Relatives of enforced disappeared persons in Mexico: identifying mental health and psychosocial support needs and exploring barriers to care

In the current study, we explored the needs for psychosocial support as well as barriers to care among relatives of enforced disappeared persons in Mexico. Interviews were conducted with 29 relatives of disappeared persons as well as with representatives from 8 organisations working with relatives. Needs and barriers to care mentioned by the interviewees were categorized and rated according to the frequency of mentioning. The interviewers, a psychiatrist and a medical doctor, assessed the emotional distress. All interviewed relatives reported and showed signs of severe emotional distress. Frequently reported mental health symptoms included suicidal thinking, sleeplessness, anxiety, changes in appetite, intrusive memories, irritability, and major role impairments. The most frequently expressed needs for psychosocial support included peer support, support when in contact with law enforcement officers, treatment of mental health conditions, religious support, and family support. The most frequently encountered barriers included having a negative opinion about the quality of available services, feelings of judgment from other people (e.g., due to incrimination), lack of available services, and not knowing where to get help. These findings emphasize the need to provide practical and informational support to relatives of disappeared persons as well as to provide emotional support during the entire search process for their missing relative, and beyond.

Key words:
ambiguous loss
missing persons
enforced disappearance
prolonged grief reactions
mental health and psychosocial support

Key implications:

There is an urgent need to provide practical and informational support to relatives of
disappeared persons as well as to provide emotional and family support during the
entire search process, including during contact with the law, searching, reconnection,
and/or before, during and after exhumations and handing over of the remains

- Psychosocial support providers should focus on living with uncertainty and refrain from pressure for closure as well as from imposing hope as a moral imperative
- Mental health care professionals need to provide adequate treatment for common mental health conditions, including depression and posttraumatic stress disorder, within a supportive context

- Relatives of disappeared persons 3 In Mexico, over 73,000 persons disappeared since 1960, and the vast majority since the 1 beginning of the "war on drugs" initiated in 2006 (Amnesty International, 2019; Sheridan, 2 2020; Villegas, 2020), over 7,000 disappeared in 2019 alone (Sheridan, 2020). According to 3 4 the International Convention for the Protection of All Persons from Enforced Disappearance (United Nations, 2007), enforced disappearance is defined as "the arrest, detention, abduction 5 or any other form of deprivation of liberty by agents of the State or by persons or groups of 6 7 persons acting with the authorization, support or acquiescence of the State, followed by a refusal to acknowledge the deprivation of liberty or by concealment of the fate or 8 9 whereabouts of the disappeared person, which place such a person outside the protection of the law" (Article 2; United Nations, 2007). 10 The situation of relatives of victims of acts of enforced disappearance is highly 11 12 stressful and a source of much suffering due to the uncertainty with regard to the whereabouts 13 of the disappeared person (Blaauw & Lähteenmäki, 2002), also termed "ambiguous loss" (Boss, 2002). Not knowing what happened to a disappeared relative places an intolerable 14 15 burden on those left behind (International Committee of the Red Cross, 2013), Social marginalization and diminished community support have also been reported in families of 16 17 missing persons (Robins, 2010). Silencing, inducement of guilt feelings, inducement to consider the missing person dead, and impunity may exacerbate the impact of forced 18 19 disappearance on families in a politically repressive context (Kordon, Edelman, Lagos, & 20 Nicoletti, 1988). Mental health conditions in relatives of missing persons bear similarities to those of 21 traumatically bereaved persons. In bereaved persons, following the traumatic death of a loved 22 one, different mental health conditions may (co-)occur. Specifically, these include prolonged 23 grief reactions, known as prolonged grief disorder (PGD; World Health Organization, 2018) 24 25
 - and persistent complex bereavement disorder (PCBD; American Psychiatric Association, 2013), posttraumatic stress disorder (PTSD), and depressive disorders. Comorbidity of these conditions has been observed in numerous studies among traumatically bereaved individuals (Djelantik, Robinaugh, Kleber, Smid, & Boelen, 2020; Heeke, Stammel, Heinrich, & Knaevelsrud, 2017; Lenferink, de Keijser, Smid, Djelantik, & Boelen, 2017; Nickerson et al., 2014; Schaal, Dusingizemungu, Jacob, Neuner, & Elbert, 2012). In a group of Cambodian survivors 30 years after the loss of a loved one during the Khmer Rouge regime (N = 775), 32% endorsed depression, 11% endorsed PTSD, and 14% endorsed prolonged grief reactions (Stammel et al., 2013).

