



RESEARCH ARTICLE

RE-IMAGINING VITILIGO AS DISABILITY: TO IMPROVE QUALITY OF LIFE

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ABSTRACT

Vitiligo is a pigmentary disorder of the human skin, with unknown etiology, affecting about 1% of population worldwide, without any predilection to race, gender and age of onset. This disorder is associated with diverse range of Social stigma, thereby affecting distribution of life chances throughout the life and especially in the development phases, thus seriously impairing quality of life of Persons with Vitiligo (PwV). Through RPWD act 2016 Indian government has empowered wider range of Persons living with Disability conditions through rights based approach to lead an improved quality of Life. It's a major holistic social welfare framework which aims at establishing inclusive environment for participation, prevention of ill-treatment, removal of social barriers, provision of holistic healthcare, recreation, establishment of safeguarding support systems to enable daily life through enhanced accessibility, catalyst for growth in developmental phases of education, skill development, and employment. Apart from increasing the disability conditions to 21, with due considerations to disability as a dynamic phenomenon this act also makes future provision for central government to add new categories of disability. This paper makes an attempt based on various disability models to conceptualize based on lived experiences of PwV with vitiligo which results in socially repelling disfigurement, can be considered as disability and how making this act little flexible for extension of certain provisions if not all can help in improving quality of Life of PwV.

Key words: Vitiligo, Stigma, Indian Disability Act, RPWD, UNCRPD, Skin Color, Pigmentation, Quality of Life, Rights based Approach.

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INTRODUCTION

Skin has a major role in the development of personality, Self-esteem and ego integrity of an individual. The skin plays an important part in social interactions, catalyzing social acceptance, and dictating extent and nature of Social participation. Visual disfigurement which may be asymptomatic can result in both verbal and non-verbal rejection which can lead to social exclusion (Tarur and Kolhe 2017). Vitiligo is a common, acquired, depigmentation of the skin, with uncertain etiology, affecting 1% of the population worldwide without any predilection to race, gender or age of onset (Parsad, Dogra, and Kanwar 2003). Vitiligo is not just a phenomena of missing skin color, but affects the entire identity of a person. Social stigma attached to it creates barriers for equitable participation. Vitiligo has been considered as one of the top three medical problems by the Indian first prime Minister Pt Nehru other two being Leprosy and Malaria (Hann, Nordlund, and Lerner 2008; Sarkar 2014). Over decades of effectively oriented public health policy, both leprosy and malaria have been effectively managed, but Vitiligo still seems to be neglected and under researched. Apart from having impaired QOL, PwV are living a life of below potential which

is a national burden. Debate on whether a condition is disability or not is often political, guided and balanced by nations financial considerations. The nature and extent of welfare orientation of disability policy of a country appears to accept certain form of disability model which its economic state of affair can sponsor, i.e. how much political will and fiscal capabilities are oriented towards such welfare measures (M. Oliver 2016). So in a developed economy broad socialistic welfare oriented interpretation for disability can be accommodated and it can recognize and support variety of conditions under this umbrella. On the other hand, a developing country may have to adopt a compelling, restrictive model of disability to cater to basic needs of needy population. After signing and ratifying UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) in 2007, process of establishing a better welfare oriented legal framework to replace the then existing Persons with Disabilities Act, 1995, started in 2010. After years of deliberations, through THE RIGHTS OF PERSONS WITH DISABILITIES 2016 ACT, a new law has been set in place, which is a welcome step. Congruous to Indian economic growth in recent years, political will for welfare provision has got momentum. Apart from enhanced recognition of disability conditions from 7 to 21, This act also visualizes disability as a dynamic phenomenon and suitably makes provisions for

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central government to add newer disability conditions in the schedule under specified disability (Government of India 2016). Effective societal enforcement of this act by the executive is the need of the hour. Suitable implementation of this act can improve distribution of life changes for PwD through education, skill improvement, employment, accessibility, removal of participation barriers, and enhanced social inclusion. This establishment of an environment of holistic empowerment of PwD, naturally results in improved Quality of life. Additionally, this new act is a dynamic legislation, having express provisions to support additional condition as disability, thus reaching out to needy classes of people in the society. Thus this legislation gives hope to institutions working on various conditions which are (Non disabling as per the current act) severely disabling than some of the currently recognized specified disability conditions (in the schedule of the act). They should carry out more research activities showcasing how societal barriers are impediment to the growth and development and also impairment of overall QOL of people suffering from the condition. Also comparison studies with QOL of specified disabilities can establish basis for strong advocacy.

