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Risk factors for participation restriction in leprosy and development of a screening tool to identify individuals at risk

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Summary The World Health Organisation International Classification of Functioning, Disability and Health defines participation as involvement in a life situation. Participation restrictions are problems experienced in any life situation, for example, in relationships or in employment. Our research explored risk factors for participation restrictions experienced by people affected by leprosy. Our objective was to develop a screening tool to identify individuals at risk. An initial round of qualitative fieldwork in eight centres in Nepal, India and Brazil identified 35 potential risk factors for participation restriction. These were then further assessed through quantitative fieldwork in six centres in India and Brazil. In all, 264 individuals receiving leprosy treatment or rehabilitation services made a retrospective assessment of their status at time of diagnosis. Their level of participation restriction was assessed using the Participation Scale. Regression analysis identified risk factors for participation restriction including fear of abandonment by family members (odds ratio 2·63, 95% CI 1·35–5·13) and hospitalization at diagnosis (3·98, 1·0–7·32). We recommend four consolidated items as the basis for a simple screening tool to identify individuals at risk. These are the physical impact of leprosy, an emotional response to the diagnosis, female gender and having little or no education. Such a tool may form the basis for a screening

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and referral procedure to identify newly diagnosed individuals at risk of participation restrictions and in need of actions that may prevent such restrictions.

Introduction

The World Health Organization International Classification of Functioning, Disability and Health defines participation as involvement in a life situation.[1] Participation restrictions may occur in any life situation across nine areas of activity and participation. These are learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, inter-personal interactions and relationships, major life areas and community, social and civic life. In the context of leprosy, participation restrictions are recognised as the outworking of the stigmatizing attitudes with which the disease has been associated for generations and the felt stigma or self-stigmatization with which those affected respond.[2]

Factors that have been suggested in the literature as contributing to leprosy stigma include deformities,[3] misconceptions about the cause or transmission of the disease,[4], religious teaching,[5], attitudes of health care professionals,[5] segregation of affected people,[5] concealment of early symptoms or of diagnosis and treatment,[6] the practice of begging by individuals with deformities, discriminating legislation and the image of leprosy portrayed by fund-raising agencies.[5,6] Other reported factors include the use of discriminatory language,[6,7] the image portrayed in the media,[8], gender,[4–9,10,11] ethnicity,[12] social class,[12,13] education or literacy,[4] knowledge about leprosy,[14] occupation[4,12] and income.[4]

While leprosy control and rehabilitation programmes have to deal with the consequences of stigma and other factors leading to participation restrictions, evidence for factors associated with participation restrictions is scanty and no instrument exists to screen people for possible risk factors. As a result, preventative activities are limited to educational measures to the general public, such as radio messages, in an attempt to reduce negative attitudes. Identifying individuals at risk and responding with tailored interventions to prevent participation restrictions would be a direct benefit to those affected. The objective of the present research was therefore to identify risk factors for participation restriction that may become the basis for a screening tool to identify people at risk. The research draws attention to the personal, social and economic consequences of leprosy and the opportunity to avert the non-medical impact of the diagnosis.

Materials and methods

In an initial round of fieldwork we used qualitative methods to identify potential risk factors for participation restriction. In a subsequent round of quantitative fieldwork we assessed these potential risk factors and identified the most effective predictors of participation restriction.

The objective of the first round of fieldwork was to identify and classify potential risk factors for participation restriction. Fieldwork drew on published work and involved data collection in one field centre in Brazil, one in Nepal and five in India. We used semi-structured interviews with 364 leprosy affected clients, their family and community members and with community leaders, head teachers and religious leaders. Focus group discussions and free listing (free association) exercises were organized with people affected by leprosy and with community members. This resulted in a list of 187 potential risk factors for

participation restriction which were reduced to a total of 35 items by an international panel of experts, including people with personal experience of the disease. Priority was given to the most common and significant factors that might be reliably assessed through a simple question-based checklist. These were classified under headings of visibility, vulnerability, identity and knowledge. Details of this analysis will be reported separately (Raju *et al.*, in preparation).