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1 Relatives of enforced disappeared persons may experience intense and persistent emotional reactions that may include prolonged grief reactions (Heeke, Stammel, & 2 3 Knaevelsrud, 2015) as well as PTSD and depression (Pérez-Sales, Durán-Pérez, & Herzfeld, 2000; Sabin, Lopes, Nackerud, Kaiser, & Varese, 2003). Forced disappearance is associated 4 with prolonged grief reactions, particularly when those left behind maintain hope that the 5 disappeared person is still alive (Heeke et al., 2015; Lenferink, de Keijser, Wessel, & Boelen, 6 7 2018). In a recent review of psychological responses among people with a missing loved one, the most consistently reported psychological symptoms were reports of depression, anxiety, 8 9 posttraumatic stress, and prolonged grief reactions (Kennedy, Deane, & Chan, 2019). In another systematic review of studies among people confronted with forced disappearance due 10 to war or state terrorism, a higher number of experienced traumatic events and closer kinship 11 12 to the missing person were identified as risk factors for psychopathology (Lenferink, de 13 Keijser, Wessel, de Vries, & Boelen, 2019). Several studies comparing psychological distress in relatives of missing versus 14 deceased persons due to violent circumstances found higher distress levels in the former 15 group. These studies were among women in post-war Bosnia and Herzegovina (Barakovic, 16 17 Avdibegovic, & Sinanovic, 2013; 2014; Powell, Butollo, & Hagl, 2010), women in Honduras 18 (Quirk & Casco, 1994), adolescents in Bosnia and Herzegovina (Zvizdic & Butollo, 2001), 19 and family members of disappeared persons in Sri Lanka (Isuru, Hewage, Bandumithra, & 20 Williams, 2019). In contrast, a study among internally displaced Colombians did not show significant differences in the severity of symptoms (Heeke et al., 2015). A study outside the 21 context of armed conflict showed that homicidally bereaved people reported more severe 22 prolonged grief reactions and PTSD than relatives of missing persons (Lenferink, van 23 Denderen, de Keijser, Wessel, & Boelen, 2017). 24 Distress in relatives of missing persons may be related to the context of ambiguity, 25 26 unhelpful community reactions, and absence of cultural and religious rituals to provide 27 meaning to a loss (Hollander, 2016). A qualitative study among relatives of enforced 28 disappeared persons during the Pinochet dictatorship in Chile (Adams, 2019) describes a 29 rupture with the relatives' pre-disappearance lives. The search for the disappeared person takes over everyday routines. Secondary stressors include impoverishment, further loss of 30 children or spouse due to emigration, cutting off ties by the extended family, ending of 31 friendships, and avoidance by neighbors. Local human rights organizations and an association 32 of relatives of disappeared persons become a main source of social support (Adams, 2019). 33 Absence of legal and government responses (Amnesty International, 2016) increase the 34

necessity for activism and collective engagement of the relatives of the disappeared persons in 1 Mexico. Activism is manifested by constant claims for the presentation of the disappeared, 2 3 showing of photographs in public, giving of testimony, and narratives about the disappeared 4 (Karl, 2014) and may be seen as a fight for rehumanization by the relatives of the disappeared (Karl, 2014), a battle for memory (De Vecchi Gerli, 2018). The denial of answers regarding 5 the fate of the disappeared leads to an impossibility to perform death rituals and mourning. A 6 7 permanent presence of the absent disappeared ensues (Karl, 2014). As a result of barriers to care, many individuals with mental health conditions never 8 9 pursue treatment (Jayasinghe et al., 2005) or receive inadequate care (Griffiths, Carron-10 Arthur, Parsons, & Reid, 2014). These barriers can include the lack of perceived need for 11 treatment, pessimism regarding the effectiveness of treatments, and unavailability of 12 treatment (Andrade et al., 2014). Among parents of children who died from cancer, the most 13 frequently reported barriers to seeking and finding support were that it was too painful to 14 speak about the loss and too difficult to find help (Lichtenthal et al., 2015). Stigma is another 15 barrier to mental health care. Stigma has been conceptualized as a negative and erroneous 16 attitude about a person, which leads to negative action or discrimination (Corrigan & Penn, 17 2015). Public stigma refers to the extent to which an individual is aware of stereotypes held by society about persons who consult mental health services (Link, 1987; Skinner, Berry, 18 19 Griffith, & Byers, 1995). Self stigma refers to the application of these stereotypes to oneself, 20 leading to internalized devaluation and disempowerment (Corrigan, 2002). 21 In Mexico, public mental health services are poorly developed (Berenzon Gorn, Saavedra Solano, Medina-Mora Icaza, Aparicio Basauri, & Galvan Reyes, 2013; Lartigue & 22 Vives, 2015; Wang et al., 2007). Of the total budget for health, only 2% is allocated for 23 mental health, mainly in the operation of psychiatric hospitals (Berenzon Gorn et al., 2013; 24 Pan American Health Organization, 2013). There is a need to integrate mental health care 25 with primary care facilities (Alarcón, 2003). Although Mexico has a national mental health 26 plan, social security coverage of mental disorders is limited, and only some mental disorders 27 are covered (Pan American Health Organization, 2013). In a report concerning 28 29 disappearances in Coahuila (Sánchez Valdés, 2016) based on interviews with 94 relatives, 40% of respondents mentioned that they had not received counseling at any time after the 30 disappearance of their loved one. 31 Psychosocial needs of relatives of missing persons have received scarce research 32 33 attention, no studies have yet examined barriers to care within this population. In the current 34 study, the composite term "mental health and psychosocial support" is used, to describe any

