Strengthening personal and family resilience: a literature review for the leprosy context

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Summary
Objective: Promoting psychosocial resilience is a concern of health and wellbeing researchers and practitioners in many fields. Enhanced resilience in settings where people face discrimination may enable them to cope more effectively and deal with exclusionary behaviour and may also enable families to become more inclusive. While there are numerous interventions to build personal and family resilience in areas such as mental health, education and HIV/AIDS, this area of focus has not been well consolidated in leprosy-related research. In response, a review was conducted to identify core elements of interventions to promote resilience in individuals and family members in the face of discrimination.
Methods: We conducted a multi-phase adapted scoping review of English literature and a narrative review of the Portuguese language literature. All phases comprised the identification of prominent themes across multiple studies and a final synthesis facilitated the identification of key principles to inform and guide leprosy service interventions.
Results: We identified three main intervention focus areas in our review: individual level, social/community level and system level. We found that in the face of discrimination, resilience can be strengthened through information provision, counselling and assisting people through coping skills acquisition. Multi-pronged interventions focusing on increasing knowledge and improving self-esteem appear particularly worthwhile.

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Conclusions: The current review indicated that interventions should be tailored to the audience and should acknowledge the need for sustainability of interventions and durability of outcomes. We concluded that interventions for resilience would be beneficial in the context of leprosy, and potentially other neglected tropical diseases.

Keywords: Coping, Discrimination, Intervention, Leprosy, Resilience, Stigma

Introduction

People affected by leprosy are often highly stigmatised.[1−3] Leprosy-related stigma may affect a person's interpersonal relationships, marriage, employment, leisure activities, social status, self-esteem, and social and religious functions.[1,3] Social exclusion and rejection of people affected by leprosy may lead to mental health problems such as anxiety, depression, emotional stress, isolation and even suicide attempts.[2,3] In some cases this leads persons affected to avoid or delay treatment, which in turn may result in permanent impairments and even greater stigma.[1] Women are often more affected by leprosy-related stigma than men.[4,5] Those working with, or related to, people affected by leprosy may also experience stigma and its effects.[3] In many countries, the focus of existing leprosy services is predominantly disease surveillance and medical treatment. Best practice psychosocial interventions have much to contribute to reduce the mental health consequences of stigma through improved or enhanced leprosy services. A key challenge is to incorporate such psychosocial interventions into day-to-day leprosy care programmes.

Efforts to address stigma and discrimination towards people affected by leprosy have focused on a number of areas including:

a) The stigmatised person, through cognitive behavioural and information-based strategies such as lay and peer counselling, self-help groups and positive change agents,[6−10]
b) The stigmatising context, through addressing community and social attitudes which may impact on the person and their family.[7,11−13] For example by enhancing personal contact between persons affected and community members through 'contact events' or the production of videos and comics,[10,11,14]
c) Discriminatory laws, policy and systems that may impact on them, such as the use of non-discriminatory terminology, integrated care and mass media campaigns[15−17]
d) Economic and livelihood issues, addressing disadvantage through socioeconomic and other practical interventions, such as micro-finance.[7,18]

Some of these approaches were investigated in a programme of initiatives to address stigma and discrimination, known as the SARI studies. They noted positive outcomes from peer counselling,[9,18,19] increased community knowledge and improved attitudes resulting from promoting direct contact (such as community meetings, education, and testimonies), and indirect contact (such as videos and comics made by people affected by leprosy).[10,11,14,18] The SARI interventions also resulted in reduced stigma and increased social participation and had some impact on the quality of life of persons affected. They found that measurable reductions in leprosy-related stigma can be achieved with relatively simple interventions, which can be adapted to different settings and target groups.[18] The authors concluded that

interventions for resilience should use a multi-pronged approach, which addresses different levels and aspects of stigma and discrimination.

One potential adaptation with scope for "multi-pronged" intervention is to work proactively at the individual and the family level, emphasising resilience and psychological strength rather than reactively, using interventions such as counselling. To date, little emphasis has been placed on building the resilience and capacity of the person and family, assisting them to withstand and overcome discrimination.[20] Beyond leprosy, the concept of resilience has attracted little research in the broader Neglected Tropical Disease (NTD) context, despite potentially aligning with many of the core concepts required to address discrimination.

