



“Nothing about us, without us”? A qualitative study of service user involvement in the development of lay-delivered psychological interventions in contexts affected by humanitarian crises

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ABSTRACT

Background: : Service user involvement has become increasingly prioritised within health research, and more recently, within mental health and psychosocial support (MHPSS). However, there is limited exploration of service user involvement in the development of lay-delivered MHPSS psychological interventions. The aim of this research was to investigate how service users have been involved in the development of lay-delivered psychological interventions for populations affected by humanitarian crises.

Methods: : Thirteen semi-structured interviews were conducted with respondents involved in randomized controlled trials (RCTs) of lay-delivered MHPSS psychological interventions, either as principal investigators or as focal points for service user involvement. Thematic data analysis was used to analyse the data.

Results: : There was a common perception that service user involvement is vital to the development of lay-delivered psychological interventions, but there was concern about how that happened in practice. Respondents desired to increase service user involvement, but they either did not know how to do this into practice or felt that they lacked the resources to do so. Recommendations were made for strengthening involvement, such as employing service users onto research teams. However, legal difficulties in compensating service users for their work were raised.

Conclusion: : Service user involvement was viewed as vital in the development of lay delivered psychological interventions, but remains predominantly tokenistic, partly due to limited guidance, time, and finances. Guidelines could support more meaningful and ethical service user involvement in lay-delivered psychological interventions in areas affected by humanitarian crises.

Introduction

Over the past five decades, there has been growing recognition of the importance of involving service users in the planning and delivery of healthcare services (Omeni et al., 2014). Existing literature documents the positive outcomes that occur when service users have the opportunity to voice their needs and share their perspectives. Service users involved in research may gain an improved sense of well-being, self-esteem and confidence (Minogue et al., 2005; Neech et al., 2018).

Service user involvement can be described as “someone becoming active in one’s own care and in the care of others in similar situations” (Goossen and Austin, 2017) and is often used interchangeably with the term “service user participation” (Thompson, 2007). However, definitions of involvement remain contentious due to the broad nature of the term and the varying ways in which it is defined in the literature thus far. A recent systematic review identified sixty-five dis-

tinct frameworks for patient and public involvement in health-related research (Greenhalgh et al., 2019).

One popular framework to conceptualise participation is the “ladder of participation” by Arnstein in 1969 (Arnstein, 1969). Ascending in order of service user power, the levels are: “nonparticipation” where service users are entirely excluded from decision making; “degrees of tokenism” where service users may be consulted but are not involved in decision making; and “degrees of power” where decision-making powers are in the hands of the service users themselves (see also Appendix A). More recent frameworks often share this stepped model of participation and involvement (Charles and DeMaio, 1993; Hickey and Kipping, 1998).

Despite the existence of numerous frameworks on service user involvement, research has highlighted limited service user involvement to date (Tierney et al., 2016). There is evidence for substantial barriers which hinder user involvement in research, including the financial burden and time consuming nature of involvement (Tait and Lester, 2005),

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a failure to provide service users with relevant information to enable them to make informed decisions, and a failure to provide sufficient opportunities for negotiation (Bee et al., 2015). This may result from the resistance of some professionals to embrace involvement due to their opposition to viewing service users as experts (Tait and Lester, 2005). Power dynamics within institutions operate as a significant barrier to service user involvement (Hodge, 2005).

Service user involvement has seen a particularly strong emergence in the field of mental health in recent years (Brett et al., 2014; Laitila et al., 2018). While most of the current research into service user involvement in the mental health field has largely focused on high-income countries (Noorani, 2013), there is also a growing interest surrounding service user involvement in low-and-middle income countries (LMICs). For example, the 2018 Lancet Commission on global mental health describes the use of three main types of patient involvement within mental health research in LMICs: consultation, collaboration, and patient-controlled initiatives (Patel et al., 2018). These broadly reflect the structure of the previously discussed frameworks of participation (Arnstein, 1969; Hickey and Kipping, 1998; Charles and DeMaio, 1993). However, a 2016 systematic review of service user involvement in mental health research in LMICs showed a lack of high quality research and a weak evidence base for work conducted involving service users (Semrau et al., 2016). Previously, most of the opportunities for involvement of service users appeared to be based on the evaluation of services, rather than active involvement in research. When considering the continuum of participation (Arnstein, 1969), this would suggest that service user involvement in mental health research in LMICs to date remains tokenistic.

