist, four nurses and a part-time social worker, although staffing levels vary across the country. Such community-based mental health interventions have been identified as the most appropriate for post-conflict and low- and middle-income contexts such as BiH (Kamali et al., 2020; WHO, 2008), yet are underdeveloped (Al-Tamimi and Leavey, 2021).

Parallel to the development of CMHCs, non-governmental ‘Associations for mutual support in distress’ (direct translation from Bosnian/Serbian/Croatian) were initiated in early 2000s. These were either run or led by people who experienced mental distress during the war. This model built on a former Yugoslav tradition of citizen associations, based on a range of special interests (from sports to disability groups). One relevant example is the Committee for Social Protection of Madness which existed in the 1980s in Ljubljana, present-day Slovenia (Flaker et al., 2015). BiH Associations were less radical in focus. Only one survivor-run Association still operates today – Fenix in Tuzla, in North-East BiH. The early 2010s saw the emergence of non-governmental organisations led by mental health professionals in collaboration with people who use mental health services. One example is Menssana in Sarajevo, Central BiH. These are frequently linked to the local CMHCs. Both types of organisations usually provide drop-ins, free time activities, training and occasional employment opportunities for people who use mental health services.

Becoming inspired by Mad Studies

The field of Mad Studies is based on diverse experiential knowledge, critical of mainstream mental health services (LeFrançois et al., 2013). While novel, Mad Studies emerged from a long history of mental health system survivor movements locally and internationally (Costa, 2014). The term was coined by Richard Ingram in 2008, drawing on the history of the ‘Mad Movement’ as presented in Irit Shimrat’s 1997 book ‘Call me crazy’ (Ingram, 2021). Beresford (2021: 7) notes that there are three defining characteristics of Mad Studies, all of which are represented in this study. First is the prioritisation of social understandings and interpretations of madness and distress. Second, an emphasis is placed on first-person and experiential knowledge. Finally, the work in the field is ‘survivor-led, but not limited to survivors of the mental health system’ (Beresford, 2021).

‘Fenix’ and other BiH Associations have been involved in research on distress caused by political conflict. Nonetheless, no study of mental distress and political conflict
conducted to date in BiH or elsewhere has asked, ‘What happened to you? How do you make sense of your experience? What helps and hinders your wellbeing?’ Aiming to contribute to the knowledge generated within the field of Mad Studies, this study had the following research questions:

How does political conflict affect people and lead to mental distress?

How do people understand and interpret their distress?

Which ways of understanding mental distress and resultant practices (professional and otherwise) do they perceive as most helpful and why?

By asking such questions, we aimed to restore ‘people’s epistemic existence’ (Liegghio, 2013: 127) in relation to their experiences of distress.

**Methodology**

**Research co-production**

The processes employed to explore these questions are not without complexity, particularly due to the composition of the four-member research team and our commitment to experiential knowing. The Principal Investigator (PI), Reima, is a social worker who is part-Bosnian, part Serb-Croatian. Since 1999, she has supported the development of associations for mutual support in mental distress, such as ‘Fenix’, and worked on the reform of mental health services in BiH. During this period, she also established collaboration with Halida, an activist from Sarajevo, also of mixed ethnic heritage, who experienced distress during the war. She has been involved in previous research on the development of BiH CMHCs with Reima, as well as a range of initiatives based on experiential understanding of distress. They both have a prior working relationship with the ‘Fenix’. The second BiH co-researcher, Jasmin, a Bosniak man, experienced distress as a soldier during the war. He later got engaged in activism and research through ‘Fenix’. The fourth co-researcher, China, is from the UK. She has lived experience of navigating the UK mental health system both for herself and family members, although does not identify per se as a psychiatric survivor. In the study, she had a role of a critical friend throughout the research process, helping to extend the understanding of the findings beyond BiH cultures, language and borders. Her role was also crucial in securing the funding for the study.

We set out to co-produce a study on distress caused by political conflict. Faulkner and Thompson (2021: 5) stress that ‘terms such as peer research, user-led research, co-production, survivor research, user involvement in research and user-focused research are used . . . without clear definitions’. Carr (2021: 143) queries whether co-production is possible given ‘the relational, systemic and structural power asymmetries’ in knowledge production. It is rare, for example, to find funding for survivor-run research in mental health or for survivor researchers to have seniority to lead on research bids (Faulkner et al., 2021; Sweeney, 2016b). It is similarly rare
to secure funding for studies led by researchers from a post-war country. Our methodological choices aimed to address such challenges in relation to the politics of knowledge production (Landry, 2017). One example of this is provided in the section on research ethics. Such challenges are more likely if people are not involved in all phases of the work or if collaboration isn’t grounded in long-standing relationships (Gillard et al., 2012).