It would appear that if individuals are enabled to be more resilient, to withstand discrimination, they may be better able to counteract exclusionary behaviour at an interpersonal level.[21,22] Indeed if practical resources are available to build and enhance the resilience of individuals and families, individuals may have more capacity to recognise and deal with discriminatory and exclusionary behaviour, and families may be assisted to be more inclusive.[23–25] Self-confidence in coping with ostracism due to stigma may improve treatment adherence and increase self-care behaviour.[26,27] In the context of leprosy and related NTDs, greater capacity, resources and focus on individual and family resilience may prevent additional pain, anguish and stigmatisation[23,25] and enhance self-care and adherence to treatment.[28]

Beyond this context, there is considerable evidence for the benefit of building resilience among vulnerable individuals,[29,30] and there are now a number of sound evidence-based approaches to building resilience within families.[31] In particular, resilience-related approaches appear beneficial for families in which a member has health concerns or a disability,[32] as well for stigmatised people in resource-poor settings.[33]

These approaches encompass key issues such as family stress, conflict, cohesion, adaptation, working through adversity, beliefs and spirituality, and broader communication beyond the family. Health promoting behaviours such as self-care to prevent disabilities and treatment adherence to the drug regimen are also affected by self-efficacy, positive self-esteem and coping abilities to face physical ailments during the course of the disease. A challenge is how to apply these indications to the reality of services in leprosy-endemic countries.

Finally, it was noted that translation of research and evidence from one focus area to another can be relatively arbitrary, lacking research-based rigour. In response, the current review drew from scoping review and thematic analysis strategies to identify core elements of interventions that promote resilience, and which can be applied to people affected by leprosy. Further, the current review drew broadly from standard peer-reviewed literature in English, from published literature reviews, and from Portuguese language publications.

Material and methods

To deal with the different types of literature in this area, the current review comprised three phases. Phase A adapted the scoping review methodology outlined by Arksey and O'Malley,[34] phase B comprised a summary of previous literature reviews which were identified through (but not included in) the scoping review, and phase C was a separate narrative review of the Portuguese literature. These methods were chosen to provide a broad overview while permitting the identification of key concepts. The Portuguese language research was chosen because it contains a body of literature (with Brazil, Angola and Mozambique being global priority countries for leprosy),[35] which is sometimes ignored in English language studies.

PHASE A: SCOPING REVIEW

This comprised the following five stages: (1) refining the research question; (2) identifying relevant studies; (3) selecting studies; (4) charting the data; and (5) collating, summarizing, and reporting the results.

Stage 1: Identifying the research question

The overall research question of the review was "What principles can be identified from a review of leprosy-relevant English and Portuguese language research on interventions to promote resilience in individuals and family members in the face of discrimination?"

Our aim was to identify core elements of interventions to build resilience that would have relevance to people and family members affected by leprosy and other NTDs in diverse contexts. For the purpose of this research, "resilience" was defined as "the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma".[36] We noted that individual, family and community resilience are extensions of the same concept.

Stage 2: Identifying relevant studies

The review of the English language literature was not restricted to leprosy. It comprised online searches of PubMed, Isidore, POPLINE, PsycINFO, Cochrane review, Cochrane database, PubMed review, and Campbell Collaboration databases in late 2017. The search terms were: resilience OR coping AND stigma OR discrimination AND intervention OR approach OR strategy OR strengthening. The reference lists of the studies that were noted as eligible were also checked.

