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Prevention of, and response to, sexual and gender-based violence, for refugees who experience communication disability: Evidence from Rwanda

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Abstract

Purpose: Risk of exposure to sexual and gender based violence increases during forced migration. Refugee girls and women with communication impairments are at particular risk, with under-identification and lack of appropriate services contributing to increased risk of abuse and limited access to support/redress. This paper describes an innovation project in Rwanda, involvingn the refugee community and service providers. The projects aimed to: a) Document sexual and gender based violence prevention and sexual and reproductive health education services, b) identify inclusive practice and challenges, c) understand refugees' perspectives on access to information and services, and d) recommend changes.

Method: The project was framed using the Humanitarian Innovation Guide and drew on action research. Individual interviews (21), focus group (81 participants) and workshops (38 participants) were carried out. Content and framework analysis were used and a Humanitarian Innovation Guide 'Problem Statement' and 'Challenge Brief' were developed.

Result: Interviews and focus group data generated seven categories and themes, including services, risks, experiences, and needs. Workshops validated findings and participants identified next steps and solutions.

Conclusion: Refugees experiencing communication disability face challenges related to sexual and gender based violence prevention and sexual and reproductive health education. Service providers face challenges meeting refugees' needs, but can identify ideas for improved inclusion.

Keywords: *SGBV & srhe;communication disability; Rwanda*

Introduction

The risk of exposure to sexual and gender-based violence (SGBV) is acknowledged to be heightened during situations of conflict and forced migration (Inter-Agency Standing Committee, 2015; United Nations High Commissioner for Refugees [UNHCR], 2015). UNHCR (2025) defines SGBV as:

> Sexual, physical, mental and economic harm inflicted in public or in private. It also includes threats of violence, coercion, and manipulation. This can take many forms such as intimate partner violence, sexual violence, child marriage, female genital mutilation and so-called 'honour crimes'. (para. 4)

Although men and boys are not exempt from experiencing violence and abuse related to their gender, women and girls are considered most at risk of SGBV. This is, in part, due to culturally influenced gender norms in some communities.

The reasons for SGBV are complex and varied, influenced by the interplay of factors such as the social and physical environment, culture, religion, legal frameworks, and the effectiveness of prevention and protection services. In conflict situations, community protection mechanisms often break down. There is a high risk of exposure to rape as a 'weapon of war' for women and girls in conflict zones, such as in the Democratic Republic of Congo (DRC),

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which has been described as the “epicentre of sexual violence in the world today” (Office of the United Nations High Commissioner for Human Rights, 2019, unpaginated).

Izugbara et al. (2018) report that people with, or experiencing, multiple and intersecting risk factors (such as being a refugee, being female, experiencing breakdown of community protection mechanisms, experiencing loss of assets and/or income, trauma or distress, being in an unfamiliar situation) are recognised to experience heightened susceptibility to SGBV. Furthermore, people who experience disability (Lawson & Beckett, 2021; Shakespeare, 2018) are at increased risk of exposure to SGBV (United Nations Department of Economic and Social Affairs [UNDESA], n.d.), due to complex factors that may include increased reliance on others for care and protection, limited mobility, limited communication, sensory challenges, and/or stigma and discrimination that may expose them to risk of neglect, abuse, and/or coercion. People who experience communication disability are at particular risk of exposure to SGBV. Evidence suggests that they are, in some cases, actively targeted by perpetrators because of their reduced ability to report abuse (Conte et al., 1989; Farrar, 1996; Keilty & Connelly, 2001; Plan International, 2013) and the likely discreditation of their story if they attempt to do so (Keilty & Connelly, 2001; UNHCR, 2003, 2011; WRC, 2014). The evidence above is focused more on people at risk of and/or survivors of SGBV than on societal and environmental causes of SGBV.

A *refugee* is a person who has been forced to flee their home and has crossed a border, seeking protection. Refugee status is granted based on compliance with the 1951 Geneva Convention and its 1967 protocol (United Nations General Assembly, 1951; 1967) that the person has fled due to a well-founded fear of persecution” (Article 1) or other defensible reason. Today, over 89.3 million people have been forced to flee their homes worldwide and 21.3 million are formally registered as refugees (UNHCR, 2021a).

Refugees who experience disability are acknowledged to be one of the most under-identified and at-risk groups in forced migration situations, often failing to access the humanitarian support they need due to physical, environmental, and social barriers to information, health, (re)habilitation, and protection access (Mirza, 2011; UNDESA, n.d.; UNHCR, 2011; Womens Refugee Commission [WRC], 2014). Despite a call to ensure “a swift and systematic identification and registration of refugees and other persons with disabilities, with particular attention to those who cannot communicate their own needs” (UNDESA, n.d., para. 9), data on the incidence and prevalence of communication impairment and related disability amongst refugee populations are extremely limited and may be significantly underestimated (Barrett et al., 2019). An ongoing lack of visibility, and hence identification, along with negative perceptions about disability in many contexts, all impact upon the availability and accessibility of life-protecting and life-promoting services (Costa, 2012; Tanabe et al., 2015), especially for those who experience communication disability and who may struggle to make their needs known.

There is an acute lack of formal and informal specific services for refugees with communication impairments, who experience communication disability. Speech-language pathologists (SLPs) are infrequently part of humanitarian health and rehabilitation teams. Additionally, 76% of the world’s refugees are hosted in low and lower-middle-income countries (LMICs; UNHCR, 2022), where there are few SLPs in public services (Wylie et al., 2016). For example, in Rwanda, at the time of writing, there were four SLPs, serving a population of 13.8 million (World Population Review, 2022). Even where SLPs are present, many have been educated on programmes using curricula designed for high-income country settings and rarely receive education or training to work in acute or protracted humanitarian contexts, which demand an in-depth understanding of humanitarian architecture and systems.

UNHCR and their implementing partners are responsible for co-ordinating the SGBV prevention and response mechanisms for refugee populations globally. Response and support systems include medical, legal and psychosocial support, and safe-space provision. Some interventions aim to prevent SGBV, including provision of sexual and reproductive health education (SRHE), that contributes to understanding sexual and reproductive health rights. In Rwanda, at the time of this project, services for refugee-survivors of SGBV were provided through a combination of refugee community specific services (e.g. refugee healthcare) and host community state services (e.g. police/judicial services). SGBV prevention services were provided through a range of routes, including SRHE delivery in schools and health services, public messaging aimed at SGBV survivors and potential perpetrators, and environmental changes such as improvements in the security of water, sanitation, and hygiene facilities and lighting in public spaces. Refugee community specific services were provided by UNHCR and by a range of implementing partners (such as multilateral agencies and international non-governmental organisations [NGOs] e.g. United Nations [UN] agencies, Save the Children, American Refugee Committee, Humanity and Inclusion) and national NGOs, that UNHCR contract on a fixed-term basis. Children’s protection services and adult SGBV prevention and response services were provided by different implementing partners.

Most SRHE and SGBV related services rely heavily on the ability to use, hear, and understand spoken language; meaning that those with communication impairments are at risk of disabling exclusion, unless services are designed to be accessible. No specific service adaptations were made for refugees who experience communication disability.

Evidence suggests that the intersection of communication disability, forced migration, and lack of inclusive and specialist services, reduces access to SRHE, increases risk of exposure to SGBV, and reduces access to protection services such as medical, psychosocial, and legal support.