The objective of the second round of fieldwork was to assess the predictive value of these 35 potential risk factors and to identify those that may be used in a screening tool. Because of the potentially severe social and economic consequences of participation restrictions, we considered a prospective study design to be inappropriate. It was therefore decided to validate the list of risk factors using a retrospective assessment of their status at time of diagnosis by individuals currently receiving treatment and presenting with participation restrictions. The key points of the study design were as follows.

A case-control study design was adopted. Cases were defined as people affected by leprosy who had developed participation restrictions at any point during the previous 2 years. Controls were people affected by leprosy who had not developed participation restrictions. To measure participation restrictions we used the Participation Scale, an assessment tool that classifies individuals as experiencing mild, moderate or severe participation restriction (van Brakel *et al.*, accepted for publication).

For each participating centre, the study population was drawn from the control area for that centre. Inclusion criteria for cases required that a person affected by leprosy be from the study population with a score of 15 or more on the Participation Scale. Controls were required to be from the study population with a score of 5 or less on the Participation Scale. Exclusions included people not willing to give written informed consent or any person whose leprosy diagnosis was made less than 6 months or more than 2 years before the date of the interview. Also excluded were people finding it difficult to communicate, e.g. due to a language barrier or mental impairment.

Cases were selected from among people who were clients of a rehabilitation programme or who were attending outpatient or field clinics in the pre-defined catchment area of the participating centre. Controls were people affected by leprosy from the same area who were attending outpatient or field clinics, but who were not (former) clients of a rehabilitation programme or known to have participation restrictions. To get an adequate distribution of key demographic variables, a selection grid was used.

A short questionnaire was designed to collect demographic and clinical data and to record each individual's retrospective assessment of their status in relation to the 35 potential risk factors at their time of diagnosis. Information was collected on 264 individuals in a total of six centres in India and one centre in Brazil. Fieldwork was completed during the period September 2002 to December 2003.

To detect an odds ratio of 3·0 or more with a power of 80% at a significance level of 5%, 100 cases and 100 controls would be needed. Guidelines for fieldwork set a target for each centre to interview 25 cases and 25 controls. This ensured a joint sample size in excess of this target. In addition, we asked the centre in Brazil to interview at least 60 cases and 60 controls, so that odds ratios for the Brazilian data could be compared with those from the Indian centres.

Data were recorded on forms and entered onto computer using a data entry system based on EPI-INFO software. The data was pooled centrally and subjected to a checking procedure. For the analysis, STATA procedures were used to produce summary statistics and for logistic

regression analyses. In the logistic regression procedures the outcome or dependent variable was coded as '1' for cases and '0' for controls. We used a series of univariate, multivariate and stepwise analyses to calculate odds ratios for potential risk factors for participation restriction.

Results

The demographic profile of cases (individuals experiencing participation restrictions) and controls (individuals not experiencing restrictions) is summarized in Table 1. There were 187 cases and 177 controls. Controls showed a younger age profile and women were under-represented.

Table 2 summarizes participants' retrospective assessments of their status at the time of diagnosis using the 35 potential risk factors. Findings are presented under the five analysis headings of assessed items, visibility, vulnerability, identity and knowledge.

ASSESSED ITEMS

We found a higher percentage of MB leprosy among cases ($P < 0{\cdot}05$) and a higher percentage of individuals recently married or still single among controls ($P < 0{\cdot}05$). This latter finding may relate to the lower age profile of controls.

Table 1. Demographic items

		Full cohort	
	Positive responses	Cases = 187	Controls = 177
Full cohort	364	51·4%	48·6%
Sex			
Male	242	60·4%	72·9%
Female	122	39·6%	27·1%
Age			
≤30 years	128	26·7%	44·1%
31–40 years	71	19·3%	19·8%
41–50 years	74	25·7%	14·7%
51 + years	91	28·3%	21·5%
Marital status			
Now single, own choice	61	10·2%	23·7%
Now married or widowed	275	79·7%	71·2%
Now separated, divorced or unable to marry	28	10·2%	5·1%
Living with			
Nuclear family	215	56·7%	61·6%
Not with nuclear family	149	43·4%	38·4%
Employment status			
Part-time	37	13·4%	6·8%
Unemployed	138	50·3%	24·8%
Full-time	189	36·4%	68·4%
Urban/rural residence			
Rural area	179	58·5%	39·05%
Urban area	185	41·2%	61·0%