Stage 3: Study selection

Two reviewers independently screened titles and abstracts to determine inclusion status (Figure 1). We included studies that described an evaluation of an intervention or interventions that aimed to enhance personal and family resilience in the context of discrimination. We excluded studies that only described factors that may influence personal and family resilience, or that only described barriers and facilitators of resilience and strategies to cope with stigma and discrimination. No specific restrictions were applied in relation to the components of the interventions, or to study design; any identified study attempting to evaluate the effectiveness of an intervention was included; qualitative and quantitative original studies as well as literature reviews were included (though as noted below, reviews were analysed separately).
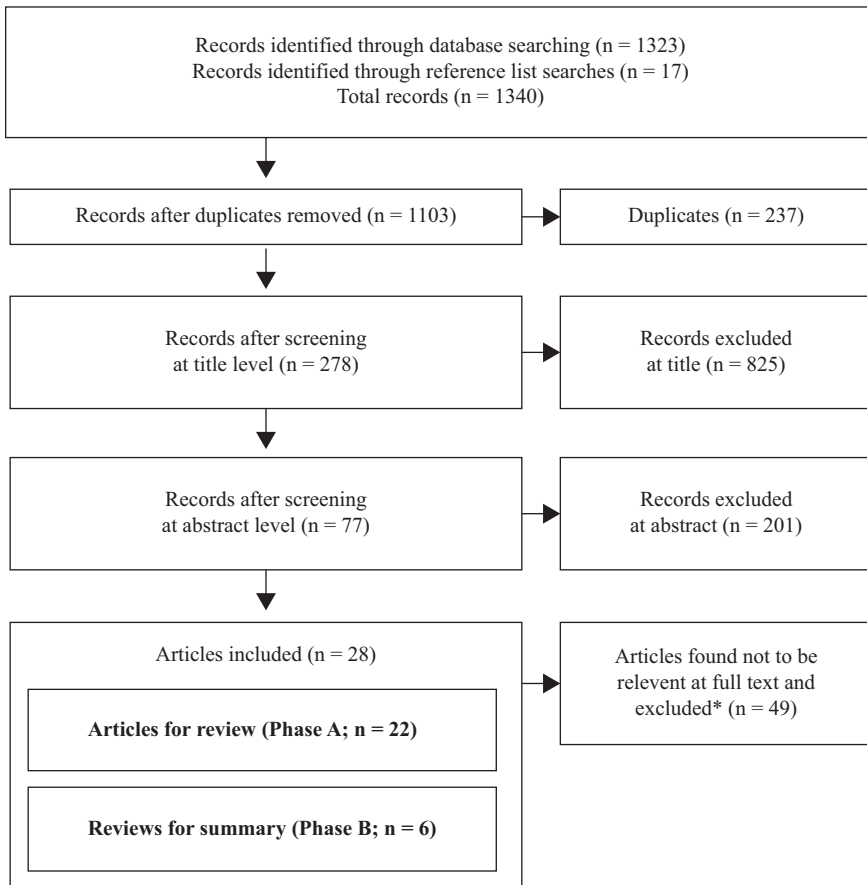
As noted in Figure 1, the search of the English literature identified 1,323 articles across the eight databases and subsequently noted 17 articles through the reference lists of key articles. Duplicates were excluded before the screening of abstracts. We identified 77 articles as eligible for full text review. Of these, 49 were found not relevant to the topic or unsuitable, resulting in 22 articles and six reviews which were included in synthesis (Figure 1).

Stage 4: Charting the data

All included articles were read by the authors. A short summary of each was made with key information (country, target condition, other focus if any, description of intervention, methodology and outcomes). Included studies were read a second time and the information about each article was refined. General information was collected as well as specific information relating to the study population, type of intervention, focus of intervention and outcome measures.

Stage 5: Collating, summarizing and reporting the results

Study characteristics were systematically mapped according to country, sample size, drop-out rate, condition targeted, population targeted, control group, follow-up,

Records identified through database searching (n = 1323)
Records identified through reference list searches (n = 17)
Total records (n = 1340)

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| Records after duplicates removed (n = 1103) | → | Duplicates (n = 237) |

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| Records after screening at title level (n = 278) | → | Records excluded at title (n = 825) |

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| Records after screening at abstract level (n = 77) | → | Records excluded at abstract (n = 201) |

↓

Articles included (n = 28)

Articles for review (Phase A; n = 22)

Reviews for summary (Phase B; n = 6)

→ Articles found not to be relevent at full text and excluded* (n = 49)

* Excluded because, does not describe an actual intervention, or intervention has not yet been piloted, or intervention not related to stigma and discrimination.

Figure 1. Selection of articles, English language scoping review.

leadership of intervention, training of leaders, level targeted, focus of intervention, core components of intervention (e.g. duration and use of media), core themes of intervention, outcomes (including outcome measures) and effect of intervention. These tables provided a clear overview of the key areas of research in terms of intervention type and core components. In addition, interventions were organized thematically in terms of intervention type.

PHASE B: SUMMARY OF EXISTING REVIEWS IDENTIFIED IN THE SCOPING REVIEW

As noted above, the bibliographic database search also yielded six literature reviews, which were considered relevant to the question of resilience. Since it was not possible to tabulate findings of these reviews directly with the other 22 studies (Figure 1), they were summarised separately to draw out key points.