However, reviews on mental health service user involvement have not addressed mental health and psychosocial support (MHPSS) interventions developed for populations exposed to humanitarian crises, such as populations exposed to armed conflict, forced displacement (e.g., refugees and internally displaced persons (IDPs)), natural hazards, and other violent and traumatic events. Such populations commonly experience significantly elevated levels of mental disorders due to exposure to violent and potentially traumatic events, forced displacement, impoverishment and substantial uncertainty about future prospects, including financial uncertainty (Charlson et al., 2019). MHPSS interventions are defined as “any type of local or outside support that aims to protect or promote psychosocial wellbeing and/or prevent or treat mental disorders” (Carll, 2008).

A key sub-set of MHPSS interventions are lay-delivered psychological interventions. These are focused, non-specialised brief psychological support interventions based on simplified evidence-based psychological therapies so they can be delivered at the community level by lay workers, including individuals from affected populations, to help address mild/moderate common mental disorders. Examples of such interventions are Problem Management Plus (PM+) (Dawson et al., 2015) and Common Elements Treatment Approach (CETA) (Murray et al., 2014). Lay-delivered psychological interventions are increasingly promoted by the World Health Organization and other key international actors because they are transdiagnostic, they maintain cultural relevance, strengthen access to mental services, and have proven effectiveness, feasibility, and scalability (Dawson et al., 2015; Murray et al., 2014).

The aim of our study is to investigate how service users have been involved in the development of lay-delivered psychological interventions as part of randomized control trials (RCTs) conducted amongst populations affected by humanitarian crises. The specific objectives are to: (Omeni et al., 2014) investigate the purpose of involving service users in the development of the intervention; (Minogue et al., 2005) explore the degree of involvement of service users in the development of an intervention; (Neech et al., 2018) characterize the degree of change to the intervention resulting from the involvement of service users; (Goossen and Austin, 2017) identify barriers and facilitators to the involvement of service users in the development of the intervention

Methods

Respondents and recruitment

This study involved interviews with respondents who were part of RCTs of lay-delivered psychological interventions delivered in humanitarian crises. The study focused primarily on RCTs given that they are, to date, the most common study design used to develop and evaluate MHPSS interventions (Elrha, 2020). The study focused on lay-delivered interventions specifically because they are considered high-priority by international agencies due to their effectiveness, feasibility, and scalability. Lay delivered psychological intervention delivered in humanitarian settings were selected from recent systematic reviews that looked at their effectiveness (Ryan et al., 2021; Papola et al., 2020). We focused on lay-delivered interventions specifically and those studies had to be conducted within geographical areas directly impacted by humanitarian crises (e.g., armed conflict, disasters) or areas which hosted populations displaced by humanitarian crises (e.g., with refugees or internally displaced persons (IDPs)). 19 studies were eligible and we verified the list of studies with experts in the field to ensure that no other study that suited our eligibility criteria was missed.

All respondents were either the principal investigator (PI) or main focal point for service user involvement in the RCT. The locations of the RCTs for the interventions covered in this study were: Colombia, Lebanon, the Netherlands, Pakistan, Rwanda, Tanzania, Turkey, Uganda, and Ukraine. The interventions were delivered by lay workers who originated from the intervention’s target population and underwent training prior to delivering the intervention. All intervention recipients were refugees or IDPs who had been forcibly displaced due to adverse consequences resulting from humanitarian crises.

The sampling of respondents was based on a purposive sampling strategy (based on the previous systematic reviews (Ryan et al., 2021; Papola et al., 2020)) combined with the utilisation of snowball sampling. The respondents were contacted via email and invited to participate. From the 19 studies identified through the literature no other additional studies were identified by our academic networks. Out of the 19 studies, we were able to interview 13 respondents (i.e. sampling 68% of eligible studies). Principles of saturation and information power was achieved after 10 interviews and no new information was gained. Appendix B includes key information on the psychological interventions that the respondents implemented on.