Context

Rwanda has a significant refugee and asylum seeker population of 135 109 (UNHCR, 2024). At the time of this project, registered refugees were hosted across six camps and in two main urban locations. SGBV prevention and response services were provided to refugees by implementing partner organisations, including Save the Children Rwanda and American Refugee Committee. Rwanda had extremely limited specialist services available for people who experience communication disability. UNHCR Rwanda's implementing partner organisations did not employ any SLPs, nor provide any specialist services for refugees who experience communication disability, beyond limited sign language training and interpretation. The accessibility of mainstream public and refugee-specific services was also limited for people who experience communication disability.

In 2015, UNHCR Rwanda conducted an in-country disability situation analysis, during which communication disability was recognised to be a risk factor for exclusion from services (Lange, 2015). Concerns related to exclusion from SGBV response services, for refugees who experience communication disability, were raised following this report. UNHCR staff approached the authors to discuss the need and potential to investigate this issue, and the team subsequently secured funding from the Humanitarian Innovation Fund to carry out an initial project to: a) Investigate existing knowledge about the intersection of SGBV risk, communication disability, and refugee status, b) begin to understand and describe the challenges to supporting refugee-survivors of SGBV who experience communication disability in Rwanda, and c) identify any reported good practice.

Acknowledgement of the risk of SGBV for people who experience disability abounds (e.g. Plan International, 2013, 2016; Sobsey, 1988, 1994; Sullivan & Knutson, 2000; UNHCR, 2011; WRC, 2014, 2015) as does that on the risk of SGBV for refugees (e.g. Bukyensengye, 2012). There is less evidence (although it is increasing) on the risk of SGBV for refugees who experience disability (e.g. UNHCR, 2011; WRC, 2014) and specifically, far less for refugees who experience communication disability. To investigate existing knowledge about the intersection of SGBV risk, communication disability, and refugee status, a literature review for this initial project was carried out on disability/communication disability, SGBV, and forced migration/humanitarian contexts. In summary, the review, which is published in full in Barrett and Marshall (2017), identified and synthesised evidence from fifteen publications and found evidence that people who experience disability are at significantly higher risk of experiencing SGBV than the general population, particularly those who experience communication disability and women/girls with hearing and/or intellectual impairments. Risk factors were found to be social, individual, and environmental, with all potentially intersecting. Refugees with functional communication limitations were found to face myriad social barriers to effective participation in SGBV services. These barriers included behavioural, attitudinal, and environmental barriers (e.g. inaccessible services and limited service provider skills and knowledge). Evidence is emerging of humanitarian organisations recognising communication inaccessibility as a barrier to accessing SGBV services, but there was little evidence of good practice in supporting people who experience communication disability to report and access support for SGBV in published literature. The literature identified technical support and specialist expertise as urgent needs. Based on the publications reviewed, in summary, our literature review (Barrett & Marshall, 2017) recommended the following:

(1) People who experience communication disability should be identified, registered, and receive inclusive SRHE and SGBV services, particularly adolescent girls,
(2) Service providers should engage in multi-agency collaboration,
(3) Services should be inclusive and non-discriminatory practice should be a standard service requirement (as per the Convention on the Rights of Persons with Disability [UN, 2016]),
(4) People who experience communication disability should be involved in service planning, and
(5) High-quality, participatory research on SGBV, communication disability, and forced displacement is needed in low and middle-income countries.

During this initial project, in order to begin to understand and describe the challenges to supporting refugee-survivors of SGBV who experience communication disability in Rwanda, focus group discussions and interviews were conducted with key stakeholders, including members of the refugee community and service providers. These data demonstrated that service providers and refugee community members in Rwanda were concerned that the lack of access to SGBV *prevention* services (specifically SRHE), contributed to heightened risk of exposure to SGBV. Anecdotal reports existed of SGBV perpetrators targeting refugees who experience communication disability. The focus group discussion data demonstrated that understanding of communication disability is extremely limited at all levels (from decision-makers to service providers) with service providers lacking knowledge about the range of communication impairments and the impact of communication disability. They also lacked skills to support and include refugees who experience communication disability when providing services. Barriers to accessing SGBV services were found to occur at every stage of prevention and response, including police reporting, medical and psychological support services, and legal support/redress. Endemic stigmatisation and discreditation of refugees who experience communication disability, by community and service providers, was reported and a widespread misunderstanding that use of sign language provides a blanket solution to communication accessibility, was identified. This initial project is reported in full in Marshall and Barrett (2018).

In response to the findings of the initial project described above, the authors worked with UNHCR Rwanda staff to secure further funding from Elhra's Humanitarian Innovation Fund. Collaboration with UNHCR Rwanda, the agency that supports the Government of Rwanda to host refugees, was central to this project and its role and values inevitably influenced its delivery.

A second, semi-systematic literature review (Snyder, 2019) was then carried out, focusing specifically on access to SRHE services (as a means of SGBV prevention) for people who experience communication disability, using search terms related to SRHE, refugees, sub-Saharan Africa, and communication disability. Six bibliographic databases and 'grey literature' were searched and a total of 417 documents were identified, with data extraction being carried out on 21 full text documents (see Supplemental material 1 for references of included documents, with each reference given a unique code). Data were analysed using thematic analysis (Braun & Clarke, 2006). Although Braun and Clarke have developed their ideas on reflexive thematic analysis significantly since (e.g. Braun & Clarke, 2021), we considered that their early (2006) version of thematic analysis was most appropriate to use for an analysis of texts. Theoretical (deductive) analysis was deemed appropriate, as texts were searched for specific data related to SRHE for people who experience communication disability and semantic codes generated. Furthermore, this approach to thematic analysis was congruent with the methodology of this series of projects (see Methodology below for further detail). Four themes and 29 sub-themes were identified. Supplemental material 2 lists each theme and sub-theme, listing the supporting documents. Figure 1 shows documents included at each stage.

The four themes were as follows:

Theme 1: Challenges to accessing SRHE, for people who experience communication disability

Nineteen publications described challenges in accessing or providing SRHE services, reported by people who experience communication disability, carers, or service providers. For example, Plan International (2017) reported that "Few health facilities or education providers offer alternative, accessible formats… These communication barriers make it difficult for young women and girls with disabilities to get health-related information" (p.176).

A number of challenges with service access were attributed to the person, including social and physical isolation, restricted autonomy, and lack of knowledge of SRHE and services (although the causes were wider than communication disability). Others were related to the intersection of communication disability with cultural and gender norms and to access age/ability-appropriate education. Additional factors limiting access to SRHE services included caregiver and service provider ignorance of the need for, and lack of materials or skills to deliver, SRHE to people who experience communication disability. Furthermore, carer and service provider discomfort with educating people they infantilise and consider asexual, hypersexual, or vulnerable, limited availability of SRHE opportunities.

Where it was available, service access was hampered by a lack of accessible information, service provider discrimination, prohibitively high costs of accessing services, and the relative absence of guidance for inclusion of persons who experience communication disability, in policy and legislation. Additionally, gaps in information, education, and communication methods for SRHE, as well as disempowerment in sexual and reproductive health decision-making and the existence of forced abortion or long-term contraception, were identified.

Theme 2: Experiences of SRHE

Ten publications reported on the experiences of people who experience communication disability and/or caregivers/service providers, when trying to access or provide SRHE services. All referenced global data and one also referenced sub-Saharan Africa specifically.

