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EDITORIAL

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What are survivors of conflict-related sexual violence saying about care?

Sexual violence, once considered as "normal" in the context of war, has been used widely by unarmed and armed perpetrators, in contexts such as Bosnia-Herzegovina, Central African Republic (CAR), Democratic Republic of Congo (DRC), Iraq, Rwanda and Ukraine, among others.[1–3] Conflict-related sexual violence is described by the United Nations (UN) as including "rape, sexual slavery, forced prostitution, forced pregnancy, forced abortion, enforced sterilization, forced marriage (and) trafficking in persons when committed in situations of conflict".[4] While women, men, girls and boys can all be victims of sexual violence, women and girls are disproportionately affected, as conflict exacerbates pre-existing gendered inequities and vulnerabilities.

The documented and undocumented (or under-documented) lived experiences of survivors indicate that the consequences of sexual violence in conflict are interdependent, and as individual as they are collective. These consequences range from the medical, including infertility, traumatic fistula, sexually transmitted infections, unwanted pregnancies, and physical disability, to the social, such as rejection from spouses, families and communities, and a loss of socio-economic opportunities.[5,6]

Dr. Denis Mukwege, Nobel Peace Prize 2018 co-laureate, and his team at Panzi Hospital and Foundation, in DRC, have learned, over the course of more than 20 years of clinical practice and socio-political advocacy, that the consequences of conflict-related sexual violence require a holistic and integrated response. Initiated in 1999 and 2008, respectively, Panzi Hospital and Foundation have developed a holistic "one-stop center" model of care, including medical, psychological, legal and socio-economic assistance for victims and survivors of sexual violence.[7] The Panzi team is today known globally for their expertise in complex gynecological repair surgery and for their holistic model and philosophy of care.

The global adoption of the Panzi model and philosophy of holistic care as a standard and a norm is one of three strategies, proposed by the Dr. Denis Mukwege Foundation, to "change the collective response to sexual violence in conflict".[8] The other two strategies are strengthening the collective voice of survivors of conflict-related sexual violence from around the world and justice and accountability. The Foundation works with the key beliefs that when victims of sexual violence have access to integrated, quality, holistic care, they can recover and heal. Further, when survivors of sexual violence have safe spaces among each other, they find solidarity and the power to become agents of change, who can participate meaningfully in decisions and processes that affect them, should they wish to do so.

To this end, the Mukwege Foundation has, since 2017, accompanied the development of the Global Network of Victims and Survivors to End Wartime Sexual Violence, or SEMA. *Sema* means "speak out" in Swahili, a phrase that carries particular weight for network members, who have endured stigma and ensuing silence. Today, over 20 countries are represented within SEMA, from Africa, Asia, South America, the Middle East, and Europe. The network aims to be a space for sharing experiences, learning, solidarity, and global advocacy. SEMA's watchwords read: "Rien sur nous, sans nous", or "Nothing about us, without us".[9]

It is with this principle in mind that we wrote this commentary, which attempts to summarize key themes emerging from what survivors of conflict-related sexual violence have been sharing with us (and others) about their needs for holistic care, their recommendations, and priorities.

The authors are from the Dr. Denis Mukwege Foundation and from the SEMA network. Our reflection is based on our work, research, advocacy and lived experiences, from different vantage points, of holistic care for victims and survivors of conflict-related sexual violence. We do not claim that our commentary below is representative, nor can it be taken as an exhaustive insight into survivors, or their complex needs, priorities or views. Yet, we aim to shine a spotlight on survivors' situated and embodied knowledge of holistic care, and remind readers of what their concerns, recommendations, and priorities must mean for care professionals in the future. Survivors as individuals and within their national networks around the world have been using different, creative, means of developing a collective memory and ultimately also a body of knowledge, on conflict-related sexual violence. One such example, is the SEMA documentary film.

In the film, which was 90% written, acted, directed, and produced by victims and survivors, members of the DRC Survivors Movement, two women (girls, really), one from a village and one from an urban setting, are victims of sexual violence. Viewers watch as they navigate the physical, emotional, and social consequences of sexual violence, including HIV/AIDS, raising and loving children born of rape, abrupt ends to education, and seemingly failed attempts to seek justice.[10]

In CAR, many survivors of sexual violence live with the physical and psycho-social consequences of sexual violence. In this context, accessing medical care can be an arduous and costly process, particularly if one is left with grave gynecological injuries or sexual, reproductive, and other health concerns requiring specialized interventions, and/or for survivors who live outside of the capital city of Bangui.

In the Mukwege Foundation's practice-based knowledge, victims' access to holistic care is not only a persistent need in the DRC and CAR—in contexts such as Colombia, Iraq, Ukraine and globally, victims of sexual violence live without or with limited/challenging access to the comprehensive care they require. Different evaluation processes at Mukwege Foundation have revealed that within national survivor networks around the world, their priorities typically include some or all forms of holistic care, especially, in some cases, socio-economic support.

To respond to these persistent needs of survivors, one of the four key objectives of the SEMA global network of victims and survivors, is "to promote the holistic model of care for victims, integrating psycho-social, legal and livelihood development support with medical care".[9] SEMA network members have shared their priorities for holistic care, in forums including the UN Commission on the Status of Women in New York, the Human Rights Council in Geneva, and at different virtual gatherings.