- 1 type of local or outside support that aims to protect or promote psychosocial well-being
- and/or prevent or treat mental disorders (Inter-Agency Standing Committee (IASC), 2007).
- 3 The current study seeks to identify mental health and psychosocial support needs of relatives
- 4 of enforced disappeared persons in Mexico and to explore barriers to care. Study questions
- 5 include: What are perceived (met and unmet) psychosocial needs of relatives of enforced
- 6 disappeared persons? What are the perceived barriers to obtaining psychosocial support? And
- 7 how is psychosocial support organized?

8 Methods

9 Setting

- As part of the ongoing project "Strengthening the Rule of Law in Mexico," the German
- 11 Corporation for International Cooperation (GIZ), providing services in the field of
- 12 international cooperation for sustainable development and international education,
- commissioned a study to identify and systematize the psychosocial needs of indirect victims
- of enforced disappearance, in particular family members. The study was performed on behalf
- of the War Trauma Foundation. Data acquisition took place from 2 October 2016 to 13
- October of the same year. Participating relatives provided written informed consent, and
- support providers provided oral consent. Transport expenses were reimbursed. All
- participants were provided with contact information of the study coordinators. For an up-to-
- date understanding of the research context from the perspective of an international agency, the
- 20 UN Office of the High Commissioner of Human Rights was contacted before the start of the
- 21 study. The preliminary findings from the current study were presented during a conference for
- relatives and support providers in Mexico City on 29 November 2016.

Selection of interviewees

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To answer our research questions, interviews were conducted with: 1) representatives of both governmental and non-governmental organizations (NGOs) working with relatives of enforced disappeared persons in Mexico, 2) members of self-support groups of relatives of disappeared persons, so-called *Colectivos Familiares*, and 3) individual relatives of enforced disappeared persons. The different interview groups were selected in order to provide a multifaceted perspective on needs for psychosocial support as well as barriers to care among relatives of enforced disappeared persons in Mexico. Given security considerations, we chose to travel to areas where the situation was relatively safe, both for the participants as well as for the assessment team. These areas were Mexico City, Coahuila, and Ciudad Juárez.

The assessment took place at the time that GIZ organized a psychosocial workshop where members of *Colectivos Familiares* and NGOs from different places in the country

where brought together in Mexico City. This offered the team the opportunity to interview relatives and representatives from different areas in the country that the team otherwise would not be able to reach.

Support provider interviews

The services of psychosocial support given to relatives of enforced disappeared persons in Mexico were mapped based on desktop research and information provided by the study commissioners in order to identify key informants. Support providers included seven professionals, psychologists and a legal advisor with extensive experience working with relatives of disappeared. Seven interviews with support providers to explore (unmet) needs for and barriers to mental health and psychosocial support were conducted by a Spanish speaking medical doctor (MB). Support providers were also asked to assist with the identification of relatives of disappeared persons to be approached for study participation.

Interviews with relatives and focus group discussions

Five interviews with individual relatives were carried out. Interviews were conducted and recorded by a psychiatrist (GS) and a Spanish speaking medical doctor (MB). Focus group discussions with self-support groups of relatives, the so-called *Colectivos Familiares*, were also conducted and recorded by a psychiatrist (GS) and a medical doctor (MB). Four focus group discussions took place with the number of participating relatives ranging between 4 and 9, involving in total 24 relatives. An interpreter joined each interview and focus group discussion to solve language issues. All participants were Spanish speaking. Sociodemographic information was obtained, including gender, age, marital status, educational background, the relationship with the disappeared person, and the time elapsed since the disappearance.

In line with previous studies (Glassock, 2006), a broad open-ended question was asked to begin the interview: "Can you please tell me about your experience since (name of person) went missing?" Other questions included: "Did you need psychological support? When did you feel supported? What has been helpful to you in dealing with the disappearance?" The extent to which relatives still hoped their loved one to be alive was assessed by asking them "How much hope do you have that your loved one is still alive?" (Heeke et al., 2015) and rating the answer on the following scale: not at all, a little, moderate, quite a bit, and a lot. Using open ended questions, (unmet) needs and barriers to care were explored. Questions included: "Among relatives of disappeared persons, do you think there is a lot of people that need psychological help? Is this help available? Who provided it? Was it helpful? What