Roles and activities within our research team build on the collaborative practices developed within co-operative inquiry (Heron and Reason, 2001) and participatory action research (Gillard et al., 2012). Co-production in the study included collaboration in all phases of the research process – from preparation of the proposal for the funders, development of the study methodology, sense-making from the fieldwork data to the promotion of the study findings. These relationships and processes, summarised in Table 1, enabled us to build trust and share decision making throughout the research process. One of the tasks for Mad Studies is to disrupt established hierarchies of knowledge production (Russo, 2021b). To our knowledge, such co-production of research on distress and political conflict hasn’t been initiated to date.

**Study methods**

We utilised qualitative narrative interviews (Faulkner, 2017), based on a premise that individuals make sense of their world most effectively by telling stories (Clandinin and Connely, 1994). The two BiH co-researchers conducted the fieldwork, which comprised 20 interviews focused on the participants’ experiences of distress and wellbeing during and after the war, rather than their engagement with mental health services. The semi-structured interview guide was developed by the whole research team (see Table 1).

Reflecting on the whole study, the BiH co-researchers stressed how important it had been to conduct the study using narrative interviews. This enabled them and the participants to develop a sense of trust and rapport. During fieldwork, each narrative was transcribed by the BiH co-researchers and checked with the study participants during a follow-up visit. The PI translated each narrative into English to facilitate engagement with the UK co-researcher.

**Study participants**

All participants were identified through the two Associations that are run (‘Fenix’) and led (‘Mennsana’) by people with lived experience of mental distress in locations where the BiH co-researchers are active. When identifying 20 study participants, the research team agreed to pay attention to the participants’ gender and age, as well as a balance between people living in rural and urban areas. In total, 10 women and 10 men took part in the study, with the age range between 26 and 70. Most of the participants were in their 40s. Achieving a balance of participants from rural and urban areas proved to be more challenging; the study included only five participants from rural settings. The majority (17) were also Bosniak, one of the three main BiH ethnic groups (alongside Croats and Serbs). This is representative of the majority ethnicities in both Sarajevo and Tuzla Cantons where the participants come from.
<table>
<thead>
<tr>
<th>Research team roles</th>
<th>Activities</th>
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<tbody>
<tr>
<td><strong>Pre-study relationships</strong></td>
<td>Principal Investigator (PI) supported the development of survivor-run initiatives in mental health in BiH between 1999 and 2007. Relationship with the BiH co-researchers stems from this work and continued over the past 20 years.</td>
</tr>
<tr>
<td>Two BiH co-researchers who experienced distress during the war (co-researchers in further text)</td>
<td>PI identified a potential funder (ISRF) and suggested the idea to the BiH co-researchers and the UK co-researcher. The proposal writing is led by the PI, but based on discussions with the entire Team, including open discussion about the funding allocation and what is possible within the available budget.</td>
</tr>
<tr>
<td><strong>Funding application process</strong></td>
<td>The research team met in Sarajevo, BiH to finalise the methodology (sampling, interview guide, analysis plans) and develop a protocol to ensure the two co-researchers are supported during fieldwork. PI provides methodological support, while the BiH co-researchers lead on the content regarding methodological choices. UK co-researcher acts as a critical friend to contextualise the work in relation to global mental health.</td>
</tr>
<tr>
<td>Full research team/authors of the article: PI</td>
<td>PI with support from the rest of the research team</td>
</tr>
<tr>
<td>Two BiH co-researchers</td>
<td>No ethical approval is required in BiH. Ethical approval is sought and provided from the PI University. Ethics application is prepared by the PI but based on the discussions and agreement from the first research team meeting in Sarajevo.</td>
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<tr>
<td>UK co-researcher</td>
<td>Fieldwork</td>
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<tr>
<th>Research team roles</th>
<th>Activities</th>
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<tr>
<td>Sense-making (analysis)</td>
<td>Second research team meeting is held in Sarajevo. In preparation, all research team members read through the transcripts and identify themes which answer the research questions and any other findings which seem of relevance to people’s experiences of distress during and after the war. Discussions within the group help identify the key study findings. Plans are made how to present and promote the findings in the UK and internationally. One co-researcher feels distressed due to the pressures of their other work. They are supported to continue to contribute to the analysis and the write-up at a pace and in ways which work for them. They lead on decisions regarding this process, clear that they can disengage fully if they wish so.</td>
</tr>
<tr>
<td>Write-up and promotion</td>
<td>PI is tasked with writing up the full research report in Bosnian, based on the agreements from the second research meeting. Draft report is reviewed and approved by both BiH co-researchers. English translation is prepared by the PI and reviewed by the UK Co-I. Both versions are published on the ‘Fenix’ and ‘Menssana’ websites. Co-researchers and their Associations continue to utilise the findings and the report within their activities in BiH. PI and the UK co-researcher are tasked to write-up the findings in English, for international audiences (as the two experts by experience don’t speak English).</td>
</tr>
<tr>
<td>Follow up (research)</td>
<td>One of the two BiH co-researchers wants to continue this work in other parts of BiH. Opportunities for further research funding are sought, based on their interests and preferences.</td>
</tr>
</tbody>
</table>
Data analysis