Data from over ten countries, including in SSA, illustrated how people who experience communication disability had experienced disrespectful treatment and stigmatisation from SRHE service providers. They reported experiencing fear when attempting to access SRHE and misperceptions about sexual and reproductive health, in part due to limited access to formal and informal services. When attempting to access existing SRHE services, they experienced difficulties finding someone who they could trust to maintain confidentiality and experienced various forms of communication inaccessibility and/or breakdown, when trying to engage with service providers. In the home, people who experience communication disability had little exposure to SRHE and experienced the family's discomfort when topics related to sexuality were raised. Finally, they

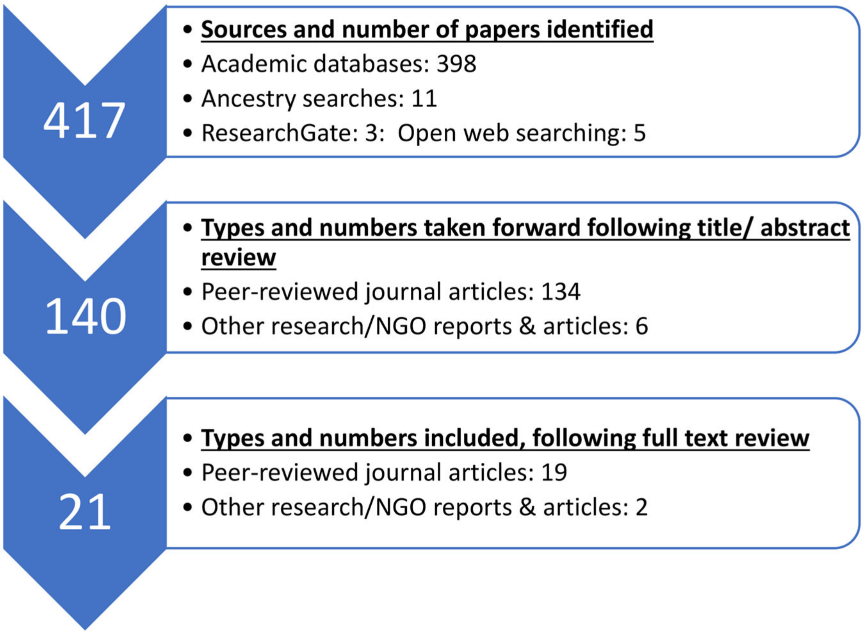


Figure 1. Flow chart of document selection for literature review 2.

experienced limitations to expression of their sexual identity and freedoms.

Similarly, service providers experienced barriers to communication and lack of training and accessible materials to use with people who experience communication disability; whilst carers experienced a lack of knowledge, skills, and confidence to provide SRHE. For refugees in sub-Saharan Africa, attitudinal barriers to service access and long wait-times for services were also common.

Theme 3: Inclusive SRHE practices

Nine publications, covering more than ten countries, described aspects of SRHE services that were inclusive of people who experience communication disability and demonstrated promising practice. Seven referenced global data and two specifically referenced sub-Saharan Africa. Global data described the development of comprehensive guidelines, policy, curricula, and training materials on sexuality education for all as foundational. Implementation of ongoing programmes where SRHE is considered a human right, integration of SRHE into existing programmes for people who experience communication disability, and mainstreaming communication accessibility, were considered existing promising practices. The literature applauded programmes that demonstrated the engagement of affected people and their families in programme design.

Two publications, covering more than three countries, referred to promising inclusive practices in sub-Saharan Africa. They described introducing SRHE integration into inclusive education practices and community-based programmes, implementing accessible teaching materials and methods, reducing healthcare costs, service provider training, and engaging parents.

Theme 4: Future recommendations

Eleven publications covering six countries, provided recommendations for future inclusive SRHE practices.

Recommendations from papers based on global data included:

(1) Development of clear, inclusive SRHE policy and guidelines (Collier et al., 2006),
(2) Involvement of people who experience communication disability in service planning (Collier et al., 2006),
(3) Development of appropriate, tailored, and accessible materials and teaching methods (Clark & O'Toole, 2007; Collier et al., 2006; Finlay et al., 2015; Güven & İşler, 2015; Louw, 2017; McDaniels & Fleming, 2016; Rohleder et al., 2012),
(4) Education and training for teachers, health professionals, support-workers, and parents (Clark & O'Toole, 2007; Collier et al., 2006),
(5) Support for people who experience communication disability to recognise abuse (Collier et al., 2006; Ingraham et al., 2000), and
(6) Further research (Collier et al, 2006; Jones et al., 2018).

Regarding sub-Saharan Africa, data originated from five countries (Ghana, Kenya, Nigeria, South Africa, Uganda) and additional recommendations, based on data from this region included:

(7) SRH rights education and awareness-raising for people who experience communication disability (Chappell et al, 2018; de Reus et al., 2015; Enwereji & Enwereji, 2008; Louw, 2017; Mprah et al., 2017; Rohleder et al, 2012; Tanabe et al., 2015) and
(8) Provision of accessible information, including using sign language interpreters, where needed, for deaf

people (Chappell et al, 2018; Enwereji & Enwereji, 2008; Louw, 2017; Mprah et al., 2017).

This second literature review demonstrated that refugees who experience communication disability face myriad barriers to accessing SRHE services – the most significant being social (attitudinal and behavioural), environmental, and structural/organisational barriers. These barriers prevent access to essential SRHE services, impacting on sexual and reproductive health rights realisation and increasing risk of exposure to SGBV. Some good practice was also documented in the literature. This included rights-based disability-inclusive approaches to SRHE (Ingraham et al., 2000; Plan International 2017), participant engagement in planning and delivery of programmes (Plan International, 2017), and development of accessible and appropriate programmes (De Reus et al., 2015; Finlay et al., 2015; 2015; Ingraham et al., 2000). Despite documentation of some good practices, there was little evaluative evidence of outcomes.

The findings from the initial project (Marshall & Barrett, 2018) and the second literature review reported here, together indicated the need to understand access to SRHE for refugees who experience communication disability, to better inform how to address prevention of exposure to SGBV. This led to the design of the innovation project reported below. See Figure 2, representing the two projects' stages.

Aims

The aims of this project were, in relation to the provision of services to refugees in Rwanda who experience communication disability, to:

(1) Document current SGBV prevention and SRHE service provision,
(2) Identify inclusive practice and challenges,
(3) Describe and understand refugees' perspectives, and
(4) Make recommendations for possible ways forward.

Methodology

The project reported below was an innovation project responding to the needs of the refugee community and service providers. It bears some similarities to action research (Lewin, 1946) but was not designed specifically as an action research project. *Action research* is a transformative and practical methodology that involves researching with simultaneous social action. It is a problem-based approach to the active generation of theory, as data are generated through following a series of steps towards planning, action, evaluating the results of the action, and critical reflection, which can lead to ongoing iterations of the research and further action in a cyclic (Koshy, 2010; O'Leary, 2004) or spiral (Kemmis & McTaggart, 2000) manner. Knowledge and action are generated simultaneously, each contributing to the development of the other. According to Reason and Bradbury (2006), action research seeks to "involve, empower, and improve" (p.3) the participants' world and paves the way for solving real issues quickly and with flexibility, as is required in humanitarian settings. Data from the initial project (reported in the Introduction/context section above) led to the iterative and responsive design of this project. Data from the initial and current projects were generated and verified by the participants; and suggestions for next steps were generated, refined, and verified as desirable and implementable, with a view to piloting and further evaluation and iterative solutions planning and testing (which was subsequently carried out in a follow-on project, mentioned in the Discussion below).

