

Health Related Vulnerability among patients from tribal communities in Kerala, India: The case of Sickle Cell Disease patients

Anupama Augustine¹ and Manju S Nair²

¹(Research Associate, Centre for Agroecology and Public Health, University of Kerala, India)

²(Professor, Department of Economics, University of Kerala, India)

Abstract:

Background: Tribal population in the Indian state of Kerala experience lot of deprivations which gets reflected in persisting vulnerabilities, particularly in their health status. Additionally, tribes in Kerala are susceptible to a genetic disease named sickle cell disease which cause premature death. Enhancement in the material, psychosocial conditions of life and primary health care facilities can improve the health and survival of sickle cell patients. The tribal people who are prone to sickle cell disease are weak in their socio-economic condition culminating in health-related vulnerability which succumbs them to untimely death. The study against this background examines the health-related vulnerability among the sickle cell patients and analyses the relative importance of demographic and socio-economic factors in determining vulnerability.

Materials and Methods: The study is based on data collected from two hundred and fifteen sickle cell patients from five communities in Kerala of which four are tribal communities. Health related vulnerability is measured in terms of nutritional, behavioural, psychological, social and financial vulnerability. Indices are selected for each of the vulnerability domain identified and scores are normalised so that vulnerability ranges from zero (no vulnerability) to one (extreme vulnerability)

Results: There is a coexistence of multiple health related vulnerabilities among the sickle cell patients from tribal communities in Kerala. Health and well-being of sickle cell patients and exposure and experience of vulnerability varies with socio-economic and demographic factors such as gender, education, community, ethnicity and income levels. Any policy attempting at addressing health related vulnerability of sickle cell patients must be comprehensive by taking into consideration the specifics related to socio-economic, demographic and cultural stratifiers.

Key words: Health-related vulnerabilities, Sickle cell disease, tribal communities

Date of Submission: 24-04-2021

Date of Acceptance: 08-05-2021

I. INTRODUCTION

The state of Kerala stands apart from the rest of India in terms of her achievements in human development, measured particularly in terms of attainments in health (Nair, 2018). However, against the overall accomplishments there exists certain marginalised groups whose health attainments are much low compared to the general population and tribes form a major segment of this group (Nair, 2021). The tribal population in Kerala is susceptible to health-related vulnerability due to several factors like poor attainments in social determinants of health including nutrition, drinking water and sanitation; low levels of health-related awareness and education, lack of proper health care facilities in their area of residence and dismal material and psychosocial conditions of life. Added to this the tribal population in certain pockets in Kerala is susceptible to some peculiar genetic diseases which makes them more vulnerable, sickle cell disease being such a disease among the aboriginal people in Kerala. Sickle cell disease is a single gene disorder causing a debilitating systemic syndrome characterized by chronic anaemia, acute painful episodes, organ infarction and chronic organ damage and by significant reduction in life expectancy (Chakravorty, S., & Williams, T. N, 2013). The disease refers to that states in which the red blood cells undergo sickling when it is deoxygenated. The sickle cell disease includes sickle cell HbC disease, sickle cell α -thalassemia, sickle cell HbD disease etc. (Firoze, 2001). Sickle cell disease with an estimated 5,200 live births each year is a major public health problem in India and although it has been described in India in numerous ethnic groups, it is most prevalent among tribes. Prevalence of sickle cell gene is 5 to 34 per cent in scheduled tribes, who lives in socio-economic disadvantage and are frequently medically underserved (Colah, 2015). Sickle cell disease is prevalent among tribal communities in Kerala too and the pilot project, conducted by Medical College in Wayanad showed that the prevalence rate is about 25 per cent among tribal people.

Sickle cell disease is not curable, however improvements in the material, psychosocial conditions of life and primary health care facilities can improve the health and survival of patients, and sickle cell pain crisis, the major symptom of the disease is accelerated by absence of these conditions. The study by Feroze, 2001 cautions about the possibility of expansion of disease since, more and more homozygotes are reaching

adulthood and the need of government intervention in ensuring effective, institutional changes and human resource development to solve this health threat. Better survival and quality of life of the affected people are dependent on the primary health care they receive, which in turn is dependent on their overall socioeconomic condition. The tribal people who are prone to sickle cell disease are vulnerable in their socio-economic condition which culminates in health-related vulnerability which succumbs them to untimely death. A comprehensive, objective picture of the health-related vulnerability of the tribal group across different socio-economic scales will provide inputs to the whole spectrum of stake holders in the area including health care service providers, patients, activists, tribal promoters etc. which will help designing of policies. Research related to sickle cell disease in Kerala is minimal, and social determinants of health and health related vulnerabilities with sickle cell disease, is an unexplored area. Against this background the study examines the dynamics of health-related vulnerability among tribal patients with sickle cell disease in Kerala.

Tribal population at risk of poor health and inequities in health care are usually considered as being vulnerable. Concept of vulnerability, especially in health literature indicates the potential risk of developing certain diseases (Grabovschi, Loignon, & Fortin, 2013). One important reason for poor understanding of health-related vulnerability of patients suffering from sickle cell disease is that, health related vulnerability in sickle cell disease is mostly equated with the number of hospital visits/hospitalization, since sickle cell anaemia crisis is the primary symptomatic manifestation of the disease and primary reason for hospital visit (Smith et al., 2005). There are evidences of direct correlation between the increase of co-existing vulnerability factors and the escalation of health care inequities in health literature (Grabovschi et al., 2013). Currently, empirical studies concerning health care inequities related to the co-existence of multiple aspects of vulnerability are very few. It is important to understand health related vulnerability, particularly of vulnerable populations and perception of these people, of their own vulnerability. This will yield insights in to the relationship between multiple aspects of vulnerability on one hand, and the access and health care utilization for patients on the other and may throw light on the processes underlying it to provide intervention.