Table 2. Retrospective assessments made by patients of their status at time of diagnosis using 35 potential risk factors identified in phase 1 of the research

	Full cohort		
	Positive responses	Cases % ($n = 187$)	Controls % ($n = 177$)
Assessed variables			
MB leprosy	273	79·7	70·1
Single or recently married	99	20·3	34·5
Believe cause of leprosy to be:			
Infection	53	12·3	16·9
Don't know	157	42·2	44·1
Other	154	45·5	39·0
Travel time >2 h	80	24·1	19·8
Visibility			
Any sensory loss	253	80·2	58·2
Any deformity	70	25·7	12·4
Any wounds	88	32·1	24·2
Need special footwear	109	43·3	30·0
Need self-care at home	161	52·9	35·0
Vulnerability			
Told family	156	83·4	85·3
Told neighbours	162	42·7	47·5
Hospitalized	106	39·6	18·1
Poor economic state	174	63·6	31·1
Economically dependent	133	48·7	23·7
Unemployed	133	49·2	23·2
Stress on diagnosis	188	61·5	41·2
Access to facilities	188	54·5	48·6
Lived with spouse	239	69·5	61·6
Lived with children	232	70·0	57·1
Accepted by carers	311	82·3	88·7
Other disease (DM, TB, HIV/AIDS etc.)	18	8·56	1·1
Any addiction	70	23·0	15·2
Member of organization	101	23·5	32·2
Family member affected by leprosy	86	21·4	26·0
Working as migrant worker	132	32·6	40·1
Identity			
Still unmarried child	67	14·4	22·6
Family member to take responsibilities	159	53·5	33·3
Self-confident	266	57·7	89·3
No education	129	46·5	23·7
1–5 years	96	28·3	24·3
6 + years	139	25·1	52·0
Knowledge			
Know leprosy may be transmitted	147	41·7	39·0
Know leprosy is curable	102	65·2	79·1
Know deformity is preventable	204	50·3	62·1
Aware of bad behaviour to affected people	92	27·8	22·6
Worry about infecting others	226	65·8	58·2

VISIBILITY

All five items showed statistically significant differences between cases and controls. Cases were more likely to have sensory loss, deformities, wounds, to require special footwear or to practise self care.

VULNERABILITY

Cases were more likely to have been hospitalized at diagnosis, to have reported economic or employment difficulties or to have reported feelings of stress. They were more likely to have feared abandonment or to be affected by another disease.

IDENTITY

All four items showed statistically significant differences. Cases reported less self-confidence and had enjoyed less education. They were more likely to have a family member who could take over their role in the family, so reducing their status.

KNOWLEDGE

We found no differences in beliefs about the cause or transmission of leprosy. Among cases, fewer people believed the disease to be curable or knew that deformity was preventable.

RISK FACTORS FOR PARTICIPATION RESTRICTION

Since the Participation Scale includes questions about employment status and membership of organisations we judged that including similar items from the potential risk factors would lead to information bias. Q13, Q14, Q15 and Q24 were therefore excluded from further analysis. Since field workers had experienced difficulties in scoring Q29 we also excluded this item. Q27 also proved problematic and was excluded.

The remaining 29 items plus other demographic and clinical items were included in a series of univariate logistic regression analysis, the results appearing in the central columns of Table 3. Findings largely reflect the associations described above. Having full-time employment and being resident in an urban area was associated with limited restrictions. Being divorced, separated or unable to marry were associated with increased restriction. Since each of these items described the individual's status at time of the assessment, they too were excluded from later analyses.

The results of a series of multiple regression analyses within each of the tabulated headings appear in the right hand columns of Table 3. These draw attention to items that show evidence of a unique association after adjusting for the effect of other items under the same heading. A total of 10 items are found to have predictive value. Sensory loss, hospitalization at diagnosis and the need to wear protective footwear are each related to the physical impact of leprosy and associated with participation restrictions. Exhibiting stress at diagnosis and fearing abandonment describe emotional responses to leprosy and was positively associated with restrictions. Having more than 5 years education was negatively associated with restrictions. Items describing roles and relationships within the family were also predictive of restrictions, as was being affected by some other (significant) disease.