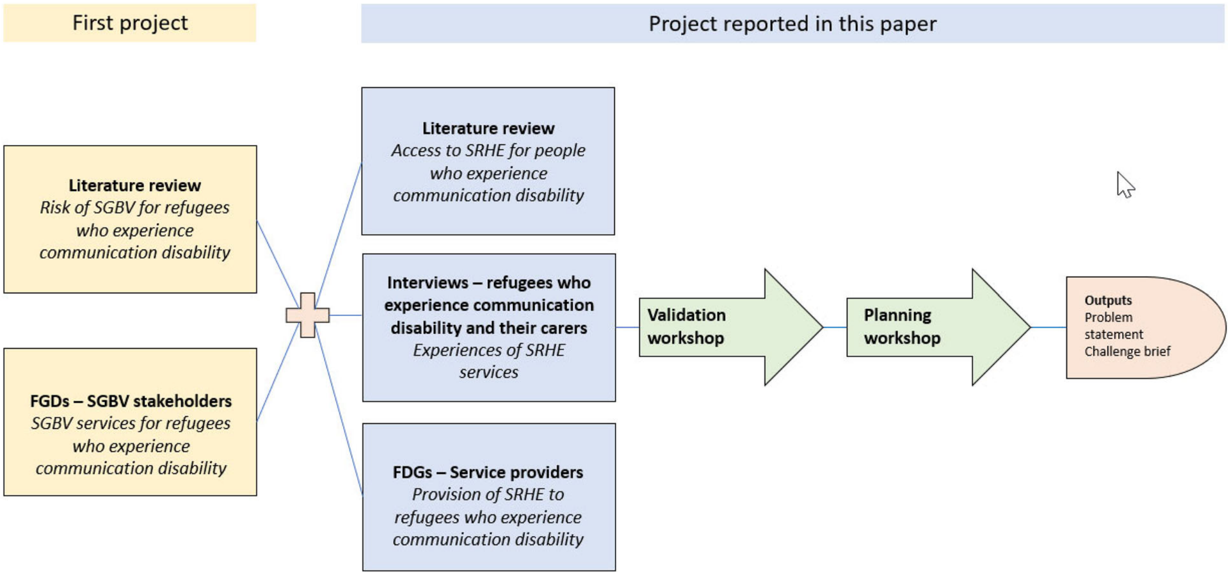


Figure 2. Projects' flow diagram.

The project team used the guidance and incorporated activities from the Humanitarian Innovation Guide (Humanitarian Innovation Fund & Elrha, 2019a), especially during participatory problem identification and solutions planning with the refugee communities and their service providers. The Humanitarian Innovation Fund (which funded this project) developed the Humanitarian Innovation Guide, a practical toolkit designed to support and structure innovation thinking and application in humanitarian contexts. The Humanitarian Innovation Guide consists of a six-stage approach: Recognition, search, adaptation, invention, pilot, and scale. Each stage includes exercises and frameworks to support innovation. The resources, time constraints, and scope of this project meant that attention was focused on stages 1–3 of the innovation process, with the intention to address stages 4–6 in the future.

The core project team, who had collaborated previously, consisted of two international UNHCR staff members (one female SGBV specialist and one female community-based protection officer) and two international, female, British SLPs (one academic and one practitioner-researcher) who did not experience disability at the time of data generation, and who have extensive experience of working in low-resource and humanitarian settings. The wider team included project supporters from UNHCR's implementing partner organisations, who were trained in basic qualitative data generation methods and techniques and who assisted in the recruitment and interviewing of people who experience communication disability and their caregivers (see below). The initiation of this project by the core project team responded to an issue identified by UNHCR, through their consultation with refugees who experience disability. That the core team did not include local researchers or people with lived experience of communication disability, reflects the relative under-recognition of communication disability among the refugee community and the lack of local SLP researchers.

Project ethical approval was granted by the authors' university (Ethos Ref number: 0379) and approval given by UNHCR Rwanda and the Rwandan Ministry for Disaster Reduction and Refugee Affairs (now Ministry for Emergency Management; Ref 1363/MDMR/DRAT18).

Data generation, integration, verification of findings, and solutions planning used several methods. Data were generated from:

(1) Individual interviews with people who experience communication disability and their caregivers,
(2) Focus group discussions with SRHE service providers, groups supporting refugees who experience disability, and representatives from stakeholder groups, and
(3) Stakeholder workshops:
    a Stakeholder validation workshop, and
    b Stakeholder planning workshop.

Data generation

Individual interviews with people who experience communication disability and their caregivers

Twenty-one individual semi-structured interviews were carried out with seven refugees who experience communication disability and 14 caregivers of refugees who experience communication disability. The interviews aimed to facilitate understanding of their perspectives, in relation to accessing SRHE services. To recruit and generate data ethically, the core team delivered three days' training to 16 UNHCR and partner organisation staff who had prior experience in disability and/or SGBV fieldwork. These 16 staff are described as *project supporters*. The training covered communication disability, accessible communication methods, community-based research, as well as provision of psychological first aid, should any (potential) participant experience distress. They identified potential interview participants using data from UNHCR databases and through their knowledge of the community in which they work. They approached potential interviewees with initial written and verbal information about the project, before returning a week later to ask if potential participants would be interested in being interviewed for the project. Participant information was then made available in three languages and three written accessibility formats, as well as verbally. Informed consent was obtained and semi-structured, face-to-face, in-depth interviews were carried out collaboratively by one of the core team and one of the project supporters. UNHCR's distress protocol was in place, in the event that any participant experienced distress. Interviews took place in a private office space in the camp, that was familiar and accessible to the participants. The seven interviews with refugees who experience communication disability all included an SLP as one of the interviewers. Both SLPs have extensive experience of working with and interviewing people who experience communication disability and were able to use accessible and inclusive communication techniques such as reduced speed, plain language, and alternative and augmentative modalities of communication support.

A topic guide was developed to ensure the topics of conversation during the interviews related to the research aims and that each interviewing team followed the same broad structure in their interviews. The focus group discussions described below helped interviewers to better understand the context. Topics covered day-to-day communication experiences, sense of safety, prior learning about SRHE, and experiences of accessing general services in the camps. Participants were not explicitly asked about experiences of SGBV or use of SGBV response services, although some chose to talk about this. Participants' preferred language/s were used, with the project supporters interpreting, as necessary. Interviews lasted 19–64 minutes and were audio-recorded if consent was obtained and the English content/translation transcribed verbatim. Where consent was refused for audio-recording, contemporaneous notes were made by the core team member present. The core team member checked through any contemporaneous notes with the project supporter, following each interview, to ensure they were as accurate as possible. The time and resource constraints of the project meant that member-checking of transcripts was not feasible, except upon request. This was offered to participants, but no-one requested to review their transcript. Core team members and project supporters debriefed regularly, to discuss any issues/concerns arising.

Interview data from individual interviews were analysed using framework analysis (Ritchie et al, 2014). Data were summarised into themes and subthemes by group and cross-tabulated, allowing for identification of inter-group themes and differences. The data were interpreted by also drawing on professional experience, new, and pre-existing understanding of the context. Findings are presented below as themes and sub-themes, with illustrative quotes.

