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**Disability, Employment and Livelihood:
An Empirical Study of Malappuram
district, Kerala**

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Abstract

Employment through various productive activities often serves as the basis of livelihood. But when it is destroyed through poor health, the entire web may be damaged. This may result in serious livelihood insecurity. The web of disability, unemployment and livelihood insecurity requires concrete empirical studies for effective policy intervention. The bidirectional link of disability with social exclusion and health impairment serves as the crux of the present paper. The paper highlights the need for social as well as institutional intervention through productive palliative care may help to reverse this negative web with much ease.

Key words: livelihood, disability, chronic illness

Introduction

Kerala, the southern state of India has always projected as a model by the social scientists mainly due to its achievements in education and health. Of these, the status of health and capacity to work are the key determinants of social activity. Present scenario of contemporary Kerala society may be characterized with two opposing social realities. On the one hand Kerala has been experiencing relatively high life expectancy rate leading to 'grey population' while on the other hand there is a pronounced rise in the morbidity rate and chronic illness.

Obviously, poor health is likely to have an adverse effect on work performance and leads to lower productivity. Thus according to human capital theory, health and labour force participation are positively correlated. This implies that better health is not only likely to lead to a higher probability of labour force participation, but also to greater income-earning potential.

It is therefore straight forward to infer that poor health of workers would negatively affect their human capital returns and in turn affect livelihood. On the basis of 125 case studies, a World Bank study concludes that chronic diseases and death are the most common causes of households' impoverishment (Narayan et al, 2000). Chronic disease may impose huge economic burden on vulnerable groups by ruining their economic prospects and pushing them into poverty. With their limited income sources they are compelled to spend a higher proportion of their income on health care. People with chronic diseases often face a terrible

choice: either to avoid medical treatment or seek health care by making out of pocket payments and plunge their family into poverty.

The deceleration of the status of health retards the overall livelihood mechanism. Livelihood vulnerabilities and its causes have long been studied by economists but the link between chronic diseases and its outcome on livelihood has been a neglected area of research. Human capital literature suggests a positive relation between health and productivity where healthy workers can work, produce and earn more.

A health system mainly performs three key roles to the people. Firstly it tries to ensure a robust system capable of preventing diseases and maintain a healthy lifestyle. Secondly the system adopts suitable measures to reverse and cure the diseases with immediate and minimal effect. Finally the system is responsible for extending relief measures for those patients who are beyond the level of cure but demand long term care and attention. The former two aspects of prevention and cure have received sufficient attention in the health system and policies. But the third aspect was almost eclipsed in the shadow of these tall pillars till recently and this segment is mainly dealt with the palliative care movement.

Even though palliative care has developed as an integral component of the health system of advanced nations, in India, it is still at the infant stage. According to the Government of India, out of the 908 palliative centres in India, more than 841 centres are located in Kerala (Ministry of Health & Family Welfare, GoI, 2012). In India 59 lakh people are in need of palliative care, but only 2% are receiving palliative support (IPM, 2013). Still there exists a huge gap between requirement and availability besides wide polarisation in the availability itself.

Context of the study

The chronically disabled people face a couple of challenges in their family and societies. The persons with disabilities are one of the most marginalised and vulnerable groups in the society (Yeo, 2001; Palmer, 2011; WHO, 2011). The inaccessibility to amenities and limited employment opportunities are the prominent reasons for this deprivation. These two key factors result in social isolation and economic exclusion. It not only affects the disabled but their families also. For people with a disability or chronic illness and for their relatives, social inclusion is not only a personal but a social issue also. However the effects of illness and disability tend to get stuck on the issue of rights, where there is a lacklustre consensus, but

fails to move into the area of active policy implementation. As a result, the disadvantages for people with disabilities or illness do not really change: they tend to be marginalised, even stigmatised and feel isolated from many parts of social and public policy as well as the labour market. Hence it is essential to evaluate the livelihood options of them and the way they participate in the labour market. It will foster framing inclusive policies for a better outlook.

Objectives

The study tries to document the ways the disabled people meet their livelihoods. It tries to generate a broader understanding on how these people manage the socio economic exclusions which prevent them from accessing services and attain some sorts of gainful employment and sustain their livelihood.

Study Design

The qualitative study was carried out in Malappuram district using case diaries and medical records of student palliative volunteers and nurses. The palliative centre located in Manjeri, Malappuram was selected for the study and the details of patients were selected from the enrolment register kept in the centre. Malappuram district is one of the pioneers in palliative movement in Kerala. The Palliative NGOs in Malappuram along with their counterparts in Kannur and Wayanad had initiated a novel community initiative named '*Neighbourhood Network in Palliative Care*' (NNPC) earlier in 1999. Since the prime linkage is between disability and employment, the study is limited to those patients who are able to engage in any kind of economic activity and the sample size is 60.