Procedure

Semi-structured interviews were conducted in English by the first author (EO), with two initial interviews being conducted by the second author (AM). A topic guide was constructed prior to the interviews and was piloted and edited following the first two interviews to incorporate any necessary changes (see Appendix C). Prior to the interviews, a working definition of ‘service users’ was provided to each respondent (i.e., “by service users, we are referring to the end users of the intervention or individuals from a similar population to the one that is thought to be the recipient of the intervention”). Respondents were asked to answer interview questions with a focus on the MHPSS intervention for which they were initially contacted, but were advised that they could also draw upon knowledge from other relevant MHPSS RCTs of focused non-specialised psychological support interventions which they had been involved in. The interviews were conducted on Zoom and audio recorded using the Zoom record function and lasted approximately 40–60 min each.

Data collection took place between March and April 2021. Prior to starting the interviews, respondents were provided with an information sheet and signed a written informed consent. The study was approved by the London School of Hygiene and Tropical Medicine (LSHTM) Research Ethics Committee (ID: 22,939). The research team ensured confidentiality by anonymizing all transcripts and removing identifiable information from codes. All interviews were deleted from the researchers’

Table 1
Purpose of service user involvement (as discussed by interviewees).

Purpose of involvement	Interviews in which the purpose was discussed (% and n)
Acceptability of intervention	76.9%, n = 10
Cultural relevance of intervention	76.9%, n = 10
Understanding needs of the population	76.9%, n = 10
Feasibility of intervention	46.2%, n = 6
Assess current barriers to mental health care	46.2%, n = 6
Making the intervention useful/helpful	38.5%, n = 5
Understanding local conceptualization of mental health problems within target population	38.5%, n = 5
Service users assisting researchers to change mode of delivery of intervention	7.7%, n = 1
Granting ownership	7.7%, n = 1

Percentages were calculated by dividing the number of participants who gave this answer by the total number of participants (n = 13).

device immediately after being transcribed, and transcripts were stored in password protected files.

Data analysis

All interviews were transcribed verbatim by the first author (EO). Thematic analysis was used to analyse the data (Joffe, 2012). As a first step, there was a period of familiarisation with the dataset whereby the first author read through the entire dataset and developed a preliminary coding framework. Two other authors (AM and DF), then contributed to the finalisation of the coding framework (reported in Appendix D). The development of the coding framework was predominantly deductive as no existing frameworks were imposed onto this original piece of work. Individual codes were clustered into themes to facilitate analysis. The first author (EO) then proceeded to code the entire dataset using NVivo 12.

Results

Participants

The total number of participants was thirteen, of which seven (54%) were male and six (46%) were female. Seven (54%) of the participants country of residence was a high-income country (HIC) and six (46%) participants resided in a low-and-middle income country (LMIC).

Themes

The result section comprises of five main themes: purpose and methods of involving service users, changes that occurred following service user involvement, perceived value of service user involvement, challenges in involving service users, and recommendations for better involvement.

The first theme is an overall representation of the reasons cited by respondents for involving service users in the adaptation of the intervention and the methods which they used to involve the service user.

Purpose and methods of involving service users

The key findings on the purpose of and methods used for involvement of service users are presented in Tables 1 and 2, respectively. Most interviewees cited acceptability, cultural relevance, and understanding needs of the population as the purpose of involving service users in the development of the intervention.

“If you want your intervention to be effective, it has to be acceptable, culturally relevant, understandable, feasible to use by the target population for whom you are doing that intervention so it’s vitally important that [...] we consult them.”

[P10]

When discussing ‘understanding the needs of the population’, respondents discussed trying to gather a general sense of the issues faced by the population, and more specifically, which mental health issues were

prevalent and which MHPSS interventions were suitable for the population.

Respondents named a variety of different methods for involving service users. Many respondents used in-depth interviews with people from the target population as a form of involvement. A much smaller number of respondents used other forms of involvement such as mock sessions and needs assessment.

“We had key informant interviews, we had free listing interviews, and we had these focus groups, and there we used a general procedure with other [NAME OF ORGANISATION] partners.”

[P4]

The second theme entitled “changes that occurred following service user involvement” has three subthemes: terminology and idioms of distress, illustration, and entire components. The main theme and its subthemes categorise the ways in which the intervention was changed following the involvement of service users. This theme encapsulates the varying impacts which service user involvement had on the interventions.