II. OBJECTIVES

- I. To assess the health-related vulnerability among tribal patients suffering from sickle cell disease
- II. To understand the relative importance of demographic and socio-economic factors in determining health related vulnerability among the sickle cell patients

III. MATERIALS AND METHODS

Two hundred fifteen patients with sickle cell disease were selected, which forms twenty-six per cent of the total eight hundred fifteen patients recorded in various institutions for treating for sickle cell disease. Respondents were chosen from the combined list of patients from different hospitals, using random number table. The sample 215 constitutes of patients from the categories of Chetty, and the tribal communities of Kuruma, Adiya and Paniya in the same proportion as that is found in the population. Researcher visited each house hold having patients and collected information regarding health-related vulnerability and health care utilization pattern. Health card and medical records from respective hospitals were examined to increase objectivity and precision of information collected.

Health Related Vulnerability is measured with respect to Nutritional Vulnerability, Behavioural Vulnerability, Psychological Vulnerability, Social Vulnerability and Financial Vulnerability

Nutritional Vulnerability

Hunger and nutritional failure are an important indicator of a patient's vulnerability to food insecurity, poverty and deprivation of well-being. It acts both as cause as well as consequence of health-related vulnerability (Mazumdar, 2014). Assessing nutritional vulnerability is very much important in understanding vulnerability of patients suffering from sickle cell disease as malnourishment intensifies disease related complications, which in turn affect ability of each patient to earn for daily living. Indicators of nutritional vulnerability includes i) Inadequate consumption of pulses/cereals ii) Inadequate consumption of fruits and vegetables iii) Inadequate consumption of fish /milk/ meat products iv) Discrimination in intra house hold food distribution v) Inadequate consumption of quality drinking water and vi) Bad cooking/ eating habits (not taking timely meals, dependency to fast food)

Behavioural Vulnerability

In order to measure the behavioural and psycho social vulnerabilities, inputs from SF-36 questionnaire, introduced by RAND corporation, a multi-purpose, generic measure which gives insights into physical and mental health of patients suffering from chronic illness is used. Behavioural vulnerability is measured through following facets, Vulnerability towards, i) Vigorous activities (running, lifting heavy objects) ii) Moderate Activities (moving a table, collecting fire wood) iii) Lifting or carrying groceries iv) Walking through hilly

areas/climbing stairs v) Bending, kneeling, stooping vi) Walking more than a mile vii) Walking outside house viii) Walking inside house ix) standing/Sitting continuously x) Household jobs (cooking/cleaning) xi) Daily life skills (Bathing or dressing yourself) xii) Difficulty in engaging in work/study xiii) Effect on work/study time (cut down time) xiv) Effect on performance of the work/study (limited in kind) and xv) Effect on accomplishments in doing work/study

The indicators measure behavioral vulnerability (effect on physical health) in two respects, one, Physical functioning and two, Role physical. Initial eleven questions measure vulnerability related to physical functioning, in order to find out to what extent disease has made the patient vulnerable to mobility especially in day to day life. Role physical measures vulnerability towards the ability to do an income earning job/ engage in any productive activities which increases his satisfaction and adds meaning to his existence.

Psychological Vulnerability

Stigmatization, each patient faces during his entire life within his family, school or in the community leads to psychological vulnerability of patients. Based on the SF-36 questionnaire, fifteen statements of psychological vulnerability were given to patients. The statements are related to the care and position he/she gets in family, community and society, his/her perceptions of dignity, attitude towards life – i) Interference of disease with normal social normal activities ii) Absence of empathy/care/love from family and friends iii) Insensitivity regarding severity of pain during sickle cell pain crisis iv) Unhappiness about life (issues related to body image etc.) v) Stigmatization and misbehaviour from family/friends/community vi) Being ignored (in school/family) vii) Multiple discrimination because of gender/caste identities viii) Depression ix) Sleeping disorders x) Feeling of insecurity xi) Hatred towards surroundings / living environment xii) Lack of support during pain crisis to get hospitalised /treated xiii) Lack of guidance/support of doctors in dealing with the disease xiv) Inability to decide course of future life (low self-esteem) and xv) Absence of progress in life (hopelessness)

Social Vulnerability

Social vulnerability refers to a combination of factors that determine the degree to which someone's life and livelihood is at risk by a discrete and identifiable event. Inference of disease in, (i) Visiting neighbours (ii) Participating in NHG (iii) Participating in religious activities (iv) Participating in sports / cultural activities (v) Participating in local social movements /patient group activities (vi) Participating in Political parties/organisations (vii) Participating in Social gatherings (viii) Participating in Functions (ix) Using Common property resources (pond, public tap etc.).

Financial Vulnerability

Financial vulnerability is a status of financial instability or a situation to the exposure of financial risk and shock (Poh, 2018). Indicators of financial vulnerability includes, i. Reduced food expenditure, ii. Reduced non-food expenditure, iii. Reduced saving, iv. Changed in occupation, v. Increase in debt, vi. Reduced spending in education, vii. Diversification of employment of family members, viii. Sale of land, ix. Sale of jewelry x. Sale of any other assets.