Table 3. Results of univariate and multiple logistic regression

		Univariate logistic regression			Multiple logistic regression		
	Demographic and assessed items	Odds ratio	*P*-level	95% CI	Odds ratio	*P*-level	95% CI
	Age ≤30 years	0·46	0·001	(0·30–0·72)			
	Age 31–40 years	0·97	NS	(0·58–1·62)	1·15	NS	(0·57–2·33)
	Age 41–50 years	2·01	0·010	(1·18–3·41)	1·71	NS	(0·85–3·46)
	Age 51 + years	1·45	NS	(0·90–2·34)	0·95	NS	(0·48–1·89)
	Female sex	1·76	0·012	(1·13–2·74)	1·38	NS	(0·82–2·35)
	PT employment	2·12	0·041	(1·03–4·37)	Excluded		
	Unemployed	3·06	0·000	(1·96–4·77)	Excluded		
	FT employment	0·26	0·000	(0·17–0·41)	Excluded		
	Urban resident	0·45	0·000	(0·29–0·68)	Excluded		
	Not with nuclear family	1·22	0·001	(0·81–1·86)	Excluded		
	Now single of own choice	0·36	0·001	(0·20–0·65)	Excluded		
	Now married or widowed	1·59	NS	(0·98–2·57)	Excluded		
	Now divorced, separated or unable to marry	2·11	NS	(0·93–4·80)	Excluded		
Q1	MB leprosy	1·68	0·035	(1·04–2·71)	1·71	NS	(0·98–2·98)
Q2	Was single or recently married	0·48	0·003	(0·30–0·78)	0·39	NS	(0·14–1·07)
Q3	Knew cause was infection	0·69	NS	(0·38–1·24)			
	Thought other cause	0·93	NS	(0·61–1·41)	0·87	NS	(0·42–1·81)
	Didn't know cause	1·30	NS	(0·86–1·98)	1·00	NS	(0·48–2·07)
Q4	>2 h travelling	1·29	NS	(0·78–2·12)	1·17	NS	(0·64–2·17)
Visibility items							
Q5	Any sensory loss	2·91	0·000	(1·82–4·65)	1·76	0·035	(1·04–2·97)
Q6	Any deformity	2·43	0·002	(1·40–4·23)	1·59	NS	(0·88–2·90)
Q7	Any wounds	2·51	0·000	(1·51–4·17)	1·33	NS	(0·76–2·36)
Q8	Needed protective footwear	4·07	0·000	(2·47–6·68)	2·90	0·000	(1·70–4·95)
Q9	Needed self-care at home	2·09	0·001	(1·37–3·18)	1·47	NS	(0·93–2·34)
Vulnerability items							
Q10	Told family	0·87	NS	(0·49–1·53)	0·86	NS	(0·42–1·77)
Q11	Told neighbours	0·79	NS	(0·52–1·20)	0·72	NS	(0·43–1·18)
Q12	Hospitalized	2·97	0·000	(1·83–4·81)	2·96	0·000	(1·73–5·05)
Q16	Stress on diagnosis	2·28	0·000	(1·50–3·46)	2·62	0·000	(1·62–4·23)
Q17	Access to facilities	1·27	NS	(0·84–1·92)	1·31	NS	(0·81–2·11)
Q18	Lived with spouse	1·42	NS	(0·92–2·20)	0·86	NS	(0·45–1·65)
Q19	Lived with children	1·76	0·010	(1·14–2·71)	2·16	0·019	(1·14–4·11)
Q20	Fear abandonment	4·05	0·000	(2·35–6·99)	3·30	0·000	(1·80–6·05)
Q21	Accepted by carers	0·59	NS	(0·33–1·08)	0·97	NS	(0·46–2·03)
Q22	Other disease	8·19	0·006	(1·85–36·14)	6·28	0·022	(1·31–30·07)
Q23	Any addiction	1·66	NS	(0·97–2·83)	1·45	NS	(0·76–2·77)
Q25	Family member affected	0·77	NS	(0·48–1·26)	0·68	NS	(0·39–1·20)
Q26	Employed as a migrant worker	0·72	NS	(0·47–1·11)	0·62	NS	(0·37–1·05)
Identity items							
Q28	Family member to take responsibility	2·30	0·000	(1·50–3·51)	2·00	0·002	(1·28–3·12)
Q30	No education	2·80	0·000	(1·78–4·39)	1·46	NS	(0·84–2·56)
	1–5 years education	1·23	NS	(0·77–1·97)			
	6 + years education	0·31	0·000	(0·20–0·48)	0·41	0·001	(0·24–0·70)
Knowledge items							
Q31	Know leprosy may be transmitted	1·12	NS	(0·74–1·70)	1·46	NS	(0·86–2·46)
Q32	Know leprosy is curable	0·50	0·004	(0·31–0·79)	0·51	0·022	(0·29–0·91)
Q33	Know deformity is preventable	0·62	0·023	(0·41–0·93)	0·68	NS	(0·40–1·18)
Q34	Aware of bad behaviour	1·32	NS	(0·82–2·12)	1·41	NS	(0·86–2·31)
Q35	Worry about infecting others	1·38	NS	(0·90–2·11)	1·31	NS	(0·83–2·09)