Changes that occurred following service user involvement

Terminology and idioms of distress

Common changes in interventions resulting from service user involvement were those pertaining to terminology and idioms of distress. The process of changing the language of an intervention often included translating the entire manual to fit the context. Some respondents also mentioned changing terminology to make sure that words and phrases were acceptable, appropriate, and non-offensive (e.g., some words used for mental health may evoke negative stigma). This also included incorporating culturally appropriate idioms of distress and understanding the ways in which distress may be communicated by the target population.

“So we would preferably use words that more or less reflect something like being overburdened by stress or [that] means you have external stressors and you can’t bear it anymore, and that for an obvious reason anyone would, of course, then be burdened too much, but that is like an external cause and it’s less stigmatizing whereas if its internal it’s more stigmatizing so we tried really very much to avoid these words.”

[P1]

Illustrations

Another change resulting from service user involvement concerned illustrations used within the intervention manual. Some respondents stated that it was important for service users that the details of the illustration suited the target population, in terms of clothing, seating position, and room decor. Respondents explained that while these appeared to be subtle changes, they helped to make the intervention more culturally relevant, which in turn could lead to more meaningful engagement from the target population.

Table 2

Methods used to involve service users in the development of MHPSS interventions (as described by interviewees).

Methods of involvement	Interviews in which the method was named (% and n)
Qualitative interviews (semi-structured, in-depth interviews)	84.6%, n = 11
Focus group discussion	46.2%, n = 6
Free listing	38.5%, n = 5
Other advisory group	38.5%, n = 5
Pilot session*	30.8%, n = 4
Needs assessment	15.4%, n = 2
Mock sessions**	15.4%, n = 2

Percentages were calculated by dividing the number of participants who gave this answer by the total number of participants (n = 13).

Note. Many interviewees mentioned using multiple methods of involvement in conjunction.

* Pilot session: a structured run-through of the intervention following incorporation of feedback from service users.

** Mock sessions: Series of informal run-throughs of segments of the intervention whereby service users would provide feedback throughout.

“They said, ‘why are they sitting on the floor, we sit on chairs. Please put them on chairs’, so we put them on chairs, and they said, ‘why is the door open, women would never sit with their backs to a door open and talk, you need to close the door’, so the changes were super subtle and were more about the context that the people were finding themselves in[...], so the translation really was much wider than the written translation.”

[P12]

Entire components

There were some contrasting reports about the extent to which the content of an intervention could be changed following the involvement of service users. Some respondents did report changing entire components and active ingredients of an intervention following feedback from service users.

“I think when we learned about the community and the problems they have, the kind of things that they were expecting, so much of the aspects of the [intervention] changed [...]. We had a battery of different skills, things that we wanted to do and at the end we said take two of them [the components] out and include two additional ones. [...] I think one of them was the meditation step because we saw that [colloquial term for anxiety] was coming a lot [...], so we included the meditation component.”

[P6]

In contrast, other respondents felt that components of an intervention were not subject to change. Several reasons were given for this such as the need to retain core active ingredients of the intervention and a lack of clarity concerning which aspects of the intervention could be changed.

“Interviewer: So, [...] the feedback from service users in the treatment cohort, didn’t really change the content of the intervention itself as that was sort of fixed...”

Respondent: “Yes, correct. All components of [intervention] are the same around the world.”

[P2]

“I think as a field we’re missing a clear joint understanding of what can and can’t be changed within an intervention to keep like, to keep it, to maintain fidelity to the, what we call evidence based original.”

[P9]

The third theme “perceived value of service user involvement” contains three subthemes: development of lay-delivered psychological interventions, improving the well-being of the service user, and granting ownership to the target population. This theme encapsulates the respondents’ perceptions of the positive impact of service user involvement on

the service user, the target population, and on the overall development of the intervention.

Perceived value of service user involvement

Development of lay-delivered psychological interventions

Respondents consistently expressed the critical importance of consulting service users when developing lay-delivered psychological interventions. It was commonly expressed that developing an intervention without service user input would be “impossible”. Some respondents went on to discuss specific reasons why involvement is so important (often citing purposes mentioned in Table 2).