Five-point scale was used for rating health related vulnerability in which one denotes disagreement (absence of vulnerability) and five denotes strong agreement to statement (presence of extreme vulnerability). Normalised index value is obtained to range between zero to one. Average value below 0.5 denotes low vulnerability and above 0.5 denotes high vulnerability and values nearer to one denotes extreme vulnerability.

IV. DISCUSSION

Table 1 shows that respondents experience moderate (0.55) nutritional vulnerability. Vulnerability against stratifiers shows that the impact of structural stratifiers in determining magnitude of nutritional vulnerability is significant. Patients who are female, illiterate and belonging to low income group experience more vulnerability, more than the average of 0.55. Most of the patients are experiencing nutritional vulnerability particularly related to consumption of fruits and vegetables, meat, intra house hold food distribution, intake of water etc. Patients belonging to Paniya category reports to have severe nutritional vulnerability (0.84) compared to patients from Chetty community whose mean value is 0.45. Similarly, illiterate patients are reported to have severe vulnerability (0.70), especially related to consuming milk/fish/meat products. Compared to other stratifiers, the effect that income makes on nutritional vulnerability is minimal.

Very high nutritional vulnerability questions the efficacy of government mechanisms such as ration and provision of nutrition kit for patients in ensuring food security. Very high rate of nutritional; vulnerability reported by Paniya community patients shows that benefits are not reaching targeted populations. Dietary habits have a very important stake in this. For instance, during the survey it was found that in Paniya house hold, food is prepared once in a day, in the afternoon, and what they usually have is gruel and food prepared of leaves

which is seen nearby. Elderly usually do not use the pulses given by the government, as they are not familiar with having it. Thus, patients are deprived of having enough fluids and vitamins on specified intervals. Younger generation are not interested in eating the traditional food being prepared at home, they always eat from nearby restaurants. Addiction to junk food is a major threat, as is the addiction to use of alcohol and pan among patients from Paniya and Adiya communities. Doctors are of the opinion that it is better to avoid food from restaurants, especially non-vegetarian food, as it can cause sudden outbreak of pain crisis.

Table 1 Nutritional vulnerability across stratifiers

Stratifiers		nv1	nv2	nv3	nv4	nv5	nv6	Average
Age	Very young	0.48	0.56	0.56	0.57	0.56	0.58	0.55
	Young	0.55	0.64	0.61	0.64	0.63	0.59	0.61
	Old	0.25	0.39	0.4	0.41	0.35	0.2	0.33
	Total	0.49	0.58	0.57	0.59	0.57	0.52	0.55
Gender	Male	0.43	0.54	0.53	0.55	0.51	0.46	0.5
	Female	0.54	0.63	0.61	0.62	0.63	0.59	0.6
	Total	0.49	0.58	0.57	0.59	0.57	0.52	0.55
Community	Chetty	0.28	0.49	0.53	0.56	0.52	0.37	0.46
	Kuruma	0.26	0.4	0.31	0.32	0.33	0.34	0.33
	Paniya	0.84	0.83	0.83	0.85	0.85	0.85	0.84
	Adiya	0.63	0.63	0.61	0.63	0.59	0.58	0.61
	Total	0.49	0.58	0.57	0.59	0.57	0.52	0.55
Education	Illiterate	0.66	0.72	0.73	0.71	0.7	0.7	0.7
	SSLC	0.46	0.56	0.54	0.57	0.55	0.5	0.53
	Higher secondary	0.5	0.42	0.5	0.5	0.35	0.46	0.46
	Degree	0.23	0.42	0.4	0.44	0.47	0.29	0.38
	Total	0.49	0.58	0.57	0.59	0.57	0.52	0.55
Income	Low income	0.48	0.61	0.66	0.67	0.67	0.57	0.61
	Medium income	0.5	0.58	0.56	0.59	0.57	0.53	0.56
	High income	0.42	0.54	0.52	0.48	0.5	0.42	0.48
	Total	0.49	0.58	0.57	0.59	0.57	0.52	0.55

Note: nv1- Inadequate consumption of pulses/ cereals, nv2- Inadequate consumption of fruits and vegetables, nv3- Inadequate consumption fish/ milk/ meat products, nv4- Discrimination in intra house hold food distribution, nv5- Inadequate consumption of quality drinking water, nv6- Bad cooking/ eating habits

Source: Estimated from primary data

Behavioural Vulnerability

Sickle Cell Disease patients experience two lifelong challenges of managing the chronic illness while accessing and navigating the health care system and the disease effects physiological, psychological, and social well-being of patients (Jenerette, 2011). Patients often experience health related stigmatization from the part of both family and health care providers, since the disease is not completely curable and the recurrent painful crisis leave the patients near to disability, which has a devastating effect on well-being of people. Table 2 shows that behavioural vulnerability of patients is 0.52, depicting moderate vulnerability. Most of the patients opined of having increased vulnerability because of doing vigorous activities (0.75), walking through hilly area, walking, bending, stooping etc. This clearly depicts the physical functioning of patients and to what extent the geographical area in which they are living is adding to their vulnerability. Regarding the impact of stratifiers, except age, all other stratifiers are affecting the magnitude of vulnerability. Female patients are more vulnerable with regard to physical health, especially in doing vigorous activities and in doing household chores. Community wise also, the vulnerability ratings are very much skewed. Patients from Paniya community is reported to have severe vulnerability (0.65) compared to patients from Adiya (0.51), Kuruma (0.48) and that of Chetty community (0.44). Similarly, education act as a detrimental factor in deciding extent of vulnerability, as illiterate are more vulnerable (0.61) compared to the educated class (0.42). However, most of the patients have reported very low vulnerability with regard to performing the daily life skill activities, which shows that the disease has not made any serious challenge to their basic survival. Only, patients who are old are reported to have difficulty (having a mean value of 0.14) in bathing/dressing own.

