A population study of prolonged grief in refugees

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Abstract

Aims. Despite the frequency that refugees suffer bereavement, there is a dearth of research into the prevalence and predictors of problematic grief reactions in refugees. To address this gap, this study reports a nationally representative population-based study of refugees to determine the prevalence of probable prolonged grief disorder (PGD) and its associated problems.

Methods. This study recruited participants from the Building a New Life in Australia (BNLA) prospective cohort study of refugees admitted to Australia between October 2013 and February 2014. The current data were collected in 2015–2016, and comprised 1767 adults, as well as 411 children of the adult respondents. Adult refugees were assessed for trauma history, post-migration difficulties, probable PGD, post-traumatic stress disorder (PTSD) and mental illness. Children were administered the Strengths and Difficulties Questionnaire.

Results. In this cohort, 38.1% of refugees reported bereavement, of whom 15.8% reported probable PGD; this represents 6.0% of the entire cohort. Probable PGD was associated with a greater likelihood of mental illness, probable PTSD, severe mental illness, currently unemployed and reported disability. Children of refugees with probable PGD reported more psychological difficulties than those whose parents did not have probable PGD. Probable PGD was also associated with the history of imprisonment, torture and separation from family. Only 56.3% of refugees with probable PGD had received psychological assistance.

Conclusions. Bereavement and probable PGD appear highly prevalent in refugees, and PGD seems to be associated with disability in the refugees and psychological problems in their children. The low rate of access to mental health assistance for these refugees highlights that there is a need to address this issue in refugee populations.

Introduction

The current refugee crisis has resulted in over 22 million refugees across the globe, and over 40 million internally displaced persons (UNHCR, 2017). Refugees experience elevated rates of mental disorder, including depression, post-traumatic stress disorder (PTSD) and anxiety (Steel et al., 2009). Considering the widespread exposure to war, civil conflict and family separation, it is surprising that more attention has not focused on grief in refugees because they can be vulnerable to much bereavement resulting from the cumulative adversity they and their loved one’s experience (Tay et al., 2016). Prolonged grief disorder (PGD) is a new diagnostic construct in ICD-11, and is described as persistent yearning for the deceased and associated emotional pain, difficulty in accepting the death, a sense of meaningfulness, bitterness about the death and difficulty in engaging in new activities (World Health Organization, 2018). A major rationale for its recognition in ICD-11 is that PGD is associated with marked mental, social and physical impairment (Shear, 2015), and is reported in approximately 7% of bereaved people (Maciejewski et al., 2016). Rates of probable PGD in refugees have varied between 8 and 54% (Craig et al., 2008; Schaal et al., 2010), but these have been in small, clinical or non-representative studies. Accordingly, these rates do not provide accurate estimates of the occurrence of PGD in refugees. The goal of this study was to conduct a population-based study of refugees to determine the prevalence, predictors and costs of probable PGD in a large, nationally representative sample of refugees. We included the analysis of potential manifestations of mental health conditions commonly reported in refugees. Specifically, we measured (a) the association of PGD with probable PTSD because of the increased risk for PTSD resulting from repeated exposure to traumatic events (Steel et al., 2009), (b) psychological distress because of the ongoing stressors experienced by refugees (Li et al., 2016) and (c) self-reported...
functional disability because of the potential impacts of marked psychological distress on functioning. Additionally, we assessed the psychological status of the children of the refugee respondents because of evidence that refugee parental/caregiver mental health can impact children’s mental health (Lambert et al., 2014). No prior studies have specifically assessed refugee childhood mental health in the context of caregivers’ PGD, and so we additionally questioned the respondents’ children about their psychological well-being.

**Method**

**Participants**

The analysis is based on the Building a New Life in Australia (BNLA) study undertaken by the Australian Government Department of Social Services (DSS) (Edwards et al., 2018). The BNLA is a longitudinal cohort study of refugees. The study was designed to recruit 1500 migration units, from specified locations, and in specified proportions according to offshore (refugee) or onshore (asylum seeker) status, and visa category. Eligibility criteria for the BNLA included: (1) being the principal or secondary applicant (i.e. the refugee applicant within a family unit) for a humanitarian visa awarded between May 2013 to December 2013; and (2) being 18 years and older. Eligible principal applicants consented to participate, as well as for other adult members of their migrating unit to be invited to participate. These secondary applicants were then invited to participate in the BNLA study if they were residing with the principal applicant. At Wave 1, there were 4035 migration units identified as potential participants of whom 2039 (50%) were contacted, of whom in turn 1509 principal applicants (equivalent to migration units [37% of potential participants]) agreed to be interviewed (along with 890 adult/adolescent secondary applicants). Wave 1 interviews were conducted between October 2013 and February 2014. Subsequent waves were conducted annually, with Wave 3 data being collected between October 2015 and February 2016. BNLA participants were recruited from 11 sites across Australia encompassing major cities and regional areas that reflected concentrations of eligible refugees across visa classes.