FGDs with SRHE service providers, groups supporting refugees who experience disability, and representatives from national level stakeholder groups

Focus group discussions were conducted to generate descriptions of SGBV prevention (including SRHE) service provision, for refugees in Rwanda. Representatives from UNHCR, five Rwandan government agencies, six UNHCR implementing partner organisations, and two organisations of persons with disabilities/disabled persons' organisations took part. Twelve focus group discussions were carried out, with a total of 60 participants, who were grouped by professional role. The participants included people with disabilities. Informed consent was obtained and focus group discussions were conducted in the capital city, Kigali, and in two refugee camps.

The team developed a topic guide for the focus group discussions, to ensure the discussion focused on generating information addressing project aims 1 and 2. Topics included (as appropriate to the group): Descriptions of SRHE/SGBV response service provision, participants' perceptions of challenges in accessing SRHE/SGBV services for refugees who experience communication disability, and participants' knowledge and experience of working with refugees who experience communication disability. Each focus group discussion was led by member/s of the core team, in English (no translation was required for these groups), lasted 52–68 minutes, was audio-recorded (if consent was obtained), and transcribed verbatim. If consent for audio recording was refused, contemporaneous notes were made in English, by a second core team member.

Participants were offered the opportunity to review the focus group discussion transcript if they wished to, but no-one requested to do so. Transcribed data/contemporaneous notes were analysed by the authors, using directed content analysis (Hsieh & Shannon, 2005), as the aim was mainly to describe service providers' knowledge and experiences. Transcripts and contemporaneous notes were uploaded to the data management tool NVIVO-10. Data were coded within NVIVO-10, using apriori categories that were generated from the topic guide and project aims. The analysis is presented as categories and subcategories, with illustrative quotes.

Stakeholder workshops

Two stakeholder workshops were held to produce a Problem Statement and a Challenge Brief and are described below:

Stakeholder Validation workshop. The analysed data from the focus group discussions and interviews were used as follows:

i. Participants were firstly given a summary of the initial project (the intersectionality between SGBV, communication disability, and refugees) and the findings from the two literature reviews described above (disability/communication disability, SGBV, and forced migration/humanitarian contexts; access to SRHE services for people who experience communication disability) – described in the Context section above. Workshop participants were then asked to comment on and verify, themes presented from the focus group discussion and interview data and the earlier data, in terms of familiarity to their work/experiences.
ii. Participants began the development of a Humanitarian Innovation Guide 'Problem Statement' and 'Challenge Brief'. The Problem Statement and Challenge Brief comprise the two final components of the Recognition stage of the Humanitarian Innovation Guide (Humanitarian Innovation Fund & Elrha, 2019a). A *Problem Statement* is defined in the Humanitarian Innovation Guide as "an articulation of your initial understanding of the (humanitarian) problem" (Humanitarian Innovation Fund & ELRHA, 2019b. para 1). A *Challenge Brief* is: "a clear statement of the problem… A discussion of why it matters…. An articulation of what's needed…. A set of strategic objectives for meeting those needs" (Humanitarian Innovation Fund & Elrha, 2019a; 2019c para 2). The Challenge Brief incorporates the Problem Statement and a number of additional components.
iii. Finally, participants began the identification of potential solutions to the identified problems of SGBV prevention and SRHE service provision for refugees who experience communication disability.

The workshop was attended by 26 people, including service providers, refugees who experience communication disability, and caregivers. Activities from the Humanitarian Innovation Guide were used to ensure a participatory approach to developing a

Problem Statement and Challenge Brief, using evidence generated from the project. Activities included considering what the problem is, when and where it occurs, who it affects, and why it matters. The Problem Statement was drafted in small groups, generating *elevator pitches* (short verbal/signed presentations – see Twitter/X #srherefugeesComDis for videos) of why the problem matters, and refining the Problem Statement to align with desired impact goals (what participants wanted to achieve). The data generated from this stakeholder validation workshop, including the draft Problem Statement and Challenge Brief (see Results below), were summarised, refined by the project team, and used to design activities for the subsequent stakeholder planning workshop, described below.

Stakeholder planning workshop. This second workshop took place over two half-days, attended by 12 stakeholders, including refugee disability and SGBV service providers, representatives from local organisations of people with disabilities, a refugee who experiences communication disability, and two caregivers. A recap of summary data and initial outcomes of the stakeholder validation workshop were presented to the participants.

Further activities from the Humanitarian Innovation Guide were used to finalise the Problem Statement and Challenge Brief. These activities aimed to understand the root causes, contributing factors and symptoms of the problem, and included 'The 5 Whys', the 'Humanitarian Parameters Box', and design activities, such as the 'design criteria' template. The outputs from these activities were then used to develop ideas for short-term, implementable solutions that could be used to simultaneously tackle the root causes of exclusion from SRHE services, as well as to ensure services are accessible for refugees who experience communication disability, using a systems strengthening approach (Humanitarian Innovation Fund & Elrha, 2019a).

Result

Individual interviews with refugees who experience communication disability and their caregivers

Framework Analysis (Ritchie et al., 2014) was used to develop three themes and eight subthemes. The three main themes are presented below, with exemplar quotes.

Theme 1: Communication disability affects safety and wellbeing

Refugees and their caregivers described their experiences of communication disability, including the challenges faced as refugee families coping with the intersecting impacts of disability, gender, and poverty. One SGBV survivor who experiences communication disability said that "life is hard and then for people with hearing and speaking impairment, it's very hard." Another refugee who experiences communication disability said:

> Men can give us money and you go and buy something. When you accept they ask you to do the sex….You ask yourself, if I refuse, how can I live here in the camp? And if I accept? So, I met many problems. You get many sicknesses. [Some people] accept without thinking because of the poverty.

And a carer of a refugee survivor who experiences communication disability reported that:

> The way that we are living now is difficult because I'm living alone – I don't have a husband and to keep surviving is difficult… In case I am sick I cannot ask my daughter to go the distribution centre or to go and get something. Having a daughter with communication disability is a very big problem.

In this context, caregivers felt that their family member was exposed to risks, contributing to their own burden of care. They often took precautions to keep their children safe, including restricting movement in the camp, especially after dark, or asking the police to watch them closely. In addition, some carers made decisions about their child's sexual safety, sometimes enforcing contraceptive measures such as implants. One carer reported "I'm not 100% sure that he is safe because sometimes I leave him doing something and then when I come back… the door is open." Another carer described her decision to give her daughter a contraceptive implant "Sometimes she goes out alone. She thinks she understands about safety but …[she doesn't]. I made the decision about her having an implant after she was misbehaving".

This risk of abuse was also felt by refugees who experience communication disability themselves. They felt that their own communication limitations left them at risk of mistreatment and made them a target for abusive behaviour. One refugee participant who experiences communication disability said that "at night, we can't hear them coming. They take you by force sometimes, because you cannot tell [about] them." Another reported:

> A young boy neighbour used to come and would ask me to accompany [him]. He would say to my sisters that he didn't want them, he wanted me specifically. I don't even feel safe at home. When I'm alone I lock the door from inside.

Theme 2: Service access affects exposure to risk

Refugees who experience communication disability and their caregivers, described how they/their family member face exclusion from services, including SGBV response services, further affecting their safety. One carer of an SGBV survivor who experiences communication disability reported that her daughter was turned away from reporting abuse "She was raped. The police came and they sent her home." Another reported exclusion from SRHE at school "Because she's not going to school, there is no way how to get that education concerning sexual and reproductive health."