One important aspect of behavioural vulnerability is that all patients have reported high vulnerability to questions belonging to 'role physical'; final three questions which enquires about to what extent their ability to do income earning/worthy work has been affected. Patients feel to have experienced severe vulnerability with regard to time (0.78), efficiency (0.80) and accomplishments i.e., the role that plays in life.

Table 2 Behavioural vulnerability across stratifiers

Stratifiers		bv1	bv2	bv3	bv4	bv5	bv6	bv7	bv8	bv9	bv10	bv11	bv12	bv13	bv14	bv15	bv
Age	Very Young	0.76	0.53	0.45	0.64	0.63	0.58	0.38	0.09	0.58	0.21	0.05	0.16	0.75	0.75	0.64	0.48
	Young	0.76	0.53	0.42	0.76	0.71	0.68	0.41	0.14	0.65	0.3	0.09	0.15	0.8	0.82	0.8	0.53
	Old	0.7	0.49	0.4	0.73	0.57	0.55	0.37	0.19	0.42	0.28	0.14	0.16	0.75	0.76	0.72	0.48
	Total	0.75	0.52	0.42	0.73	0.67	0.64	0.4	0.14	0.6	0.28	0.09	0.16	0.78	0.8	0.76	0.52
Gender	Male	0.71	0.5	0.39	0.7	0.6	0.59	0.41	0.15	0.53	0.23	0.1	0.15	0.75	0.77	0.7	0.49
	Female	0.8	0.55	0.45	0.76	0.75	0.69	0.39	0.13	0.67	0.34	0.08	0.16	0.82	0.83	0.81	0.55
	Total	0.75	0.52	0.42	0.73	0.67	0.64	0.4	0.14	0.6	0.28	0.09	0.16	0.78	0.8	0.76	0.52
Community	Chetty	0.64	0.39	0.26	0.66	0.58	0.54	0.33	0.15	0.47	0.29	0.09	0.14	0.67	0.67	0.64	0.44
	Kuruma	0.7	0.45	0.34	0.64	0.53	0.55	0.4	0.22	0.42	0.3	0.19	0.25	0.73	0.77	0.7	0.48
	Paniya	0.91	0.73	0.66	0.89	0.88	0.83	0.52	0.1	0.91	0.31	0.04	0.14	0.96	0.96	0.95	0.65
	Adiya	0.76	0.55	0.47	0.76	0.72	0.66	0.35	0.08	0.63	0.21	0.03	0.08	0.79	0.8	0.76	0.51
	Total	0.75	0.52	0.42	0.73	0.67	0.64	0.4	0.14	0.6	0.28	0.09	0.16	0.78	0.8	0.76	0.52
Education	Illiterate	0.84	0.64	0.55	0.83	0.8	0.78	0.49	0.21	0.75	0.43	0.16	0.21	0.84	0.86	0.83	0.61
	SSLC	0.74	0.51	0.42	0.71	0.64	0.6	0.4	0.12	0.55	0.25	0.07	0.14	0.76	0.77	0.73	0.49
	Higher secondary	0.85	0.5	0.35	0.85	0.75	0.64	0.17	0.00	0.71	0.03	0.03	0.1	0.89	0.92	0.92	0.51
	Degree	0.58	0.33	0.15	0.57	0.54	0.55	0.29	0.14	0.54	0.21	0.05	0.13	0.77	0.77	0.73	0.42
Total	0.75	0.52	0.42	0.73	0.67	0.64	0.4	0.14	0.6	0.28	0.09	0.16	0.78	0.8	0.76	0.52	
Income	Low income	0.73	0.44	0.37	0.73	0.71	0.64	0.34	0.12	0.6	0.32	0.07	0.12	0.74	0.75	0.7	0.49
	Medium income	0.76	0.53	0.44	0.74	0.68	0.64	0.4	0.13	0.6	0.27	0.09	0.16	0.8	0.8	0.77	0.52
	High income	0.7	0.54	0.35	0.66	0.58	0.61	0.47	0.21	0.6	0.33	0.14	0.17	0.76	0.82	0.75	0.51
	Total	0.75	0.52	0.42	0.73	0.67	0.64	0.4	0.14	0.6	0.28	0.09	0.16	0.78	0.8	0.76	0.52

Note: bv1- Vigorous activities, bv2- Moderate Activities, bv3- Lifting or carrying groceries, bv4- Walking through hilly areas/climbing stairs, bv5- Bending, kneeling, stooping, bv6- Walking more than a mile, bv7- Walking outside house, bv8- Walking inside house, bv9- Standing/Sitting continuously, bv10- Household jobs, bv11- Daily life skills, bv12- Difficulty in engaging in work/ study, bv13- Effect on work/study time, bv14- Effect on performance of the work/ study, bv15- Effect on accomplishments in doing work/study
Source: Estimated from primary data

