Ethical issues arising in research with people with mental health conditions

November/December 2021

Case study
Maximising meaningful and impactful mental health research for Syrian refugees during Covid-19 – co-creation, local relevance and ethical practice

Presenter: Dr. Clara CALIA – Lecturer in Clinical Psychology, School of Health in Social Science, University of Edinburgh c.calia@ed.ac.uk

Team members: Prof. Lisa BODEN: Chair of Population Medicine and Veterinary Public Health Policy/ Global Academy of Agriculture and Food Security, University of Edinburgh
Dr. Shaher ABDULLATEEF: Cara Syria Programme;
Maria AZAR: Association pour la protection de l'enfant de la guerre (APEG);
Joy ABI-HABIB: Save the Children International; Joseph BURKE: Research Fellow, School of Health in Social Science, University of Edinburgh

Brief description of the research project
The One Health FIELD Network[1] brings together diverse, multidisciplinary expertise to increase food system resilience and to support short and long-term sustainable development in fragile and complex contexts. It draws together international and local expertise, which includes among its members: Syrian Academic Expertise for Agriculture and Food Security (SAE-AFS), various disciplinary schools from the University of Edinburgh and the non-governmental organisation Cara. It has been established around five pillars: Partnerships, Food Security and Safety, Gender Equality, Natural Resources, Livelihoods and Labour, and Health and Well Being. The last of these explores the physical and mental health impacts of food and livelihood insecurity and displacement.

From the Field was a research project launched by the Network to explore the impact of Covid-19 on the lives and livelihoods of Syrians living in Lebanon, Iraqi Kurdistan, Jordan, Syria and Turkey using bespoke remote ethnographic approaches. It was implemented between April and September 2020. The University of Edinburgh and Cara identified and worked with local researchers to co-create and deploy questionnaire surveys using accessible technologies to 100 Syrian refugees in the region. These local research collaborators acted as key respondents to help navigate Syrian idioms of distress, interrogating the applicability of the proposed standardised measures and providing qualitative feedback on their own experience of the research process. Data was collected on the mental health of respondents who were facing enormous pressures and diminishing supports in their day-to-day lives, exploring the linkages between their psychological wellbeing and food security, a key concern of the local population.

Background
Frameworks for understanding mental health amongst those fleeing the Syrian conflict have been criticised for often adopting ill-fitting models which are divorced from their sociocultural contexts.[2] The mental health constructs adopted may not be cross-culturally valid and their focus on illness and disorder may exacerbate cultures of stigma, misinterpret local idioms of distress, and potentially lead to an overemphasis on the role conflict-trauma at the expense of social determinants of mental health.[3,4]

Ethical issues with commentary

The central ethical question facing the project was how can we co-create an international research project with local mental health researchers/practitioners and displaced Syrians which is locally relevant and impactful? The project has led us to focus on the following key aspects:

1. The 'From the Field' project placed Syrian and host community researchers at the centre of the design and implementation of the study primarily through its collaboration with Cara (The Council for At-Risk Academics). Working with Cara as a partner helped achieve the project's goal to be meaningful and impactful by engaging a network of local experts who could support the project's research aims, while also enhancing protective links to help at-risk academics. The collaborative discussions that followed resulted in recommendations to create a nascent network of expertise exploring the transition and long-term contingency planning for food security and health in Syria. It was imperative that the research questions guiding *From the Field* would be valuable to the individuals participating, contributing positively to the lives of those affected by the Syria crisis.

2. The Short Warwick-Edinburgh Mental Well-Being Scale, S-WEMWBS,[5] was selected for its cross-cultural validity in a wide variety of contexts, including for Arabic speakers. Its non-invasive, positively-worded orientation was suitable in this challenging humanitarian context. Additionally, it could take into account both dimensions of affect and functioning in order to capture changes in mood and the impact of daily stressors. As a team, we reflected on the decision to identify measures which we thought could do the best job at revealing the dimensions of psychosocial functioning over and above claims to making diagnostic categorisations which may be less practical in acute humanitarian crisis. We also considered the extent to which studies like ours contribute to identifying the elements of psychosocial functioning relevant to those affected by humanitarian crisis[6] and if they can help enrich potentially simplistic descriptions of displaced persons as 'vulnerable' or 'resilient'.