would you recommend to improve the support given to the relatives of enforced disappeared 1 2 persons?" 3 Focus group discussions started by obtaining socio-demographic information, as well 4 as the extent to which relatives still hoped their loved one to be alive. Questions to explore (unmet) needs and barriers to care were very similar to the individual interviews: "In your 5 group, are there many people you would think need psychological help? Is this help 6 available? Who provided it? Was it helpful? What would you recommend to improve the 7 support to relatives of enforced disappeared persons?" 8 9 **Analysis** 10 Descriptive analyses were used to summarize demographic and background 11 information. The two first authors applied content analysis to the interviews and focus group 12 discussions. First, we identified themes emerging from the interviews and focus group 13 discussions with relatives and the interviews with support providers. Themes derived from interviews with support providers fully overlapped with the themes that were identified from 14 15 interviews and discussions with the relatives, except the *need for staff support*, which was only mentioned by support providers. Second, we rated the frequency of occurrence of these 16 17 themes across both the individual interviews and the focus group discussions. Third, we ordered the themes according to frequency of mentioning. Subsections of the interview and 18 focus group discussions were analyzed by the two authors independently to verify the results. 19 20 **Results** 21 **Psychosocial support providers** 22 Psychosocial support providers were identified at different levels, including selfsupport groups, non-governmental organizations, the private mental healthcare system, and 23 24 State providers. The latter providers included the Comisión Ejecutiva de Atención a Víctimas 25 (CEAV) and the Procuraduría General de la Republica's psychological team, among others. Table 1 provides an overview of identified psychosocial support providers. 26 27 Table 1 28 **Characteristics of interviewed relatives** 29 Table 2 presents sociodemographic characteristics of the interviewed relatives. In 30 brief, most relatives were female, middle-aged, who had received higher education. Most disappeared persons were male (apart from Ciudad Juárez, where most disappeared persons 31 32 were females) and the mean time since the disappearance was 6 years. Table 2 33

Mental health in relatives of disappeared persons

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All interviewed relatives reported and showed signs of severe emotional distress, including intense sadness, rage, despair, exhaustion, relational stress within families, and loneliness. Frequently reported mental health symptoms included suicidal thinking, sleeplessness, anxiety, changes in appetite, intrusive memories, irritability, and major role impairments.

Responses to the question: "How much hope do you have that your loved one is still alive?" (Heeke et al., 2015) varied. One of the relatives described a feeling of "being torn apart between hope and despair." Hope was experienced as both positive: "Hope keeps me going," "We need to nurture the hope every day," and painful: "Hope is part of my pain." A wish for reunion with the disappeared loved one was often prominent: "I want them to find him, so that I can rest and can put him to rest." Hope for the disappeared to be alive could take on the form of imagining the current situation of the disappeared: "To perform forced labor, that is why they take young men."

Relatives reported exposure to a variety of additional stressors secondary to the disappearance, including receiving death threats, social exclusion and discrimination (e.g., not being hired for jobs, children being shut out by peers), financial problems, and being denied access to justice.

For all relatives, their sense of identity appeared to have been changed by the disappearance of their loved one. They introduced themselves as 'the father, the mother, the brother or sister' of the disappeared loved one. Some also mentioned that they had found strengths they never knew they had, for example the strength to confront authorities and to testify.

Met and unmet mental health and psychosocial support needs

Table 3 presents an overview of (unmet) needs for psychosocial support with frequencies of mentioning by relatives and support providers, respectively. The need for emotional support was the most frequently expressed need by relatives. Within focus groups, peer support was acknowledged: "Here we are not judged, and our children are not judged." "My only family now is the *colectivo*." Relatives experience social exclusion and stigmatization by the community: "They avoid us as if we are diseased (having plague) and that hurts." Several relatives mentioned that they had tried to keep the disappearance a secret because otherwise this would decrease their chances of being hired for jobs. Others talked about their children being excluded by peers. Relatives expressed feeling distanced from their circle of family and friends. Many relatives do not see their friends and family anymore: "We have nothing left to talk about".

Table 3

The second most frequently mentioned need by relatives included support when in contact with law enforcement officers. Not being taken seriously by authorities and remarks such as "I'm sure your son is just drunk"; "He must be off with a new girlfriend," and "He must be involved with *narcos*," were experienced as hurtful, heightened the stress, and caused distrust regarding the search efforts undertaken by authorities. Several relatives mentioned that authorities had shown them photographs or videos of human remains, often gruesome images, telling them that their relative was amongst these remains without formal proof (e.g., DNA research). Others were promised support on the condition that they would stop their search.

The need for treatment of mental health conditions was mentioned frequently by relatives and support providers. However, only few relatives mentioned that the received professional mental health support had been helpful (see also the next paragraph). The need for religious support was mentioned by relatives, but not by service providers.

The need for support during search efforts, as well as before, during, and after exhumations was indicated more often by support providers than relatives. However, relatives indirectly indicated this specific type of support needs. They reported that being confronted with presumed remains of the disappeared led to varying reactions. For one mother, the remains represented a bond with the deceased: "When I feel bad, I go to the piece of bone that I received, and we talk together." However, lack of trust in authorities, sometimes combined with the hope for the disappeared to be alive, led many relatives not to believe that the remains are of their lost loved one. "They just give me a bone to shut up." "I want my daughter; I don't want a piece of bone."