Analysis of the interviews was facilitated through a research team meeting in Sarajevo (see Table 1). Prior to the meeting, three Team members read and re-read the interviews individually, using the research questions to guide consideration of each story collected through the interviews. These were then discussed at the team analysis meeting to finalise our joint findings. Thematic narrative analysis within the team allowed us to keep the stories ‘intact’ by theorising from each story, rather than component themes across all of the personal narratives gathered through the study (Kohler Riessman, 2008: 53). This was also demanded by our participants who wanted their stories to be heard (see the Findings below).

Research ethics

Ethics procedures for the study were based on Faulkner’s (2004) Guidelines for the ethical conduct of research carried out by mental health service users and survivors. These informed the development of the information sheet, consent form and the protocol for the whole team collaboration during the study. These documents allowed us to: (1) plan for potential distress by both researchers and the study participants, before, during and after the fieldwork, (2) agree how to address that through mutual support and (3) in the case of study participants, through their preferred sources of support. Ethical approval was obtained from the University of Sussex.

The Protocol was tested when one of the BiH co-researchers attempted suicide towards the end of fieldwork. The attempt was caused by pressures related to taking part in a variety of advocacy and mental health promotion activities, rather than research. Following initial recovery, the co-researcher decided that they no longer wanted to take an active part in the analysis phase. They did want to continue to participate in the whole-team discussions about the study, reflections on the fieldwork and discussions about analysis led by the other team members. They were also happy to read all the versions of the overall team analysis and contribute to the research report. These decisions were led by the co-researcher and supported by the whole Research Team. Emotional labour within and outside the research team was acknowledged and supported, rather than pathologised (Faulkner and Thompson, 2021).

The BiH co-researchers faced additional ethical and power challenges during fieldwork. A psychologist active in one partner organisation asked to sit in on the research interviews. Their rationale was that this would help the BiH co-researcher, to ensure the ‘professional quality’ of their work. We did not permit this. Nonetheless, this example raises concerns about how much professionals involved in purportedly collaborative Associations in BiH understand and value experiential knowledge.

Study shortcomings

Study participants should have been paid or obtained a food parcel to thank them for their time. UK University partners also provided a challenge as administrators for a collaborative and coproduced project. Almost all payments to the BiH partners were delayed
by several months. This caused an impact of seismic proportions for the BiH partner organisations which have limited sources of income. It also impacted the quality of life of the BiH co-researchers during the study and deserves further consideration and attention for co-produced research in general.

**Findings**

This section is organised around the key themes that emerged across all 20 interviews which answer the study questions. All quotes are presented under pseudonyms and with a brief reference to the participants’ gender, ethnicity and age group. They are contextualised in relation to other experiential knowledge generated through survivor research and within Mad Studies.

**Being heard**

One of the key messages from all the people who took part in the study is that they don’t feel listened to and ‘seen’ in the wider society. They want their stories to be heard and to shape understanding of their experiences within the wider BiH society. Asja, a Bosniak woman in her 30s, started her interview by saying:

“I wanted to take part in this study to tell you my story as much as I have strength to share it. I want other people to hear it and see it”.

