

Key sources of strength and resilience for persons receiving services for Hansen's disease (leprosy) in Porto Velho, Brazil: What can we learn for service development?

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Background: Individuals affected by Hansen's disease (leprosy) often experience stigma and discrimination. Greater psychosocial resilience may enable people to deal with such discrimination. This study aimed to explore sources of strength and resilience for individuals affected by Hansen's disease in Brazil.

Methods: We used a cross-sectional study design with a qualitative approach. Semistructured focus groups were conducted. Analysis comprised thematic categorisation of transcripts.

Results: Thirty-one participants were included: 23 individuals affected by Hansen's disease and 8 healthcare providers. We found that while a few individuals affected were provided with formal psychological support in the early phases of their treatment, many noted the importance of providing such support at this time. Most participants described relationships with and social support from family members, friends and with others affected by Hansen's disease as their primary source of resilience. A key context for building resilience was through the peer-level sharing and engagement experienced in self-care and support groups. Participants also emphasised the importance of providing appropriate information about Hansen's disease and the importance of beliefs and spirituality.

Conclusions: Hansen's disease services should seek to build resilience in early treatment through counselling and during treatment and beyond by having people affected getting together. Across both settings supporting family and social relationships, providing accurate information and acknowledging spiritual beliefs are important.

Keywords: discrimination, health services, leprosy, psychosocial resilience, relationships, stigma.

Introduction

Since the introduction of multidrug therapy (MDT) in 1982, the management of Hansen's disease (leprosy), a neglected tropical disease (NTD), has advanced considerably and millions have been cured from the disease. However, the transmission of its pathogen *Mycobacterium leprae* is ongoing, so the primary focus of Hansen's disease services in many countries is on disease surveillance and medical treatment. However, many people affected emphasise that the adverse psychosocial consequences of the disease outweigh the physical and functional dimensions.^{1–3} In response, therefore, meaningful Hansen's disease services should also attend to psychosocial corollaries of the disease.⁴

A commonly reported psychosocial concern for many individuals affected by the disease is Hansen's disease-related stigma and discrimination. This adversely affects psychological well-being and is linked with depression and even suicide.³ It also impacts social participation,^{5–8} with negative consequences for interpersonal relationships, social inclusion, social status, education and even employment.^{7–9} It is therefore not surprising that a diagnosis of Hansen's disease can profoundly and negatively affect an individual's general quality of life^{5,10–12} and, specifically, their psychosocial well-being.^{4,10,12,13}

Within psychologically oriented research, efforts to address Hansen's disease-related stigma and discrimination have largely focused on the stigmatised person, the stigmatising context and broader systems.^{14,15} Corresponding interventions have sought

to treat the individual affected, or influence community attitudes or change existing laws and policies. Few approaches have sought to address discrimination from a resilience perspective. That is, few have sought to enhance well-being by building the psychosocial capacity of the stigmatised individual to withstand social challenges and overcome discrimination. Resilience, the capacity to overcome and thrive in the face of adversity,¹⁶ aligns closely with some of the skills that may benefit people to overcome discrimination at an individual level.

Resilience-related skills and thinking may enable people to thrive when faced with adversity¹⁷ and may have a positive effect on general quality of life, happiness, psychosocial well-being and even longevity.^{17,18} Factors associated with resilience include optimism, positive thinking, self-efficacy, problem-solving skills, attachment to others and faith. Resilience also appears to be associated with enhanced social support,^{16,18–21} which may in itself be a protective factor in stressful situations.²² Research suggests that while all people are resilient to some degree, there are also a number of resilience-related behaviours or qualities that can be learned.^{16,21,23}

This would indicate that in the Hansen's disease context, if more opportunities and resources were available to build and enhance the psychosocial resilience of people affected, then they may be better resourced to recognise, counteract and deal with discriminatory behaviour. To date, the concept of resilience has not been the focus of much research in the Hansen's disease and NTD area. Greater understanding of what factors contribute to the resilience of individuals affected and their family members could meaningfully inform Hansen's disease service development. Given the similarities in stigma types, manifestations and impact among NTDs,²⁴ lessons learned from this research can also inform service development for other stigmatised conditions, such as other NTDs.

The current study is part of a larger project that aims to develop and pilot an intervention to build individual and family resilience against Hansen's disease-related discrimination. The project has three phases: a scoping review¹⁵ about evidence-based resilience promoting interventions in the context of stigma and discrimination; the current study explores the sources of strength and resilience of an initial sample of individuals affected by Hansen's disease and experienced health service providers in the context of Hansen's disease treatment; and a third phase underway in India, where the principles of resilience promotion found in the scoping review plus the lessons learned from the current study inform the design of a pilot intervention to build resilience among families that are experiencing Hansen's disease.

