Capitalizing on the experiential knowledge of survivors of sexual and gender-based violence: a participatory approach to improving the quality of healthcare

Narrator: Welcome to this podcast dedicated to feedback from a participatory research project carried out in the province of South Kivu, in the Democratic Republic of Congo, initiated by Doctors of the World Belgium in collaboration with a researcher in education and training sciences, affiliated with the Education Ethics Health laboratory at the University of Tours. In this episode, we will delve into the heart of this project which aimed to experiment with an innovative approach to support survivors of sexual violence in developing their empowerment by drawing on their own skills and knowledge gained from their experiences. We will have the privilege of hearing the voices of those who collaborated on this inspiring initiative. Their testimonials will give us a unique insight into the concrete impact of this research on survivors' quality of life, as well as the tangible benefits of integrating survivors' experiential knowledge to improve the quality of healthcare. Now, let's get to the heart of the matter by listening to the first testimonial. The latter will give us the background to the research and the problems identified in the field that led to the origin of the project and the need to carry out this participatory research. This is a unique opportunity to hear directly from key players about the challenges they faced and the motivations behind this innovative initiative. Without further ado, let's hear them.

Louisa Ben Abdelhafidh: I'm Louisa Ben Abdelhafidh, and at the time of the research, I was head of operational research at Doctors of the World Médecins Belgium. Doctors of the World Belgium is an NGO that fights for the right to health for all, and for universal and equitable access to this right. Doctors of the World Belgium has been working in DRC, and especially in South Kivu, for many years on the theme of the right to sexual and reproductive health. At Doctors of the World, this theme includes a strong focus on the fight against gender-based violence and the care and support of victims and survivors of gender-based violence. We also have a tradition of taking an empowerment approach to this issue, and to all issues where project beneficiaries and stakeholders are at the heart of the approach and the thinking behind this care. In DRC, in South Kivu, the problem of gender-based violence is unfortunately well-known throughout the world. Everyone knows that there is a problem of chronic violence in this region, and that women are the main victims of this violence. In addition to the obvious physical and psychological consequences of such violence for those who suffer it, there is also the stigmatization and rejection to which they are subjected. This reinforces the gender inequalities already present in society, and further hampers these people's ability to act. Doctors of the World has been working for many years on the care of victims of sexual violence in South Kivu, but also elsewhere, always with an approach based on the one-stop center, i.e. with four

pillars of care: the medical pillar, the psychosocial pillar, the legal pillar and the socioeconomic pillar. And Doctors of the World, particularly in DRC, is involved in psychosocial activities. We therefore conceived this project as a continuation of this four-pillar approach, with a focus on empowerment, bearing in mind that the patients had already used the four pillars, so we wanted something that would be part of the continuity of this model of care. We started thinking about this internally, and at Doctor of the World, we wanted to and have always tried to add a research dimension. Research responds to a need to be more intelligent and reflective about our practice, and to use scientific methods to achieve this, enabling us at some point to decentralize and take a complex look at our practice. It was in this context of reflection that Anne-Laurence Halford approached us to set up the fieldwork for her thesis. We had many exchanges and worked a lot together on methodology. That's really what's interesting for an NGO, to be able to benefit from the expertise of a researcher who at some point puts himself at our service to complement us and reflect on our practice, but also to teach us new methods. When we discussed the results we were trying to achieve, the problems we were having with our fieldwork, Anne-Laurence Halford came up with the idea of doing participatory research. It's something we were already used to doing at Doctors of the World, we'd done it on other themes, but we hadn't yet experimented with this vision of research-action-training. We also wanted to be innovative and take part in this new approach, where people, in a process of empowerment, are themselves the creators of the knowledge we receive. And we particularly appreciated this approach, which was both innovative and very destabilizing for professionals who are sometimes used to always being in a position of knowledge. So it was a way of reflecting on our practices, as well as being a way for the project's beneficiaries to reflect on their situation and life experiences.

Anne-Laurence Franzini-Halford: When we designed this participatory research, we drew on previous studies that have shown that recognizing and valuing experiential knowledge strengthens the power of individuals and communities to act. It is a powerful lever for supporting marginalized populations in asserting their rights and bringing about change. In the context of South Kivu, the knowledge of survivors of sexual violence is often ignored or even marginalized, relegating their skills to a secondary role in community management. Addressing this issue is crucial. To achieve this, we have set up an innovative system combining research, action and training. In a confidential and secure setting, we encouraged the sharing of participants' stories to identify the knowledge gained from their experience. We then supported them in developing strategies for valorizing this knowledge and deciding together how to disseminate the results of the research. The research-action-training project lasted six months and involved 22 survivors. It was facilitated by a team consisting of myself as researcher and my colleague, Jacques Kimina Mungilima, psychologist for the Doctors of the World mission. During the group sessions, exchanges took place in Swahili, with Jacques providing simultaneous French interpretation between the participants and myself.