They did also, however, report some evidence of emerging inclusive practice, including personal connections acting as advocates. One carer of a refugee who experiences communication disability reported on a positive experience she had with an advocate "There is a person who represented people with communication disability then … he helped me to solve the issue." Others accessed some information through school reproductive health programming (albeit biologically, rather than rights focused). A refugee participant who experiences communication disability reported "The teachers teach us about it … reproduction."

Theme 3: Desire for protection and autonomy

Refugees who experience communication disability and their caregivers, described how they want access to SRHE, to reduce the risk of exposure to abuse and to facilitate good decision-making. One refugee who experiences communication disability said "I want to learn more so that I can be able to protect myself." A carer reported a similar desire for their child who experiences communication disability "In case there is a school that can take that child, they can educate her to show her a good thing or a bad thing".

They recognised the difficulties associated with trying to access SRHE services without support and discussed how an advocate would be a helpful addition to the support services available, but this had not been made available to many of them through formal channels. They also discussed the desire to access specialist communication support services and treatment, including access to sign language training and surgical interventions overseas, to enable them to access mainstream services and to promote independence. Some refugees and carers had heard about overseas cochlear implant treatment. One refugee said "You get this treatment and you hear like others." A carer also expressed their desire for a cure "If she's lucky to get the treatment and that it's cured, and then that also she can perform in her life".

FGDs with SRHE service providers, groups supporting refugees who experience disability and national level stakeholder groups

Using the transcripts and contemporaneous notes, three categories and 11 sub-categories were developed, using content analysis. The main categories are presented below, with key quotes.

Category 1: Social and knowledge barriers to service access increase risk

Like refugees who experience communication disability and their carers, participants considered refugees who experience communication disability to be at heightened risk of abuse, including SGBV. Several categories of barriers to service access were identified in the focus group discussion data that were thought to contribute to this heightened risk. These included social and knowledge barriers. Social barriers included stigma and discrimination, stemming from a lack of knowledge and understanding of the causes and nature of communication disability, and a lack of human rights culture within communities, were both acknowledged to be rife. One service provider reported that "The lack of human rights culture … the person with communication disability … actually, these persons are seen as not being [considered] a fully human being like others".

Participants discussed their own understanding of communication impairment and disability. There were some notable gaps and misunderstanding, for example there was a focus on 'hearing and speech impairment' as a diagnostic label, to the exclusion of other communication difficulties, such as in understanding language. There was also a belief that tongue-tie is a primary cause of developmental speech and language difficulties. Participants considered it challenging that the refugee communities' attitudes and beliefs about communication disability include that it is considered synonymous with hearing impairment and deafness. This belief may explain, and subsequently be reinforced by, the sign-language focused services provided for refugees with communication impairments, to the exclusion of other forms of communication access strategies or support. One representative of a national organisation of persons with disabilities highlighted this by saying that "In the entire community, when you have a communication disability, when you can't talk, you are deaf".

Furthermore, identification of communication impairment and associated disability, so essential to understanding service access requirements, was considered challenging due to a perceived lack of their own staffs' understanding about communication disability and its potential impacts. A service provider participant reflected that "Our minds [are] confined into physical disabilities and sometimes mental health issues".

Additionally, participants considered that the prevailing assumption that people who experience disability do not need SRHE, because they are thought to be asexual, undesirable, or unable to make autonomous decisions about their safety and sexuality, contributed to the lack of focus on accessibility of services for this population. Service providers recognised this from their own work, with one reporting that "They [refugees who experience communication disability] are at risk when they don't know where to find the services, when they don't have that information. People think they don't need those services like other people do".

Category 2: Institutional barriers to service access increase risk

Participants discussed agencies' responsibilities for providing SRHE and/or SGBV response services to children and adults, and the institutional barriers to service access. These included limited staff knowledge and skills related to communication disability and the people who experience it, a lack of communication-disability sensitive approach, termination of programme support (e.g. when the implementing partner changes), and the physical location of services. One national stakeholder highlighted this when he said "We exclude them from many services – we don't prioritise them in many things".

A lack of accessible information about sexual and reproductive health and about the services available, was considered a leading cause of heightened risk to abuse. Participants acknowledged that refugees who experience communication disability are unable to access information about sexual and reproductive health on an equal basis with others, as it is not generally available in multisensory formats. A service provider reflected on the accessibility of SRHE services when he said "Many [refugees who experience communication disability] lack SRHE as they are all verbal sessions, so it's difficult for them to access".

Category 3: Opportunities to improve SRHE for people who experience communication disability

Service providers identified a small number of existing strategies that could be built on, to help refugees who experience communication disability to access information and services. These included a range of information available in pictorial and print format. A service provider said that "We have like the posters, we have brochures, we have post-cards, we have small booklets, we have … a range of materials." There was, however, no evidence of further multi-sensory format information (e.g. for those who may require information in audio, or easy-read, format) or evaluative evidence of their effectiveness in facilitating service access for refugees who experience communication disability.

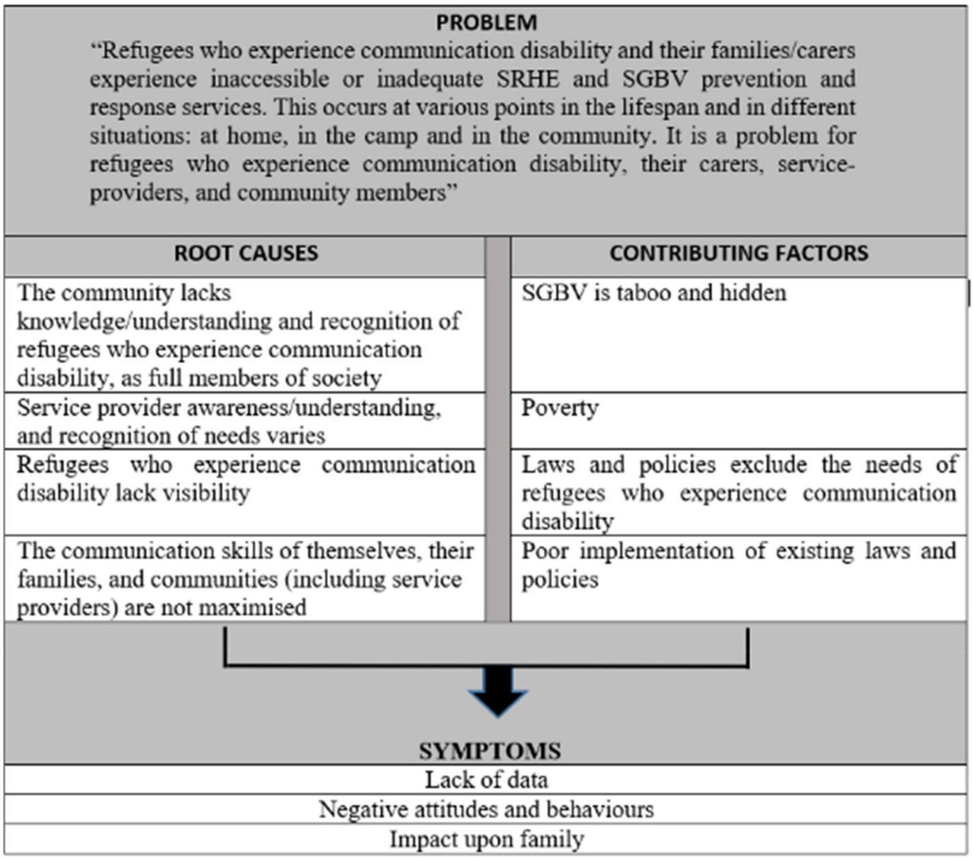
Additionally, service providers identified support needs for themselves, and for refugees who experience communication disability, to ensure equitable, accessible SRHE services. They desired training on communication disability and alternative communication methods, materials, community-based interventions, and increased opportunities for cross-sectoral engagement. A service provider thought "You cannot train everyone but if you take a small group, and maybe there's people around the community, train them and then they also can go training others".