Materials and Methods

Study design

This study used a cross-sectional design with a qualitative approach. Semistructured focus group discussions were conducted to gain insight into the sources of strength and resilience of an initial sample of individuals affected by Hansen's disease and experienced service providers.

Study site

Focus groups were conducted at a secondary level public health facility, the Osvaldo Cruz Polyclinic, a State of Rondônia Reference Center for Hansen's disease located in Porto Velho, Brazil, in December 2018. Approximately 300 people affected by Hansen's disease are seen at the facility each month. The location caters to a large number of patients coming from various regions of the state of Rondônia, northern Brazil, in the Amazon region, who, despite having completed the drug regimen for active Hansen's disease, still require care. Reaction management, physical rehabilitation and prevention of disabilities self-care groups are some of the services provided in addition to regular MDT treatment. It is located in an urban centre of about 539 354 inhabitants according to the population estimate for 2020 by the Brazilian Institute of Geography and Statistics. In 2019, the number of new cases registered in the health surveillance system was 122.²⁵

Study population and sampling methods

People with an understanding of Hansen's disease and Hansen's disease services, namely (1) people directly affected by Hansen's disease and (2) clinic staff working closely with persons affected, were included in the study. Data were collected until data saturation was reached; we estimated that this would be reached when at least 10 individuals per participant group were included. People aged <18 y and those unable to speak Portuguese were excluded. Healthcare providers were only included if they had specific responsibilities for Hansen's disease services.

Participants were selected through convenience sampling from among those present at the clinic at the time of the group discussions. Potential participants were contacted via the Osvaldo Cruz Polyclinic, with general and personal invitations offered to people with an understanding of Hansen's disease and Hansen's disease services.

Data collection

Data were collected over a 2-wk period in December 2018. We used semistructured small focus groups. In these groups, an interview guide with points and questions to trigger and sustain the discussion and engagement of all participants was used. Participants were asked to speak about what in their experience gave them (or people affected by Hansen's disease) strength, courage and the means to face discrimination. In addition to audio recording, the facilitator (the second author, an individual affected by Hansen's disease, highly experienced in qualitative research) took written notes and sought clarification where required. All focus groups were conducted in a private space in the health facility. Separate focus groups were held for health workers and for people affected. Except for one focus group, participants who were in self-care groups and those who were not, were not mixed. All focus group discussions were conducted in Portuguese and audio recorded; the discussions lasted from 19 min to 1 h 33 min.

Data analysis

The audio recordings of the focus group discussions were transcribed verbatim, also noting periods of silence and emotional

Table 1. Demographic information of participants

	No. of individuals affected (n=23)	Health providers (n=8)
Average age, median (range)	53 (26–70)	52 (31–67)
Gender, n (%)		
Female	12 (52%)	6 (75%)
Male	11 (48%)	2 (25%)
Education, n (%)		
No education	4 (17%)	0 (0%)
Primary level incomplete	13 (56%)	0 (0%)
Primary level complete (8 y)	3 (13%)	0 (0%)
Secondary level complete (12 y)	3 (13%)	1 (12%)
University level complete (>16 y)	0 (0%)	7 (87%)
Occupation, n (%)		
Health worker (higher education)	0 (0%)	6 (75%)
Health worker (secondary education)	0 (0%)	2 (25%)
Rural worker	1 (4%)	0 (0%)
Home maker	1 (4%)	0 (0%)
Urban unskilled worker	3 (13%)	0 (0%)
Not occupied	1 (4%)	0 (0%)
Social security beneficiary	17 (74%)	0 (0%)
Group support		
Not in self-care groups	11 (48%)	n/a
In self-care groups	12 (52%)	n/a

expressions. Where there were local language expressions, they were edited to common Portuguese grammar. These transcripts were translated to English by the second author (ZBSP) and a translator who is fluent in English and Portuguese, with care taken to ensure the meanings of terms and expressions were communicated. A total of 234 pages of transcript was reviewed by the three investigators (ZBSP, PK, AvtN). Based on agreed summaries, the investigators identified the main categories of relevance to the notion of building resilience in the context of Hansen's disease services. Whenever necessary, the original transcription in Portuguese was referred to for clarity.

