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SHORT REPORT

Focusing anti-discrimination efforts in areas of most relevance to people affected by leprosy

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Summary We conducted a brief survey using a number of dimensions of the Principles and Guidelines accompanying the Resolution on the elimination of discrimination against persons affected by leprosy and their family members, to increase our understanding of the dimensions of discrimination which impact most closely on people affected by leprosy. Our study included 265 participants from 20 different countries. We found that participants reported higher levels of discrimination on practical and personal issues, and lower levels of discrimination on more abstract issues that didn't impact them directly. These findings may inform implementation of the Principles and Guidelines, providing justification for prioritising practical and local measures, which are likely to have the most immediate impact on people affected by leprosy.

Introduction

For many people affected by leprosy the social and psychological consequences of the disease have greater impact than the physical dimensions.^{1,2} The effects of leprosy-related stigma and discrimination profoundly affect all aspects of social participation, including close relationships, social and community participation, opportunities for education and employment,^{3,4} with some people being forced to leave their home and family.^{5,6}

Attempts to reduce the level and impact of discrimination have included focusing on: the individual,^{7,8} community and social context^{9–11} as well as policy and legislation.^{12–14} In December 2010, the United Nations General Assembly unanimously adopted Resolution

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A/RES/65/215, which calls for eliminating stigma and discrimination against people affected by leprosy and their family members.¹⁵ The Resolution is clearly a significant and important document, however its application to inform anti-discrimination strategies requires some operationalisation. The Principles and Guidelines of the Resolution are multifaceted, so priorities for action are not readily apparent. As part of a larger programme of work, we conducted a brief survey using a number of dimensions of the Principles and Guidelines to increase our understanding of which dimensions of discrimination impact most closely on people affected by leprosy.

Material and Methods

This study used a cross-sectional, non-random survey design with a mixed methods approach. It was conducted in 2016 across 20 countries: India, Brazil and Indonesia (which together account for over 80% of all new cases detected globally)¹⁶ as well as Afghanistan, Bangladesh, China, Colombia, Democratic Republic of the Congo, Ethiopia, Guinea Bissau, Liberia, Mozambique, Nepal, Nicaragua, Nigeria, Pakistan, Paraguay, Sierra Leone, Sri Lanka and the United Republic of Tanzania. An overview can be found in Table 1.

Participants were recruited on behalf of the third author who has a leadership role as a person affected by leprosy (purposive and convenience sampling). Participants were contacted through organisations of people affected by leprosy, leprosy hospitals and field offices of the International Federation of Anti-Leprosy Organisations (ILEP) member organisations. Selection criteria were (a) people affected by leprosy, (b) living in an endemic

Table 1. Number of responses to the questionnaire per country

Country	Responses to questionnaire		
	Male (<i>n</i> = 154)	Female (<i>n</i> = 111)	Total (<i>n</i> = 265)
India	36	31	67
Bangladesh	21	13	34
United Republic of Tanzania	16	9	25
China	11	4	15
Paraguay	9	4	13
Nepal	7	5	12
Sri Lanka	4	8	12
Liberia	6	6	12
Sierra Leone	8	3	11
Guinea Bissau	6	4	10
Pakistan	8	2	10
Brazil	4	4	8
Democratic Republic of the Congo	4	4	8
Nicaragua	4	4	8
Ethiopia	4	2	6
Afghanistan	2	4	6
Mozambique	2	2	4
Nigeria	1	1	2
Indonesia	0	1	1
Colombia	1	0	1

country, (c) with the ability and the willingness to answer questions, either in face-to-face format or as a written questionnaire. Where required, local facilitators (in 20 countries) administered the questionnaire in a face-to-face format, in the local language of the participant.

The questionnaire encompassed broad issues of rights, questions of participation as well as more practical questions such as the right to marriage, citizenship and work. The questionnaire consisted of multiple choice and open-ended questions. The current commentary provides an overview of key multiple choice question responses. A summary of qualitative responses will be provided in a later publication.