“I think they [the service users] are not even just helpful, they’re crucial. I don’t think you can provide, super sure that you can’t provide, a service unless you have the service users involved, because you don’t know what services they need, just very, very fundamentally so you really do need to have them in the loop, and not even just in the loop, you need to have them in the middle of the game.”

[P12]

Some respondents stressed the importance of involving service users by describing the negative consequences resulting from omitting service user involvement, and how interventions are likely to fail in such circumstances.

“Importantly, if you don’t actively engage with representatives from the community themselves, the research is going to go nowhere because people may not understand, they may not see the relevance, they may just decide not to engage actively.”

[P13]

Improving the wellbeing of the service user

A noteworthy matter which was raised in multiple interviews is the notion that simply being involved in the development process could lead to improvements in the wellbeing of the service user. For example, multiple respondents explained how focus group discussions involving service users in the community had turned into something comparable to a “support group”. Service users shared and bonded over their common issues and coping strategies, which led to a mutual understanding and created a support network between individuals.

“They would talk about their problems and they, some people would say like, ‘well, I experienced that and something that helped me to go, to move forward or to continue with my life was to do this’ and so a lot of people would say like ‘yes I tried that as well’ so it was kind of like a support group which seemed to be really useful to connect people once again, to learn new skills from other people and to feel supported”

[P6]

Granting ownership to the target population

The idea of service user involvement being beneficial as it “grants ownership” of an intervention to the population was discussed in multiple interviews, although the rationale behind the concept appeared to lack consistency between the interviewees. One respondent stated that the importance of having local ownership was to ensure the safety of the population.

“The [intervention] is technically an intervention that was developed outside of the context in which it is currently employed, and with that comes a risk of harm because you may, yeah, you may go against the grain of existing coping strategies and that’s something we wanted to avoid.”

[P8]

Another respondent described the idea of granting ownership as a way in which service users would increase buy-in to the intervention and therefore become bigger advocates for its sustainability.

“I think ownership, community ownership and buy-in by having the service users involved in the design process and thinking about sustainability, and maybe these people who are actually involved in the design can then become the facilitators and then kind of really take this on as something that’s theirs, that’s meaningful to them.”

[P9]

However, the respondent also recognised that the concept of community ownership goes beyond simply committing to the involvement of service users in the development of the intervention.

The fourth theme “challenges in involving service users” represents the main obstacles within the process of service user involvement, which were named by the respondents. The first subtheme explains the difficulties involved in compensating service users for their time and work. The second subtheme explains how target populations may be resistant to being involved within the process of adapting interventions and the various reasons for this.

Challenges in involving service users

Compensating the service user for their involvement

Respondents often mentioned difficulties in compensating service users for their time and effort in being involved in the development of an intervention. Some respondents acknowledged that the service user was the most qualified person to work within intervention development and should therefore be compensated fairly for their work. However, this was difficult to do in practice, as some refugees were not able to earn money due to legal requirements limiting their access to paid employment.

“It was challenging under this funding stream to pay them fairly because, yeah, the most qualified people are often the refugees themselves and, in some cases, they have statuses that prevent them from earning money [...] so although they were qualified, you can’t really get at them without jumping through all sorts of loopholes, [...] we would have to give them vouchers in one country, we would have to do all sorts of weird things that we did to try to make it fair and we, I don’t think we really achieved it because they were doing a lot more work than we paid them for, than we were able to pay them for.”

[P12]

Some respondents described how a lack of compensation caused difficulties as the service users had no material incentive to attend meetings.

“Interviewee: I think people are quite interested to get involved but like actual attendance at the meetings and so on can be challenging...”

Interviewer: Is there any reason for the low attendance, that you know of?

Interviewee: Um, I think when we’re not giving something like tangible, an immediate in return.”

[P7]

It was reported that within the period of involvement, service users sometimes requested compensation, or further support, in the form of business loans and job opportunities. Some respondents named this as a difficulty in service user involvement because service users needed more support than what could be granted and were more interested in other forms of support than being involved in the development of a mental health intervention.

“Many people also mentioned that besides the psychological therapies or services, they also need like some loans, you know, to be able to work, to build like a small chicken [feed] [...] And like, just to be able to buy stuff to sell it once again and things like that, [...]. We also had like a bunch of people that were coming and thought they were like, going to get a job opportunity or something like that.”