Several relatives mentioned that family support would be helpful because the disappearance took a serious toll on their family life. Within families, reactions to the disappearance of relatives differed, sometimes leading to tensions among family members. Eight of the 25 interviewees (32%) who were married at the time of the disappearance of their child, mentioned that tension with their spouse, as a result of the disappearance and different approaches to searching, led to divorce. As one relative mentioned "I am divorced because we had very different ways of assimilating the pain."

The search for the missing loved one was mentioned to be so overwhelming, that relatives often did not know what to do and where to start. Support in setting priorities regarding the many actions needed to be taken following the disappearance was highly appreciated by the relatives who had experienced this kind of support. As the search for a

1 missing child could take much time and resources, it was hard for parents to keep up with

taking care of their other children. One mother mentioned that because of her dedication to

3 the search for her missing son, she did not attend the graduation of her daughter. Her daughter

had told her: "Do you realize I have not only lost my brother? I have lost you too." Some

parents reported that their children had feelings of guilt following the disappearance. Some

6 parents reported keeping their children at home out of fear that they would also disappear.

7 One parent mentioned that her daughter became rebellious and wanted to go out at night,

hoping to be kidnapped just like her sister, so they would be reunited, and she could help her

sister to escape. Some mothers covered up the disappearance of their partner ("daddy had an

accident"), while others brought their children to protest marches or on searches for mass

11 graves.

A psychosocial support need that was mentioned by 3 of the 7 support providers and none of the relatives was the need for staff support. Support providers expressed emotional burden and sometimes safety concerns.

Barriers to psychosocial support

As shown in Table 4, the most frequently identified barrier to obtaining professional psychosocial support for relatives was having a negative opinion about available services. This opinion appeared to be rooted in negative experiences. Pressure for closure was experienced negatively: "They tell me to stop searching, but I cannot, a mother has a heart for who is with us and who we lost." "He kept saying that I had to stop searching, but I cannot live without my son." A father who was wearing his son's clothes in order to feel close to him reported that he had been asked: "Why are you wearing the clothes of a ghost?" Other examples of pressure for closure from the side of support providers that were reported by the relatives included: "Why do you continue? Aren't you afraid? Move on with your life, why don't you spend your energy on those you still have?" Several interviewees described how little time there was available for consultations and that they found it hard to be attended by different people each time. Not knowing where to get help and lack of available services in their neighborhood were also among the most frequently mentioned barriers. Barriers that were frequently mentioned by support providers included care provider discontinuity and not having adequate transportation.

Table 4

Discussion

Relatives of enforced disappeared persons in Mexico have been confronted with a variety of severe stressors and potentially traumatic events, such as intense and prolonged

knowing where to get help.

uncertainty about the whereabout of their loved ones, difficulties with representatives of the law, incrimination, stigmatization, intimidation, and even death threats. Most relatives expressed a clear need for psychosocial support and experienced barriers for obtaining such support. The most frequently expressed needs for psychosocial support included peer support, support while contacting the law, treatment of mental health conditions, religious support, and family support. The most frequently encountered barriers included having a negative opinion about the quality of available services, feelings of judgment from other people, and not

The different frequencies in which interviewed relatives and support providers described needs and barriers appear to reflect the difference in experiences between interviewed agencies and relatives. For example, the fact that only two interviewed relatives had received remains of their loved ones may explain the relatively low number of relatives that mentioned the need for psychosocial support when remains are returned to families.

Despite these differences, there was a high level of agreement between themes raised by support providers and relatives. This is consistent with a high level of commitment and collective engagement that seems to characterize the efforts of the support providers involved in our study.

Among relatives of missing persons with high levels of distress, holding on to hope that the loved one will return may be seen as a strategy to avoid emotions associated with the thought that the separation is permanent (Clark, Warburton, & Tilse, 2009). However, pressure for closure paradoxically leads to increased resistance (Boss, 2002) and may in the context of enforced disappearance serve politically repressive aims (Kordon et al., 1988). Unlike treatment for bereavement-related psychopathology, an intervention for relatives of missing persons should not be focused on closure or coming to terms with the irreversibility of the loss, but on tolerating the ambiguity surrounding the loss (Boss, 2002; Kordon et al., 1988; Lenferink, Wessel, de Keijser, & Boelen, 2016; Robins, 2010). Mental health professionals dealing with relatives of missing persons may therefore label the situation as one of ambiguous loss (Boss, 2002), externalize the cause to alleviate guilt, and normalize emotional reactions. They need to refrain from pressure for closure. Family relational problems may be approached by engaging other family members in the treatment and encouraging them to share their perceptions even though they differ (Boss, 2002). The needs of siblings of missing young persons deserve special attention (Clark et al., 2009).

