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Benefits and challenges of a community-based programme for women living with HIV in Mali

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ABSTRACT

Gundo-So is a community-based programme developed by and for women living with HIV (WLHIV) in Mali through the ARCAD-Santé-PLUS association. It provides support, co-constructed with WLHIV, to develop strategies on whether or not to disclose their status. The aim of the ANRS-12373 research is to evaluate the impact of this programme in the short and medium term. As part of this research, semi-structured interviews were conducted with participants (14). These interviews were analysed thematically. Three themes are presented here: positive feedback from the programme, which enabled them to be listened to and supported them both psychologically and financially. The impact of the programme on the participants' social network is also described, in terms of the links made with peers met during the programme. Finally, a new perspective on issues such as disease management, which improved through the contribution of knowledge, and also through the development of psychosocial resources. The programme enabled participants to acquire psychosocial skills, the ability to effectively self-manage their condition, and strategies on whether or not to disclose their HIV status. Participants' empowerment and social support in relation to the disease were developed through the programme, particularly through the links created with other women living with HIV.

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1. Introduction

Community-based research is characterised by a collaborative, participatory approach with the populations concerned by the research subject in order to meet their needs. Research is done by, with and for the population. Targeting vulnerable populations, two objectives underlie this research: one is scientific and aims to increase scientific knowledge through adapted methodologies; the other is of social utility and aims to implement actions and strengthen the capacity of communities so as to trigger a social transformation (Bauquier et al., 2017; Bekelynyck, 2011; Demange et al., 2012). Community members are involved throughout the project, and researchers work in collaboration with them, harnessing each other's expertise and developing new skills (Demange et al., 2012).

Community-based research fosters the development of a process of empowerment of the population. This empowerment, employed in many fields without any consensus on its definition, refers to the capacity of individuals to exercise control over their environment in the ways that they wish (Cattaneo & Chapman, 2010; Le Bossé, 2003). It designates both a process (*empowering*)

and a result (*empowered*) (Le Bossé, 2003). While it is mainly studied from an individual point of view, it can also be seen at organisational, community and societal levels, all of which are interconnected (Keys et al., 2017).

It was with this in mind that the “Gundo-So: la chambre des confidences” (“Gundo-So: chamber of secrets”) programme was created by and for women living with HIV in Mali. It aims to provide women with the proper tools to disclose their HIV status or keep it secret, so they can make an informed decision and put in place appropriate strategies depending on the situation.¹

In Mali, 110,000 out of 18 million people were living with HIV in 2021 (ONUSIDA, 2021). The number of women living with HIV (WLHIV), aged 15 years and over in Mali was thus estimated to be 53,000 (ONUSIDA, 2021). Beyond the medical issues at stake, WLHIV also faces social and psychosocial issues, particularly due to unequal gender relations (PNUD, 2020). Women are generally economically dependent within their couple or their families and therefore have little decision-making power (INSTAT, 2019). Since 2006, people living with HIV (PLHIV) in Mali

have been legally obliged to disclose their serostatus to their sexual partner(s) within six weeks after their diagnosis (Loi 06-028, Prévention, prise en charge et contrôle du Vih, 2006). Disclosure of HIV status is a complex step which PLHIV have to adapt to suit their situation. Indeed, the disclosure by PLHIV of their serostatus can be synonymous with support (moral, financial) from relatives, but can also lead to stigmatisation and rejection by family and friends (Machtinger et al., 2015; Sow, 2013).

The Gundo-So programme leads participants to reflect as a group on the different situations where they would wish to either disclose their status or keep it secret. Various tools and exercises from Malian culture are used for these purposes. Using a participatory approach, the strategies are discussed according to the context, and each woman develops a concrete action plan. Gundo-So might be seen as a therapeutic education programmes (TEP). Indeed, TEP aims to teach knowledge about the disease, for instance via knowledge acquired about HIV and its treatments but can also focus on the development of skills, abilities and self-knowledge as coping mechanisms and psychosocial skills (WHO/Europe, 1998). Therapeutic education has developed in a context where chronic diseases are increasingly on the rise.

An assessment of the short- and medium-term effects of Gundo-So is made on the basis of the trial's main evaluation criteria using a mixed quantitative and qualitative data approach. In parallel and complementary to this assessment, the research aims to understand the issues relating to the development of empowerment among participants in the programme, and how it is reflected in everyday life.