Table 4. Results of logistic regression - overall predictive model

		$R^2 = 0{\cdot}29$		
		Odds ratio	*P*-level	95% CI
	Age 41–50 years	2·36	0·012	(1·21–4·59)
Q5	Any sensory loss	2·33	0·006	(1·27–4·25)
Q8	Needed protective footwear	2·57	0·003	(1·38–4·78)
Q9	Needed self-care at home	1·90	0·024	(1·09–3·32)
Q11	Told neighbours	0·52	0·024	(0·29–0·92)
Q12	Hospitalized	3·98	0·000	(2·17–7·32)
Q16	Stress on diagnosis	3·38	0·000	(1·95–5·86)
Q20	Fear abandonment	2·63	0·005	(1·35–5·13)
Q22	Other disease	12·13	0·005	(2·09–70·45)
Q25	Family member affected by leprosy	0·52	0·037	(0·28–0·96)
Q28	Family member to take responsibilities	1·78	0·036	(1·04–3·03)
Q30	Education 6 + years	0·49	0·011	(0·28–0·85)

The results of stepwise logistic regression are presented in Table 4. This analysis identified a set of 12 items that were the most effective predictors of outcome and accounted for 29·3% of the observed variation. These were age 41–50 years, any sensory loss, needing protective footwear, needing to practice self-care at home, hospitalization at time of diagnosis, stress at diagnosis, fearing abandonment, suffering from another disease, and having a family member who would take over family responsibilities. In contrast, telling neighbours, having a family member previously affected by leprosy and education of 6 + years were identified as risk factors for reduced restriction. These are representative of the demographic, visibility, vulnerability and identity headings but not the knowledge heading.

The final step in the analysis was to compare findings between India and Brazil and between men and women. The results of separate stepwise logistic regression analyses are summarized as follows.

Brazil, men and women combined

Risk factors for increased participation restrictions included having a family member to take responsibilities, sensory loss, no education and female sex (all $P < 0{\cdot}05$ or less). Fearing abandonment approached statistical significance. Informing family members of the diagnosis was a risk factor for reduced restriction ($P < 0.05$; 27% of observed variance).

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India, men and women combined

Risk factors for increased participation restrictions included being hospitalized at diagnosis, stress on diagnosis, needing to practice self-care at home, fearing abandonment, knowing leprosy may be transmitted to others and suffering from another disease. Items associated with reduced participation restriction were having family members previously affected by

leprosy and knowing that leprosy is curable (all $P < 0{\cdot}05$ or less). 6 + years of education approached statistical significance (37% of observed variance).

Men, India and Brazil combined

Risk factors for increased participation restrictions included being hospitalized at diagnosis, stress on diagnosis, needing protective footwear, needing to practice self-care at home, fearing abandonment, having a family member to take responsibilities and suffering from another disease. Having 6 + years of education was a risk factor for reduced participation restrictions (all $P < 0{\cdot}05$ or less, 30% of observed variance).

Women, India and Brazil combined

Risk factors for increased participation restrictions included having wounds, being hospitalized at time of diagnosis, age 41–50 years, stress on diagnosis, needing to wear protective footwear, having sensory loss and fearing abandonment. Having family members previously affected and telling neighbours of the diagnosis were identified as risk factors for reduced restrictions (all $P < 0{\cdot}05$ or less, 32% of observed variance).