Results

Demographics

Thirty-one participants were included in 10 small focus group discussions (2–5 participants per group). Three groups comprised only female participants, one group consisted only of males and the other six groups were mixed gender. A total of 23 individuals affected by Hansen's disease and 8 healthcare providers were included. Of the total of 23 people affected by Hansen's disease, 12 (n=12/23) were in self-care groups. These self-care groups consist of people undergoing MDT, rehabilitation or both. Their meetings focus on physical self-care and social activities to promote self-confidence and self-esteem.

Most participants were female (n=18/31). The average age of all participants was 54 (range 26–75) y. Most participants did not

have a paid job; they received social welfare benefits due to advanced age or due to physical disability (n=17/31). The other participants were unskilled urban workers, a rural worker, a home-maker or were not in an occupation but without receiving any welfare benefits (n=6/31). As a qualitative pilot study, focused on understanding the nature and variety of participants' experiences, rather than comparing groups or variables, we did not collect specific clinical data; however, an overview of the demographic information of the participant groups can be found in Table 1.

Based on our focus group feedback, all participants with Hansen's disease described a degree of discrimination in at least some, if not most, aspects of their lives. The group interviews explored 'sources of strength and resilience' for individuals affected by Hansen's disease through open-ended questions. The following themes were identified.

Themes

There is a need for psychosocial support in early treatment to facilitate resilience

Despite the existence of psychological services in the Hansen's disease programme in Brazil, several participants noted that they went through the process of diagnosis and early treatment without any formal psychosocial support.

No doctor helped me! They just gave the medicine, I took the medicine, I did not even tell my story because

I was ashamed there (FG6, women affected by Hansen's disease).

Focus group discussions indicated that participants were expecting that psychosocial and adjustment issues would be addressed alongside initial medical care. However, in most cases, they only met medical personnel, who often did not have the time or capacity to focus on these issues.

When I came in I already spilled everything out right away, I was crying, I was telling everything [to the doctor] (FG6, women affected by Hansen's disease).

Some participants explained that their experience of early treatment and diagnosis undermined their strength and resilience.

The overall picture of early treatment as described in these focus groups was that there were few opportunities for focusing on psychosocial resilience. Likewise, staff explained that such services were not a high priority and difficult to provide with scheduling challenges and staff turnover. It seemed that the provision of psychological support was not a high priority in this service.

She [psychologist] does not have a proper corner to talk. [She sees people] there, with everyone else walking in and out, it does not work (FG9, men and women affected by Hansen's disease).

Indeed, this was also true of other services:

Often, patients from other health facilities, already under treatment, arrive without any [psychological] guidance (FG5, health worker).

However, it was also clear that some early treatment staff took the time to listen and support patients. People affected drew a sense of resilience from the positivity provided by staff.

The treatment we do here [at the facility], they take good care of us. We receive that strength and encouragement not to give up (FG9, men and women affected by Hansen's disease).

In one focus group, an example was given of a medical practitioner who was very helpful in providing people with psychological and emotional support. This was also noted by service providers. It was clear from this focus group that such support by medical staff was deeply appreciated.

Counselling in early treatment is helpful in supporting resilience

A few participants reported receiving formal psychological support as part of their early treatment. They noted that they had drawn strength from this one-to-one counselling and described it as crucial, enabling them to understand the effects of the disease, to cope with their situation and to start to build their strength.

It was very difficult! It was the stage of treatment that was the most difficult... [The counsellor] helped me a lot. Because until then... I did not talk to anyone. That thing was trapped inside me. That was very bad for me. I cried a lot. I got depressed once. After I started having psychological counselling, I started to improve (FG8, women affected by Hansen's disease).

That day, when the doctor told me [I had Hansen's disease], I was finished! Then he saw that I was very worried, so he sent me to talk to her [psychologist]. From that time on I talked to her, it was... It was like growing up, everything changed in me (FG9, men and women affected by Hansen's disease).

Family and social relationships contribute to resilience

In most focus groups, participants talked about relationships and the social support they received as their primary source of strength. Focus group participants described drawing strength and resilience from their relationships with family members, from relationships with close friends and, importantly, from relationships that they had subsequently developed with others affected by Hansen's disease.

In many cases, participants described family as their key source of strength. This was true for both their family of origin and for their spouse and children:

For me, what... gave me more strength was my children (FG6, women affected by Hansen's disease).

In my family I said: 'I have this disease here!' But everyone supported me, no one turned their back on me (FG4, men and women affected by Hansen's disease).