They also considered that refugees who experience communication disability need inclusive SGBV prevention and response services, education and/or communication training and accessible materials, opportunities to build trusting relationships with service providers, and access to role models and peer support. A SRHE/SGBV service provider expressed "If you train only community health workers it will not work. It will work when we train people with communication disability together with these people, so they understand each other".

Stakeholder validation workshop. Workshop participants stated that data from the initial project (described in the earlier Introduction context) and the data from this project (focus discussion groups and individual interviews) accurately reflected their experiences as SGBV/SRHE service providers, stakeholders, and service users. The draft Problem Statement (Humanitarian Innovation Fund & Elrha, 2019b) that was produced in this workshop recognised that some good practice exists, whilst acknowledging that some people with communication impairments continue to experience disabling exclusion from services. Representatives from service provider organisations made commitments to apply evidence and learning from this and the initial project, to their practice, and to advocate for the provision of communication accessible SGBV prevention and response services, including SRHE. Activities that supported the development of the Challenge Brief (Humanitarian Innovation Fund & Elrha, 2019c) and implementable solutions, were fed into the Stakeholder Planning workshop (below), where they were refined and finalised.

Stakeholder planning workshop. In this workshop, a smaller group of key stakeholders collaborated to finalise the Problem Statement and components of the Challenge Brief. The root causes, symptoms, contributing factors to these symptoms, and the finalised Problem Statement, were agreed and are summarised in Figure 3.

The diversity of participants' knowledge of the local context, provision of services, policy and laws, are likely to have influenced their understanding of, and description of, the root causes and contributing factors that were identified (see Figure 3). The humanitarian parameters were made explicit, identifying who are the persons of concern (a humanitarian term) to whom this challenge applies. They were agreed to be 'Refugees who experience communication disability and their families, in Rwanda'.



PROBLEM

"Refugees who experience communication disability and their families/carers experience inaccessible or inadequate SRHE and SGBV prevention and response services. This occurs at various points in the lifespan and in different situations: at home, in the camp and in the community. It is a problem for refugees who experience communication disability, their carers, service-providers, and community members"

ROOT CAUSES	CONTRIBUTING FACTORS
The community lacks knowledge/understanding and recognition of refugees who experience communication disability, as full members of society	SGBV is taboo and hidden
Service provider awareness/understanding, and recognition of needs varies	Poverty
Refugees who experience communication disability lack visibility	Laws and policies exclude the needs of refugees who experience communication disability
The communication skills of themselves, their families, and communities (including service providers) are not maximised	Poor implementation of existing laws and policies

SYMPTOMS

Lack of data

Negative attitudes and behaviours

Impact upon family

Figure 3. Causes, contributing factors, and symptoms of the identified 'problem'.

It also made explicit the importance of this challenge to both users and organisations, by stating that a solution is required because 'it affects people with communication disabilities' ability to contribute to the community, voice and agency, Sexually Transmitted Infections (STIs), unwanted pregnancy, psychological effects of abuse etc.'.

An *impact goal*, a statement of what stakeholders want to achieve, was agreed amongst participants. This was: Refugees who experience communication disability consider that they receive accessible and appropriate SRHE and SGBV prevention/response services.

Finally, 'next steps' were agreed, to work towards achieving the impact goal. These included addressing the root causes of the problem, reviewing good practice within and outside of Rwanda, generating further data on communication disability and adapting/designing appropriate interventions.

Participants were aware of the need for urgent action, the lack of external resources, the limits in their influence on the development of services, and the need for provision of communication disability experts, at least in the short term. This resulted in agreement on several immediately implementable solutions, including:

(1) Training for service providers and the refugee group,
(2) A community sensitisation strategy about communication disability,
(3) Community-level interventions (e.g. home visiting, a 'buddy system'),
(4) Picture-based alternative and augmentative communication materials,
(5) Generating further data on the impacts of communication disability and possible solutions, and
(6) Engaging in policy change with UNHCR and the Government of Rwanda.

Discussion

Refugees who experience disability, are one of the most marginalised and at-risk groups of people in the world (Mirza, 2011; UNDESA, n.d.; UNHCR, 2011; WRC, 2014). People who experience communication disability, particularly those in LMICs, are also known to be excluded from research on issues that directly affect their lives and wellbeing (Jagoe et al, 2021). The series of activities reported in this project and in Marshall & Barrett (2018) address this issue and corroborate the work of Izugbara et al (2018). They indicate that intersectionality of refugee status and communication impairment can result in experiences of disabling exclusion, marginalisation, and increased risk, for individuals and their families, particularly in relation to SGBV prevention and response.

The first aim of this project was to document current SGBV prevention and SRHE service provision. The data demonstrates that the SGBV prevention and response services, including SRHE services that are provided to refugees through the humanitarian system, are not fully accessible to refugees who experience communication disability. Service providers recognise that there are numerous barriers facing refugees who experience communication disability, in relation to accessing SGBV and SRHE services. These include the lack of a human rights-based approach, limited knowledge (about the range of types of communication impairment and disability) and skills, the design (e.g. based on spoken language), and the location of services. Service providers wished to improve access to services.

The second aim of this project was to identify inclusive practices and challenges in relation to SGBV prevention and SRHE services. The data show that exclusion from these services is exacerbated by communication disability-related stigma and lack of knowledge about, or interaction with, people who experience communication disability, amongst both the community and service providers. This, coupled with a lack of service-provider knowledge and skills to provide inclusive, appropriate services across the service chronology (SRHE, SGBV prevention, post-SGBV response, and ongoing recovery, as well as a lack of understanding of SRH issues among refugees who experience communication disability), serve as major barriers to inclusion, protection, and realisation of rights.

Although there is some discussion in the literature of efforts to include refugees who experience communication disability in SRHE and SGBV services (Jones et al, 2018; Tanabe et al, 2015), most report small-scale projects and there is little robust evaluation of methods, resulting in a lack of evidence for interventions. Indeed, the paucity of evidence demonstrates that the needs of those who experience communication disability are not routinely considered. This lack of consideration was reflected in the results from this project, as service providers acknowledged that refugees with communication impairments are more at risk and are marginalised in inclusion efforts, in comparison to those with more visible or understood impairments. It was further reflected in the scant examples of promising practice within the humanitarian system in Rwanda (mainly focused on visual materials).