Disability Models through Ages

State's Policy towards disability historically has been guided by dynamic nature of disability model. Disability model is nothing but a sociological representation of disability. These representation shows dynamic nature due to ever occurring structural changes in the society. Hence the nature and extent of a particular condition to be perceived as disability is dynamic which is very much dependent on the socioeconomic condition of the society. Historically, disability models have been developed through social practices of segregation, constructed through negative ideology. However, due to post-modernist view, in recent decades and recent socio-economic-technological advancements, this exclusion oriented approach has seen paradigm shift towards social model and more pragmatic multidimensional approach. However, it appears that certain strands of older models still exist in some or the other form which must be identified and curated.

Moral Model: presents the earliest understanding of disability, which has been viewed as a punishment for sin. Passing from generations to generations, this understanding has now become cultural beliefs and is operating even today. These beliefs contribute to Labeling and stigmatization process which eventually leads to social exclusion. So modern legal framework for disability should enshrine provisions to address origins of social exclusion. Suitable Penal and redress provisions must be enshrined in the act not just for benchmark disabilities but for a wider range of conditions which are prone to social barriers. An inclusive society can be achieved only through this approach. One simple example that can be cited here is of vitiligo, in the absence of scientific explanation of the root cause, and treatment, various superstitions, cultural beliefs tries to explain the cause and are often recognized as origin for labelling and social stigma. Social practices still adopted by various section of society creates a sense of barrier for social participation for persons suffering from this condition and also creates tremendous anxiety, self-isolation, avoidance and other associated defensive behaviors which leads to self-imposed isolation from the society (Tarur and Kolhe 2017). These considerations must pave way for suitable amendments to RPWD act making it as an effective social transformation tool to mitigate social stigma.

Worth Based Model: historically utilitarian thinking has considered PwD as unproductive species in the society and rationale was built for their exclusion from workspace. We can see such theories operating even today in our ocular centric modern society. even potential burden is seen as unworthy. (Barel *et al.*, 2009) Even though corporates resorting to CSR recruit physically disabled persons, often its managerial philosophy, innovations and execution approaches may be oriented, in this corporate efficiency driven culture, to eliminate those unworthy individuals who are burdened with various conditions which are still not included under specified disabilities in the new act. Getting a deserving job may be very much difficult for a young person having socially repelling disfigured face. An effective disability act must recognize pervasiveness of this utilitarian thinking and associated impact on Persons ailing from various conditions which are not recognized by this act. Also this act should empower such persons with additional skill development and educational opportunities especially in their employment and developmental phases (Barel *et al.*, 2009; Dommergues *et al.*, 1999).

Charity Based Model: Interpreted the condition of persons with disabilities within a context of poverty, abandonment by families and social vulnerability (Griffo 2014) charity institutions took these persons as residents. Criticism is that these institutions institutionalized segregation approach to PwD which increased their social exclusion, stigma and made them socially undesirable. We still see such institutionalised models operating with the objective of taking care of inmates but actually they have become asylums, doing more harm to individuals than benefits. However at the outset it appears that this model is not operating in vitiligo space.

Productivity Model: developed during industrial revolution focused on segregation based on productive nature, so PwD were not seen as workers under this model. Today's ocular centric modernity still carries this mind-set and has established various barriers for disfigured people, disabling them to live empowered living on equitable basis. (Griffo 2014).

Medical Model and Social Model: Medical model views all disability as the result of some physiological impairment due to damage or to a disease. Focus of this model is to provide socio-medical rehabilitation treatment in order to regain functionality (Llewellyn and Hogan 2000; Thomas 2004). Contrarily Social model considers society as disabling factor but the physical condition acting as a trigger to society's behavior hence places onus entirely on society. Medical model can't be effective in conditions which are asymptotically disfiguring, as there is no medical cure. Their disabling experiences are mainly due to appearance repelling effect in social interactions, associated social barriers have been built leading to social exclusion. So some conditions even though physically not disabling, are severely disabled due to societal barriers for participation and discrimination. Probably their experiences of disability may be more than some of the persons having benchmark disability as specified in the act (M. J. Oliver 2012; Clarke 1999; G. Kent 2000).

Contemporary Perspectives towards Disability

Critical analysis of disability studies, presents 2 broad perspective to look at a condition as disability or not. Outlook of the society on a particular condition as disability:

In this perspective since society is disabling the individual having that condition, interventions would be oriented to removing the barriers for participations and individual empowering through rights based approach. Personal outlook of a particular condition: even though society may not overtly consider a condition as disabled, individual having that condition may consider so depending on life experiences and outcomes form social interactions. This perspective may emerge in an individual which depends on personal identity and locus of control, and this perspective is quite dynamic, changes from one person to other and also for a same person its dynamic changing with context and circumstances. Thus a sum total of all our life experiences; our physical and mental abilities; our families, friends, peers, and events around us form this representation.