[P6]

Resistance from communities

A lack of compensation for service users was also sometimes cited as one of the reasons for communities resisting being involved in the development of interventions.

“i’ve also heard that [they’re] not always, they’re not always happy to help with this and it also depends on the money you give them for doing it, right? If you give them a voucher of twenty euros that helps a lot, and the [Nationality] people, they are working here, they come to the [Name of Country of Intervention] only to work here. So, every hour they spend in [Name of Country of Intervention] the should be paid, right, for them. Otherwise, they would go back to their children”

[P1]

However, various additional reasons for communities not being willing to engage in the development of interventions were mentioned. One reason for resistance was sensitivity towards being encouraged to partake in activities which are imposed upon them by unknown external groups. Consequently, building trust with the target population was described as a challenging process for respondents.

“The nature of the [Name of Country] war means that you just have distrust and mistrust in every, every, every layer and every conceivable connection and you can’t really anticipate it so that was a really big challenge... to gain, to gain that trust.”

[P12]

“So we came to talk with them and, and they were resistant, they were resistant like because [...]“you are trying to come here to impose something that we haven’t asked for, why do you think we need you”. It’s tricky to gain their confidence, [...] people can say that “they are too serious, they are too difficult” and, yes, they are difficult because what we have done to them is historically has been abusive.”

[P5]

These populations were therefore, at times, initially resistant to being involved with interventions brought to them by unknown research teams. However, it appears that such issues could be resolved through building trust with community leaders and increasing communication with community members.

“When you go into these communities there is always some pushback from the communities and having key people like leaders that would allow us to get in touch with the community, show them what you’re trying to do and, and that you, and that you are going to take them into account, to not only understand them better and to design the instruments of your study in a better way, but also to shape the intervention that you want to use according to their needs is really useful.”

[P6]

The final theme “recommendations for better involvement” represents the main suggestions from respondents of how service user involvement can be better utilised in the future, through two subthemes: employ people from the target population onto research teams and increase engagement with service users.

Recommendations for better involvement

Employ people from the target population

Employing people from the target population was consistently suggested as the best way to improve involvement of service users for a multitude of reasons. Respondents often stated that having people on the team who had a deeper understanding of the issues faced by the target population and therefore knew the appropriate way to address them was paramount to the success of service user engagement. Respondents described how, due to the nature of MHPSS interventions in areas impacted by humanitarian crises and the resulting socioeconomic deprivation of the target population, there was generally an uneven power dynamic between the researcher and the service user. Employing people from the community could help to bridge this power dynamic, resulting in a more trusting relationship and, as a result, the opportunity to elicit more meaningful engagement from the service user.

“They [the research team] have to be from a similar cultural background and so we, we do make efforts to hire local researchers, who understand the sensitivities of the populations, who are able to engage with the population [...] And then that ensures that you’ll get meaningful responses from your target audience.”

[P10]

“They [workers from the target population] are the face when they go to the communities, the villages, and this is going to be easy for the community to accept, because there is always going to be push back, in a way. At least that’s what we experience here. There’s always like this kind of sentiment that well, they always come and do the thing, get their money, and leave the community like that, you know.”

[P6]

One participant further explained how people from the target population on the research team can improve relationships with potential service users. Populations have previously experienced negative consequences of being involved with research teams who have conducted their research in pursuit of financial gain, and then left the setting. This participant suggested that having people from the target population on the research team could ensure that past negative experiences with researchers do not prevent the population from being involved in other research/ interventions. Therefore, adding weight to the idea that employing people from the target population is necessary for the research team to build trust with potential service users.

“I would like to explore further how we can push the boundaries a bit there. I think what we, what we are doing is pretty middle of the road and it would be nice to see if you could, for example, have co-PI who is a [country] refugee.”

[P8]

Some respondents considered the idea of increasing service user engagement by employing a service user to work at a high position on the research team, for example as a co-PI, but none of the respondents had implemented this in practice.

Increase engagement with service users

Respondents often stated that service user involvement should happen much earlier than it usually does. For example, service users should be consulted before an intervention is chosen for the target population. Very few respondents stated that service users had been involved at this point, despite some stating the benefits of doing so.

“I think there are ways we could have probably brought in service users more intentionally from the beginning.”