All data were entered into a Microsoft Excel database, and simple descriptive analyses of the data were conducted. As an organisational exploration, ethical approval was not obtained, however, all participants were informed about the nature and objectives of the study and were asked to provide verbal consent.

Results and Discussion

Our study included 265 participants, of whom 111 were women. The sample population was largely older adult; the mean and median age of respondents was 50, women being younger (median 45) than men (median 54). Level of impairment, based on respondent recall was mostly rated at the severe end. Using the WHO's grading system for impairments, 41 respondents (15.4%) recalled being classified as Grade 0 impairment, 44 respondents (16.6%) as Grade 1 and 178 respondents (67%) as Grade 2 impairment.

Tables 2, 3 and 4 provide an overview of key stigma and discrimination issues noted by respondents. Table 2 deals with broad issues of rights, Table 3 deals with national level engagement, and Table 4 deals with practical aspects of discrimination.

First, the differences in the responses which describe aspects of discrimination across types of question are of particular interest. It appears that when questions pertained to broad or conceptual issues, such those in Table 2 and 3, only about 30% of respondents indicated the

Table 2. Views of people affected by leprosy pertaining to broad issues of rights as noted in the Principles and Guidelines

Factor		Gender N (%)		Disability Grade N (%)			Total
		Male	Female	ND	G1	G2	
People affected by leprosy have the same political rights as non-affected people	Yes	108 (70)	63 (57)	19 (43)	22 (56)	128 (74)	171 (65)
	No*	38 (25)	40 (36)	18 (41)	16 (41)	44 (25)	78 (29)
	Do not know	8 (5)	8 (7)	7 (16)	1 (3)	2 (1)	16 (6)
	Total	154 (100)	111 (100)	44 (100)	39 (100)	174 (100)	265 (100)
People affected by leprosy have the right freely choose their place of residence	Yes	95 (62)	51 (46)	20 (45)	19 (48)	107 (60)	146 (55)
	No*	49 (32)	44 (41)	14 (32)	17 (42)	60 (34)	93 (36)
	Do not know	9 (6)	16 (23)	10 (23)	4 (10)	11 (6)	25 (9)
	Total	153 (100)	111 (100)	44 (100)	40 (100)	178 (100)	264 (100)

*This is a combination of two responses: "no" and "sometimes".

Table 3. Views of people affected by leprosy regarding national level engagement, as noted in the Principles and Guidelines

Factor		Gender N (%)		Disability Grade N (%)			Total
		Male	Female	ND	G1	G2	
People affected by leprosy are actively involved in policy/ programme decision making that directly concern their lives	Yes	75 (50)	45 (41)	20 (45)	19 (46)	80 (45)	120 (46)
	No*	50 (33)	31 (28)	9 (20)	13 (32)	59 (34)	81 (31)
	Do not Know	26 (17)	35 (32)	15 (34)	9 (22)	37 (21)	61 (23)
	Total	151 (100)	111 (100)	44 (100)	41 (100)	176 (100)	262 (100)
The state is actively engaged with key opinion makers about ending discriminatory messages on leprosy	Yes	65 (46)	46 (46)	26 (63)	16 (48)	68 (41)	111 (46)
	No*	45 (32)	21 (21)	7 (17)	10 (30)	49 (30)	66 (27)
	Do not Know	31 (22)	33 (33)	8 (20)	7 (21)	49 (30)	64 (27)
	Total	141 (100)	100 (100)	41 (100)	33 (100)	166 (100)	241 (100)

*This is a combination of two responses: “no” and “sometimes”.

more discriminatory response, and about 50–60% indicated a lack of discrimination. The direct converse was the case when the questions were more specific and practical (Table 4). In response to the questions noted in Table 4, which pertained to experience of equal rights to work, equal access to public spaces, relationships and discriminatory language, consistently over 50% of respondents identified discrimination.