Stigma as Disability

Social Stigma contributes to the overall burden of an illness. Researchers have recognized stigma as a contributory factor for various illness and aggravation of the same. (Gerry Kent 1999; Weiss, Ramakrishna, and Somma 2006) Health related stigma has been studied as a specified subject these days and methods are being explored to reduce the disease burden though stigma interventions. In addition to burden on illness, stigma creates serious, often long term impact on psycho-social-spiritual wellbeing of the person affected which alters the personality and places the affected person in lowered social hierarchy. Thus stigmatization process results in status loss and social exclusion. (Bruce G Link and Phelan 2001; B. G Link and Phelan 2006). Even though stigma is highly contextual, varying based on the disabling condition, cultural, structural set up of the person and the society, intrinsically some health conditions are so much stigmatized that it results in social exclusion. Thus it can be synthesized that health conditions which are stigmatized in a society that has led to social isolation, exclusion due to intrinsic societal barriers for participation are disabling to create an inclusive society, hence they must be brought under the ambit of disability act.

Organ Failure, Stigma, Societal Barriers and Disability

Careful analysis of disability acts that has evolved over years in developed nations shows good observations. Coverage of conditions has expanded from functional capabilities to intellectual capabilities and to organ failure. Some acts include temporary disabilities as well. Also the extent of disability i.e. benchmarking has been getting reduced slowly thereby covering more and more section of people in the society. In Indian act it is currently now at 40%. Disability act provisions initially oriented towards rehabilitation of persons suffering from functional disability, jeopardizing individual's independent mobility and overall living. Hence scope of organs was biologically limited to Musculoskeletal/Locomotor system and sense organs (with exclusions to Nose and skin functions). Initially only permanent functional incapacity of high magnitude in any of these organs were considered as disability, as the disability act became more and more welfare oriented, extent of benchmarking has been reducing which has now come to 40% Expanded version of disability act, along with reduction in benchmarking of these functional disabilities, expanded provisions also started giving coverage to conditions like

- Neurological
- Organ failures

- Learning and intellectual disorders

Further expansion to disability act has carried provisions to cover wider range of organ failures, tissue or cellular disorders, seizures, chromosomal or syndromic conditions, neurometabolic or degenerative conditions, In Developed economies, where orientation towards disability as a social model is intensive, disability has been expressly defined in their acts, inclusions of specified disabilities conditions have shown dramatic increase having included conditions like disfigurement, dermatological, respiratory, Gastroenterological and other condition (Commonwealth of Australia 1992; Senate. 2008). It's evident from comparison that Indian act has been expanded in 2016 however there is good amount of ground still needs to be covered, probably the economic growth that is in front of us can make this realize. Stigma as defined by Goffman in his seminal essay, as an "attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one"(Goffman 1963). Extending this concept, Link and Phelan attempt to define stigma as a process of interrelated components where in the presence of power, a distinguishing human difference is labelled, followed by association of negative stereotypes, resulting in separation of labelled persons, depending on extent of power, impact of status loss, discrimination etc. are experienced by the labelled person. (Bruce G Link and Phelan 2001).

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Disfigurement as Disability

Disfigurement can be considered as an important social phenomena, Kent (Gerry Kent 2002a) quotes from an earlier study on disfigurement (Rumsey. 1998) that approximately 10% of the global population possess some kind of disfigurement, and 2–3% may be having it on exposed areas, thus visible to society, impacting their social interactions and eventually their overall QoL. People who are disfigured face

issues in social interactions, at times even suffer social exclusion. Hence disfigurement is disabling to people. The same has been duly considered in new Indian disability act by providing protection to acid attack victims.

Lived Experiences of Persons with Vitiligo – Society Induced Disability

Vitiligo as an enigmatic skin disorder which is highly stigmatized in many societies, mainly due to prevailing cultural beliefs which could not be refuted due to scientific inability in explaining the cause and providing the treatment (Tarur and Kolhe 2017). Society's penchant to appearance contributes to this stigma further, as persons with vitiligo (PwV) face multitude of defensive behavioral tendencies in social interactions and especially with a stranger. Since majority of PwV report onset of vitiligo by the time they reach third decade of their life, its impact in developmental phases of self is very high as vitiligo greatly influences distribution of life chances, education, skill development, marriage, employment which happen within first 3 decades are seriously affected due to the predicament in "self" mainly triggered by vitiligo. Persons with vitiligo demonstrate systemic disadvantage in their life and fall down in multiple parameters eventually ending up with loss of status in society, discrimination, Bullying, sometimes abuses. The attitude shown by society towards Pw V is highly culturally oriented, penchant to appearance makes dominant persons in group to dictate the terms in a subtle manner so that Pw V are isolated, and this peer discrimination may not happen in blatant manner. PwV experience helpless situation, at one end they are physically and, intellectually capable enough for full societal participation. Realizing their potential and capabilities their "Self" often craves for free and full societal participation on equitable basis and associated mechanisms and faculties are oriented. But on realizing barriers in participation in social encounters, rejection in interactions is experienced mainly due to socially repelling disfigured appearance. Many People attempt to cope up with these social challenges in high spirit, but many of them end up in stressful living and their focused attention in development in one or two areas make them weak in many other areas, thereby, ultimately suffering more than people who don't challenge.