The Wave 3 data also included the assessment of participants’ children. The primary caregiver (not necessarily the primary refugee applicant) was invited to complete a child module with respect to up to two children in their care; if there were more than two eligible children in a household, two children were randomly selected. Two principles were applied to sampling children: (1) up to two children from each family could participate; and (2) older children (aged between 11 and 17 years) were preferentially selected over younger children because the former were able to provide self-report responses in addition to parental reports. Based on these criteria, youth were selected by randomly selecting up to two children aged 11–17 years old in each migrating unit. In households where there were two or more children aged 11–17 years old, two randomly selected children in this age group were selected. The current child data focus on the child self-reports.

Interviews were conducted using computer-assisted personal interview (CAPI) and computer-assisted self-interview (CASI). CAPI enabled field interviewers to ask questions displayed on the screen and enter responses from the participant directly into a computer. CASI allowed for participants to respond privately to self-report questions using a computer interface (assistance provided when needed). Interview questions and associated written material were translated from English into nine languages including Arabic, Burmese, Dari, Hazaragi, Persian, Chin Haka, Nepali, Swahili and Tamil. In most cases, participants were matched with an interviewer who was a native speaker of their respective language; however, few participants opted for translated/interpreted interviews. The Wave 3 data were collected after a residency period of 2–3 years in Australia (for 87% of the sample). In addition to the previous waves, Wave 3 included an assessment of bereavement and probable PGD. At Wave 3, there were 1767 adult refugees interviewed, and 411 children provided self-report data.

**Measures**

**Demographic interview**

The face-to-face interview assessed a broad range of demographic and household factors.

**Prolonged grief disorder**

Bereavement was assessed by asking respondents if someone close to them had died. If respondents answered in the affirmative, they were asked the following questions regarding a death that occurred at least 6 months earlier. To assess probable PGD, we employed a screening measure for PGD that was used to assess probable PGD following Hurricane Katrina (Shear et al., 2011). Four questions were asked about grief in the past 30 days associated with their bereavement: (1) How often have you found yourself or yearning for the people who died? (2) Have you had trouble accepting the death? (3) Do you feel bitter over their death? (4) Do you feel that life is unfulfilling, empty, or meaningless since their death? Each response was answered on a five-point scale (1 = not at all, 5 = several times a day/overwhelmingly). The initial use of this measure following Hurricane Katrina found that a principal axis factor analysis yielded one meaningful factor with an unrotated eigenvalue of 2.7, and factor loadings of at least 0.77 for all items (Shear et al., 2011). A final question asked that each of these symptoms had been happening for at least 6 months. We scored these responses to identify probable PGD in a way that is consistent with the ICD-11 PGD criteria. Specifically, the definition of probable PGD was operationalised as the presence of yearning for the deceased at least every day, and at least two of the three other potential PGD symptoms being endorsed at least at moderate levels.

**Post-traumatic Stress Disorder-8**

The Posttraumatic Stress Disorder-8 items (PTSD-8) (Hansen et al., 2010) is an eight-item self-reported screening measure for probable PTSD that was used to assess the caregivers’ PTSD symptoms. The PTSD-8 is designed for assessing trauma symptoms in refugee populations, and assesses four intrusion, two avoidance and two hypervigilance items. Participants rate the symptoms on a four-point Likert scale (1 = not at all, 4 = most of the time) reporting how much the symptoms bothered them in the past week. Probable diagnosis of PTSD is met if at least one symptom from each of the three PTSD-8 subscales has an item score of 3 or 4 (indicating the symptom is present ‘sometimes’ or ‘most of the time’ for at least one item in each subscale) (Hansen et al., 2010). This measure was administered at all three waves and had an internal consistency (Cronbach’s α) of 0.91–0.92 across waves.
Severe mental illness
The Kessler Screening Scale for Psychological Distress (K6; Kessler et al., 2010) was used to index severe mental illness in the previous 4 weeks. Participants rate each symptom of depression or anxiety on a five-point Likert scale (0 = none of the time, 4 = all of the time), with scores $\geq 19$ classified as severe mental illness. The K6 has been used cross-culturally across many studies in numerous languages, with scores $\geq 19$ classified as severe mental illness (Australian Bureau of Statistics, 2012). In the present study, the internal consistency of the K6 was 0.91.

