

19/03/15 Dr Jane Cooper

Exploring the experiences of returned Ebola Virus Disease workers from the United Kingdom

Study Site: Location of interviews: United Kingdom – one month's duration.

Proposed start date of data collection for study: April 2015

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Glossary

EVD Ebola Virus Disease

HIV/AIDS Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

MDRTB Multiply Drug Resistant Tuberculosis

MSF Médecins sans Frontières

OCA Operational Centre Amsterdam

PHE Public Health England

UK United Kingdom

WHO World Health Organisation

Background

Anecdotal reports and hearsay indicate that health care workers returning from Ebola Virus Disease (EVD) programmes have faced some challenges including reactions from friends and family, as well as a period of health monitoring and some restrictions during the 21 days after leaving affected countries. Some aspects and instances of returning “volunteers” have received considerable media attention, and some testimonies have been published¹.

However, no published research has yet explored such experiences. Themes that emerge during the course of this research will guide the ongoing literature review, and choice of interpretative frameworks; a brief account of potential relevance is included below.

Some anecdotes of being shunned by others suggest that literature on stigma may be relevant to emerging findings. Following Goffman’s classic work², ‘stigma’ has been explored in a variety of contexts, and definitions have been discussed³. At this stage, reference to ‘stigma’ or ‘stigmatisation’ is not intended to imply any particular definition; in particular, a suggestion that “stigmatising behaviours” can be distinguished from medically appropriate precautions⁴ is not endorsed; this study seeks primarily to capture lived experiences of social interaction.

Stigma and its processes have been studied in relation to modern disease epidemics such as HIV/AIDS and MDRTB; in both, health care workers have, at least in some locations and at some times, faced reactions and anxieties about their perceived potential as carriers of disease. Both those communicable diseases have been socialised differently over time, in that perceptions and representations of the disease, of potential treatments and of the success of control measures have been dynamic. Those considerations also apply to Ebola Virus Disease; its evolution in West Africa, the lack of containment, and spread to urban areas and across borders were accompanied by a global sense of dread and fear which might seem to have both reflected and influenced national and international responses, and

media reports. Outside the field of communicable disease, 'stigmatisation' of health workers has been explored in those working with disparaged client groups^{5 6}.

With a wider lens, the experience of HIV/AIDS informed an account of epidemic psychology⁷, identifying waves of fear, suspicion, stigmatisation, moralising interpretations and competing strategies for action, and favouring a Meadian approach in locating these human phenomena in our capacities for language. BSE gave rise to a reflective essay on geopolitical impacts of infectious disease, including national stigmatisation⁸. Goffman's classic work on stigma characterised impression management as the challenge for the discredited, and information management as the challenge for the discreditable; this might seem relevant to coping and disclosure strategies at both individual and collective levels.

Social identity theory⁹, and social representations¹⁰ may also be relevant to discussion of emerging findings. Goffman's subtitle referred to "spoiled identity". A review of the social psychology of stigmatisation¹¹ suggested an updated identity threat framework. A recent paper on stigma and mental health nurses characterised such workers as a stigmatising, de-stigmatising and stigmatised group, and found these issues significant to mental health nurses' identity challenges. Goffman's courtesy stigma, or stigma-by-association, was explicitly cited in a paper on health professionals working with sex workers¹², describing narratives of contagion, contamination and corruption.

A previous EVD outbreak, more rapidly contained, generated publications on perceptions and social representations in the UK^{13 14}. In the current EVD epidemic, both quarantine measures and stigmatisation reactions to survivors¹⁵ in affected countries have been reported, with impacts in terms of family and community relationships and livelihoods; some survivor support networks have been formed. Anecdotal reports have also indicated avoidance and stigmatisation of health care workers in affected countries, who have suffered high rates of infection in unprotected settings. The Ugandan EVD outbreak of 2000 was the setting for a small study of EVD survivors amongst health care workers¹⁶; this identified not only the experience of being "ostracised", alongside the fear of infecting others, but also the implications for disclosure and outbreak control.