PHASE C: PORTUGUESE LITERATURE NARRATIVE REVIEW

Having completed a review of the broader literature beyond leprosy in the English language review, we narrowed the Portuguese language review to research pertaining to these diseases, which was our area of interest. The narrative review of the Portuguese literature was conducted by the third author and drew from searches of: BVS-Regional, BVS-Brazil and BVS-Psychology in Biblioteca Virtual de Saude (Virtual Library of Health), and Portal de Periodicos CAPES (Higher Education Human Resources Development Commission: Scientific Journals - Ministry of Education of Brazil) in late 2017. The search terms were: resiliencia/resiliency OR empoderamento/empowerment OR coping AND discriminaçao/discrimination OR preconceito/prejudice OR estigma/stigma AND hanseniase/Hansen's disease OR leishmaniose/leishmaniasis OR filariose/filariasis OR tracoma/trachoma OR doenças tropicais negligenciadas/Neglected Tropical Diseases. The searches included peer reviewed articles and thesis/dissertations in Portuguese. These searches resulted in 1,022 articles (Figure 2). During the screening phase, references without abstracts or full text available and duplicates were excluded. All remaining (n = 955) titles/abstracts were read. Articles which did not describe an intervention to promote resilience, or did not pertain to coping with stigma, discrimination or prejudice (n = 868), were excluded. The remaining 77 articles were retrieved in full text format where possible, and assessed for suitability. Full text articles were included in the analysis if they described:

- An intervention adopted in the context of stigma/discrimination/prejudice,
- Provided adequate details of the implementation of the intervention,
- Described the target population of the intervention,
- Described the use of evaluation methods,
- Provided information regarding the impact of the intervention.
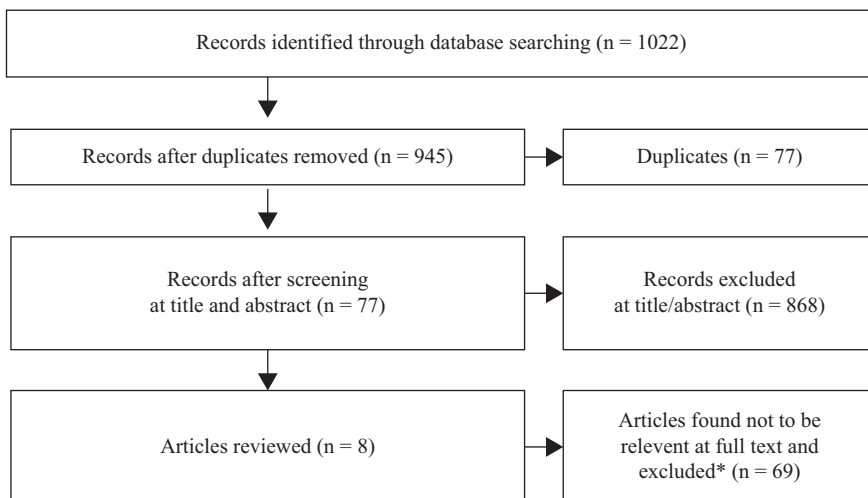
* Excluded because, does not describe an actual intervention, or intervention has not yet been piloted, or intervention not related to stigma and discrimination.

Figure 2. Selection of articles, Portuguese language narrative review.

Six articles, one Masters and one Doctoral thesis met the criteria and were included in the synthesis, drawing from a range of target populations and types of intervention.

Results

PHASE A: SCOPING REVIEW

Across the 22 original studies from the English literature, sample sizes ranged from four to 244 with an average of 84 participants. Four studies had a sample size of less than 25 people.[37–40] The drop-out rate was stated in 13 studies, and ranged from 0 to 27%. Two studies had a drop-out rate of over 20%.[41,42] Except for five,[37,39,40,43,44] all studies had a follow-up phase. Eight did not have or did not mention a control group.[37,38,40,43,45–48] Just under half (10/22) of the studies were conducted in the USA.

Target of interventions

Most interventions targeted people living with HIV/AIDS (11/22) or psychiatric/mental illness (10/22). Most resilience interventions only targeted persons with the conditions (15/22) or their contacts (10/22); two targeted both.[43,46] Ten (10/22) interventions were focused at the intrapersonal (individual) level, four at the interpersonal (small group interactions) level, eight targeted both, but no reviewed interventions targeted the structural (social-political environment) level.