While the importance of family as a source of strength was evident for the majority of participants, we noted that for some, family could be a source of rejection and discrimination.

In some cases, friendships were seen a source of considerable practical support, which enabled participants to be more resilient.

She said: '[C]ome here, to my house, with your children.' I with my children! She had five and I three [children]. [She said:] 'So let's raise these children' (FG6, women affected by Hansen's disease).

Some participants described their existing and new friendships with individuals not affected by the disease as a key source of strength.

My friends always supported me, thank God I never suffered any prejudice! (FG4, men and women affected by Hansen's disease).

Responses from individuals affected and service providers showed that many people looked to their friendships for emotional strength. In many cases, friends supported their resilience. However, as with families, in a few notable examples, the opposite was true.

Peer relationships contribute to resilience

Beyond the theme of family relationships and friendships as sources of resilience, the majority of our focus group participants emphasised the importance of relationships with peers affected by Hansen's disease as a source of strength. Relationships with peers were instrumental for psychosocial support and sharing of experience.

My strength was... my friends from the [self-care group] meeting here (FG10 men and women affected by Hansen's disease).

Participants saw their relationships with those also affected by Hansen's disease as core to effectively coping and being resilient.

Because we talk to friends and we get stronger. One is giving strength to the other (FG7, men affected by Hansen's disease).

Indeed, many emphasised that their communication with and relationships with peers comprised the sharing of information, venting of frustrations and sharing of experiences. This reciprocity and ability to identify with each other's experiences and situations resulted in mutual benefits and contributed to their resilience.

To give strength to others, start helping others who have the disease. You feel stronger! (FG9 men and women affected by Hansen's disease).

Self-care groups and support groups contribute to resilience

A core theme of our focus group discussions related to participants' experience of self-care and support groups as a key source of strength. Interestingly, the healthcare providers interviewed also emphasised the importance of peer support, self-care and self-help groups. They emphasised that it is important to actively encourage these groups and to include family members to further reduce stigma:

She managed to recover, and improved her physiognomy, her self-esteem was up there... In self-care, she found support (FG1, health worker).

Participants gave strong indications of the psychosocial strength they had derived from self-care and support groups.

[There are times] that you do not want to do anything... Do not want to see anybody... Do not want to talk to anyone... You feel down... And do not want to do anything, but the group gives us self-esteem to talk, to be entertained, it is where we tell our problems, where we share what we are feeling... I take it as a life lesson. I listen to them talk and take some lesson for me. I'm sure that what I say, they also take a little bit for them. Because what I've been through... Today I have overcome... I am already a victor for having gone through what I went through: the difficulties, the sadness, the depression that I went through, and I am here today,

and I say: 'I'm very strong, despite all that' (FG8, women affected by Hansen's disease).

As with the examples of strength derived from friendships with others affected by Hansen's disease, many focus group discussions emphasised the sharing of life experience with others. It appears the mutual nature of the discussions helped them build resilience. Despite not being intended for addressing psychosocial concerns, self-care and self-help groups provide an opportunity for learning from those who have been in similar situations, thereby increasing learning and resilience.

Resilience-related benefits described from engaging in such groups include deriving support from and providing support to those who are new or at their most vulnerable.

We are very strong for each other. When we meet, people talk a lot, when we meet, people give strength to one another. Sometimes we come and see the other, like her [another participant] there who cannot talk, and we talk a lot to her, give her a lot of affection... Today she cannot speak, but in a month or two months, she can do it (FG8, women affected by Hansen's disease).

Self-care and support groups are also a source of fun, which was an important source of strength.

We get involved, which is very cool. The games are very good, we danced, we played, we jumped, we have fun here, you know, for me the self-care group is very good, especially for my mind (FG6, women affected by Hansen's disease).

Providing information about Hansen's disease is beneficial in enhancing resilience

Our focus groups with affected individuals, as well as those with health staff, emphasised the importance of providing accurate and accessible information about Hansen's disease in building resilience in the face of Hansen's disease and discrimination. Healthcare providers recognised that correct knowledge can combat stigma and contribute to resilience.

This stigma is still very much related to... The ancient leprosy... There's still this prejudice, this stigma... The lack of information. I think we have to inform better (FG2, health worker).

People affected also noted the link between information and stigma:

This lack of knowledge causes stigma (FG7, men affected by Hansen's disease).