2. Methods

The ANRS 12373 Gundo-So research is a randomised trial with two arms: an immediate arm (G1) and a delayed arm (G2), allowing for an inter-arm and intra-arm comparison. The delayed arm is the control group. A total of 224 WLHIV aged 18 and over, diagnosed for ≥ 6 months and < 5 years were recruited from one of the six ARCAD Santé PLUS treatment sites in Bamako. This study focuses only on the qualitative data in order to comprehend how the participation in Gundo-So could affect their lived experience of HIV. Semi-structured interviews were carried out with fourteen of the participants in the programme between April 2019 and January 2020, at three of the six research sites. The participants were identified by the facilitators of the programme according to their availability and their understanding of French. The interviews

presented here took place after their participation in the Gundo-So programme. They were conducted by a researcher in social-health psychology and a Bambara interpreter. The written consent of the participants was obtained upon their inclusion in the research, after they were informed by the facilitators, orally, of the objectives of the research, its nature, its advantages and its disadvantages. During the interviews, the participants were again informed orally of the objectives of the research and their consent was confirmed.

3. Analysis

For this article, the interviews analysed were conducted after the fact, i.e., an average of 2 and a half months after the participants had taken part in the 9 sessions of the Gundo-So programme. A reflexive thematic analysis of the interviews was carried out (Braun & Clarke, 2021). After being familiarised with the transcript we coded each interview. Secondly, we looked for transversal patterns and collated them into themes and sub-themes, sharing a meaning gathered on a central idea (Braun & Clarke, 2013). A thematic tree was built as visual tool to illustrate connections between them.

4. Results

Fourteen participants were interviewed individually after participating in the nine Gundo-So sessions. However, only thirteen interviews were analysed. One of the interviews was set aside due to the participant's incoherent comments, that did not allow for proper analysis. After verification, the persons and events mentioned by the participant didn't exist or hadn't taken place. The characteristics of the participants are shown in Table 1.

Table 1. Sociodemographic characteristics of the participants (14).

Participant	Age	Marital status	No. of dependents	Economic activity
1	Missing data	Widow	7	None
2	30	Married	4	Small business
3	34	Widow	2	Small business
4	33	Widow	3	Small business
5	28	Married	0	Small business
6	33	Married	1	Small business
7	42	Married	2	Housekeeper
8	29	Married	2	Small business
9	27	Married	3	Small trades
10	39	Married	3	Small business
11	31	Married	3	Small business
12	25	Married	1	Student
13	40	Divorced	3	Housekeeper

4.1. Thematic analysis

The analysis highlighted the different themes present in the text corpus (Braun & Clarke, 2021). Four main themes emerge from this analysis: Gundo-So experienced as a positive experience, improved management of HIV, a social life impacted by the programme, and the experience of precariousness, which limits the impact of Gundo-So. Here, the focus will be on the first three themes (Figure 1).

4.2. Gundo-So: a positive experience

The programme was described in a positive way by the participants, all of whom were satisfied with it.

4.2.1. Social support between WLHIV: feeling listened to

In the participant’s view, Gundo-So represented a place for advice and support, as much to do with issues concerning treatment as about the secrecy of their serostatus, and their relationships with their family and husband.

Gundo-So helped the women feel better: they were not so sad and were more positive about HIV. Some participants reflected this change in their state of mind by taking care of themselves physically: “But I’ve changed with Gundo-So. I braid my hair, I dress properly ... I mean, I do tattoos and stuff, I look after my appearance” (Participant 8, 29 years old, married). Overall, Gundo-So brought peace of mind to these women. HIV was no longer a source of anxiety.