Psychological Vulnerability

Table 3 shows psychological vulnerability experienced by sickle cell patients and the average score is 0.49, representing moderate vulnerability. Patients are reported to have experienced vulnerability in terms of interference of disease with normal social activities (0.58), insensitivity of family/doctors regarding severity of pain during sickle cell pain crisis (0.56), unhappiness about body image (0.54), feeling of being ignored (0.52), sleeping disorders (0.55), insecurity of future life (0.54) and esteem (0.55). However, they don't experience severe depression or difficulty in getting hospitalized. All the structural stratifiers act as detrimental factors in deciding psychological well-being. Patients who are young, female, illiterate and belonging to low-income group are more vulnerable to psychological distress. To patients belonging to very young group, being ignored in family/school forms the foremost reason for psychological distress, while for patients who are young the major issue is interference of disease with normal social activities. Youngsters are said to have vulnerability due to insensitivity of family, unhappiness of body image, insecurity of future life and esteem. To old patients, insensitivity of family regarding severity is the major factor. Gender wise analysis shows that, male is complaining about lack of self-esteem and severity of pain. For female, other than interference with normal social activities, unhappiness about body image and sleeping disorders are the major contributing factors for psychological distress. For patients from Chetty community, pain and interference with normal life is a major issue. Patients from Kuruma community are reported to have least psychological distress, and the least bothering factor for them is easiness to get hospitalized. Patients from Paniya community are depressed, stigmatized, insecure, hopeless about life and insecure about future life. Patients from Adiya community also experience almost the same psychological issues.

Table 3 Psychological vulnerability across stratifiers

Stratifiers		ps1	ps2	ps3	ps4	ps5	ps6	ps7	ps8	ps9	ps10	ps11	ps12	ps13	ps14	ps15	ps
Age	Very Young	0.61	0.53	0.56	0.52	0.52	0.64	0.55	0.32	0.6	0.49	0.41	0.42	0.44	0.56	0.5	0.51
	Young	0.63	0.53	0.59	0.59	0.52	0.53	0.5	0.4	0.59	0.6	0.48	0.39	0.43	0.59	0.54	0.53
	Old	0.37	0.39	0.44	0.37	0.34	0.33	0.33	0.22	0.35	0.35	0.23	0.17	0.22	0.39	0.3	0.32
	Total	0.58	0.51	0.56	0.54	0.49	0.52	0.48	0.36	0.55	0.54	0.43	0.36	0.4	0.55	0.5	0.49
n	Male	0.46	0.39	0.47	0.45	0.42	0.41	0.37	0.31	0.42	0.43	0.34	0.28	0.38	0.48	0.4	0.4
	Female	0.7	0.62	0.65	0.63	0.57	0.63	0.59	0.4	0.68	0.64	0.52	0.44	0.42	0.63	0.59	0.58

	Total	0.58	0.51	0.56	0.54	0.49	0.52	0.48	0.36	0.55	0.54	0.43	0.36	0.4	0.55	0.5	0.49
Community	Chetty	0.5	0.37	0.4	0.39	0.28	0.35	0.27	0.25	0.38	0.39	0.29	0.22	0.24	0.38	0.26	0.33
	Kuruma	0.43	0.33	0.41	0.4	0.35	0.39	0.36	0.25	0.31	0.34	0.25	0.11	0.21	0.42	0.3	0.32
	Paniya	0.82	0.77	0.8	0.79	0.79	0.77	0.75	0.55	0.87	0.83	0.68	0.67	0.66	0.83	0.84	0.76
	Adiya	0.61	0.6	0.69	0.63	0.63	0.62	0.61	0.41	0.71	0.66	0.54	0.5	0.55	0.63	0.66	0.6
	Total	0.58	0.51	0.56	0.54	0.49	0.52	0.48	0.36	0.55	0.54	0.43	0.36	0.4	0.55	0.5	0.49
Education	Illiterate	0.73	0.74	0.75	0.76	0.76	0.71	0.73	0.43	0.76	0.72	0.71	0.51	0.56	0.74	0.75	0.69
	SSLC	0.55	0.45	0.52	0.48	0.43	0.49	0.43	0.36	0.49	0.49	0.35	0.33	0.36	0.51	0.44	0.44
	Higher secondary	0.64	0.57	0.64	0.53	0.46	0.46	0.42	0.25	0.92	0.71	0.5	0.57	0.57	0.67	0.75	0.58
	Degree	0.44	0.25	0.29	0.36	0.23	0.28	0.23	0.23	0.3	0.39	0.27	0.11	0.21	0.3	0.17	0.27
	Total	0.58	0.51	0.56	0.54	0.49	0.52	0.48	0.36	0.55	0.54	0.43	0.36	0.4	0.55	0.5	0.49
Income	Low income	0.7	0.52	0.61	0.61	0.47	0.58	0.5	0.35	0.52	0.6	0.45	0.42	0.44	0.59	0.49	0.52
	Medium income	0.57	0.5	0.56	0.54	0.51	0.52	0.49	0.37	0.55	0.54	0.44	0.36	0.4	0.55	0.5	0.49
	High income	0.57	0.5	0.51	0.48	0.35	0.45	0.36	0.29	0.6	0.5	0.35	0.3	0.33	0.51	0.46	0.44
	Total	0.58	0.51	0.56	0.54	0.49	0.52	0.48	0.36	0.55	0.54	0.43	0.36	0.4	0.55	0.5	0.49