Except for two studies all interventions included a stigma reduction component.[37,44] Two studies focused on building family resilience.[42,49] Three of the included studies did not directly focus on building personal or family resilience.[45,50,51] An overview of the levels of interventions can be found in Table 1.

Outcome measures used

While this was not the primary focus of our review, we noted that across the 22 articles, a total of 50 different measures or scales were used. Outcomes were assessed using a variety

Table 1. Levels of intervention

Focus	Example
Individual level Persons affected	• Training in countering discrimination and resisting internalized stigma • Social skills training, goal attainment programme, problem solving techniques/cognitive problem solving, emotion regulation, motivational interviewing • Cognitive behavioural therapy or counselling • Coping skills training • Education sessions • Interaction with people affected, sharing of personal experiences and 'testimonies' of people affected
Group level Small group Community	• Peer support or group support • Small group interactions and discussions • Video & video-conferencing based behavioural intervention, photovoice • Role play • Games • Community participatory intervention • Education sessions • Promotion through community leaders and media (radio, TV)

of validated and ad hoc questionnaires, as well as qualitative indicators drawn from interviews and focus group discussions. The measures included scales on self-esteem, stigma, empowerment, self-efficacy, coping, quality of life, mental health and functioning/symptoms. The most commonly used formal questionnaire was the Rosenberg Self-Esteem Scale, used four times. The Internalized Stigma of Mental Illness, Generalized Self-Efficacy Scale and Boston University Empowerment Scale were each used three times in the reviewed studies. In addition, the Coping Self-Efficacy Scale, Center for Epidemiologic Depression Scale, Global Assessment of Functioning Scale and Devaluation of Consumer Families Scale were used twice. 42 scales or measures were all used once. Interviews, focus group discussions and general discussion were used as indicators of outcomes across four articles.

Core components of interventions

Across the reviewed studies, resilience-related interventions comprised coping skills training (16/22), educational programmes (13/22), interactive workshops (8/22), support groups (7/22), cognitive behavioural interventions (5/22), or interventions that utilised cognitive problem solving or motivational interviewing strategies to facilitate behaviour change.

While some reviewed studies had multiple intervention components, the most commonly reported interventions were educational (19/22), counselling (11/22) or both (8/22). Counselling interventions ranged from 2–24 sessions, with an average of 11. These were typically spread over several weeks (range 1 day – 6 months). All interventions with a counselling component targeted people affected, three interventions also targeted community members.[43,46,50] The interventions with an educational component had on average seven sessions (range 1–19) spread over several weeks or months (range 4 hours – 2 years).

The majority of interventions included some form of educational or informational component (19/20). As reflected in Table 2, these involved media, such as video, radio and television. Other approaches used included lectures, presentations, workshops, group discussions, peer education, posters, t-shirt messages, question-and-answer sessions, performance, role play, a march through town, beauty contest, illustrations, storytelling, photographs (photovoice), information materials, testimonies from advocates, psychoeducation. Most educational interventions were delivered in small group (support group) format. Some interventions focused on the training of social skills, coping skills or problem-solving skills. Some made use of homework.

Interventions were delivered in a variety of settings, including community centres, healthcare practices, workplaces and university campuses. Most were delivered in face-to-face format, led by professionals (17/22), or people affected (9/22), but often accompanied by professionals (6/9). Where interventions were not delivered face-to-face, they were delivered by computer or video. An overview can be found in Figure 3.

Outcomes

Reviewed articles described the following outcomes at the individual level:

- Increased individual level coping,
- Reduced stigma,
- Reduced stigma stress,

Table 2. Interventions with an educational component

		English Language Articles		
Author, year	Focus	Use of media	Number of sessions	Programme Duration
Apinundecha et al. 2007	Community	No	Unknown	Unknown
Barroso et al. 2014	Persons affected	Video	>12	90 days
Blignault et al. 2009	Community	Radio and television	6 Community & 2 workplace sessions	2 years
Chidrawi et al. 2015	Persons affected and peers	Workshop	>2	Several days
Conrad et al. 2009	Peers	Lectures, peer education	3	One day
French et al. 2015	Persons affected and peers	Workshops, lectures, posters, messages on t-shirts, Q&A, presented a psychodrama/performance, march through township, song, beauty contest	>2	>1 month
Fung et al. 2011	Persons affected	Social skills training, group sessions	16	Several weeks
Harper et al. 2014	Persons affected	Group sessions, peer education	Unknown	>days
Krauss et al. 2006	Community	Role play, lectures, illustrations, group discussions, video, mapping of HIV-related resources, presentation	6	6 months
Link et al. 2002	Persons affected	Group sessions, discussions	16	8 weeks
Lucksted et al. 2011	Persons affected	Lectures, discussions, workshops, problem-solving, story telling	9 × 90 minutes	9 weeks
Nyamathi et al. 2013	Persons affected	Lectures	6 × 45 minutes	6 months
Perlick et al. 2011	Family members of persons affected	Video, group discussions, PowerPoint, lectures	1	75 minutes
Rao et al. 2012	Persons affected	Video, group discussions, role play, peer education, support groups	2	2 afternoons
Rasi et al. 2013	Persons affected	Workshops/self-help groups	19	19 weeks
Rüsch et al. 2014	Persons affected	Group peer education, workbook	3 × 2 hours	3 weeks
Russinova et al. 2014	Persons affected	Group peer education and discussions, photographs (photovoice), 'information'	10 × 90 minutes	10 weeks
Wu et al. 2008	Service providers	Role-plays, games, group discussions, testimony by an HIV advocate, information materials.	1	4 hours
Yang et al. 2014	Caregivers	Psychoeducation, peer-family group format	3	3 weeks

Table 2. *Continued*

		Portuguese Language Articles		
Author, year	Focus	Use of media	Number of sessions	Programme Duration
Pinheiro *et al.* 2014	Peers	Lecture - health education, focusing on disease symptoms, treatment and transmission.	1	unknown
Andrade and Iriart 2015	Persons affected	Health education on HIV treatment, regular testing, prevention, self-esteem workshops.	ongoing	ongoing
Fernandes *et al.* 2011	Service providers	Lecture on epilepsy, its stigma, its management and social interaction exercises.	6 × 1 hour	3 months
Gonçalves 2013	Persons affected members of patient associations, service providers	Lecture by a psychiatrist on medication, side effects, patient rights, accompanied by a booklet distributed to each participant followed by discussion among participants facilitated by peers.	20 × 1 hour	10 months
Onocko-Campos *et al.* 2013	Persons affected, service providers	Lecture by a psychiatrist on medication, side effects, patient rights, accompanied by a booklet distributed to each participant followed by discussion among participants facilitated by peers.	20 × 1 hour	10 months

Figure 3. Overview of frequency of intervention components.

- Increased self-esteem and self-efficacy,
- Enhanced help-seeking behaviour,
- Enhanced empowerment,
- Lessened secrecy,
- Recognition of perceived benefits of disclosure,
- Reduced depression.

The review also noted the following outcomes at the community/general public level:

- Increased community level and family level coping,
- Reduced stigma,
- Improvements in attitudes and behaviour towards people affected,
- Altered social distance, greater readiness for change.

Most reviewed articles reported short- to medium-term effects. Four studies found no or very little improvement in outcome measures after the follow up period.[41,52–54]

PHASE B: SUMMARY OF REVIEWS

The six reviews comprised: narrative reviews,[55,56] formal systematic reviews[57,58] and more general multi-level reviews.[21,59] While they all pertained to stigma and discrimination rather than resilience *per se*, a number of relevant dimensions could be identified. The reviews covered stigma pertaining to people with epilepsy,[55,56] people with mental illness[57] and people living with HIV/AIDS,[58,59] as well as stigma in general.[21] The key focus points for intervention were the general public, and those directly affected.