3. How can we best ensure the psychological wellbeing of both displaced individuals *and* local mental health researchers? Participating in this kind of research can itself have an impact on mood and self-perception: a research study can fulfil the express need of displaced people to speak about issues affecting them, while local mental health researchers may find themselves emotionally affected by participants' responses. Research participants may be frustrated if their immediate needs are ignored in research. The sociocultural background which made the local researchers more knowledgeable of the particular expressions of mental distress, also exposed them to stress. In humanitarian contexts, cultural countertransference can emerge between the researcher and the researched[7] and different types of empathy may manifest[8]. Mental health researchers require access to suitable training, clear referral pathways to respond to participants' stated needs, protocols for situations of harm risk and clinical supervision.

4. *'From the Field'* was underpinned by the Global Research Ethics Toolkit https://www.ethical-global-research.ed.ac.uk/toolkit[9] which has been developed in collaboration with more than 200 researchers from more than 30 countries representing 60 different disciplines. Rather than ethical regulation, it offers a flexible frame of reference which promotes contextual ethical reflection and accountability within the research process and among research teams.[10] Shaped by the toolkit, the project developed a space within which team members could work with respect of each other's experiences and multidisciplinary knowledge to ensure that ethical reflections were embedded within the project's collaborative practice. It provided a framework within which different team members could engage with a variety of complex practical and conceptual challenges facing the project on an equal footing with others without assumptions or fear of judgement.

Conclusions and two recommendations

Our work suggests that culturally-attuned, locally-driven mental health research is essential to a positive conceptualisation of mental health conditions, and is necessary if we are to understand the prevalence and presentation of common mental health conditions.

- Mental health research for displaced populations must ensure measures are fit-for-purpose in the sociocultural context in which they are used, and diagnostic tools and interventions should integrate an appreciation of the daily stressors people face.
- Invest in the capacity of local mental health researchers and support the development of ethical systems of research care so they can safely undertake research with those experiencing mental health distress.

References

1. ONE Health Field Network: https://www.onehealthfieldnetwork.org

2. Hassan, G., Ventevogel, P., Jefee-Bahloul, H., Barkil-Oteo, A., & Kirmayer, L. J. (2016). Mental health and psychosocial wellbeing of Syrians affected by armed conflict. Epidemiology and psychiatric sciences, 25(2), 129–141. https://doi.org/10.1017/S2045796016000044

3. Wells, R., Wells, D., Lawsin, C. (2015). Understanding psychological responses to trauma among refugees: The importance of measurement validity in cross-cultural settings. Journal and Proceedings of the Royal Society of New South Wales 148, 60-69

4. World health statistics (2014) WHO Press, World Health Organization, Geneva 27, Switzerland. ISBN 978 92 4 156471 7

5. Clarke, A., Friede, T., Putz, R. et al. Warwick-Edinburgh Mental Well-being Scale (WEMWBS): Validated for teenage school students in England and Scotland. A mixed methods assessment. BMC Public Health 11, 487 (2011). https://doi.org/10.1186/1471-2458-11-487

6. Tay, A., & Silove, D. (2017). The ADAPT model: Bridging the gap between psychosocial and individual responses to mass violence and refugee trauma. Epidemiology and Psychiatric Sciences, 26(2), 142-145. doi:10.1017/S2045796016000925

7. Foster, R.P. The Clinician's Cultural Countertransference: The Psychodynamics of Culturally Competent Practice. Clinical Social Work Journal 26, 253–270 (1998). https://doi.org/10.1023/A:1022867910329

8. Lachal, C. (2007). Le partage du traumatisme : comment soigner les patients traumatisés. Le Journal des psychologues, 253, 50-54. https://doi.org/10.3917/jdp.253.0050

9. Global Research Ethics – A Toolkit: https://www.ethical-global-research.ed.ac.uk/

10. Reid, C., Calia, C., Guerra, C., Grant, L., Anderson, M., Chibwana, K., Kawale, P., & Amos, A. (2021). Ethics in global research: Creating a toolkit to support integrity and ethical action throughout the research journey. Research Ethics, 17(3), 359–374.https://doi.org/10.1177/1747016121997522