Vedad, a Bosniak man in his 50s, noted:

“The key thing that should change going forward is to listen to the people who use services a bit more. Stories like mine should shape how professionals understand us. I just hope to keep on living and to feel as well as I do now”.

Based on this finding, the main written report of the study includes all 20 narratives, published in Bosnian/Serbian/Croatian and English (Maglajlic et al., 2020). These are now used, for example, to educate BiH professionals and BiH public on people’s experiences. Presenting them in this way honours the wishes of study participants and enables ‘re-storying of their experiences away from professional interpretations and explanations’ (Liegghio, 2013: 124). Similar to survivor research, our process enabled ‘telling a clearer story of what happened, making it visible and attributing a sense of reality to them’, albeit not finite and finished (Tomlinson and De Ruysscher, 2020: 1282).

**Evidence for a social model of distress and madness**

All 20 participants identified that their distress was caused by experiences of violence and injustice. Narratives in our study reveal external circumstances which led to emotional distress (Lee, 2013). This echoes Shimrat’s (2013: 146) statement – ‘I have yet to find a single person who did not enter the [mental health] system after some precipitating trauma’.
Male participants linked their distress to combat-related violence and their struggle to integrate into the realities of post-war life as former soldiers:

“War had a massive impact on me. The town itself and all that had happened. I don’t know how to define it, the impact of war. There are two entities now, Federation and Republic of Srpska, but we move everywhere, across entity borders. My problem is that I don’t know whom to spend time with, whom to talk to, who can be my mate. That is what I think about. I have lost trust, but I also forgave some people because war made them ill, too”. (Amar, a Bosniak man in early 40s)

Female participants’ accounts on the causes of distress were more varied. While some attributed their distress to war experiences, others linked it to the gender-based violence experienced elsewhere:

“This all started after I was attacked by a man. He followed me, abused me verbally and, finally, he physically attacked me. This is why I have spent six months locked up in my house. I felt I shouldn’t go out and had all the symptoms that I mentioned earlier. I have lost my job, too, all because I wouldn’t leave the house”. (Ajša, a Bosniak woman in early 20s)

Beyond the distress caused by the war or gender-based violence, some women like Dragana, a Bosnian Serb in her 50s, also noted how much she was also hurt and distressed by experiencing injustices caused by nepotism, favouritism or corruption:

“My first crisis happened in 1992, while I was a refugee. . . [but] it was only when we came back to BiH, where I got a job in my own profession when I realised that something really wasn’t right. The mood swings just continued, regardless. I functioned well at work, despite working with people who had very different mentality and questionable qualifications for the jobs they had. . . employed through nepotism and political affiliations. . .Because I wouldn’t partake in [corruption that took place], I was transferred to work as a librarian for half the salary. While I worked there, I really hoped that there would be an inspection, a financial control of some sort and that they would all get arrested. I really couldn’t understand how such corruption can remain unpunished. But inspections never came. My new library job wasn’t well-paid and I had a lot of expenses. This caused me to react very emotionally and I wound up on the Psychiatric Ward”.

These findings echo those from the mental health survivor research in the UK where many ‘survivors make connections between their distress and broader social causes and consequences, including poverty, isolation and stigma’ (Beresford, 2020, p. 1338). Our findings corroborate Beresford’s call for a social model of madness and distress (Beresford, 2020), as ‘the biomedical model depoliticises health and madness, holding the individual accountable for their wellbeing, without meaningful consideration of social, political and economic factors’ (Ashcroft and Van Katwyk, 2016, in Daley and Van Katvyk, 2021: 257).

Importance of community-based support and mutual relationships

Participants stories suggest that they appreciate support found in mutual relationships with their families, friends, other people who experienced distress, but also in relationships with
the community-based mental health professionals. In that respect, participants’ views and experiences are far more ‘anti-coercion rather than anti-psychiatry’ (Szasz, 2010, in Reaume, 2021: 99). This was to be expected as ‘our thinking about madness doesn’t start with a blank slate: it takes place on territory already occupied by a powerful and well-established psychiatric discourse’ (Russo, 2016: 63).

For the majority of participants, the initial experience of distress led to their first contact with mental health services. Within that space (of service provision), people start to appropriate medical language to make sense of their experience, for themselves and those around them. Kenan, a Bosniak man and a former soldier in his 40s, noted:

“Those war-related nightmares, isolation and fear had led me to seek help from my local Community Mental Health Centre (CMHC). I got in touch with them and started a treatment with a psychologist and a psychiatrist. They recognised that it’s PTSD”.