Note: ps1- Interference of disease with normal social normal activities, ps2- Absence of empathy/care/love from family and friends, ps3- Insensitivity regarding severity of pain during sickle cell pain crisis, ps4- Unhappiness about life, ps5- Stigmatization and misbehaviour from family/friends/community, ps6- Being ignored, ps7- Multiple discrimination because of gender/caste identities, ps8- Depression, ps9- Sleeping disorders, ps10- Feeling of insecurity, ps11- Hatred towards surroundings /living environment, ps12- Lack of support during pain crisis to get hospitalised /treated, ps13- Lack of guidance/support of doctors in dealing with the disease, ps14- Inability to decide course of future life, ps15- Absence of progress in life, ps- Average index value
Source: Estimated from primary data

Social Vulnerability

Table 4 shows that social vulnerability experienced by sickle cell patients is 0.53, i.e., moderate vulnerability. Disease has made vulnerability in participating in cultural activities and structural stratifiers are significant. As is seen in other vulnerabilities, gender, community and education plays an important role in deciding magnitude of social vulnerability. Females are reported to have experienced more vulnerability especially in attending functions and in participating in cultural programs. Community wise, patients from Paniya community are experiencing social stigma within and outside the biosocial group, i.e., for patients from Chetty and Kuruma communities, involvement in patient group activities is not limited by social stigma, but patients from Paniya community are streamlined within the patient groups, evidenced by a high mean score of 0.75 compared to that of 0.26 and 0.29 of other communities. For instance, patient group meetings being conducted at venues of community-based organisations naturally reduces participation of patients from other communities. In Chetty and Kuruma communities, patients are well organized and they maintain a cordial relation among themselves, which enable them to work together to achieve their rights and entitlements from the government. But, patients from Adiya and Paniya community are not well informed of the social movements that is demanding equal right for their communities. During survey, patients from Paniya community complained that sometimes they are not informed about the patient meetings and at sometimes lack of communication devices makes it difficult for the organizers to inform patients from these communities about the day-to-day developments. Social stigmatization at cultural, political and religious levels increases the vulnerability of persons and it hinders social mobility and social movements.

Table 4 Social vulnerability across stratifiers

Stratifiers		s1	s2	s3	s4	s5	s6	s7	s8	s9	sv
Age	Very Young	0.6	0.6	0.54	0.71	0.46	0.37	0.55	0.68	0.53	0.56
	Young	0.57	0.59	0.56	0.65	0.49	0.51	0.56	0.61	0.55	0.56
	Old	0.32	0.35	0.32	0.32	0.26	0.31	0.36	0.38	0.3	0.33
	Total	0.54	0.55	0.52	0.61	0.45	0.46	0.52	0.58	0.5	0.53
Gender	Male	0.39	0.43	0.39	0.51	0.35	0.39	0.4	0.49	0.44	0.42
	Female	0.68	0.67	0.65	0.71	0.54	0.52	0.65	0.68	0.56	0.63
	Total	0.54	0.55	0.52	0.61	0.45	0.46	0.52	0.58	0.5	0.53
Community	Chetty	0.49	0.48	0.37	0.41	0.24	0.26	0.39	0.46	0.27	0.37
	Kuruma	0.34	0.36	0.39	0.48	0.29	0.29	0.37	0.51	0.41	0.38
	Paniya	0.75	0.77	0.75	0.88	0.75	0.78	0.76	0.76	0.78	0.78
	Adiya	0.59	0.61	0.63	0.73	0.57	0.53	0.62	0.64	0.61	0.62
	Total	0.54	0.55	0.52	0.61	0.45	0.46	0.52	0.58	0.5	0.53
Education	Illiterate	0.72	0.72	0.72	0.75	0.66	0.68	0.73	0.74	0.72	0.72

	SSLC	0.49	0.51	0.45	0.54	0.4	0.41	0.47	0.53	0.44	0.47
	H. S	0.64	0.57	0.71	0.82	0.35	0.42	0.53	0.53	0.42	0.56
	Degree	0.34	0.35	0.39	0.6	0.26	0.21	0.35	0.55	0.41	0.39
	Total	0.54	0.55	0.52	0.61	0.45	0.46	0.52	0.58	0.5	0.53
Income	Low income	0.67	0.61	0.59	0.61	0.45	0.42	0.55	0.68	0.42	0.56
	Medium income	0.52	0.55	0.52	0.61	0.45	0.47	0.52	0.57	0.52	0.52
	High income	0.48	0.5	0.46	0.6	0.4	0.4	0.51	0.6	0.48	0.49
	Total	0.54	0.55	0.52	0.61	0.45	0.46	0.52	0.58	0.5	0.53

Note: s1- Visiting neighbours, s2- Participating in NHG, s3- Participating in religious activities, s4- Participating in sports/ cultural activities, s5- Participating in local social movements/ patient group activities, s6- Participating in political parties/ organisations, s7- Participating in social gatherings, s8- Participating in functions, s9- Using common property resources, sv- average index value
Source: Estimated from primary data

Financial Vulnerability

Financial vulnerability is a status of financial instability or a situation to the exposure of financial risk and shock.(Poh, 2018). Debates over financial inclusion versus economic efficiency of financial institutions have favoured in terms of economic efficiency (Nair, 2016) and financial inclusion aspects of institutions, particularly commercial banks have decreased after the implementation of financial sector reforms (Nair & A, Sreejith, 2021) which has added to financial vulnerability of marginalized groups. Financial vulnerability reduces patient’s ability to perform income earning activities and most of the patients are dependent on their families for living. Along with this, increased expenditure of treatment throughout the whole life, throws households in to financial crisis and to debt trap. Table 5 shows the financial vulnerability of sickle cell anemia patients.