Trauma history
To assess the extent of exposure to traumatic events, at Wave 3, caregivers were administered a modified version of the Harvard Trauma Questionnaire Trauma Events Module (Mollica et al., 1992) that indexed ten potentially traumatic events. This measure comprises events that are relevant to refugee experience (e.g. combat exposure, imprisonment, murder/disappearance of family members) and has been widely used with refugee populations (Hollifield et al., 2002).

Post-migration stressors
The BNLA indexed post-migration stressors commonly experienced by refugees in resettlement period. Specifically, respondents were asked to dichotomously indicate if any of the ten life events caused them stress; events included work, housing, finances, family safety, discrimination, school/study, caring for family, conflict with neighbors, language barriers or acculturation.

Strengths and Difficulties Questionnaire
The Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001) was used to assess the children’s psychological problems. The SDQ comprises 25 items measuring behavioural, emotional and social problems that children can report on a three-point Likert scale (0 = not true, 2 = certainly true). It comprises of five subscales: conduct problems, hyperactivity, emotional symptoms, peer problems and prosocial behaviour (this analysis focuses on the four difficulties subscales). In the current study, all items (except the prosocial items) were summed to establish a total difficulties score (range 0–40). The SDQ possesses good internal consistency for screening child psychiatric disorders (Goodman, 2001), and is a widely used measure of adjustment among refugee populations and has comparable factor structures across ethnic groups (Richter et al., 2011).

Data analysis
All analyses incorporated the Wave 3 participant survey weight, which was based on visa subclass, capital city, age and country of birth information (Australian Government, 2017). We initially report the frequencies of refugees with and without probable PGD, along with $\chi^2$ analyses of main associated outcomes that include demographic characteristics, psychological comorbidities and help-seeking. We then report adjusted odds ratios of the likelihood of developing probable PGD in relation to exposure to different types of traumatic events and current stressors. These calculations adjusted for age, gender, marital status and country of origin to determine the impact of adverse events on the likelihood of probable PGD beyond the influence of these factors. To determine the association between childhood mental health and caregiver PGD, proportions of children with psychological difficulties on each of the SDQ subscales were compared in terms of children whose caregiver had and did not have PGD. All child data were related to the primary caregiver data because the primary caregiver provided the child data; accordingly, all analyses of child data included a cluster effect of the migration unit.

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In this sample of 1245 adult refugees, 474 (38.1%) reported experiencing bereavement. Of those who were bereaved, 75 (15.8%) respondents indicated they experienced probable PGD; this represents 6.0% of the entire cohort. The observed prevalence of probable PGD is markedly lower than reported in most prior estimates of PGD in refugees, which have reported PGD in 8–54% (Craig et al., 2008; Schaal et al., 2010). These studies comprised relatively small samples and were often recruited from...
treatment services. The current study comprises a nationally representative sample and therefore probably reflects a more accurate index of the prevalence of PGD in refugees. In this sense, this finding accords with meta-analytic evidence that rates of psychological disorder in refugees tend to be lower in larger and more representative studies (Steel et al., 2009). It is noteworthy that the prevalence of PGD in these refugees was nearly twice that of a previous nationally representative sample that found PGD in the general community was 3.7% (Kersting et al., 2011).

The presence of probable PGD was strongly associated with psychological comorbidity and impairment, including PTSD, severe mental illness (as measured by the K6), reported disability, not being employed and difficulty trusting others in the community. There is much evidence of high levels of comorbidity with PGD, including anxiety, depression and PTSD (Melhem et al., 2001; Simon et al., 2007). There is also much evidence that PGD is associated with work and social functioning impairments (Prigerson et al., 1997; Bonanno et al., 2007). In the context of concerns about refugees adjusting to their new lives in the host country, these patterns are noteworthy because they highlight that persistent grief problems are associated with compounded psychological and social challenges that are likely to interfere with refugees’ capacities to optimally adjust to their new settings.