Narrator: Now let's hear a participant explain to the group how she would present the research to an outsider.

A participant, story read by Renelde Kahababo Namukara: If I find myself outside the group and someone asks me what I've done in the group, I'll first introduce the group and tell them we're a women's group. There are no dads! (Laughter). There's only one dad who's with us, but he's not really one of us. I'm going to tell him that in our group, we're with moms who've been through something, but I'm not going to tell him what it is any more. I'll tell her that in our group we have objectives. In the first objective, I'll tell her that we're in the research. Secondly, I'll tell him we're looking for knowledge. Thirdly, I'll tell him that if we've already got the knowledge, we're going to share it with the community and make the most of it. And then, if the person asks me questions, how do we go about research? We do the research through the difficult events we've been through. Everyone talks about what they've been through, and sharing stories is where we get our knowledge.

Anne-Laurence Franzini-Halford: To co-construct knowledge and capitalize on experience, each group self-narration coaching session was organized in four stages. First, each participant had an individual moment to explore a facet of her life story through a specific exercise. This was followed by a time of collective sharing, when each participant could decide to share her story, in whole or in part. This was followed by a joint reflection to identify the learning and knowledge gained from these stories. Finally, we moved on to a synthesis phase to capitalize on the day's achievements. Through these exercises, participants were encouraged to explore the key moments in their story, their successes: the moments when they overcame trials or resolved difficulties. By sharing their stories, we sought together to identify the strategies, attitudes and behaviors that had helped them overcome these challenges.

Jacques Kimina Mungilima: Women sometimes don't know the strategies that were useful, that helped them to survive until then, to overcome, not to be killed, even though they had faced human atrocities. Sometimes they don't really realize it, but when they try to listen, to exchange with others, through group sessions, in a homogeneous group of course, they manage to discover and really understand what helped them, and it's in this sense that they won't feel like people who are exhausted, who hadn't done anything about their situation, and so the strategies we put in place in the situation can also be useful in life. Some of these women, despite having lost everything they had - their dignity, their property and sometimes their husbands - have developed strategies to survive, not only for themselves but also for their children and their families, and it's these strategies that start from nothing, they have nothing and yet they still have innovative ideas that have enabled them to get by and live until then.

Anne-Laurence Franzini-Halford: At the end of the collective self-narrative support sessions, the participants brought to light a body of experiential knowledge that they linked to certain themes that they felt were crucial to a better understanding of the

experiences of survivors of sexual violence in the context of South Kivu. Among the themes they wished to highlight in their collective strategy were: knowledge derived from their experiences of the repercussions of sexual and gender-based violence on their daily lives, the strategies they put in place to survive, and their journey through the healthcare system.

Narrator: Let's listen to the story of a participant who shares her experience of the care process, from the moment she was found by a youth patrol at night after being sexually abused, to the end of her treatment and her return to her neighborhood.

Participant: That's how they picked me up, the young people who patrol at night. They took me to the Red Cross. The Red Cross took me in. They realized they couldn't take care of me, so they called Doctors of the World. Doctors of the World came and helped me so much. I didn't recognize myself, but that's the story they told me. By the time I'd been at the Red Cross for three weeks, I could see that I could stand up again. Until then, I couldn't walk. I was like someone who was weakened. They put me on a little bike and I rode around the Red Cross lounge. As the bandit there had forbidden me to reveal the secret, they chased me all the way there. When they came, I realized that my life was already in danger. I realized that I'm like someone who has suffered a lot and has no peace. As God doesn't reject his own, they pulled me out of there and took me to the reforestation hospital. They put me in the clinic and there I felt a little at peace. The psychologist helped me get rid of the thoughts I had, because I thought I was going to kill myself. In any case, he was concerned about me. I realized that I too am a person among many others, because I thought I wouldn't be like I was before. That's why they say don't despair, there's always help. After my situation, my health deteriorated. I was taken to Panzi. They really took care of me. God helped and I came back here. In the neighborhood, people used to make fun of me. If I passed by, they'd say, "You have no shame, even though you'd been raped". I saw myself as a useless person. One mother told me: "No, it happens, it can happen to anyone, don't worry". I'd started to normalize it. Even if someone told me that's why you'd been raped, I'd say, "Well, that's the way it is, it happens".

Anne-Laurence Franzini-Halford: Sharing stories about the care process was crucial for the group. It helped identify key elements that contributed to recovery, such as sympathetic listening, psychological support, home visits, as well as family and social support. At the end of the research, the participants put forward a major objective: to make their voices and experiences heard in order to contribute to improving the quality of care. Some of the participants shared their stories, highlighting the obstacles they encountered in their interactions with healthcare staff and care structures, which had hindered their recovery. Here are just a few of the obstacles identified:

- An often neglected and superficial welcome;
- Drug stock-outs and lack of supplies;
- Lack of consideration and neglect of the emotional state of beneficiaries;

- Lack of explanation of medical procedures;
- Abuse of power, such as asking for money for free medical services.