Table 5 Financial vulnerability across stratifiers

Stratifiers		f1	f2	f3	f4	f5	f6	f7	f8	f9	f10	fv
Age	Very Young	0.47	0.58	0.27	0.72	0.3	0.62	0.59	0.22	0.21	0.27	0.43
	Young	0.5	0.61	0.46	0.73	0.37	0.7	0.67	0.37	0.4	0.43	0.53
	Old	0.35	0.5	0.48	0.62	0.55	0.52	0.61	0.52	0.58	0.58	0.53
	Total	0.47	0.59	0.43	0.71	0.39	0.66	0.65	0.37	0.4	0.43	0.51
Gender	Male	0.42	0.5	0.38	0.63	0.39	0.58	0.58	0.41	0.34	0.42	0.47
	Female	0.52	0.68	0.49	0.79	0.38	0.74	0.71	0.33	0.45	0.43	0.56
	Total	0.47	0.59	0.43	0.71	0.39	0.66	0.65	0.37	0.4	0.43	0.51
Community	Chetty	0.44	0.67	0.82	0.77	0.8	0.73	0.71	0.8	0.77	0.75	0.73
	Kuruma	0.25	0.36	0.25	0.52	0.35	0.44	0.47	0.25	0.39	0.38	0.37
	Paniya	0.7	0.75	0.36	0.88	0.12	0.85	0.8	0.2	0.13	0.26	0.51
	Adiya	0.51	0.56	0.18	0.66	0.13	0.58	0.57	0.11	0.19	0.2	0.37
	Total	0.47	0.59	0.43	0.71	0.39	0.66	0.65	0.37	0.4	0.43	0.51
Education	Illiterate	0.66	0.73	0.33	0.76	0.23	0.65	0.65	0.25	0.26	0.33	0.49
	SSLC	0.43	0.55	0.44	0.71	0.43	0.65	0.65	0.4	0.42	0.45	0.52
	H. S	0.14	0.39	0.35	0.57	0.07	0.85	0.6	0	0.32	0.35	0.36
	Degree	0.36	0.57	0.66	0.65	0.6	0.67	0.58	0.58	0.59	0.57	0.59
	Total	0.47	0.59	0.43	0.71	0.39	0.66	0.65	0.37	0.4	0.43	0.51
Income	Low income	0.56	0.72	0.59	0.75	0.5	0.75	0.69	0.46	0.46	0.49	0.6
	Medium income	0.47	0.58	0.42	0.71	0.37	0.66	0.64	0.36	0.38	0.41	0.5
	High income	0.39	0.52	0.36	0.66	0.35	0.57	0.59	0.39	0.46	0.46	0.48
	Total	0.47	0.59	0.43	0.71	0.39	0.66	0.65	0.37	0.4	0.43	0.51

Note: f1- Reduced food expenditure, f2- Reduced non-food expenditure, f3- Reduced saving, f4- Changed in occupation, f5- Increase in debt, f6- Reduced spending in education, f7- Diversification of employment of family members, f8- Sale of land, f9- Sale of jewelry, f10- Sale of any other assets, fv- Average index value
Source: Estimated from primary data

Average financial vulnerability of sickle cell patients is 0.51 which shows moderate vulnerability. However, it is evident from the table that compared to other communities, patients from Chetty community is more financially vulnerable. Vulnerability index score for Chetty community is 0.73, which is far greater than that of Kuruma community (0.37), Adiya community (0.51) and to that of Paniya community (0.51). It implies that the financial status of patients from Chetty community has decreased because of the disease. Vulnerability of female patients is higher (0.56) compared to that of male (0.47).

The analysis shows that, socio economic position of patients has a significant role in deciding health and well-being of patients, and there exists inequities on the basis of socio-economic and demographic factors such as gender, community, education and income. Among the stratifiers, gender and community are the most important stratifiers. The analysis undisputedly proves that the inequities in the socio economic and political context are evident through the structural stratifies, which creates avoidable disparities in health. The analysis found that female patients who are illiterate and belonging to Adiya and Paniya subclass of tribal ethnic group are the most vulnerable compared to all others. Decentralised health governance systems can play a major role in reaching the tribal people (Nair, 2016) and hence the Local Self Government Institutions are implementing targeted programs to ensure better care to down trodden people, particularly to tribes. As a part of this, pension was first introduced to tribal patients and along with that nutrition kit is also given. Government has simplified the procedures for giving nutrition card to tribal people. However, it is understood from the analysis, that even though these initiatives are there, condition of tribes are still worse. A close look into the issues shows that, there are inherent issues in the policies itself. Government programs