However, some people go beyond this barrier and reach a stage of self-acceptance and appear to have successfully navigated through all the societal barriers. But the ratio of persons who reach this stage is quite less as majority of the people demonstrate substantially impaired deviations in their behavioral and cognitive tendencies due to adoption of defensive mechanisms which eventually leads to self-imposed social isolation, impaired overall Quality of Life. All these factors that impact overall personality, life outcomes, seriously affecting Bio-Psycho-Social-Spiritual dimensions of Pw V. The sad part is that this is completely avoidable, curable, if society acts correctly. Pw V can't develop immune to such stigmatization process, power differential existing at various strata of society, constantly stigmatizes at varying degrees. So if we have to establish an inclusive society with full participation from all Pw V, society must act first, eliminate all forms of enacted stigma. Because the fear of being stigmatized can exist in a person as long as there are stories of experiences of stigma by someone having vitiligo. In India, in fact south Asia and Africa as well, PwV demonstrate intensive stigmatic experiences and impaired QOL, as

compared to west. This can be attributed mainly to black-brown-dark shades of skin color contrasting with depigmented skin resulting in increased repulsive feeling in social interactions. Additionally, these societies having rich and traditional cultural background comprises of numerous customs and superstitions underpinned by cultural beliefs. Various comparative quantitative studies based on Dermatology Life Quality Index (DLQI) have shown that south Asia – African PwV experienced impairment of quality of life to greater extent than their peers in the west (Mishra *et al.*, 2014; Sangma, Nath, and Bhagabati 2015; Dolatshahi *et al.*, 2008; Ghajarzadeh, Ghiasi, and Kheirkhah 2012). So these observations of life experiences of PwV in India frames a compelling rationale to seek protection of disability act.

Extending New Disability Act for Empowering PwV

The new RPWD act is multidisciplinary, taking orientation towards social model, this act goes beyond traditional medical model of rehabilitation for physical deformities. Many PwV themselves don't consider themselves as disabled, that may be mainly due to their high locus of self-control over vitiligo or their vitiligo may be hidden or spread to lesser extent. However, there are larger section of PwV who are now asserting that vitiligo has disabled them based on their life experiences. Taking a balanced approach, following provisions can be sought through disability act.

- Catalyzing provisions like reservation, free education, and employment may not be extended to PwV.
- Institutional provisions of employment exchange, discrimination towards PwV must be necessarily extended which can help breaking the barriers for societal participation,
- Since cultural belief takes a powerful position in stigmatizing vitiligo, there are few cultural practices that are contributing to stigma, banning those practices like exhuming PwV dead body for seeking rains through this act
- Support to NGOs who can work on empowering lives of PwV can be strengthened through this act.
- Exploitation of PwV is prevalent in wide scale but it is often subtle and rarely blatant, it is pervasive right from medication, to intimate space of marital relationship. Suitable provisions must be made to address these pain areas.

Conclusions and Directions to Further Work

Disability act in India is evolving into a multidimensional social model from rehabilitation orientated medical model. This act appears to be quite dynamic, in terms of provisions and also inclusions of disability conditions. So this is a correct futuristic structure in place. However still more ground needs to be covered by including more conditions so that additional sections of society are addressed. Effective execution of this act and judicial activism in interpreting and enforcing principles and provisions of this act is the need of the hour. Social stigma in its pervasive nature affects social participation of individuals affected, future amendments to disability acts must include portions of provisions to address health related stigma. Vitiligo is one enigmatic disorder which is asymptomatic, physically non-impairing except for sunburn, is extremely societally disabling due to repelling appearance. As appearance dictate outcomes of social interactions, Pw V

suffer social stigma, discrimination, status loss. Certain provisions in the disability act in future amendments can be tailored to orient to mitigate societal disabling factors towards Pw V. Getting disability benefits itself at times is stigmatizing in our society, PwV may not advocate for such benefits however their lives would be drastically improved if society becomes more inclusive, with removal of barriers for their participations and culturally unhealthy customs are stopped.

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