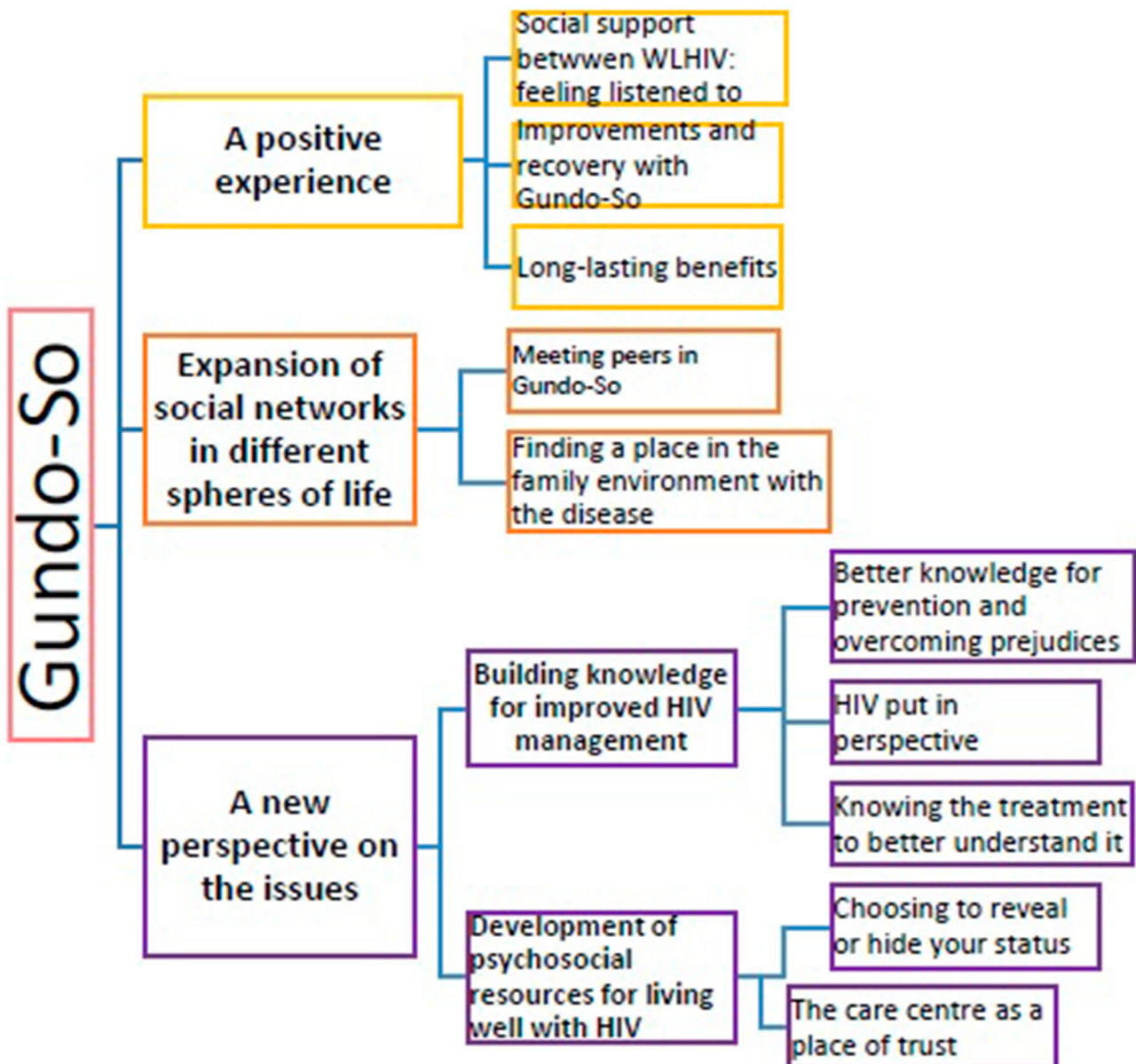


Figure 1. Main themes resulting from the thematic analysis of the post-GS interviews considered in this article.

4.2.2. Improvements and recovery with Gundo-So

Gundo-So also represents financial assistance. Indeed, the compensation paid for transport meant that the women could improve their daily lives by buying food, by helping in childcare, or by investing in their economic activity. Some groups also set up a tontine, a collective savings association, during Gundo-So. Each woman was thus able to start again with a larger amount of money in one go.

4.2.3. Long-lasting benefits

After the programme ended, some participants stressed that Gundo-So continued to be of benefit to them: the tools and strategies acquired during the sessions were still being used, particularly certain tools that they were able to keep, such as the shopping basket (used during the programme to keep the various tools received during the sessions).