Methodology

The study made use of quantitative as well as qualitative techniques in order to accommodate the own experiences of people suffering from diverse disabilities. For articulating their experiences and concerns case studies, interactions with family members and participant observation are done. These qualitative interactions focused more on their feelings, emotions and expectations. The qualitative field notes prepared as part of this are used as basis for framing relevant questions to various dimensions such as attitude of society, livelihood and institutional aspects related with the use of resources, nature and magnitude of supportive groups and access to resources. Besides it, key informant interviews with volunteers have also undertaken to get a holistic approach. A retrospective analysis is done to compare the

changes and challenges they face in between the phase of complete alienation from socio economic activities to the present stage.

Results

Table 1: Introductory characteristics of patients

Introductory characteristics		n	%
Age group	<30	7	11.67
	30-49	21	35
	50-69	26	43.33
	70 Above	6	10
Gender	Male	39	65
	Female	21	35
Marital Status	Married	21	65.63
	Single	7	21.87
	Married with separated	4	12.5
Living arrangement	Nuclear	20	33.33
	Extended	35	58.33
	Living Alone	5	8.33
Housing status	Own	38	66.333
	Rent	22	36.67
Economic status	APL	18	30
	BPL	42	70
Source of livelihood	Monthly income (wages of own& family members)	23	38.33
	Assets	13	21.66
	Saving	12	20
	Borrowing	8	13.33
	Others	4	6.66
Employment status	working	13	35
	Not working	37	65
Previous employment	Government sector	6	10
	Private sector	13	21.67

	Self Employed	47	78.33
	Not employed	7	11.66
Type of disease	Accident prone	8	13.33
	Lifestyle diseases	7	11.66
	Cancer	12	20
	Kidney Failure	6	10
	Heart Diseases	9	15
	Old Age	18	30
Prolongation of illness	<1year	10	16.67
	1-2years	12	20
	2-5 years	9	15
	>5 years	29	48.33
Monthly health expenditure	<1000	9	15
	1000-5000	21	35
	5000-10000	25	41.67
	>10000	5	8.33
Accessibility to public services	Accessible	19	31.67
	Accessible with assistance	24	40
	Not accessible	17	28.33
Financial aid by government	yes	40	66.67
	No	20	33.33
Vocational training	Yes	26	43.33
	No	34	56.67

Source: Field data

Livelihood strategies

The way of access and use of assets within a specific social, economic, environmental and cultural context can be termed as a livelihood strategy. So livelihood strategy is not limited to a particular activity. Several related activities may collectively decide a livelihood strategy. It may either be a primary or a secondary activity and either be performed individually or as

part of a group. The only condition is that it should be capable of providing any kind of monetary or other improvement for the person who engages in it.

Out of the 60 samples, 23 people meet their livelihood through any kind of productive activity by the members of the family. And another 12 persons are financially well off and they meet the livelihood through their savings. The income from property and other assets also help 13 disabled people to meet their livelihood. Only 11 people contribute to their family income in some ways. That is only 18.33% are presently capable of engaging in any gainful economic activity. The rest of the 81.67% are dependent either on others or on their previous earnings and assets.

This expresses the extent to which chronic illness retards people from economic activities and reduce their productivity and participation in labour market. Another striking inference is that prior to the onset of chronic illness only 11.6% were not employed and illness brought out a skyrocketing of the rate of non participation in labour market from 11.66% to 81.67%. Through qualitative interactions the patients expressed their disgust and lack of confidence. Many of them strongly feel that now they have become a liability to the entire family. This is creating a couple of emotional problems for them.

Even though 43.33% have received vocational training the pathetic health condition often retards them from practicing it. The skill acquisition in the form of vocational training has mainly received through palliative care movement. The foot print movement mainly helped the disabled to get skills in producing minor products like umbrella, pens, dolls, plastic flowers, flower pots etc. These are marketed through trade fairs organised by the palliative movements itself. The raw materials are supplied by the movement and products are collected by the volunteers.

The skill training is generally done at the palliative centre by availing the service of expert trainers. The disabled are generally assembled in the palliative centre on specific days and receive assistance. For this transportation facilities are also arranged. But in some particular cases (where the disabled are incapable of moving to external settings but able to manage the activity) the training will be offered at the source that is at their home itself.

Only 35% are engaging in these activities. Even though the financial contribution of the patients through engaging in minor activities like making of dolls, umbrella, paintings, figures etc. is very meagre and not able to meet their livelihood and medical expenses, it

creates self confidence and offers a relief from their miseries. It helps them to look forward with a positive approach. Even when the disability could not be reversed, the activities of palliative care both in terms of medical and career assistance make people productive and optimistic.

Poverty

The study reveals the dismal picture that 70% of the disabled are below the poverty line. For them access to health care and regular medication is a burning problem. Poverty acts both as the cause and effect of disability. The serving of poverty as the cause emerges in two instances with limited access to education and limited access to health care. Some case studies have reasserted the disabilities caused due to unsafe and hazardous working conditions. In these cases the prime reason is the limited education with lack of skills. Falls from heights, several accidents at unsafe work places come under this category. Besides it poverty also leads to belated diagnosis of chronic ailments and lack of adequate health care. Similarly prolonged illness and need of continuous medical assistance dries up the financial resources of the family.