While clearly the major burdens in terms of both disease and indirect impacts have fallen on affected countries, exploration of the experience of returnees to the UK may illuminate relevant identity processes, and offer relevant lessons for organisational management in a complex arena.

Study sites

Médecins sans Frontières (MSF) has been selected as the study organisation, based on expected numbers of returned volunteers and completeness of data, as well as a long track record in quality research and organisational learning. The UK was selected as the study site, offering efficiency in terms of logistics and language, and also sufficient numbers for useful data capture.

A brief summary of MSF EVD programmes & workers

MSF has been running EVD programmes including Treatment Centres in affected countries since early 2014, and currently employs 325 international and around 4150 national staff¹⁷. MSF protocols to deliver care and control transmission, and to ensure and monitor the health of workers, were available, based on experience in previous outbreaks over many years. In the latter part of 2014, other organisations and national governments established programmes in, and/or sent volunteer workers to, affected countries. In parallel, national protocols for the monitoring of returned workers, and the screening of travellers, have been established in many countries.

MSF international workers have, to date, numbered some **[insert]** in total. Infection of MSF workers has been relatively rare, being reported in **[insert]** international workers, and **[insert]** national workers; **[insert]** of the latter have died. Most cases in national workers have been attributed to exposures in the community. No cases of infection due to secondary transmission from infected MSF international workers have been identified. **[check]**. To date, **[insert]** MSF international workers have returned to the UK; **[insert]** of these have undertaken more than one mission. No UK returnees have been infected **[check]**

Overall aim:

To describe and explore the experiences of UK EVD workers during the period following their return

Specific objectives:

1. To explore experiences, perceptions, and views of interactions with family and friends
2. To explore experiences, perceptions, and views of interactions with the general public
3. To explore experiences, perceptions, and views of interactions with colleagues and managers in returning to work

4. To explore experiences, perceptions, and views of public opinion and media coverage
5. To explore experiences, perceptions, and views of policy implementation
6. To identify potential lessons, and areas for potential future research, relevant to the management of staff and programmes

Methods:

This study will be conducted using a qualitative, descriptive research design and will take place in the UK over a period of one month. This choice of methodology was chosen as the most appropriate to answer the research question, which seeks to describe and explore EVD returnees experiences on return to the UK.

This research uses a flexible participatory technique in which an interview topic guide is adapted during and between interviews in light of responses and specific contexts, using open-ended questions and prompts in a participant-led process. Detailed transcription, reading, coding and interpretation will commence with the first interview, informing subsequent interviews. This is an external research project with a researcher from the UK. The study is taking place outside the framework of ongoing MSF programme activities and will coordinate with the existing organisational liaison with, and support to, returnees.

Participation in the study will be voluntary and interviews can be stopped at any point. Respondents' names will not be used and it will be ensured that individuals cannot be identified in the report (either by name, individual details or through use of identifying job descriptions). Interviews will be recorded where possible, with permission being requested from respondents beforehand and tapes being destroyed once transcribed.

Sampling and recruitment strategy:

MSF will contact those on a database of returned EVD workers with details of the project, inviting potential volunteers to discuss participation with the researcher. Recruitment will be conditional upon consent; the initial sampling will seek a mix of participants, e.g. by role (clinical/non-clinical/managerial), date of return, age, gender, and geographical location. Recruitment will proceed in tandem with interviewing, aiming to achieve a minimum of 15-20 participants, to comply with LSE guidance, and with published advice on the number of participants likely to be needed when seeking disconfirming evidence or interviewing heterogenous samples, with the ultimate aim of achieving saturation in terms of emerging concepts and themes¹⁸.

Data collection and analysis:

An interview topic guide with open-ended questions will be used to conduct the in-depth interviews, which will be in English. Tape-recorded interviews will be transcribed. Transcripts will be read and coded iteratively in order to identify and revise emerging thematic networks as described in detail in the literature^{19 20}.

Interpretation will be driven by the iterative and reflexive identification and revision of emerging themes. The social identity approach, and social representations, are expected to be key underlying theoretical frameworks.