4.3. Expansion of social networks in different spheres of life

4.3.1. Meeting peers in Gundo-So

By participating in the programme, women were able to meet and bond with other women living with HIV. Before Gundo-So, they felt alone in their situation and were socially isolated. Participation in the programme allowed them to meet other people, feel less alone and be able to socialise once again. For some, strong ties were forged through the activities. Once the programme ended, some women stayed in touch: through the centre where they meet to take their treatment; by visiting each other, or by phone. These exchanges are an opportunity for the women to go over the advice given during Gundo-So and to continue to help each other. Some, however, are no longer in contact with others, sometimes because of a lack of financial means or out of fear that their status will be discovered. Gundo-So also helped participants to approach other PLHIV outside their group in order to give advice.

4.3.2. Finding a place in the family environment with the disease

Relationships with their families and loved ones were also impacted by their participation in the programme. The women have seen a revival of social relationships given that it is now easier for them to hide their status:

it's had an impact on my relationships, with my friends and my neighbours, my family. Because before, I kept out of the way, I stigmatised myself, I didn't approach people, now I'm awake, I communicate with people, I approach people. (Participant 13, 40 years old, divorced)

The family, especially the children, husband and mother, can be a source of support in managing the disease: they listen to them or can help them with medication.

4.4. A new perspective on the issues

4.4.1. Building knowledge for improved HIV management

4.4.1.1. Better knowledge for prevention and overcoming prejudices. The participants learned and improved their knowledge of HIV and its treatment through the programme. Some knew very little about it before: they sometimes had a mistaken perception of HIV, and many prejudices about this infection. This acquired knowledge helped them overcome this.

Using the information and new knowledge acquired through Gundo-So, the participants tried to adopt HIV prevention with their friends and relatives, without necessarily disclosing their status. Status sharing also allows the family to become a new source of support in the management of HIV: someone who will listen to them, or help them in taking their treatment.

4.4.1.2. HIV put in perspective. The women felt that HIV is no longer perceived as a fatal illness, and its seriousness has decreased. They are now less concerned that their serostatus will be conspicuous. HIV is not so much on the participants' minds anymore: it generates less stress, which is more often related to the mere fact of coming to the centre for treatment.

4.4.1.3. Knowing the treatment to better understand it.

The advice exchanged and the information taken onboard during the group sessions enabled them to better understand the issues relating to their treatment. This means that they have better treatment management, and see positive effects: the majority of them feel well. Through the programme, strategies were shared on how to take the drugs correctly and how to hide them, without the risk of disclosing their status: "What I liked about the programme is the way I can hide, hide my status and hide my treatment from my neighbours, my parents" (Participant 9, 27 years old, married).

4.4.2. Development of psychosocial resources for living well with HIV

4.4.2.1. Choosing to reveal or hide your status. The Gundo-So programme enabled some participants to disclose their status, or to decide not to reveal their HIV status without problems through the strategies and advice given during the sessions. Decisions to

disclose after the programme was made according to the women's needs and went down well. Some women have not yet disclosed their status but plan to do so, when conditions are right, or when the need arises. Other women, on the contrary, do not wish to disclose their status and do not find that a problem.

4.4.2.2. *The care centre as a place of trust*

The healthcare professionals they met at the centre were an important source of support for the women. The fact that some of the facilitators also shared their status with them was important and made dialogue easier: "it was very beneficial to know that the people who work here also have the same problem as us" (Participant 2, 30 years old, married).

5. Discussion

In this article, we have tried to understand how participating in a community programme could influence the participants' experience and their empowerment.

The advice and knowledge shared at Gundo-So meet the aims of TEP. Gundo-So is therefore a TEP programme built around a community-based approach. Very few TEP programmes have been developed collaboratively, however, this type of programme design has proved to have greater relevance and accessibility and improve the dissemination of projects; in particular when it comes to reaching minorities, those in vulnerable situations, or those with poor access to healthcare, as evidenced by some Gundo-So participants (Gross et al., 2017) Through working together and setting up the project with and by the population, a unique feature of community-based approaches, results were obtained outside of the primary objective of the research (Demange et al., 2012; Minkler et al., 2003). This makes it possible to respond in a more relevant way to the needs of the population and to develop more appropriate tools, all the more so in a West African context, given that, as underlined by Iguenane et al. (2018), targeted skills and the contents of TEP programmes are not always suited to such contexts.

Through the programme, links were established between the participants who were often isolated, enabling some of them to develop a network that provided them with social support. This social support makes them less stressed about the disease, enables them to receive help and regain a social life. As documented in the literature social support reduce symptoms of depression, anxiety and risk behaviour, and is positively linked to a better quality of life and mental health, this could be investigated through the questionnaire's data (Green, 1993; Qiao et al., 2014; Seffren et al., 2018).