   At the general public level, challenging stigma and discrimination in the community, the reviews analysed a number of different public education activities (such as school education programmes) and broader social marketing efforts.[55,56] Such interventions seek to increase knowledge,[56] address stigmatising beliefs, attitudes,[56,57] and behaviours;[21] they seek to challenge myths, misconceptions and misunderstandings.[56] In keeping with the studies described in phase A, the phase B review found that community or public knowledge of a stigmatised condition can be improved by activities such as public education, and even that this improved knowledge results in improved in attitudes in the short term, but these changes to attitudes and inaccurate beliefs are not usually sustained over time.[55,56]

All of the reviews noted a dimension more closely aligned with resilience, namely supporting and enhancing the psychological and social strength and coping of individuals affected by a stigmatised condition. Interventions tended to be for individuals, pairs or small groups,[21] with "psycho-education" or combined education and counselling as the most frequently tested intervention.[21,57] Again, this aligned closely with the studies reviewed in Phase A. In terms of outcome, such psycho-educational programs for adults would appear to improve knowledge, coping skills and level of felt stigma.[21,56] It was noted that interventions that enhance skills for coping through focusing on self-esteem, empowerment, and help-seeking behaviour have become increasingly well regarded,[57] and indeed one review concluded that support groups should be seen as an effective and useful "standard" intervention.[58]

It was noteworthy that where different approaches to providing information or building coping skills were compared, there were generally no differences in effectiveness between the approaches.[59] Consistent with Phase A studies, Phase B reviews concluded that increasing knowledge and improving self-esteem were likely to be helpful.[56]

Despite the positive outcomes noted, reviews of public interventions as well as interventions for persons affected noted that gains achieved typically did not demonstrate persistence over time.[56] While this was noted in phase A, the phase B reviews provided some further analysis. Common concerns across the reviews were: lack of theoretical framework for the intervention,[57] poorly structured interventions,[56] and weak evaluation criteria.[59] Some noted that definitions, measurements, and conceptual frameworks varied considerably across reviewed studies.[57] Importantly, few of the studies which were included in the reviews assessed sustained changes over time,[59] and very limited attention was paid to the possible long-term impact of the interventions.[56,59]

PHASE C: NARRATIVE REVIEW OF PORTUGUESE STUDIES

In keeping with findings of similar Portuguese reviews,[60] and in contrast with the English language studies reviewed, we found that relevant studies were predominantly qualitative. We noted that empowerment and resilience were often used interchangeably.[61] There was some recognition that resilience and positive self-image were linked to family traits, although these were seen as resulting from family cultural systems instead of genetically determined.[62] All reviewed studies emphasized that resilience can be fostered through interventions.

As with the main scoping review (Phase A), the range of group interventions described in the Portuguese literature varied widely in terms of intensity, duration and type of intervention, ranging from one day[63] to 10 months[64,65] or continuous.[28,66] Some were facilitated by peers[67] or peers accompanied by professionals[64,65] and others were led by external professionals.[28,63,66,68,69] Many groups were single sex,[28,66,67] and some were highly structured with contracts and stated rules and objectives.[64,65,68] All studies described a degree of facilitator training for supervision.

Also in keeping with the main scoping review, the majority of interventions (5/8) had an educational or informational component (Table 2). Beyond these, interventions included cognitive behavioural approaches,[68] structured discussion approaches[64,65] and support group format.[66,67,69] The number of participants in the groups varied, from six to 20 participants.

Outcome measures in the Portuguese literature included qualitative assessments,[67] narrative indicators obtained in interviews,[64–66] or ethnographic means of evaluating intervention outcomes.[66] Some reviewed interventions included a participatory assessment of the risk the stigmatized person might face in every level of life.[66,67] Risk assessment encompassed threats to the individual's aspirations and desires, and recognition that for marginalized persons, there is a "heightened probability that basic needs, rights, and access to resources will be thwarted by circumstances beyond one's immediate control".[61] Some studies also assessed the resources available to the stigmatized individual to attain the desired status change, such as stigma reduction, recognition, respect and human rights.[66,67] Where quantitative outcome assessment tools were mentioned in the Portuguese literature, they included resilience scales,[28,68] depression inventory,[69] stigma scales,[68] quality of life scales[69] and other questionnaires.[63–65,68] Across the reviewed Portuguese studies, interventions were conducted in health services,[28,65,69] universities,[64] schools,[63] or community.[66,68]

Discussion

SCOPING REVIEW

As expected, the intended recipients or 'targets' of interventions were either people affected or their community/contacts, but rarely both. Most interventions focused on the intrapersonal (individual) level and/or the interpersonal (small group interactions) level. The most commonly reported interventions were educational, counselling or both. While there was a strong emphasis on practical psycho-education, there were also vast differences in intensity and duration of such interventions. Some interventions with an educational component used media, such as video, radio or television. Outcome measures were diverse, with a strong reliance on quantitative measures, the majority of which were published scales. We found that many interventions did not have a proper follow-up or did not include a control group. Most reported only short- to medium-term effect. We did not find much evidence of long-term effects. In addition, most interventions were from high income countries, only eight (out of 22) interventions were developed and piloted in low- or middle income countries.