It would appear that it is in practical day to day issues that discrimination is most acutely experienced. The relatively lower figures for broad and conceptual issues may be an indication that implementation of the Principles and Guidelines is not necessarily a straightforward process. While both broad conceptual issues and specific practical issues should be included, it will be important to prioritise those areas which impact people most directly, that is, the areas in which people’s practical freedoms are restricted.

Second, it is also noteworthy that the number of people reporting discrimination (29%–58%) seems relatively low across all questions, for what is one of the most stigmatised diseases known.² In comparison, other studies have reported much higher levels of perceived discrimination.¹⁷ It may be suggested that using terminology from the Principles and Guidelines to guide this survey may have led to it appearing to be quite abstract for the respondents. Indeed, the substantial number of people affected by leprosy who gave a “do not know” response (up to 27%) also suggests a degree of uncertainty about the focus of issues in this survey.

These findings suggest that when planning interventions to measure and address discrimination, we will need to prioritise issues that directly impact the lives of people affected by leprosy. While that might suggest micro-level interventions are important (such as those that will enable a person to work in a particular place), it may also include macro-level interventions (such as tackling discriminatory policies in employment and recruitment). The key factor would appear to be the practical relevance to people in their day to day life.

Table 4. Views of people affected by leprosy regarding practical aspects of discrimination as noted in the Principles and Guidelines

Factor	Gender N (%)		Disability Grade N (%)				Total
	Male	Female	ND	G1	G2		
People affected by leprosy experience the same right to work	Yes	26 (24)	9 (21)	9 (22)	54 (31)	72 (27)	
	No*	53 (49)	20 (45)	24 (60)	88 (50)	134 (52)	
	Do not know	29 (27)	15 (34)	7 (18)	34 (19)	56 (21)	
	Total	108 (100)	44 (100)	40 (100)	176 (100)	262 (100)	
People affected by leprosy enjoy equal access to public spaces	Yes	44 (40)	12 (27)	18 (44)	86 (49)	116 (44)	
	No*	58 (52)	25 (57)	19 (46)	88 (50)	133 (50)	
	Do not know	9 (8)	7 (16)	4 (10)	3 (2)	15 (6)	
	Total	111 (100)	44 (100)	41 (100)	177 (100)	264 (100)	
Personally experienced same right to work as everyone else	Yes	19 (26)	11 (38)	6 (19)	48 (35)	65 (32)	
	No*	41 (56)	12 (41)	22 (68)	74 (53)	109 (55)	
	Do not know	13 (18)	6 (21)	4 (13)	17 (12)	27 (13)	
	Total	73 (100)	29 (100)	32 (100)	139 (100)	201 (100)	
Leprosy used as a reason for divorce or marriage denial	No	27 (25)	15 (34)	10 (24)	43 (24)	68 (26)	
	Yes**	58 (52)	10 (23)	22 (54)	110 (63)	143 (55)	
	Do not know	26 (23)	19 (43)	9 (22)	22 (13)	50 (19)	
	Total	111 (100)	44 (100)	41 (100)	175 (100)	261 (100)	
Discriminatory language has been used	No	38 (37)	20 (50)	18 (55)	65 (38)	103 (42)	
	Yes***	64 (63)	20 (50)	15 (45)	107 (62)	143 (58)	
	Total	102 (100)	40 (100)	33 (100)	172 (100)	246 (100)	

*This is a combination of two responses: "no" and "sometimes".

**This is a combination of two responses: "sometimes" and "frequently".

***This is a combination of two responses: "against me" and "against others".

Conclusion

When participants provided responses on more abstract issues which didn't impact them directly, such as 'citizenship', they reported some, but not extensive discrimination. However on issues that were more personal, such as marriage and work, they described higher levels of discrimination. Clearly, it is important to raise awareness among governments and civil society of the UN Resolution against discrimination and the Principles and Guidelines. However, these findings suggest the need to emphasise and prioritise practical and local measures, which may impact people affected by leprosy most directly.

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