The problems faced by relatives of disappeared persons occur at the intersection of sociopolitical, cultural, and biopsychosocial dynamics. Underlying sociopolitical causes of

- enforced disappearance include organized crime practices, regulations, policies, conditions, 1 laws, traditions, and events (Amnesty International, 2016). Cultural factors may increase the 2 3 risk of enforced disappearance for individuals belonging to vulnerable groups (e.g. indigenous communities, migrants, children, women, journalists, and human rights defenders) (De 4 5 Vecchi Gerli, 2018) and shape individual and collective responses, including mental health responses (Beristain, Villa, Ruiz, & Vial, 2017; Karl, 2014). Individual reactions may 6 7 additionally be understood within a biopsychosocial framework. Our study is unique in applying a mental health and psychosocial support perspective to the situation of relatives of 8 disappeared persons. Given the scale of the problem, both within Mexico and globally, 9
 - There is a need to protect and promote the mental health and wellbeing of staff and volunteers working in complex and sometimes dangerous circumstances (Connorton, Perry, Hemenway, & Miller, 2011). Staff support is essential for all volunteers and professionals involved in mental health and psychosocial support of relatives of disappeared persons. It includes information on prevention of burnout and dealing with criminal threat, as well as opportunities for intervision and supervision on a structural basis.

improving mental health and psychosocial support for relatives of disappeared persons is a

Study strengths and limitations

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key priority.

The current study provides unique empirical data on mental health and psychosocial support needs as well as barriers to obtaining psychosocial support in relatives of enforced disappeared persons. Some important limitations must be kept in mind when interpreting the results. Firstly, we only had access to people who were supported by a self-help group or NGO. Thus, our findings may underestimate the needs of a substantial number of relatives who lack such support and cannot be generalized to all relatives of disappeared persons in Mexico. Secondly, the mapping of psychosocial support providers is limited to certain geographical areas. Thirdly, due to the bilingual nature of the data, the interviews and focus groups discussions were not transcribed. However, we performed content analysis immediately following the interviews and focus groups discussions and checked subsections of the audio recordings independently for verification. Fourthly, our participants were selected based on practical considerations rather than representativeness. According to official figures, 74 percent of the overall reported disappeared persons were men (Villegas, 2020), against 86.2% in our sample. Relatives of missing persons due to the mass kidnapping from Ayotzinapa Rural Teachers' College were non-Spanish speaking (Beristain et al., 2017), whereas in our sample, all participants were Spanish speaking. The lack of data on (relatives

of) missing persons in Mexico precludes any firm conclusion from being drawn about

representativeness.

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Implications for practice and research

Basic guidance and do's and don'ts for law enforcement personnel and other public officials regarding communication with relatives of disappeared persons could help prevent additional stress to the emotional burden of relatives. Table 5 presents some basic do's and don'ts, adapted from the do's and don'ts from the IASC Guidelines on MHPSS in Emergency Settings (Inter-Agency Standing Committee (IASC), 2007) and the Psychological First Aid Guide (World Health Organization, War Trauma Foundation, & World Vision International, 2011). Locally adapted basic guidance should ideally go through a consultation process with relatives themselves and different actors in the field of mental health and psychosocial support. A strategy to disseminate the guidance should then be prepared and implemented.

Table 5

There is currently very limited empirical evidence supporting the effectiveness of psychological interventions in relatives of missing persons. Symptoms of posttraumatic stress disorder, depression, and prolonged grief may be addressed using empirically supported interventions for dealing with traumatic loss, including psycho-education, mobilizing social support, exposure, and behavioral activation (Smid et al., 2015). A small study using dialogic exposure yielded preliminary evidence for beneficial effects in relatives of war-missing persons (Hagl, Powell, Rosner, & Butollo, 2015). In a pilot study among Dutch adults who reported clinical levels of psychological distress following the disappearance of a significant other, cognitive behavioral therapy with mindfulness coincided with reductions in psychopathology levels (Lenferink, de Keijser, Wessel, & Boelen, 2019). In former Yugoslavia, community-based interventions combining education projects and participation in ante mortem data collection as well as providing a support network for families of the missing have been found beneficial (Keogh, Ayers, & Francis, 2002). Integrated forensic expertise and psychosocial support may be useful for addressing the psychosocial needs of families in order to resolve uncertainty and to recover the remains of their loved ones (Keogh et al., 2002). A model of psycholegal accompaniment has been developed in Peru, and represents an interdisciplinary approach, based on close collaboration between the psychological and legal teams (Rivera-Holguin et al., 2019). Because empirical evidence is largely lacking, more studies are urgently needed to increase insight in the effectiveness of mental health and psychosocial support interventions for relatives of missing persons.

Information on available mental health and psychosocial services for relatives of disappeared persons needs to be available to the relatives. Mental health and psychosocial support to relatives of enforced disappeared persons needs to be integrated in the academic curricula of psychologists, psychiatrists, and other mental healthcare providers.