such as nutrition kit and pension are aimed at reducing the financial burden of patients, i.e. to affect the proxy variable 'income'. The whole analysis shows that income is not the only major determinant of health inequity, so that measures aimed at subsidizing cost of food or treatment is not enough to lessen health inequity. For instance, a patient from Adiya community, who lost his younger brother due to the same disease, was sharing his experience. His younger brother died on the way to hospital college, and he remembers that at that time, neither he or his family were aware of the consequences of sickle cell pain crisis, and finally when they decided to take him to the hospital, his condition was worse, and, when they approached the nearest hospital, he was referred to Medical College Hospital which is 140 km away, and they were unable to find an ambulance. In this case, it was neither shortage of income or food, that cost his brother's life, but it was lack of awareness, absence of adequate specialty care within the district and phobia of allopathy treatment that resulted in the catastrophe. Many incidents can be identified like this. So before deciding which structural stratifier is to be targeted, it is important to have a good understanding of the situation at grass root and which factors are to be targeted so as to lessen health inequities, which is possible only with community participation. Gender is an important determinant, but there is no initiative, either from the part of state or from the part of civil society to address gender specific issues in Sickle Cell Disease. Also, when addressing stratifiers such as, community more caution has to be taken.

V. CONCLUSION

Kerala's experience is well documented in literature as a model of development, showcased by attainments in social sector, particularly in health as evidenced by the general indicators of mortality and life expectancy being at par with that of the developed nations. However as against the general trend of improvement in health status of the population, there exists outliers in Kerala who are eluded from the whole experience of development, tribal communities being one such outlier. In addition to the lower levels of health attainment, the tribal communities in Kerala suffer from particular genetic diseases which makes their life even more vulnerable. Sickle cell disease, a single gene disorder causing a debilitating systemic syndrome characterized by chronic anemia, acute painful episodes, organ infarction and chronic organ damage and significant reduction in life expectancy is such a genetic disease seen among some tribal communities in Kerala. The paper identified five domains of health-related vulnerability viz; - Nutritional Vulnerability, Behavioural Vulnerability, Psychological Vulnerability, Social Vulnerability and Financial Vulnerability among the sickle cell tribal patients in Kerala and although patients experience vulnerability in all these aspects the intensity of vulnerability depends on the socio- economic and demographic features. The socio-political context perpetuates stratification in society and it in turn determines socio-economic position of people within the hierarchies of class, status, and power. The article authenticates that education, income, occupation, gender, social class and ethnicity/race differentiates the exposure and experience of health-related vulnerability among the tribal sickle cell patients. Any policy attempted at targeting these population must not be a blanket one, but must give importance to addressing these social determinants of health- related vulnerabilities.

REFERENCES

- [1]. Blaikie, P., T. Cannon, I. Davis & B. Wisner. *At Risk: Natural hazards, People's vulnerability, and disasters*. London, Routledge. 1994.
- [2]. Chakravorty, S., & Williams, T. N. Sickle cell disease: a neglected chronic disease of increasing global health importance. *Global child health*.201548–53.
- [3]. Colah, Roshan B., Malay B. Mukherjee, Snehal Martin, and Kanjaksha Ghosh. Sickle Cell Disease in Tribal Populations in India. *Indian Journal of Medical Research*.2015; 141: 509–15.
- [4]. Feroze, M. Sickle Cell Disease. *Integrated Rural Technology Centre, Palakkad*.2001.

- [5]. Grabovschi, C., Loignon, C., & Fortin, M. Mapping the concept of vulnerability related to health care disparities: a scoping review. *BMC Health Services Research*.2013;13:94.
- [6]. Jenerette, C. M. & B. C. Health- related stigma in young adults with sickle cell disease.NIH Public Access. 2011;102(11), 1050–1055.
- [7]. Mazumdar, S. 'Assessing Vulnerability to Chronic Undernutrition among Under-Five Children in Egypt: Contextual Determinants of an Individual Consequence Assessing Vulnerability to Chronic Undernutrition among Under-Five Children in Egypt: Contextual Determinants of anemia.*International Journal of Population Research*.2014;
- [8]. Nair, M. S. Public Health Interventions by Local Governments in Kerala: An Effectiveness Analysis. *BMJ Global Health*.2016;16, 1-19.
- [9]. Nair, Manju S & M V, Sajeev. Human development status of particularly vulnerable tribal groups in Kerala. *Indian Journal of Economics and Development*.2021;17(1):45-54.
- [10]. Nair, Manju S. Financial inclusion vis-à-vis economic efficiency: The case of commercial banks in India. *Productivity*. 2015;55 (04), 338 – 351.
- [11]. Nair, Manju S. Human Development and Economic Growth in Kerala: Sustainability Issues. *Productivity*.2018;59(1): 81-91.
- [12]. Nair, Manju S., & A, Sreejith. Financial Inclusion of Scheduled Commercial Banks in India. *IOSR Journal of Humanities and Social Sciences*.2021;26(4).58-63.
- [13]. Poh, L. M. Review of Financial Vulnerability Studies', *Review of Financial Vulnerability Studies*. 2018;5(2):127-134.
- [14]. Smith, W. R., Bovbjerg, V. E., Penberthy, L. T., McClish, D. K., Levenson, J. L., Roberts, J. D., Aisiku, I. P. Understanding pain and improving management of sickle cell disease: the PiSCES study.*Journal of the National Medical Association*.2005.97(2),183–193.

Anupama Augustine, et. al. “Health Related Vulnerability among patients from tribal communities in Kerala, India: The case of Sickle Cell Disease patients. The Christian Narrative.”*IOSR Journal of Humanities and Social Science (IOSR-JHSS)*, 26(05), 2021, pp. 01-09.