However, participants also stressed the value of peer support provided through the Associations for mutual support in mental distress. Esma, a Bosniak woman in her 30s, stressed:

“I have realised how important the Associations [for mutual support] are for the quality of life of mental health service users. It is important to take them seriously and realise how important they are. I realised I can function in a team. I first got involved in the cookery section and made a meal with another member for everyone there. . . If I can’t go, I get in touch with others and they support me nonetheless. A few other Association members and I also have a group chat. It is important to feel supported. If services were not available, the only way we’d survive is if we have full and unconditional support from our loved ones. My Dad and my Auntie are like that, always by my side. People who don’t have that would find it difficult with no support. We can’t fight alone”.

This echoes experiences from other countries, such as Canada and the UK. Shimrat (2013: 154) notes ‘ironically, we got a real sense of community from . . . other “sick” people’. Beresford (2016: 48) highlights how important such organisations are ‘to take forward our struggles as mental health service users/survivors. . . . This is likely to be much more effective than trying individually to influence the service system and broader politics’. However, the concern is that such initiatives may turn into ‘business of mutual aid’ (Fabris, 2013: 130) where mental health professionals become involved or mutual support becomes professionalised.

People’s overall sense of wellbeing was weaved together and supported by spending time with their loved ones (families and friends), doing what they like to do, being able to spend time with people who had similar experiences to their own, as well as contributing to their family life and income. Tarik, a Bosniak former soldier in his 50s, explains:

“My family. . . they support and help me in every way. . . I became a father, too. My son is . . . my guiding star and the aim that keeps me going towards recovery. . . I can share everything with my family, friends and a close relative who had a similar illness. He even experienced similar symptoms.”
I love working around the house, gardening, taking care of the fruit plants and all the flowers. I find it really fulfilling and I feel better when I’m active. I no longer use any other services, bar my GP and my psychiatrist. I see them once per month for a check-up and to get my therapy. I sometimes visit the Association. A friend of mine visits the Association, too. . . All I do is what I choose and enjoy doing.

Talking with my friends and family helps me the most. I also have coffees and go fishing with my mates. It helps me to relax. . . I just focus on catching a fish. . . I don’t receive any benefits. My wife and I live off her income. I mainly do house maintenance and gardening. Occasionally, that helps me to earn a few Marks [Bosnian currency].”

Johnston (2020: 151) autoethnographic account of his experiences of distress in Canada shows how ‘family members and peers can provide critical support’. The key difference we noticed is that men, like Tarik, were able to start their own families, while women, like Esma, mainly continued to live with their parents and other birth relatives.

Reflecting on her experiences in the UK, Smith (2019: 698) expresses a concern that supportive families may be leaned on too much as ‘a necessary economic asset to the [mainstream mental health services]’ without any resources or support. Equally, ‘survivors volunteer work benefits the mental health system, providing unpaid training for mental health professionals, or creates alternative supports for other survivors’ (Landry, 2017: 1451). Such under-resourcing and lack of recognition is particularly evident and impactful in rural areas, leading to isolation:

“Both I and other members have to pay for transport to visit the Association in town and that is really expensive. However, if I don’t visit regularly, I’d go back to how I was before, when I didn’t have such services and support in place. It would be far better for there to be similar Associations across BiH and to make them accessible to everyone”. (Sandra, a Bosniak woman in her 20s)

**Impact of poverty and the broader socio-economic and political context**

Sandra is not alone in highlighting problems caused by insufficient income. Poverty and the wider socio-economic and political context were highlighted as a key concern for many participants. Josip, a Bosnian Croat in his 60s said:

“I don’t feel ill nor do I think of myself as mentally ill. I think we live in a catastrophic country, where you don’t have any rights, and where each service costs a packet. Pensions and all income is low and you can’t live off of it”.