Participation in Gundo-So expanded the participants' social networks and allowed them to meet and share about their disease, Cederbaum et al. (2017) highlight the fact that the social network size among WLHIV seems to decrease the fear of disclosing their serostatus, in our study, we didn't find more disclosure from the participants but feel more comfortable with it (Cederbaum et al., 2017). These data show that the data from mainly Western studies are also mirrored here in a Malian setting, although complementary analyses are needed (Casale, 2015; Casale et al., 2015; Seffren et al., 2018).

As a community-based programme, Gundo-So aims to empower participants. The results presented here can be compared with the development of the components of psychological empowerment in the Zimmerman and Eisman model (2017). New insights into HIV, treatments and services contribute to the interactional component, which corresponds to the ability to understand one's environment and to be aware of available resources (Zimmerman & Eisman, 2017). Skills related to sharing or withholding HIV status, developed during the sessions, can also be included in this component. The activities encourage the participants' sense of self-efficacy to be able to decide not to reveal or share their status as they wish, and can be tied to the intrapersonal component, referring to the way in which individuals perceive themselves and their ability to influence their setting. The provision of financial resources and the formation of tontines by some of the groups can be put into perspective via the behavioural component. Indeed, in disadvantaged environments, the management and securing of resources have been underlined as difficult (Zimmerman & Eisman, 2017), while access to resources allows individuals to develop a certain control over their environment (Le Bossé, 2003; Wallerstein, 2006), in this case the programme provided them with resources so that they could feel less stress about economic concerns and be able to carry out other activities, including those related to HIV. In addition, the sessions encouraged the participants to get involved in the group, which is linked to the development of empowerment by creating relationships of support and cooperation (Miguel et al., 2015; Zimmerman & Warschausky, 1998) A development of the psychological empowerment of the participants can be seen, through its development over the long term would require further study.

For many participants, Gundo-So provided an opportunity to meet and bond with other WLHIV for the first time, resulting in bonds that sometimes lasted beyond the programme. These bonds can be related to the concept of the *sense of community*. It designates the feeling of belonging that individuals have towards

a community and is a first step in building a community (McMillan & Chavis, 1986). It comprises four components, which seem to be initiated through participation in the programme: belonging to the group, which takes the form of organising the group into a village with its codes; influence can be represented through the advice and support exchanged among the women during the sessions; satisfying needs, on the one hand by each woman's success in hiding or sharing her secret, and on the other hand by mutual help and by the setting-up of tontines; finally an emotional connection kept up beyond the programme via instant messaging and face-to-face meetings. A positive sense of community is linked to increased participation in community activities and actions (Bermea et al., 2019; Reed & Miller, 2016), which could enable women to get involved in actions in favour of WLHIV in Mali.

Nevertheless, certain limits already appear as obstacles to keeping up a community of WLHIV, and thus to the development of empowerment at a more macro level. Long before HIV, one of the main concerns of the participants remains financial, preventing them from covering their needs. This makes it difficult to invest in a community, thus reducing the potential for development and empowerment. These results raise the question of the development of community research among the most disadvantaged populations. It appears that a holistic, more general approach is needed to work with such populations.

The Gundo-So programme is thus experienced in a positive way by the participants, who develop psychosocial and self-care skills in relation to their illness. In doing so, they participate in the development of their empowerment. The value of the programme also seems to lie in the social support provided by peers, and the fact that it is run by WLHIV. Together, these elements make it possible to support participants in their decisions to share or decide not to reveal their HIV status.

Note

1. The programme is made up of an individual assessment meeting, nine weekly two-hour meetings in groups of eight women, and an optional group meeting. The sessions are led by two facilitators from the association. Each meeting is organised around a topic and includes activities and tools specific to Malian culture, which were initially proposed by the women concerned. Each woman is given a shopping basket in which she can keep the items used during the sessions. During the first session, the group is invited to organise themselves into a village: the participants choose a village chief, nicknames, a name, a song, etc.

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Ethics approval

The research has been validated by the INSERM ethics evaluation committee (opinion no. 18-474) in France and by the ethics committee of the National Institute for Public Health Research in Mali (no. 2018/174/CE/FMPOS).

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