The project will also include review of relevant grey literature in the form of guidance and policies from MSF, Public Health England (PHE) and the World Health Organisation (WHO).

Limitations

This is a qualitative study, and as such the findings will be informative rather than directly generalisable, either to other MSF returnees, or to those with other organisations. Subjectivity is an inherent feature of qualitative research; supervision by 2 experienced qualitative researchers will promote continuous and appropriate researcher reflexivity. Validity will also be promoted by detailed accounts of methods and findings; LSE dissertation guidelines recommend use of verbatim (but unidentified) quotes, and advise inclusion of one interview transcript.

Inclusion criteria

All UK-returned MSF volunteers who consent to initial discussion will be eligible

Exclusion criteria

Participation will not be sought from any whom MSF advise are unsuitable for any reason, or from those not responding to an initial invitation to further discussion.

Supervision

The Principal Investigator will discuss methodology and other issues with formal Supervisors at the London School of Economics and Political Science (LSE) at regular project review meetings, at other *ad hoc* meetings with other LSE Faculty staff, and with Beverley Stringer of the MSF UK Programmes Unit, who is a trained Anthropologist.

Resources

Necessary costs will be borne by the researcher.

Data management, analysis and protection

After transcription all tapes will be destroyed. Transcripts will be identified by code not name. Information will be password protected and stored on a personal computer to which the researcher has sole access, in a secure location, not on a network or remote server. Back up will be on a separate hard drive.

The researcher will sign a confidentiality agreement with MSF, and will also sign a data agreement stating that data gathered may only be used for this research project, and that all data must be kept in a manner that respects confidentiality and protection of data. Data collected will form the basis of a dissertation to be submitted as part of an MSc in Organisational & Social Psychology. Data may not be shared with others, presented or published without consent from the Medical Director of MSF OCA.

Informed Consent

The consent process will include outlining the purpose of the study, stating that participation is voluntary and advising that the respondent can change their mind about participating at any point. Consent will be discussed verbally to ensure respondent comprehension, with voluntary written consent then being obtained. The intended written consent form is appended to this proposal, along with a participant information sheet.

Confidentiality

Participants' names will not be included in any of the project write up. Each respondent will be given a code corresponding to the time of interview and only the researcher will be able to link code to name. No data will be left unattended or accessible to others.

However, participants will be advised at the outset that any disclosure which may represent a breach of protocol will be shared with MSF (see informed consent form).

Social Value

This project will explore experiences of UK EVD returnees, to deepen understanding, and will seek to identify lessons and mitigation strategies in terms of recruitment and management of staff, and of programme management, primarily for MSF. These may be

relevant to other organisations, and to other programmes and humanitarian emergencies, particularly those involving communicable diseases.

Potential Risks

Those working in the EVD response will have been exposed to distressing experiences. Additionally, some experiences of stigmatisation by family and friends may have been distressing. There is the potential for such distress to be made salient by interviews. Awareness of this potential will guide interview questions. Liaison will be maintained with the existing MSF volunteer support network (please see appended informed consent form).

Additionally, interviews may generate disclosures which may represent a breach of protocol. Such disclosures will be shared with MSF UK Human Resources for further discussion and assessment. Participants will be advised of this requirement prior to interview and asked to confirm this understanding on the written consent form.

Respect for Recruited Participants and Study Population

Feedback mechanisms will be used to ensure participants are aware of the findings and outcomes of the study. Respondents can choose to opt in or out of this feedback process prior to interview commencement. Summary findings of the study may also be made available to other volunteers via MSF Human Resources and the volunteer support network, and to other managers via usual organisational communication channels, at the discretion of MSF.

Independent Review

Following discussion of the project with supervisors, a project summary identified as “low risk” has been approved by the LSE research ethics committee. This protocol submitted to MSF will also be shared with LSE supervisors.

The research and publication records of supervisors are available:

<http://www.lse.ac.uk/socialPsychology/faculty/Jenevieve%20Mannell/home.aspx>

http://www.lse.ac.uk/socialPsychology/faculty/bankole_falade/home.aspx

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