[P9]

However, one participant pointed out that lay-delivered psychological interventions are generally designed to be adaptable to different situations, therefore it makes sense to involve service users at the adaptation stage. However, there was recognition that involving service user input at conceptualisation stage of the base model of the intervention may also be beneficial.

“It would have been nice to have input from participants earlier in the process. Yeah, although it’s kind of the whole point, it’s kind of the whole point of the [Name of NGO] interventions is that they’re kind of designed to be like, flexible or adaptive or contextualizable to different situations, but potentially involving more service users in the development stage of the like base model of the [Name of Intervention] would have been helpful from [Name of NGO]’s side.”

[P7]

In some cases, increasing engagement with service users appeared to be seen as a boundary rather than a goal. There appeared to be some uncertainty surrounding the practicalities of how service users could be involved to a higher level, therefore suggesting that the idea had not passed the stage of conception. However, respondents express the desire to push the boundary and increase involvement.

“You know, token participation somewhere on the, the left side of the spectrum. I would say our approach falls, our approach falls somewhere in the middle. I think it would definitely be interesting to push the boundaries a bit to see if you could be more participatory.”

[P8]

Despite this, some respondents proposed moving away from what commonly appears to be a rigid and somewhat inadequate structure of service user involvement in favour of utilising service users in more creative and design-orientated roles within the adaptation of interventions.

“We’re actually like taking a step back from what we originally proposed, and having community design workshops where we’re bringing together service users and community members to really be part of the development and design, which I think we’ll see how it goes but it’s kind of a step in the direction you’re talking about of meaningfully engaging with service users, not just in terms of what needs to be changed, but what we need to start out with [...], forever people have recognized the importance of involving the community and service users like that’s something that I don’t think anyone will dispute, but I do feel like maybe we haven’t done it in the right way, more like in a meaningful enough way.”

[P9]

Discussion

This study sought to investigate how service users were involved as part of the development of lay-delivered psychological interventions. The findings displayed the variation in which involvement was conceptualised and used by respondents.

Respondents discussed a range of reasons for involving service users in the development of lay-delivered psychological intervention. Most reasons centred around acceptability, cultural relevance, and understanding the needs of the population. Acceptability has been cited as a purpose for service user involvement within MHPSS interventions and the mental health field more generally (Yates et al., 2015). In the literature on MHPSS interventions more specifically, some research has advocated for the importance of involving service users during the cultural adaptation phase for the purpose of ensuring the cultural relevance of an intervention (Perera et al., 2020).

Interestingly, few respondents justified the need for involving service users based on more ethical arguments. In the general literature,

granting ownership of the intervention to the target population is more commonly discussed as an outcome of involvement (Adams et al., 2020; Rass et al., 2020), rather than a purpose of it.

Respondents shared how involving service users in the development of the intervention had resulted in changes to it (language, terminology, images, etc.). Importantly, there were contrasting opinions regarding the extent to which an interventions' content and core components could be changed following feedback from service users.

A systematic review of mental health interventions amongst disadvantaged populations described multiple studies which reported struggling to both adapt interventions to better suit the needs of communities while retaining the meticulous standardisation required in RCTs (Cyril et al., 2015). Therefore, the tension between maintaining fidelity to evidence-based interventions and the ability to tailor the content to suit the population remains a possible challenge to service user involvement.

An additional challenge concerns compensation to the service users for their work. In some of the trials included in this study, financial payment was not possible due to legal limitations surrounding paid employment for refugees. Past research on the involvement of service users in mental health research has outlined the importance of compensating service users for their involvement as payment validates the contributions of service users and because offering payment encourages research teams to make use of the knowledge gained from the service users for the purpose of gaining a proper return on their investment (Syrett, 2011). While financial payment can be difficult due to legal limitations, research teams have previously compensated study service users using in-kind contributions such as phone credit, refreshments, and transportation cost coverage, but this was often perceived as being an insufficient form of compensation. Therefore, ensuring the compensation of service users may also incentivise research teams to pursue more thorough service user involvement which goes beyond tokenism (Romsland et al., 2019).