The likelihood of developing probable PGD was significantly heightened by exposure to a wide range of trauma and non-traumatic stressors. Not surprisingly, murder or disappearance of family members and separation from family were two of the traumatic events that had the strongest association with probable

Table 3. Adjusted odds ratios and 95% confidence intervals for associations between prolonged grief disorder and post-migration stressors (controlling for age, gender, marital status and time since arriving in Australia)

| Participants (N = 1245* [unweighted: 1302]) | PGD (n = 75 [99]) | No PGD (n = 1171 [1203]) | AOR | 95% CI | p |
|---------------------------------------------|------------------|--------------------------|-----|--------|---|
| Family waiting to come to AU 35 47.3 642 55.2 | 0.76 | 0.48–1.20 | 0.2399 |
| Does not speak English well 48 63.8 634 54.8 | 0.89 | 0.53–1.48 | 0.6506 |
| Look for paid work in last 12 months 15 20.5 448 39.2 | 0.57 | 0.32–1.03 | 0.0634 |
| Receives government benefits 70 94.0 860 74.1 | 3.71 | 1.32–10.38 | 0.0124 |
| No friends in Australia 6 8.2 65 5.7 | 1.29 | 0.41–4.08 | 0.6600 |
| Has experienced discrimination 9 12.7 86 7.4 | 2.38 | 1.06–5.34 | 0.0361 |
| Does not trust neighbourhood 11 17.7 199 19.4 | 0.91 | 0.47–1.75 | 0.7751 |
| Does not trust Australian community 16 29.3 178 17.5 | 1.81 | 0.89–3.69 | 0.1021 |
| Does not trust government 6 8.5 81 7.4 | 1.48 | 0.48–4.53 | 0.4938 |
| Does not trust health professionals 7 9.4 75 6.8 | 1.52 | 0.55–4.18 | 0.4178 |
| Support from ethnic communityb 40 54.5 589 51.3 | 1.01 | 0.76–1.33 | 0.9674 |
| Support from religious communityb 42 57.3 617 53.9 | 1.04 | 0.78–1.39 | 0.7900 |
| Support from other groupsb 52 70.8 725 63.8 | 1.19 | 0.85–1.65 | 0.3063 |
| Feels welcome in Australiac 9 11.6 137 11.8 | 0.97 | 0.68–1.37 | 0.8453 |
| Sense of belonging in Australiad 15 19.4 195 16.9 | 1.07 | 0.82–1.41 | 0.6075 |

a The is maximum N: sample sizes below are reduced by missing values.
b Three-point scale (‘yes’, ‘sometimes’, ‘no’).
c Four-point scale (‘always’ to ‘never’: percentage for ‘sometimes/never’).
d Five-point scale (‘always’ to ‘never’: percentage for ‘sometimes/hardly/never’).

Table 4. Means on primary caregiver-reported SDQ subscales

| SDQ subscales | PGD (N = 26) [40 children] | No PGD (N = 313) [498 children] | t | p |
|----------------|-----------------------------|---------------------------------|---|---|
| Emotional problems | 3.10 0.29 | 2.10 0.12 | 3.23 | 0.0013 |
| Conduct disorders | 1.53 0.27 | 1.41 0.11 | 0.44 | 0.6639 |
| Hyperactivity | 3.26 0.38 | 3.00 0.16 | 0.57 | 0.5719 |
| Peer problems | 2.48 0.22 | 2.41 0.09 | 0.77 | 0.7691 |

The 339 primary caregivers are 95.8% of primary caregivers, and the 538 children are 94.6% of children.
PGD. Violent death is one of the strongest predictors of PGD (Neria et al., 2007), which may be attributed to the suddenness of the loss, concerns about how the person died or possibly associated PTSD. There is increasing evidence that mental health problems of refugees are compounded by the level of stressors in the post-migration period (Li et al., 2016). The observation that probable PGD was associated with more post-migration difficulties accords with this evidence; it is difficult to disentangle the directionality of this association because whereas these stressors may compound grief responses, persistent grief may also contribute to stressors.