Narrator: To ensure that their experiences are considered in healthcare structures, one participant chose to make her story public. Her story, shared in the group, is read here by a member of our team.

Participant: When I arrived at the care facility, first of all, I didn't know who I should go to with my problem, and when I saw a care worker, telling him what had happened to me, I could see that it was as if he didn't care about me, about what I was saying. Sometimes he'd be talking to someone else in the room, sometimes he'd be on the phone. He'd cut off the story, and when he was treating me, he didn't show the courage that he was treating someone who'd been through a serious situation. Following the interview and medical examinations, I was sent to another carer who also told me to be patient, saying he was treating, but instead of treating, he was talking to everyone and going back and forth without finishing. Then he'd come back to me very late. As I was already annoyed by their attitudes, in addition to the health problem that had brought me here, I felt neglected and thought that these people wanted to get rid of me. Stories like that, for someone who was already sick, made me think and feel guilty. I thought: did I come here to be humiliated or to be taken care of?

Anne-Laurence Franzini-Halford: Thanks to the power of the collective, participants developed their capacity for expression and action. By taking an active part in discussions in a confidential and secure setting, they were encouraged to share their experiences and ideas. This enabled them to gradually restore their sense of legitimacy and self-esteem. This participatory approach helped them to overcome their fears and doubts, to rediscover and fully accept themselves. Not only did this experience boost their self-esteem, it also helped them gradually reclaim their place in society. They now feel able to express themselves without shame or inhibition, drawing on the experiences shared within the collective to act in favor of their autonomy and contribute to change in their community.

Participant: What I've found in this group is that right now I have peace and joy because I wasn't able to stand up in front of people to express myself. But now I too can stand up anywhere. I can decant, I can solve the problems people have, without feeling ashamed. It's taken away the shame and given me strength.

Anne-Laurence Franzini-Halford: By sharing their stories, by collectively seeking to understand the strategies that each of them had developed both to survive sexual violence, and by identifying the skills they had acquired along the way to empower themselves, the collective has capitalized on a reservoir of experience that each of them can now draw on to find solutions to their difficulties, to orient themselves in the future by

seeing themselves as full actors in their own lives, but also actors within society, actors of change.

Participant: We've already been out in the field, and we've already raised awareness through the knowledge we've gained in the group. I learned that when someone was talking about their life stories, I learned how to work, and I also realized that studying is an important part of sharing. Still in the group, I learned that I personally still have to discover who I am. I realized that people shouldn't underestimate themselves, because when we shared our knowledge here, some people would say no, I'm like that, all that. That's when I realized that people mustn't underestimate themselves, they must accept themselves as they are. And we're going to continue raising awareness among others, so that they can't have this fear, so that they don't have to underestimate themselves.

Anne-Laurence Franzini-Halford and Renelde Kahababo Namukara: At the end of the research, the participants decided to unite in a collective they named: "collectif des femmes battantes", in Swahili: "kikundi ya wanawake wapambanaji". They have chosen to continue sharing their experiences, helping each other and finding solutions together to life's difficulties. They have also decided to pass on the knowledge gained from their experiences with the same voice, that of their collective. This knowledge is intended to benefit not only survivors, but also all those involved in preventing, combating and dealing with sexual and gender-based violence.

Narrator: Let's also listen to the testimony of the Doctors of the World Belgium psychologist involved in this project, who tells us about the significant impact this experience has had on his professional practice.

Jacques Kimina Mungilima: I learned a lot because I didn't realize that women or survivors also had knowledge at their own level, or strategies that could be activated to get by, but also that women didn't realize what they had put in place to overcome the difficulty, that it could be activated, or at least reactivated on the surface so that they realize that we also have capacities within us that enable us to survive. So the RAF was a real opportunity for me to understand other aspects of the care and support process for survivors of sexual violence to which I had little allegiance.

Anne-Laurence Franzini-Halford: This research has highlighted the crucial importance of valuing the experiential knowledge of beneficiaries, particularly survivors of sexual and gender-based violence, as well as all those for whom we need to guarantee access to rights and healthcare. An approach centered on beneficiary participation and recognition of their knowledge is essential to guarantee more effective and respectful care. By integrating their perspectives and placing them at the heart of the care process, we are working to build a more equitable and inclusive healthcare system. This approach contributes to greater justice in healthcare, enabling everyone to access quality care adapted to their specific needs, while influencing healthcare policies to support the right to health for all.