However, they emphasised that such information had benefit for their own adjustment and understanding and that it was beneficial to discuss the information with peers. In the context of a focus group discussion on the topic of accurate information on how contagious Hansen's disease is, one participant stated:

It is very good to talk to the doctor, to get rid of the doubts, and to always have a group, so as to be able to ask questions, to talk about the experiences (FG4, men and women affected by Hansen's disease).

Including beliefs and spirituality is beneficial for greater resilience

Finally, another source of strength and resilience reported by some of our participants was their beliefs, their spiritual life and their relationship with God.

It is God! God gives us much strength! I seek God! I seek and thank God. He has helped me very, very, very much (FG4, men and women affected by Hansen's disease).

Many participants referred to praying to God. Participants stressed the importance of religion and the strength they gained from praying.

I prayed to the Lord, to my Father in Heaven, I prayed a lot to the Lord... My strength, I asked God for it. And I thought a lot about my kids, because I, my problem, was very difficult (FG6, men and women affected by Hansen's disease).

Discussion

In keeping with the widely recognised psychosocial needs of persons affected by Hansen's disease²⁶ and the potential importance of psychosocial resilience in the face of discrimination,¹⁵ the current qualitative study provides key perspectives on what services might do to help those affected and their families to build strength and resilience. Based on the perspectives of people affected and service providers in Brazil, services should provide psychosocial support (particularly one-to-one counselling) in early treatment; recognise that family and social relationships are very important for building resilience; foster peer relationships (ideally incorporated into self-care groups); ensure that accurate information about Hansen's disease is provided; and acknowledge the place of beliefs and spirituality in building psychosocial resilience.

The theme of direct psychological support and counselling was key in our findings. This study found that people affected drew strength from psychosocial support and specifically the opportunity for counselling in early treatment. The importance of such support is also stressed in the WHO guidelines for strengthening the participation of individuals affected by Hansen's disease in Hansen's disease services, i.e. 'psychological support and counselling are crucial to the successful treatment of people diagnosed with leprosy'.²⁷ It is clear that counselling can help individuals cope with hardship and challenges and, indeed, may help people to become more resilient.²⁸ In light of indications from our recent literature review¹⁵ and focus group data, it would appear that counselling might also be a vital tool for services to enhance psychosocial resilience in the context of Hansen's disease.

In the current study, those participants who had only been seen by medical personnel (who may not have had the time or capacity to focus on their psychosocial and adjustment concerns) also described feeling that their resilience was undermined. Our focus group participants were clear that formal psychosocial sup-

port provided in early treatment aided their resilience. It is noteworthy that this study was conducted in Brazil, where there is a degree of psychological support available in the general Hansen's disease programme. While it may be that the presence of some services may have increased awareness of the need for such support, it also provides an indication for those countries where no such services exist, i.e. that people affected may gain great benefit from such support.

Another major finding in our study was the importance of family and other relationships and social support in building resilience. Participants described gaining strength from their relationships and the support they received. While it is generally understood that social relationships and support play a key role in a person's health and psychosocial well-being,²⁹ these findings align with more specific studies that link social support with resilience.^{18-22,30} Social support appears to be beneficial for people experiencing stress,^{31,32} may protect against depression and anxiety³³ and may assist people to cope with stressful events.³³

Substantial research associates social support with psychosocial well-being³¹ and quality of life.^{34,35} The current findings suggest that such social support is also vitally linked with resilience.²⁰ Social support can help build resilience because it can be a means of gaining functional, emotional, material and informational assistance.²⁰ Relationships can increase resilience by helping people to regulate emotions and solve problems by talking through issues.^{21,36,37}

The importance of the role of family and other relationships for building strength and resilience was reported by all focus groups. This aligns well with the resilience literature, which clearly links such connections with a person's ability to cope with adversity.^{30,38} Family relationships provide many of the advantages of social relationships noted above (reducing stress and anxiety, improving quality of life and providing practical support), but at a more significant level. While it is also true that some of our participants described family and other relationships as sources of discrimination and stress, it was clear from the responses that they saw the need for services to optimise such relationships, towards building resilience and strength.