There was a statistically significant association between probable PGD and worse emotional difficulties in children. There is considerable evidence that parental mental health is associated with the psychological health of their children, with most attention given to the relationship between Holocaust survivors' mental health and the psychological well-being of their children (van IJzendoorn et al., 2003). There is also much evidence of refugees' mental health potentially impacting on their children's psychological health, with one meta-analysis suggesting parental PTSD had a moderate impact ($r = 0.35$) on children's psychological problems (Lambert et al., 2014). This association could be attributed to several factors. There is evidence that adult mental health problems negatively impact parenting behaviour, which in turn can influence children's psychological well-being (McLeod et al., 2007). It is also possible that parental PGD directly impacted child mental health via modelling or adverse effects of negative mood by the parent. We emphasise that the findings regarding the children's psychological difficulties are interpreted cautiously because the number of children of caregivers with probable PGD was small, and so definitive inferences about the relationship between refugees' PGD and their children's mental health awaits replication with larger sample sizes.

A concerning finding in this study was that only 56.3% of those with probable PGD had received psychological assistance. Help-seeking among people with PGD is often low, with one study finding that only 43% of those with PGD sought mental health assistance (Lichtenthal et al., 2011). Moreover, refugees display very low levels of mental health service utilisation (Kinzie, 2006). Sub-optimal help-seeking in bereaved refugees may be due to stigma about attending mental health services (Papadopoulos et al., 2003), ignorance of appropriate referral opportunities (Bartolomei et al., 2016) or avoidance of confronting emotional discomfort associated with their grief (Lichtenthal et al., 2011). The current finding highlights the need to overcome the apparent barriers for refugees with PGD to access mental health services. Interestingly, 35% of respondents without PGD had received psychological help in Australia. This could be attributed to (a) refugees receiving help for psychological conditions other than PGD (e.g. PTSD, depression), (b) having been successfully treated for PGD that was resolved by the time of this assessment or (c) provision of psychological supports for bereaved refugees without regard to their PGD status.

These observations are qualified by several methodological limitations. First, probable PGD was assessed with an abridged measure of PGD; although the screening measure complies with the ICD-11 symptom definition of PGD, it did not include an index of grief-related impairment which is one of the ICD-11 requirements; greater confidence in the observed rates of probable PGD would be achieved with a complete diagnostic measure of PGD. Relatively, we recognise that cultural variations exist in the conceptualisation of prolonged grief, and our measure may not have optimally accommodated for these differences in the different ethnicities represented in this cohort. Second, this assessment of bereavement responses was embedded in a large study of many factors relevant to refugee adjustment, and accordingly many factors directly relevant to the development of PGD could not be adequately assessed; this precluded investigation into many potential predictors, such as the type of death, relationship to the deceased, attachment issues and mourning rituals. Third, this sample focused on refugees who were granted permanent protection visa prior to arrival in Australia and did not include current asylum applicants; this sampling resulted in this cohort not including refugees who may have some of the adverse experiences associated with seeking asylum, such as being in a detention camp. As this sample comprised refugees who had been granted humanitarian visas, it is also possible they were more trauma-exposed than some other refugee groups. Fourth, most of the sample were accompanied by family members, which may moderate the extent to which we observed problematic grief reactions because being separated from family members may exacerbate separation anxieties, which could compound grief responses. Fifth, respondents were able to respond to questions using self- or interview-administered formats, and this may have introduced some variability; we were not able to differentiate between these formats because respondents chose the format for each question depending on their literacy and confidentiality needs in response to specific questions.

In summary, this report highlights the elevated risk that refugees have for problematic grief reactions. This risk is not surprisingly associated with their exposure to traumatic loss that is often associated with war or conflict, but is also apparently heightened by the level of ongoing stressors in the refugees' postmigration setting. A significant proportion of refugees do not seek assistance for their PGD, and this points to the need for removing barriers to accessing appropriate care. In the context of strong evidence for the efficacy of grief-focused therapies in alleviating PGD symptoms (Bryant et al., 2014; Shear et al., 2016), there are good reasons to provide more targeted programmes to address the persistent grief problems experienced by refugees.

**Data.** The data that support the findings of this study are available from the Australian Institute of Family Studies but restrictions apply to the availability of these data, which were used under licence for the current study, and so are not publicly available. However, data are available from the authors upon reasonable request and with the permission of AIFS. The data can be requested from http://www3.aifs.gov.au/bnla/index.html.

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**Conflict of interest.** None.

**Ethical standards.** Ethics approval was granted by the Australian Institute of Family Studies Human Research Ethics Committee (LISHM 13/03).

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