Similarly the increased borrowing for meeting the livelihood put them in a debt trap which ends up in an inevitable spiral. And the most dismal thing is that 12 people lost their permanent residence as a result of the treatment for disability and consequent debt spiral. Hence disability leads to permanent loss of assets with limited option for regaining it. When a large number of people are living below the poverty line with dependants to support people postpone the medical needs. The presence of dependants not only creates emotional strain but huge income liability. This magnifies the gap between income and ability to meet livelihood. In the survey majority of the respondents had admitted that they had an income which could not meet the expenses. Out of the 33 respondents with dependants, only 20 are capable of meeting the livelihood needs of dependants' efficiently. In these cases, education, housing, food etc. gets priority over health needs. They have also complained of the limited access to better facilities and services to the dependants. The spreading of intergenerational poverty even affects other healthy family members also. Hence the web is not confined to disabled alone.

Attitude of Society

The disabled generally face two types of alienations- personal as well as social. To a great extent personal alienation emerges out of the health barriers and miseries of illness. The accident prone cases owe much to this. The inability for movement is the most troubling issue for such patients. Hence supports to ensure mobility within the limitations is core to the remedy. The provision of wheel chairs, water beds and other mobility friendly amenities offered by the palliative centres address this fundamental issue to an extent.

The interactions with both the patients and volunteers have revealed the indifferent and even negative attitude of the society to the patients. The illness is treated as a pure health situation. The role of society in supporting the situation has not gained enough momentum. The sole exception is the activities of the palliative volunteers. People are generally less concerned about the ill-health of people. A social alienation either intentionally or unintentionally is often suffered by the family. The limited access to public amenities along with disable unfriendly amenities complicates the situation. Till now the social role has not diagnosed well in the reversal of disabilities. Only with continued activities and effective policies of government, this could be realised.

Institutional Support

Financial assistance is very crucial for the disabled because of their lowered access to gainful economic activities and escalating cost of continued medication. Since in the study population only 11.116% are engaging in any kind of economic activity, the extent of marginalisation is comparatively high. Besides, 70% belong to BPL category. Hence any type of organisational assistance will be of immense help to this group. Disabled pensions and other assistance offered by the government are accessible to 66.67%. The Kerala having improved welfare measures also concentrate on the pensions for disadvantaged and marginal sections. It is a symbol of the organisational efficiency and welfare indication of the state. The representatives of local self governments also concentrate in this case. The rest of them are either unaware or in the course of processing. The non availability of assistance create multiple discrimination for the patients.

Access to resources and barriers of entry

The accessibility to entry into public services is a measure of the robustness of livelihood strategy. The disable friendly public amenities are a symbol social progress also. It will reduce the barriers to entry and help the disabled to come out of the self isolation. The analysis shows that only 31.67% people have access to public services. The public services

like roads, various public transport vehicles, government and other buildings are accessible to them despite their disabilities. The people having lesser intensity of disability and access to modern facilities come under this category. These people are capable of attending medical checkups and temporary outing and one of the favourable outcomes is that this helps them to integrate with the external world in a better way.

But there exists a disparity among the males and females. Males have more access to facilities than females. The orthodox gender unfriendly ways create hurdles for women to move out and integrate with external world. The limited access to social and economic services confines females to home itself. The social and cultural norms create additional difficulties. It is an example of the delayed assistance of institutions. In several cases, the potential of them is not properly tapped and is denied of economic and other supports.

Another section is able to access the facilities but only with the assistance of care takers or family members. But here the gender disparity is very narrow. With wheel chairs and support of the supporters these people are able to move and access the public amenities in a limited way.

The most disadvantaged section is those who are completely bedridden and completely alienated from the outside world. They are the victims of social isolation. Besides the severe disability, in some cases the absence of disable friendly amenities also restricts the mobility. Poverty, social norms, less development and limited access to public transport system owing to the remoteness of the area etc. are the major bottlenecks towards this. For them the activities of volunteers and palliative activists offer a strong emotional support and alleviate the extent of social exclusion.

Conclusion

Disability is a burning issue with a bidirectional link with social exclusion and health impairment. Hence it is not easy to tackle and rectify. It can not be easily remedied through neither pure health measures nor pure social interventions. A harmonious compilation of both with suitable policy directives may alleviate the intensity of the situation. The foremost requirement is the effective documentation and classification of various disabilities with due importance. Lack of sufficient and credible baseline data often handicaps the effectiveness of policy. Only through this the context and need of most suitable intervention whether medical or social could be designed and implemented. The adequate representation to the opinion of

disabled and their organisations along with the organisations will help to attain the desired outcome.

The development of disable friendly public amenities and the integration of palliative care to the general health system is the need of the hour. The illness can not be discarded as a pure individual health issue. Effective psycho social intervention and support in terms financial assistance and employment provision will cater their needs in a better way.

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