In the SEMA film mentioned earlier, viewers are reminded not only of the devastating consequences of sexual violence, but also of the transformative potential of holistic care that responds to the complex needs of an individual victim. High-quality clinical interventions must be combined with trauma-informed, survivor-centered, and diverse forms of care, in order to heal the different harms caused by sexual violence in conflict. Yet, this type of care, envisioned also by the Panzi model and philosophy, is nowhere near being universally available or accessible. In survivors' lived experiences, fear and stigma present formidable barriers to coming forward and seeking care, even in contexts where it may be available.

A study sponsored by the Mukwege Foundation, together with the International Conference for the Great Lakes Region, affirmed that according to survivors of sexual and gender-based violence, (their) "recovery can only be partial if they do not benefit from all the services of a holistic model (of care)". Survivors shared with the independent research team that even when some services are available, these are, in their view, minimal, and access to legal and socio-economic support are generally missing.

The aforementioned regional study demonstrated five key barriers to accessing holistic care for victims and survivors of sexual and gender-based violence in the African Great Lakes region: distance, a lack of information about available services, stigma, lack of financial means, and corruption. Survivors explained how the centralization of services in urban areas, usually capital cities, excluded those victims and women and girls usually most affected by conflict from being able to access to care. Corruption and the long duration of judicial proceedings were also shared by victims as major deterrents to pursuing legal redress after sexual violence.

Relatedly, survivors know collectively that even when care is readily available and accessible, it is generally not survivor-centered or trauma-informed. In survivors' lived experiences, care professionals can be sources of re-traumatization and further harm, leading them to abandon seeking care, to encourage others to do the same, and/or to live with the consequences of receiving "bad care".[11] This is notably true for victims of sexual violence who may be from minority groups, those who have specific accessibility requirements, or who may face other barriers to care.

In the Mukwege Foundation's experience, while there is usually enormous political and individual will to see survivor-centered holistic care become a reality, we have also seen that even in high(er)-resource settings, a survivor-centered and holistic ethos of care is still not present. How can this will be transformed into action? How can care professionals adopt a survivor-centered and holistic approach in practice?

"Nothing about us, without us" comes immediately to the co-authors' minds, when it comes to the most concrete recommendation for all care professionals, meaning that all of the steps, before, during, and after care, must be done together with survivors. On the individual case level, survivors say that care professionals being transparent about risks and potential concerns about different clinical interventions or forms of support permit them to make informed decisions about their own care—which is critical for victims, patients and/or clients who have already been robbed of a sense of control, agency, and physical integrity. On an institutional and macro-level, meaningful survivor participation in decision-making, processes, and policies on care is crucial.

It is with this lens that we wrote this editorial, as a reminder of what survivors' voices are saying now about care and what it means for the future.

During the regional study commissioned by the Mukwege Foundation, survivors shared several key recommendations for donors, governments, service-providers, and policy-makers in their respective countries and in general. Out of these reflections, the following themes repeatedly appeared: the need to better fund services to ensure their wide availability and accessibility by all victims and survivors; the need to ensure survivor-leadership in decisions and processes related to care (not only for themselves); and finally the need to reinforce continuous efforts to build the capacities of care professionals, who may inadvertently or expressly cause them further harm and traumatization if they are insensitive and/or unskilled in dealing with victims of psychological trauma. Survivors of sexual violence must feel compassion and empathy from their care provider, and the care provider must also have the necessary tools to maintain a compassionate and professional posture with the individual.

The Panzi holistic care model proposes an approach that is rooted in compassionate, dignified, trauma-informed, and survivor-centered care. We argue that this compassionate and survivor-centered approach to care promotes a conducive environment for victims to denounce violence and receive quality care. It therefore provides an important case study to be learned from, in terms of ensuring a future global standard for care for victims of conflict. Research on the effectiveness and the quality of Panzi's holistic care model shows that survivors' reported satisfaction was very high but varied

depending on sociodemographic factors. Challenging access to justice and reparations, socio-economic opportunities, and possibilities to return to home communities may all negatively impact victims' experiences and their satisfaction with care, as also illustrated earlier by the narratives of survivors.[12] To survivors of conflict-related sexual violence, access to justice and reparations provides them with the individual redress they require, and contributes to their overall resilience, while also stemming cycles of violence in society. It is crucial for medical care professionals to recognize these and other social needs of the victim or patient, social factors impacting their care, and to consider how their own roles can contribute to the victim's success as they go along the holistic care pathway.

The Panzi model and philosophy of care thus calls for a type of "social medicine".[13] The model requires medical (and all) care professionals to include principles such as community, political action, and collaboration in organizing care services in their daily practice. In addition to "Nothing about us, without us" and general guiding principles, medical care professionals must consider their duty of care to victims of sexual violence as including trauma-informed care, speaking out, using good offices, working alongside survivors themselves, and fostering effective collaboration with their counterparts in the legal, psychosocial, and social services sectors, in order to achieve the vision and ethos of truly survivor-centered and holistic care in the future.

KEYWORDS

care, conflict-related sexual violence (CRSV), ethics of care health, holistic care, sexual and gender-based violence (SGBV), women peace and security (WPS)

AUTHOR CONTRIBUTIONS

Both authors meet ICMJE author guidelines for this paper and have substantially contributed to its drafting by a brief survey of literature, and the contribution of lived-experience narratives and revision, respectively. Both authors agreed on and approved the final version to be submitted. The authors present a shared reflection in the paper.

CONFLICT OF INTEREST STATEMENT

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DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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