Many relatives expressed that the support they received from peers, the support they were able to provide to peers, as well as the sharing of information is very important to them. Strengthening peer support groups is essential, as this promotes practical support, sharing of information, and emotional support. Within peer support groups, maintaining hope as a group norm and/or moral imperative is not recommended as it may impair emotional processing.

Culturally sensitive psychosocial support for relatives of disappeared persons in Mexico integrates collectivistic approaches to psychotherapy (Qureshi, 2020), normalizes emotional responses to ambiguity (Boss, 2002), charts culturally appropriate rituals that may facilitate coping (Smid, Groen, de la Rie, Kooper, & Boelen, 2018), and explores spiritual matters from a place of authenticity (Qureshi, 2020).

The findings in this study emphasize the need to provide practical support information to relatives of disappeared persons as well as to provide emotional support in dealing with uncertainty and grief or reconnection that may ensue the search process. Given the severity of suffering associated with ambiguous loss and the ubiquity of ambiguous loss in humanitarian crisis situations across the globe, there is an urgent need for further research and advocacy to improve availability of and access to effective mental health and psychosocial support interventions for relatives of disappeared persons.

Table 1. Identified psychosocial support providers

	Organization	Activities
Governmental	Procuraduría General de	Leads, coordinates and supervises the search
	la República (PGR)	for disappeared persons and the forensic
	Unidad Especializada en	investigation, with the aim to prosecute those
	Búsqueda de Personas	responsible for the crime. Part of their mandate
	Desaparecidas*1	is to attend and inform relatives of disappeared
		persons on the progress of the investigation. It
		has a psychosocial team, consisting of eight
		psychologists providing psychosocial support
		to victims.
	Comisión Ejecutiva de	Mandate is threefold: immediate support to
	Atención a Víctimas* ²	victims of crime (such as security, medical and
	7 tteneron a vietnias	psychological support); support to victims in
		general (including legal assistance, transport,
		medical and psychological support; link to
		other governmental support programs);
		reparation (has, amongst others, a reparation
		fund). It has a team of 10 psychologists within
		Mexico City, and psychologists in the offices
		in the different states. It has some legal
		autonomy within the Mexican government.
	Comisión Nacional de	,
	los Derechos Humanos ³	Responsible for promoting and protecting
	los Derechos Humanos	human rights in Mexico, mainly for alleges
		abuses perpetrated by government officials. It
		provides non-binding recommendations to
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Health sector	Secretaría de Salud ⁴	Emergency care and basic medical care for all citizens that have little resources.
		CONSAME (Consejo Nacional de Salud
		Mental) ⁵ : ambulant mental health services in
		21 states.
		Servicios de Atención Psiquiátrica ⁶ :
		psychiatric services
	Instituto Mexicano del	Social security system for private employees
	Seguro Social ⁷	
	Instituto de Seguridad y	Health care for government workers
	Servicios Sociales de los	
	Trabajadores del Estado ⁸	
	Private (Mental) Health	
	Services	
NGOs	Centro de Derechos	Provides legal support and advocacy (not only
NGOS	Humanos Agustin Pro	in case of disappearances). Also accompanies
	Juárez (Centro ProDH)*9	relatives during their search for relatives and
	Como Hobii)	the truth.
	Comisión Mexicana de	Does lobbying, research, outreach campaigns
	Defensa y Promoción de	and legal defense. Accompanies individual
	los Derechos	
	Humanos*10	persons (e.g. in court cases). Collaboration with <i>colectivos</i> of relatives of enforced
	11umanos*	with colectivos of felatives of emforced

		disappeared persons. Workshops for different groups, also on protection of forensic evidence when relatives are searching for (mass) graves
		on their own.
	Colectivo Contra la Tortura y la Impunidad* ¹¹	Dedicated to a state free of torture and ill- treatment. Works on documentation of torture, mental health and psychosocial services to torture survivors and their families, and capacity building of health professionals.
	Nuestra Aparente Rendición* ¹²	Aims at giving voice to victims of disappearances, linking civil society with journalists and academics. They also accompany families.
	Serapaz* ¹³	Dedicated to peace building and transformation of social conflict. It supports civil society initiatives, research, publications, capacity building, and support to processes that contribute to peace. They also accompany relatives of disappeared persons in the (legal) process of relatives' searching.
Self-help groups (colectivos familiares)	Fuerzas Unidas por Nuestros Desaparecidos ¹⁴	Provides peer support when in contact with the law. Comprises 12 <i>colectivos</i> , some of which do searches themselves.
	Other networks	E.g., Red de Enlaces Nacionales, Red Eslabones por los Derechos Humanos

^{*}Representatives were interviewed as support providers for the current study

¹http://www.portaltransparencia.gob.mx/pot/estructura/showOrganigrama.do?method=showOrganigrama&_idDependencia=00017