Ilma, a Bosniak woman also in her 60s, noted how important it is to know one’s rights and entitlements, particularly as some people have to pay contribution costs for their medication:

“I lived off this tiny pension for a few years without knowing that, as a mental health patient, I am also entitled to receive an additional benefit for care and support. I first heard of it from
my psychiatrist at the CMHC who referred me to a social worker. The process of preparing the documentation did take a while, but I managed to get that additional benefit. . . I should have been told about this when they released me from the hospital, but they didn’t. I tell this to everyone, and I help out when and if necessary, because I know we all need the money. The meds I take weren’t on the essential list until a while ago [a national list of medicines that don’t require a patient charge for them], so I used to pay 60-70 BAM pcm for them (cca 30-35 EUR)."

Money is an essential need for people who experience distress (Landry, 2017), and yet issues of poverty and class are frequently lacking from analysis of people’s experiences of distress (Fabris, 2013). Beaupert and Brosnan (2021: 128) stress that Mad Studies should focus on and spotlight this ‘inseparable’ link between oppression due to distress and ‘life-threatening injustices of poverty, inadequate social welfare, capitalism, occupation or war’.

Protecting the right to self-determination

Much like Ilma, other people we spoke to highlighted the importance of accessing information and advice on their rights and entitlements. This wasn’t solely an issue related to poverty alleviation, but also ensuring that people feel heard, and their wishes adhered to. Those who experienced compulsory hospitalisations were troubled by their experiences and a lack of choice and control over their lives while hospitalised. Džana, a Bosniak woman in her 40s noted: ‘The worst thing is that they don’t allow me to keep my hijab in hospital, saying that I may hang or strangle myself with it. That is such a humiliation’.

Lee (2013: 113), in their analysis of systemic violence endured by the Canadian psychiatric survivors, notes how ‘human agency has been compromised by [such] denial of self-determination in mental health care’.

This extends and reverberates into family life, too. Much as they are a source of support, families can also be a source of oppression or surveillance in the name of care. Reflecting on her relationship with her son, Nejla, a Bosniak woman in her 50s, explains:

“I would love for my son to no longer live in constant tension, watching my behaviour and thinking, each time there is a change in my behaviour, good or bad, that he has to take me to the Hospital! I think that the psychiatrists made him paranoid that he has a duty to hospitalise me every few months. I feel so much better since I’ve been going to the Association. . . but he still observes me constantly and it really bugs me. . . I really feel good now and I don’t see a reason why I should go into the Hospital again”.

Experiences by Nejla and others suggest that support people require should ensure protection to their right to self-determination, enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Beaupert and Brosnan (2021: 128) stress, however, that instruments such as the CRPD can have limitations in ‘countries where there is deep socio-economic inequality and governments may not recognise the status of people with psychosocial disabilities as rights holders’.
Conclusion

While not generalisable, the findings spotlight experiential knowledge and the relationality of distress caused by political conflict in BiH. The core of both the study origins and the findings are relationships. Participants stressed the need for long-standing, mutual, inter-dependent, respectful relationships with families, friends, people with similar experiences and their communities. Experiences by the people who took part in the study also highlight social causes and consequences of distress, and the prevailing impact of poverty and injustice on their lives. While community-based and non-coercive professional mental health support was valued by all participants, their concerns and fears suggest that human rights support and advocacy should be made equally accessible. Participants stressed that they want to have agency in their lives and for their right to self-determination to be respected.

Placing these findings in dialogue with other experiential knowledge of distress suggests that experiences and support needs are similar – regardless of whether they are experienced in conflict/post-conflict contexts or not. This is interesting and relevant as the specialist mental health services are promoted as valuable and necessary to meet the needs of people who experienced political conflict (Kamali et al., 2020; WHO, 2008). Our findings do suggest that non-coercive, community-based support is valued. They also suggest importance of social justice and human rights initiatives, as well as poverty alleviation, led by people with experiential knowledge of distress.

Our findings also suggest that there is a need for further exploration of people’s experiences of distress based on their gender. While most of the female participants didn’t start their own families, a few of the men did. Experiences in rural areas are equally important to explore. Considering experiences in our team and rising concerns in literature (Rose and Kalathil, 2019), there is also a need for clearer and more elaborate guidelines for funding and ethical co-production between survivor researchers and self-declared or carefully identified social science allies. Fortunately, the research team will be able to work on this. Thanks to additional funding by the British Academy, we are able to extend our work to other parts of BiH.

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Notes

1. For details, see: http://www.mentalnozdravlje.ba/the-mental-health-context-in-bosnia-and-herzegovina.

2. One of the two administrative entities in BiH created following the Dayton Peace Accords, with responsibilities for the organisation of health services.

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