The third aim of the project was to describe and understand refugees' perspectives about SGBV prevention and SRHE services. Refugees in Rwanda who experience communication disability and their caregivers, expressed their thoughts about marginalisation, the impact of communication disability, and the protection risk they face in their communities. Refugees who experience communication disability want to be included in services and so they want more accessible SRHE, SGBV prevention, and other services, to increase their safety, independence, and autonomy. Caregivers need support to ensure their children are knowledgeable and equipped to make good decisions about their sexual health and safety, reducing the burden of care caregivers feel they face. Additionally, they expressed the need for specialist services to address communication impairment.

Literature on SGBV and on SRHE, from beyond Rwanda (referenced Marshall and Barrett (2018)) and in supplemental material 1), reflects some of the experiences of, and is confirmed by, refugees who experience communication disability, caregivers, and service providers in Rwanda. The integration of data from multiple sources from this project and the initial project described in the Introduction context section above, strengthens understanding of the barriers to accessing SGBV prevention and response services, for refugees who experience communication disability.

The final aim of the project was to make recommendations for possible ways forward. By using the Humanitarian Innovation Guide (Humanitarian Innovation Fund & Elrha, 2019a), the team was able to go beyond simply reporting the risk factors, opportunities, and challenges; and in collaboration with key stakeholders, use locally generated evidence to identify practical and implementable interventions in a real-world, complex, humanitarian context, that fit within the parameters of the humanitarian system. With little robust evidence in the literature, the Humanitarian Innovation Guide activities created novel and context-appropriate opportunities to plan meaningful, responsive, realistic, and sustainable solutions. Only one of the six immediately implementable solutions that were agreed, focused directly on people who experience communication disability, with some changes designed to have wider system impact (e.g. engaging with UNHCR/Government of Rwanda on policy change). These recommendations may reflect growing awareness of communication disability, recognition of the value of human-rights focused responses, and recognition that specialist communication disability services (e.g. speech-language pathology) are unlikely to be an option in the short-medium term.

The collaborative process of the authors working directly with UNHCR and stakeholders, using the Humanitarian Innovation Guide, resulted in the authors being able to use their expertise as SLPs, as evidence was gathered and analysed. For example, focus group discussion and interview evidence (as well as the authors' wider experience of working with the refugee community in Rwanda) suggests that many service providers believe that sign language is an easy and implementable solution to communication inaccessibility for all refugees who experience communication disability. This belief could serve to stall progress in providing accessible and appropriate SGBV services and result in the ongoing disablement of refugees with other forms of communication impairment that do not benefit from sign language use. It may also have wider implications for protection and the right to safely express sexuality (Collier et al., 2006; Pownall et al., 2012). As a result of the collaborative nature of the project activities, it was possible to discuss this issue with stakeholders and thus exclude a focus on sign language training (which is already in place) from the Problem Statement and Challenge Brief.

Interpretation of the findings generated in this, and previous projects has led the authors to recommend that future developments should include:

1. Humanitarian service providers acquiring skills in interaction with people who experience communication disability (supported by Burke et al., 1998; Lange, 2015; Plan International, 2016; WRC & IRC, 2013; WRC, 2014; WRC, 2015),
2. Sharing global evidence of documented good practice on appropriate SRHE/SGBV services for refugees who experience communication disability, as it arises,
3. Developing, testing, and evaluating interventions that support refugees who experience communication disability, in SRHE/SGBV prevention and response (supported by Mikton et al., 2014; Plan International, 2016; WRC, 2014), and
4. Raising awareness and offering education to communities and service providers about the challenges facing refugees who experience communication disability, more broadly (supported by Lange, 2015; Plan International, 2016; WRC, 2015).

This unique collaboration, using research methodology combined with Humanitarian Innovation methods, produced novel findings and ongoing partnerships. This distinctive project gave refugees who experience communication disability and their caregivers (who often experience disabling exclusion by proxy (Barrett, 2019), a rare opportunity to engage in problem identification, voice their experiences, needs, and wishes, as well as actively engage in needs-led solutions planning. The collaboratively developed Challenge Brief highlighted potential practical next steps and has since led to a responsive, broader project, identifying community priorities in relation to people who experience communication disability. This, in turn, led to a project that trained refugee community members about communication disability and accessible communication, fronting the voices and addressing the needs of refugees who experience communication disability and service providers (UNHCR, 2021b).

Challenges, reflections and limitations

This project was not without challenges and limitations. It was only possible to carry out consultations in two of the six refugee camps in Rwanda, and urban refugee communities were not included. The range of communication impairments and associated disabilities experienced by the participant group was limited, with most participants identifying as D/deaf or hard of hearing, or caregivers of these groups, perhaps due to the self-reported limited understanding of communication impairment and disability by project supporters, or some types of communication impairment and disability being hidden, unidentified and/or under-recorded (Barrett & Marshall, 2017). The breadth of voices of refugees who experience communication disability was therefore narrower than expected.

The acute shortage of SLPs, particularly those with project leadership and research experience, across much of East Africa, resulted in European SLPs leading this project. The two other project team members were international UNHCR staff. Neither refugees nor people who experience communication disability initiated or had leadership roles in this project, because the original challenge was identified by UNHCR through the latter's community consultation exercise, held in 2015 (Lange, 2015). A project team that did not include refugees or people who experience communication disability inevitably influenced the project design, data collection, analysis, and interpretation. The team reflected on the relative positions of power between the team and refugee community participants. Using interpreters who were known to refugee participants and unfamiliar (University) consenting processes, may have impacted data generation, as may the presence of unfamiliar 'outsider' interviewers. Although project supporters were trained to recruit refugee participants as ethically as possible, there are numerous ways in which the team's position may have affected the project. Collaboration between three organisations, across two continents, with differing priorities and pressures, required honesty, transparency, flexibility, and a shared understanding of the need for robust evidence (Levine, 2016).

The Humanitarian Innovation Guide provided a structured process to gather disparate data from a range of stakeholders and to synthesise it collaboratively (through the two workshops). This process permits a more rapid focus on solutions (particularly important in acute humanitarian contexts) compared to some research projects, although this could arguably impact on rigour.

Although every effort was made to be responsive to community and service provider identified priorities, authors recognise the cultural and experiential lenses through which the project was designed, and data generated and interpreted, as non-refugee, non-disabled, academics, and practitioners from a high-income country. Openness and transparency about the positionality of the core team members, methods of data generation, and the challenges and limitations to the project, will allow readers to judge the transferability of the findings.

Conclusion

People with communication impairments are known to be misunderstood, stigmatised, and underserved in LMICs including Rwanda, resulting in disabling exclusion from essential services. Data generated across methods and time (2016–2019) in this project and in the initial project, reported briefly in the Introduction context above, and in detail in Marshall and Barrett (2018), demonstrate that refugees who experience communication disability face increased risk of exposure to SGBV across social, personal, and environmental domains. This paper has highlighted challenges for refugees who experience communication disability and their service providers, in accessing and providing SRHE services, to facilitate protection, autonomy, and rights realisation. The data generated in this project (via focus group discussions, interviews, and two workshops) resulted in the production of a Problem Statement, Challenge Brief, and a realistic plan for future action to address the challenges identified. They also provide recommendations that can be used to advocate for the needs and wishes of refugees who experience communication disability, as well as for the support of communities and services to develop capacity to meet those needs effectively.

These recommendations will go some way to ensuring that refugees who experience communication disability are better able to realise their sexual and reproductive health rights, protect themselves from abuse, exercise autonomy in decision-making regarding their sexual and reproductive health, and access a full range of prevention and response services if required, on an equitable basis with others in their community.

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