Some respondents described the unequal power dynamics existing between research teams and service users. The power dynamic between researchers and service users in humanitarian settings has previously been documented in literature, some of which suggests that the utilisation of service users in research is a transactional relationship rather than one depending on relational engagement (Lokot, 2019). One respondent stated that the nature of working with populations that have been exposed to humanitarian crises is that there will always be a power dynamic, and it is important for research teams to be conscious of this. One respondent suggested that one partial remedy for this power imbalance is to employ people from the target population as part of the core research team. This necessitates a redistribution of power by having research teams working in partnership with people from the target population and would therefore approach the upper levels of Arnstein's ladder of participation (Arnstein, 1969). However, it is important to consider the risks resulting from having affected populations collect data for research teams, such as the relationship becoming exploitative. Previously, refugee research assistants have spoken about their sense of alienation, exploitation, and disillusionment within their roles in research (Sukarieh and Tannock, 2019). Therefore, in order to safely employ people from the target population, there must be an increased guidance that can support more ethical practice, and ethical review committees including criteria on how affected populations can be more ethically involved in research.

Many respondents expressed that they would have liked to involve service users earlier in the process, in more stages, or in more meaningful ways. Respondents who suggested involving service users earlier discussed the possibility of engaging with service users before approaching them with an intervention that has already largely been developed. Respondents also discussed involving service users throughout the development process by employing them in a role within the research team. Overall, respondents seemed to highlight that there is room for improvement when it comes to involving service users in the development of

MHPSS psychological interventions. The importance of involving people from the outset rather than later in the project has been highlighted in previous research (Lokot and Wake, 2021).

The study has some key implications. Various recommendations were made by respondents to improve service user involvement. These included involving service users earlier in the process, involving them in roles which surpass consultation, providing fair compensation, and offering service user roles within research teams for the duration of the development of the MHPSS intervention. Therefore, the study findings suggest that there is a need for structured guidelines on service user involvement when developing psychological interventions in areas affected by humanitarian crises. This would be a first step in ensuring that research teams are clear on what level of involvement they are currently achieving and how to progress in this area. This may help research teams to have a clearer perception of how they are able to involve service users, and most importantly, how they are able to improve service user involvement.

Overall, this research sheds light on the need to progress past the use of tokenistic forms of involvement when developing lay-delivered MHPSS psychological interventions for populations affected by humanitarian crises. In the context of Arnstein's ladder of participation (Arnstein, 1969), ideally service user involvement should reach the level of 'partnership'. This would necessitate a redistribution of power towards the service user and allow the service user the opportunity to work collaboratively alongside research teams. However, the data collected conveyed that the predominant level of participation is tokenistic and there is a distinct lack of representation of higher constructs of participation in current practice, in such contexts.

A key strength is that this is the first study focusing on the involvement of service users in the development of lay delivered psychological interventions. Due to the limited number of MHPSS psychological interventions which are lay-delivered we were able to interview PIs and other relevant research staff from almost 70% of eligible studies and can therefore be confident that we have obtained high representation from the field.

The study has a few limitations. The study focused solely on RCTs which means that information on service user involvement in other types of study designs in humanitarian settings is not addressed. RCTs typically have increased financial and institutional support, making them a unique type of intervention to assess. Secondly, some respondents had been involved in the intervention development several years prior to the interview with them which may have impacted memory recall. For example, some respondents were able to respond confidently to some questions but not to others, sometimes stating that they could not remember such details. This may also be a result of respondents being heavily involved in some stages of service user involvement and not others, e.g., being involved in recruitment of service users and not being present for the actual involvement (e.g., qualitative interviews, focus group discussions). A third limitation was the potential of social desirability bias. This may have prevented some PIs from participating in the study or prevented study respondents from divulging too much information for fear of their research being perceived in a negative light.

Conclusions

The study investigated how service users were involved as part of the development of lay delivered psychological interventions. Despite an overwhelming belief that service user involvement is vital in the development of MHPSS interventions, there was a perception amongst respondents involved in delivery of MHPSS interventions that the involvement of service users remained predominantly tokenistic. Respondents expressed a desire to increase involvement of service users, and some specified ways in which this could be done, such as having a service user in a co-PI position. A lack of time and financial means were highlighted as barriers for the involvement of service users.

Declaration of Competing Interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.jmh.2022.100087](https://doi.org/10.1016/j.jmh.2022.100087).

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