Small numbers prevented us comparing models by gender within each country. However, the analysis did identify common risk factors and drew attention to important differences, most noticeably in including female sex as a risk factor in Brazil but not in India. Fear of abandonment was common to all four analyses. Items from the visibility heading appear to be of less significance in Brazil than India.

Discussion

The present research has drawn attention to the impact of stigmatizing attitudes and actions towards people affected by leprosy. While it did not differentiate between enacted stigma and self-stigmatization, the analysis has drawn attention to the relative importance of items describing the visibility of symptoms, to demographic factors and to the vulnerability, identity and knowledge of the individual affected. Impairment status was just one of a number of variables carrying the risk of participation restriction.

Given the many social and cultural differences it is not surprising that differences were found between countries and between sexes. In India visibility was an important issue, for example, the need to practice self-care or to wear protective footwear and the risks attached to hospitalization at time of diagnosis. In Brazil, lack of education, female gender and losing status within the family stood out as a risk factor for participation restrictions. In Brazil patients are more likely to be admitted to general hospital, which may be less stigmatizing than admission in a leprosy referral hospital in India. Education was an important factor in both countries, individuals with no education experiencing restrictions while those with 6 or more years of education experience reduced restrictions. These similarities and differences may be further explored and understood as a reflection of the cultural context in each country and the arrangements for delivery of leprosy services.

In relation to reported factors associated with stigma our results confirmed the importance of deformities, gender, education and socio-economic status. To the list we may now add stress in response to the leprosy diagnosis and fearing abandonment. In contrast, 6 or more

Table 5. Outline for a screening tool to identify individuals at risk of participation restrictions

	Screening for risk of participation restriction	
Q1	*Physical impact* Does the patient have any sensory loss, disability or wound or need to practice self-care at home or wear protective footwear?	Yes/no
Q2	*Emotional response to diagnosis* Does the patient fear spouse or family would abandon him/her or exhibit signs of stress on diagnosis?	Yes/no
Q3	*Gender* Is the patient a woman?	Yes/no
Q4	*Education* Did the patient have 5 or less years schooling?	Yes/no
Q5	*Optional:* *Additional question(s) relevant to the local situation*	*Yes/no*
No. positive responses	*Actions required of primary level staff*	*Action taken*
0	*No action required*	
1–2	*Provide advice, refer for POD training as appropriate, monitor situation at each return visit*	*Yes/no*
3–4	*Refer for appropriate counselling or preventive interventions by rehabilitation workers*	*Yes/no*

years of education and having a family member previously affected were identified as risk factors for reduced restrictions.

The objective of our research was to develop a simple screening tool for use at time of diagnosis to identify individuals at risk of participation restrictions. Consideration of the risk factors described here suggests that different screening tools are needed for India and Brazil. However, we suggest that a set of just four consolidated items may be identified as the basis for a generic tool that may be relevant to both India and Brazil. These are presented in Table 5 and include most of the risk factors listed above. In some locations it may be necessary to include one or more additional items reflecting local conditions.

The proposed screening would take place at the time of diagnosis. Individuals with a positive response to three or four of the items in the screening tool should be identified as at risk and be referred to counselling or rehabilitation services for appropriate preventive action. Individuals with positive responses to just one or two items may receive informal advice or counselling and should be monitored at subsequent follow-up visits. Used in this way, the screening tool would provide the means to protect people affected by leprosy by preventing their stigmatization. Since it consists of a minimal number of questions, the tool should take no more than a few minutes to complete. It would be unethical to use the form where the necessary rehabilitation or counselling services are not available.

Since the current research has relied on retrospective data the format and effectiveness of the proposed screening tool should be the focus for further research. As noted above, planning a prospective study raises ethical issues of how to respond to individuals who are judged to be at risk. However, using the proposed tool, the Participation Scale and comparing alternative high and low intervention strategies may be an acceptable means to assess its predictive value.

Conclusion

In conclusion, this research has drawn attention to the impact of the leprosy diagnosis, its personal, social and economic cost, and the risk factors associated with participation restriction. A set of four consolidated items is proposed as the basis for a screening tool that would identify individuals at risk and draw attention to the need for interventions to prevent participation restrictions. These were physical impact, emotional response to diagnosis, gender and education.

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