Another key finding in our study was the importance of self-care and peer support groups in fostering resilience. Such groups are very common in Hansen's disease services, albeit with a primary focus on ulcer treatment and disability prevention.^{39,40} Self-care groups have been seen to have substantial benefits in managing impairment^{39,41-43} and group members often report benefits beyond improved wound care, such as in social participation.^{39,41-43} There were strong indications from our study that such groups also provide substantial psychosocial benefit and contribute to resilience. Again, this aligns well with previous research identifying such groups as effective for promoting resilience. The benefits of connection to a group of peers is known to have a variety of physical and psychological benefits^{33,44-46} and promote resilience.^{15,20,22} People affected by Hansen's disease in self-care groups in Ethiopia also reported increased confidence, dignity, self-respect and a sense of belonging.⁴¹ Peer support has been found to build autonomy and community⁴⁶ and may enable stigmatised people to develop new ways of thinking about themselves and develop a more positive self-image,⁴⁶ all vital to a greater sense of resilience. These findings suggest that Hansen's

disease services should seek to build resilience in early treatment, possibly by utilising (peer) group counselling.

Our focus group participants also emphasised the importance of accurate information, provided to them, as well as to their families and others around them. For the layperson in Brazil, Hansen's disease is largely unknown, unlike more common tropical diseases that affect large numbers of people. As such, many are unaware of it until the point of diagnosis.⁴⁷ Providing people affected and families with accurate and meaningful information about the disease would appear to challenge myths and stigma,^{15,48} which also contributes to resilience. Indeed, the provision of information is a vital dimension of most interventions for resilience in the face of discrimination.¹⁵

Finally, another common source of strength and resilience reported in the present study was participants' beliefs and their spiritual lives. Studies in other fields have also found that spirituality and faith can increase resilience to stigma.^{49,50} Among our participants, in response to questions about 'sources of strength', there were clear indications that beliefs were important. Earnshaw et al.⁵⁰ argued that spirituality can restore self-worth and perception of a sense of control. These would appear to be particularly valuable assets in the face of stigma and discrimination. It has similarly been reported in the literature that spirituality can buffer people from the negative impact of stigma, i.e. the meaning-making and framing that comes through faith can enhance resilient behaviours.^{49,50} Our results align closely with the observation that relying on faith can provide individuals with a sense of control, positively contributing to resilience and the capacity to overcome adversity.⁵¹

While the above themes were apparent in the feedback provided by focus group members and align with indications in literature from a variety of sources, it should be acknowledged that this study also had a number of limitations. First, although we did not seek a large number of participants, the sample for this study was small, highly localised and narrowly selected. Typically, qualitative studies such as this one seek to explore in-depth with a few participants rather than strive for a representative sample, so while the study is appropriate for its intended purpose, this information may not be representative of all those individuals affected.

Second, including service providers in our sample was both a strength and a limitation. The strength resided in being able to include service provider perspectives (given that our interest is relevant to current service provision); however, recognising their small number led us to conclude that a separate study focusing on a diversity of service providers across a variety of locations may have been preferable.

Third, some factors that are unique to the Brazilian context should also be acknowledged. As noted above, Brazilian public health services that include psychological services may not be representative of Hansen's disease services in other endemic countries. Likewise, the strongly Roman Catholic and Christian profile of the Brazilian population may have influenced our findings, but may not necessarily be representative of other Hansen's disease-endemic countries.

Finally, it should be acknowledged that while the above themes are informative from the perspective of key stakeholders, they are not necessarily going to be effective in increasing resilience. The issue of effectiveness is a topic for future research.

In reality, some aspects that deplete or prevent resilience may not be amenable to change within the resources of Hansen's disease services. However, despite these qualifications, the current study provides some useful indicators of what actions services might support or initiate to help those individuals affected and their families build psychosocial strength and resilience.

Conclusions

Based on the current findings, interventions for promoting resilience for people affected by Hansen's disease who face stigma and discrimination could be targeted at two main points. First, during the initial part of treatment, after diagnosis, there would appear to be substantial benefit in providing resilience-focused counselling. Providing such a safe environment for people to express emotions and concerns early on was strongly recommended.

Second, during treatment and beyond, having people affected getting together (in self-care or self-help groups) seems to be beneficial. This is likely to help people experience a sense of partnership and a shared understanding of resilience. Across both settings, the importance of supporting family and social relationships, providing accurate information and acknowledging spiritual beliefs are important.

Authors' contributions: AvtN, ZBSP and PK conceived the study; AvtN, ZBSP and PK designed the study protocol; ZBSP supervised the fieldwork and collected the data. AvtN, ZBSP and PK analysed the data. AvtN, ZBSP and PK drafted the manuscript; AvtN, ZBSP and PK critically revised the manuscript for intellectual content. All authors read and approved the final manuscript. ZBSP is guarantor of the paper.

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Data availability: The data that support the findings of this study are available on request from the corresponding author.

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