

Keeping our core values ALIV[H]E. Holistic, community-led, participatory and rights-based approaches to addressing the links between violence against women and girls, and HIV

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Abstract

There is increasing recognition that violence against women is a barrier to sexual and reproductive health and rights, and a cause and consequence of HIV. In this viewpoint, we describe the recently published Action Linking Initiatives on Violence Against Women and HIV Everywhere (ALIV[H]E) framework [1]. The potential of this framework is explored in terms of it contributing to paradigm change to achieve the sexual and reproductive health rights of women experiencing, or living in contexts of, violence and/or HIV. We go on to suggest that a holistic approach to research and evaluation is vital to strengthen learning and expand the evidence base on violence against women and HIV.

Keywords: violence against women and girls, sexual and reproductive health rights, HIV

Introduction

There is increasing recognition that violence against women (VAW) is a barrier to sexual and reproductive health and rights (SRHR) [2,3], and a cause and consequence of HIV [1,4]. (It should be noted that the points we raise and the evidence cited often relate to violence against women and girls [VAWG], but for consistency with the ALIV[H]E framework, in this paper we will refer to violence against women [VAW].) The prevalence of VAW, and HIV among women, is alarming. In 2016, 44% more young women (15–24 years) acquired HIV than young men in the same age group; 52% of all adults living with HIV are women [5]. Globally, one-in-three women experience physical and/or sexual violence by an intimate partner, or sexual violence by a non-partner, during their lifetime [2]. In some settings women who experience intimate partner violence are 50% more likely to acquire HIV compared to those who do not [6].

Worldwide acknowledgement of the links between this epidemic of VAW, HIV and the denial of sexual and reproductive health and rights has been slow. Now, however, development, health and human rights actors, funders and policy-makers are starting to develop evidence-based responses to address the intersections.

Research on ‘what works’ to prevent VAW is still an emerging field [7–9]. The narrow definition of what constitutes evidence prioritises systematic reviews and randomised control trials (RCTs) and relegates other forms of knowledge to the status of anecdote: actions and interventions that women and programme implementers see as successful often merit no more than a rating of ‘insufficient evidence’ or ‘effectiveness undetermined’ [10]. Knowledge gained from lived experience or day-to-day work at community level does not contribute to the evidence base, resulting in a lack of consideration of this knowledge in global policy-making processes, guideline development and funding programmes. Some recent exceptions include the new *Consolidated guideline on sexual and reproductive health and rights of women living with HIV* [11], the Sex Workers Implementation Tool [12], and the TRANSIT tool for programming with transgender people [13].

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The ALIV[H]E framework promotes ‘evidence-informed’ as opposed to ‘evidence-based’ policy and practice [14], which does not require, and often excludes, participatory, qualitative and community-driven approaches. ALIV[H]E aims to support a deeper and broader understanding and implementation of gender-transformative initiatives to address HIV and VAW, build a more holistic evidence base, and enable women ‘in all our diversities’ to claim their sexual and reproductive rights.

The ALIV[H]E framework

ALIV[H]E is grounded in participatory, woman-centred and women-led approaches. Aimed at NGOs and community-based organisations (CBOs) working with community members, and those addressing HIV and other SRHR issues in the context of VAW, it provides a structured way to respond to HIV, incorporating an understanding of the different forms of violence women face. ALIV[H]E challenges the structural and cultural violence [15,16], which can be perpetuated when decision-making, research and programmatic processes and structures fail to take seriously the voices and priorities of those with the deepest understanding of violence and HIV.

ALIV[H]E guides users through seven steps, containing nine actions, to analyse, implement, monitor and evaluate evidence-informed programming and policy work on the intersections between VAW and HIV for women. It draws on rights-based tools and approaches developed by women’s organisations and HIV organisations, as well as on the formal evidence base, providing examples relating to women in all their diversities. It thus builds on the thinking and practice of communities and actors who have been deeply engaged in work on these issues for many years [17–19]. The ALIV[H]E framework envisages these steps and actions being used to guide reflections over the course of a project to provide a structure for the application of the core values throughout its lifecycle.

Principles underpinning the ALIV[H]E framework

ALIV[H]E was created through an iterative learning process involving organisations in Kenya, Malawi, South Africa, South Sudan, Zimbabwe and India. It builds on the ‘expertise by