The interventions that seemed to be more effective:

- Had more than one session,
- Were spread over several weeks,
- Targeted multiple levels (interpersonal and intrapersonal), and
- Involved persons affected in planning or execution of the intervention.

In general, we found that resilience-related interventions that had multiple intervention components were more effective than interventions that had only one component.

SUMMARY OF REVIEWS

From the six reviews covering over 150 articles, it would appear that stigma can be reduced (and resilience strengthened) through a variety of intervention strategies including information, counselling, and coping skills acquisition.[59] It is clear that the intervention should fit the audience,[55] however since good interventions affect multiple levels of an ecological system in multiple ways,[21] the effects of different multi-pronged interventions are likely to be quite comparable.[59]

A key conclusion from this review of reviews is that interventions focusing on increasing knowledge and improving self-esteem appear worthwhile. Further, and in keeping with the Phase A findings, we noted that in the same way that stigma and discrimination are complex and multi-dimensional, so resilience interventions should seek to influence a person's ecological system, and should seek to build mutually reinforcing reciprocal processes, seeking outcomes at different levels.[21]

NARRATIVE REVIEW OF PORTUGUESE STUDIES

Across the Portuguese literature there was a stronger theoretical perspective using a critical social sciences approach[65–67] or a health inequalities emphasis on social vulnerability and access.[63,64,66,68] From the Portuguese literature we concluded that interventions should have a human rights foundation, whether they target individual level, interpersonal level or social systems level resilience. As in similar Portuguese reviews,[30,62,70] resilience was described as having both individual/personal dimensions, as well as systemic/collective/family/social/contextual dimensions.[28,64–68] As a result, groups, and especially intergroup relations are seen as important resources in fostering resilience.[64–69] It appears that interventions should not only focus on "internal" or individual dimensions of psychological resilience, but also include social participation and structural dimensions, such as patient rights.

Conclusions

In keeping with our stated goal of identifying principles for resilience interventions, we noted from the literature that the process of an intervention should include the following.

- it should comprise more than one session,
- it should be spread over several weeks, and
- it should involve persons affected themselves in planning or executing the intervention
- it must be targeted to fit the audience, and
- it should seek to build sustainability of outcomes.

In light of concerns noted in some papers, we also noted the need to be mindful of protecting individuals from further harm, during the intervention, as well as beyond.

Our overview of the three phases of our review indicated that the content should include multiple intervention components (which are interconnected parts of an ecological system). Three dimensions include:

1. Individual level (intrapersonal) focus, using cognitive behavioural approaches, with a strong psychoeducation and knowledge-building aspect, which should ideally also use support groups for persons affected. Specifically, such approaches might focus on:
   - Improving self-esteem
   - Building psychological strength
   - Building social confidence
   - Boosting individual coping, focus on coping skills and level of felt stigma
   - Addressing self-esteem and empowerment help seeking
   - Developing appropriate help seeking behaviour

2. Social/community level (interpersonal) focus, targeting peers, families and communities of people affected. Such approaches might emphasise psycho-education and knowledge sharing. They may use participatory activities to help these people understand and identify with persons affected. They often include structured discussions, with groups, families, or local communities, using group dynamics to enhance level of understanding and identification with persons affected.
3. System level (structural) focus – which might be targeted towards the wider public, and may include informational and educational activities and campaigns. They may also include information or advocacy which focuses on contextual issues and social participation, and may include a focus on patient rights and human rights.

Finally, we noted from shortcomings identified in our multidimensional review, that interventions for building resilience should seriously consider how to make the intervention sustainable and the outcomes more durable.

Contributions

AN, PK and ZP conceived the study; AN, PK and ZP designed the study protocol; AN and PK conducted the scoping review of the English language literature. ZP conducted the narrative review of the Portuguese language literature. AN, PK and ZP analysed the data. AN and PK drafted the manuscript; ZP critically revised the manuscript for intellectual content. All authors read and approved the final manuscript. PK and ZP are guarantors of the paper.

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