²http://www.gob.mx/ceav

³http://www.cndh.org.mx

⁴http://www.gob.mx/issste

⁵http://www.consame.salud.gob.mx/#

⁶http://portal.salud.gob.mx/contenidos/tramites/sap.html

⁷http://www.imss.gob.mx

⁸http://www.gob.mx/issste

⁹http://www.centroprodh.org.mx/¹⁰http://cmdpdh.org/quienes-somos/

¹¹http://www.contralatortura.org.mx

¹²http://nuestraaparenterendicion.com

¹³http://serapaz.org.mx

¹⁴https://es-es.facebook.com/FUNDEM.Mx; https://fuundec.org

Table 2. Characteristics of interviewed relatives (N = 29)

V	,	,
	N/M	% / SD
Gender		
Female	24	82.8
Male	5	17.2
Age (M, SD)	54.00	9.16
Marital status		
Married or cohabitating	16	55.2
Divorced	8	27.6
Widow(er)	2	6.9
Single	3	10.3
Education		
Lower	7	24.1
Middle	7	24.1
Higher	15	51.7
Relationship to lost person: missing person is		
Son	21	72.4
Daughter	4	13.8
Brother	3	10.3
Husband	2	6.9
Years since disappearance (M, SD)	6.07	1.71
Received presumed remains of disappeared		6.9
Норе		
Not at all	3	10.3
A little	5	17.2
Moderate	8	27.6
Quite a bit	5	17.2
A lot	8	27.6
·		

Note. Values represent numbers, percentages unless indicated otherwise.

Table 3. (Unmet) needs for psychosocial support

	Relatives $(N = 29)$		Support providers	
	N	%	N	%
Peer support	21	72%	4	57%
Support when in contact with the law	19	66%	5	71%
Treatment of mental health conditions	12	41%	4	57%
Religious support	12	41%	0	0%
Family support	11	38%	4	57%
Information about common emotional reactions	11	38%	2	29%
Support with setting goals and priorities	9	31%	3	43%
Crisis support	9	31%	4	57%
Support when remains are returned to families	8	28%	4	57%
Support during search efforts	6	21%	5	71%
Support before, during and after exhumations	5	17%	5	71%
Place and/or day of commemoration	2	7%	0	0%

Table 4. Barriers to psychosocial support

		Relatives (N = 29		Support providers	
	N	%	N	%	
				100	
Having a negative opinion about quality of available services	21	72%	7	%	
Feelings of judgment from other people (e.g., due to criminalization)	17	59%	5	71%	
Lack of available services	12	41%	3	43%	
Not knowing where to get help	9	31%	4	57%	
Cost of services (e.g., due to financial problems)	8	28%	2	29%	
Not having adequate transportation	4	14%	3	43%	
Care provider discontinuity	4	14%	5	71%	
Fear of services not being confidential		3%	2	29%	
Lack of perceived need for emotional support (e.g., prioritizing searching)		3%	1	14%	

Table 5. Do's and don'ts in supporting relatives of disappeared persons

Do's	Don'ts		
Respect safety, dignity, and rights.	Don't force help on people, and don't be intrusive or pushy.		
Listen to people and let them know you are listening.	Don't pressure people to tell their story.		
Try to find a quiet place to talk and minimize outside distractions. Be	Don't interrupt or rush someone's story (for example, don't look at		
patient and calm.	your watch or speak too rapidly).		
Acknowledge how they are feeling, e.g.: "I'm so sorry to hear this. This	Don't judge how they are feeling. Don't say: "You shouldn't feel that		
must be very difficult for you."	way."		
Acknowledge the efforts relatives have made to find their loved ones.	Don't judge relatives for they have or have not done to find their		
	loved one. Don't say "Why didn't you"		
Be aware of, and set aside, your own biases and prejudices.	Don't judge/incriminate the missing person.		
Be honest and trustworthy.	Don't exaggerate your skills.		
Provide factual information. Be honest about what you know and don't	Don't provide information to people you have not verified. Don't		
know, for example "I don't know, but I will try to find out about that for	make up things you don't know. Don't make false promises.		
you."			
Give information in a way the person can understand – keep it simple.	Don't use technical terms.		
Respect privacy and keep the person's story confidential, if this is	Don't share the person's story with others, without informed consent.		
appropriate.			
Respect people's right to make their own decisions.	Don't make decisions for people.		
Acknowledge the person's strengths.	Do not tell someone else's story or your own troubles.		
Help people to prioritize things to do, helping them to gain – as good as	Don't tell people what their priorities should be.		
this is possible under the circumstances – control over the situation.			
Respect people's search activities and people's hope to find their	Don't pressure people to give up searching.		
relatives alive			

Note. Adapted from the do's and don'ts from the IASC Guidelines on MHPSS in Emergency Settings (Inter-Agency Standing Committee (IASC), 2007) and the Psychological First Aid Guide (World Health Organization et al., 2011)

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