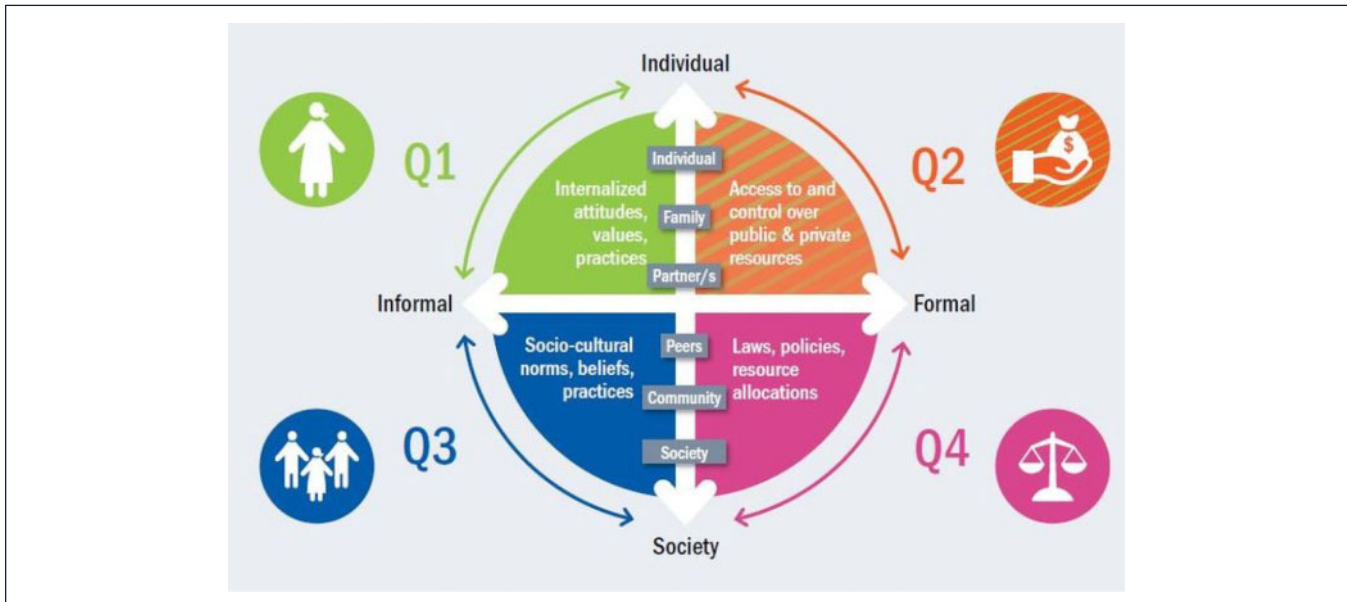


Figure 1. ALIV[H]E change matrix. Source: Salamander Trust *et al.* [1]

experience' [20,21] of women living with and affected by HIV around the world, and uses the pronouns 'we' and 'our' to reflect this ownership and the principles underpinning the ALIV[H]E framework including:

- Meaningful involvement of women living with HIV/AIDS (MIWA) in the entire process of development (the process is described in [22]);
- Recognition that women living with HIV and/or who have experienced violence have different overlapping and intersecting identities, which influence how they experience such processes, and addressing this through a programme global reference group that aimed to include women 'in all our diversities' and ensure that any response addresses the discrimination different groups of women face;
- Designing processes that illuminate how social identities intersect and overlap with related power systems;
- Holistic, assets-based and appreciative approaches focusing on solutions on key areas of change related to the individual, society, services, resources, laws and policies and that underscore positive experiences, examples and potential.

ALIV[H]E is part of an emerging acknowledgement of the ethical, practical and social imperative to ensure that policy and guideline development must include at its heart those people who will be most affected. It is closely aligned to the principles used in the recent *Consolidated guideline on sexual and reproductive health and rights of women living with HIV* [11], which departed from usual practice by being informed by, and centred on, the experiences and expertise of women living with HIV. Indeed, ALIV[H]E could provide a useful framework to aid the participatory and women-centred development of other such guidelines in the future.

There are seven core values at the heart of the ALIV[H]E response to VAW and HIV: human rights, sexual and reproductive health and rights, gender equity and equality, respect for diversity, safety (from violence in all its forms), participation, and evidence-informed.

These core values are in line with reviews suggesting that the best results are from programmes that are holistic, people-centred and people-led, work across sectors and involve multiple stakeholders,

and which instead of focusing on problems take a more positive or 'appreciative' approach which builds on strengths [23,24] and considers the need to develop community ownership in each setting [1,25].

The ALIV[H]E change matrix

The ALIV[H]E change matrix (Figure 1) is at the heart of the ALIV[H]E framework and is based on Gender at Work's change matrix [26] and the World Health Organization's Wheel of Change [17], presenting four areas of change along axes of individual/society and informal/formal.

This tool for situating change is closely related to other existing tools, and recognises that it is women's rights organisations and the movement they are part of that have driven the most effective work in all four quadrants [27]. (Association for Women in Development [AWID], ActionAid, Amplify Change and the Global Fund for Women have all developed similar tools for analysing and capturing change in different areas where power is exercised.) It is important to be aware of how work on one quadrant can effect change in others [28] and that addressing two or more quadrants makes for stronger impact.

Changing the paradigm: research and learning

Whose research counts?

Projects that make a positive difference to women's lives often remain relatively unknown. In Malawi, the Coalition of Women Living with HIV and AIDS (COWLHA) has implemented *Stepping Stones* programmes in 12 of the 31 districts of the country. (*Stepping Stones* is a training programme on gender, generation, HIV, communication and relationship skills [<http://steppingstonesfeedback.org/>].) External evaluation of the work found it led to significant improvements for women and communities, with impressive reductions in violence [29,30]. The same is true of more recent work conducted in Malawi as part of the ALIV[H]E development by COWLHA and SAFAIDS (Southern Africa HIV and AIDS Information Dissemination Service) [31,32]. However, when the US Government funded research on Malawi focusing on HIV and VAW, there was no mention or knowledge of this work (personal communication, Alice Welbourn, Salamander Trust). The ALIV[H]E framework Global Reference Group members

have spoken of similar experiences of work led by women being ignored in policy formulation.

The current paradigm explicitly separates researchers and evaluators from the ‘community’, through fear of ‘contaminating’ the data, and awards greater power, prestige and visibility to Western researchers compared to their counterparts in the countries where much of the research takes place [33]. International conferences are dominated by researchers trained to maintain their academic ‘objectivity’, with women living with HIV often invited only to give personal testimonies. This divide means that even those researchers with personal experience of VAW or HIV make no reference to that experience in their research.

Some feminists have long recognised the political and subjective nature of knowledge generation, and the importance of community participation and ownership of knowledge created [34]. The reality is that women with experience of VAW and/or living with HIV (and their organisations) are active in many kinds of research. Women such as Susan Paxton (in the Asia Pacific region), Jeni Gatsi (in Southern Africa) and Violeta Ross (in Latin America) are prolific activists and researchers, to name but three [35–37]. The International Community of Women Living with HIV/AIDS (ICW) has a significant research programme. ICW East Africa has a focus area called: ‘Researching our concerns and issues often missing from academic, scientific and development circles as well as women, HIV and human rights movements, yet critical to HIV policies’. (See for example the ICW Global website: www.iamicw.org/resources/research; the ICW East Africa website: www.icwea.org/publications/?category=1; or the ICW Latina website: <http://icwlatina.org/>. ICW is also part of the Stigma Index partnership: www.stigmaindex.org/. The Stigma Index is a tool, developed and used by people living with HIV, that measures and detects changing trends in relation to stigma and discrimination experienced by people living with HIV.) By embracing a participatory approach and methodology, the ALIV[H]E framework attempts to create a roadmap towards paradigm change.

Capturing complex processes of change

Fundamental changes to cultural and social norms take time [4]. Systematic reviews and RCTs cannot capture this kind of complexity; at their best, they can only answer the question of what works, rather than how and why, for which qualitative research is needed [38]. Furthermore, results-based approaches and evaluations based on a short timeframe narrow the focus [39–41], and put development practitioners under ‘pressure to tell a positive, simple story that demonstrates programme impact, preferably backed up by numbers’ [34], despite the fact that ‘telling the story of changes in women’s lives is complex and messy’ [42].

The ALIV[H]E framework recommends drawing on formal sources of data, despite their inevitable shortcomings. Yet it also encourages its users to enable communities to present their own ideas of what needs to change. Frameworks exist that can help to establish indicators of change that are measurable and in line with community priorities. SPICED (Subjective, participatory, interpreted and communicable, cross-checked and compared, empowering and diverse and disaggregated) indicators, for example, shift the focus away from donor priorities, and put community priorities first [43]. Needless to say, these community priorities are not homogeneous – NGOs and funders should understand that less powerful groups within communities need space and time to discuss and present their own priorities as part of the research process. This approach not only aids analysis of the way they can be excluded from decisions, but also helps to suggest how change can be effected [44].

Empowering approaches to research *and* evaluation require flexible and iterative processes and definitions of evidence that can capture shifting priorities, as communities develop their idea of what needs to change and how. They also require collaborative working between research organisations and those working at community level in more activist or programme-delivery roles.

Partnership working and the ALIV[H]E framework

The development of the ALIV[H]E framework involved both research and community organisations, to bring together those working with the formal evidence, and those with lived experience or an understanding of what works drawn from programming and implementation experience. Often, these were new partnerships, requiring each side to learn how to work and communicate effectively and respectfully with the other. Such collaborative work also requires funding and support to create the time and space needed for joint reflection, which makes the most of the different contributions and expertise of researchers, communities and community organisations, and which is able to explore tensions which emerge between the different perspectives and approaches. Power dynamics may favour researchers; with people feeling that they are seen as mere research subjects and not collaborators; use of technical language and academic jargon that excludes community collaborators; research that extracts information without being supportive or empowering; and international researchers claiming ownership of ‘data’ and information about people’s lives with their contribution often relegated to a footnote of thanks (personal communications), and without due recognition of the contribution of national researchers in the research country [33]. In addressing VAW, the ‘collective wisdom, knowledge and experience’ of women’s rights activists and advocates is vital, and must not be made invisible and marginalised [45].

Conclusion

The ALIV[H]E framework enables us all to understand how approaches to VAW in the context of HIV could be different. It champions holistic approaches, supports the work of communities, and feeds diverse community perspectives into evaluation and research frameworks and evidence. By ensuring that those most affected by HIV and violence are involved, it leads to a sense of shared ownership, better learning, better application of learning, and increased sustainability. This progress is desperately needed, and can only happen if the understanding of what constitutes evidence becomes much broader. By providing a structured way for researchers, NGOs and CBOs alike, to reflect on their work and translate it into evidence which is also, and most critically, meaningful at community level, and its insistence on the importance and application of values, the ALIV[H]E framework can contribute to furthering this understanding over time.

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Declarations of interest

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