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UNDERSTANDING THE LIFE EXPERIENCES OF EDUCATED PERSONS WITH DISABILITIES THROUGH A PHENOMENOLOGICAL APPROACH

KEY WORDS: Phenomenology, Persons With Disabilities, Life Experiences, Qualitative Research

Dev Nandan Kumar*

Research Scholar (Ph.D.), Amity Institute of Education, Amity University, Uttar Pradesh *Corresponding Author

Prof. (Dr.) Mala Tandon

Professor, Dy. Director & HOI, Amity Institute of Education, Amity University UP, Lucknow Campus

ABSTRACT

The most immediate impression of disability is paradoxical. The way people think about disability affects the care and education of PWDs. Myths and misconceptions about disabilities are common. Promoting negative images of disability is a form of discrimination because it creates barriers to full citizenship for people who have a disability. Phenomenology is concerned with the study of experience from the perspective of the individual, 'bracketing' taken-for-granted assumptions and usual ways of perceiving. These experiences are called lived experiences. This type of research is used to study areas in which there is little knowledge. Phenomenological research methods are very different from the methods used in quantitative research and has sometimes been viewed as so-called soft science, rigorous, critical, and systematic. Phenomenological and associated approaches can be applied to single cases or to serendipitous or deliberately selected samples.

Introduction

People's life is normally divided into five stages namely infancy, childhood, adolescence, adulthood and old age. In each of these stages an individual finds himself in different situations and faces different problems to survive and complete their life cycle. Specially, when we are talking about persons with disabilities, in that case their problems cannot be visualized due to existing attitude of the society. Disability was earlier considered to be a medical problem to be dealt with by doctors only. Today, the medical model is being replaced by the developmental and sociological model due to enactment of the Rights of persons with Disabilities (RPD) Act, 2016. In India according to Census 2011, there are 2.68 crore Persons with Disabilities who constitute 2.21 percent of the total population. These include persons with visual, hearing, speech and loco-motor disabilities; mental illness, mental retardation, multiple disabilities and other disabilities. The percentage of persons with disabilities in the USA is 12%, in the UK is 18%, in Germany is 9%, in Sri Lanka is 5%, in Pakistan is 9%. This variation is due to the way we estimate disability.

The Right to Persons with Disabilities Act, 2016 has come into force with effect from April, 2017; and according to new Act the number of categories of disabilities has gone up from 7 to 21. Further, the Constitution of India guarantees equality of all citizens. But, persons with disabilities have been, in reality, facing stigma, discrimination and neglect due to socio-psychological and cultural reasons. Disability when compounded with discrimination doubles the quantum of disability. There is a wide spread underestimation of the abilities and potential of persons with disabilities due to general public perception and prejudices, thereby creating a vicious cycle of under achievement. This in turn results in inferiority complex among them which further harms their growth. It has taken a long period of time to educate ourselves to demystify the meaning of disability and fight myths and misconceptions of disability.

A society which cares for persons with disabilities is considered to be the best, as disability affects not only the individual and family but also society and the nation. Studies have shown that non-inclusion of persons with disabilities in the development process has several implications, as stigma of disability may result in loss of income and additional cost to the person with disability, for their care providers and other family members. This also results in loss of education and social exclusion to them and their family. Education, employment, access to buildings, transport and information systems have, in the past, been difficult for persons with disabilities to access due to non discrimination of society towards persons with disabilities.

On one hand we are talking about empowerment of persons with disabilities, full participation and making the right real, but the actual condition is different in the society. Ground reality is that

persons with disabilities are facing hidden attitudinal barriers in their personal, professional and social life. There are no rules or bindings to change attitude of the society, siblings and family members where persons with disabilities still facing difficulties. Therefore it is important to study life experiences of persons with disabilities in qualitative manner.

It is also a fact that the journey of life cannot be quantified; it goes beyond numbers, data and figures. Experiences of people cannot be caged into water tight compartments alone. They need to be understood, experienced and echoed in a human manner. When we are talking about persons with disabilities, it is more difficult to understand their feeling, emotions, attitudes towards society etc. This can be achieved through phenomenological approach. The phenomenological method is the only way to understand feeling, thinking, happiness, attitudes, emotions of persons with disabilities. It is important to study life experiences of persons with disabilities in personal, professional and social domains. The phenomenological approach includes day-to-day experiences, their success and struggle, their triumphs and pain etc.

To summarize, limited research exists regarding the life experiences of persons with disabilities in India. Such research is essential to pinpoint areas for change and, simultaneously, to highlight effective practice. In this approach, we can explore the day-to-day experiences of persons with disabilities to know the actual feeling of persons with disabilities regarding their success, struggle triumphs and pain in regard to their personal, professional and social life.

It is also fact that on one side we are talking about empowerment of persons with disabilities, full participation and equal opportunity in society including personal and professional life but the actual condition is different in society and still persons with disabilities are facing hidden attitudinal barriers in their personal, professional and social life. There are no rules or bindings to change attitude of the society, siblings and family members where persons with disabilities still facing difficulties. Therefore it is important to study life experiences of persons with disabilities in qualitative manner. The studies done so far are Quantitative in nature, focusing on statistics but the need of the hour is to concentrate on the journey of persons with disabilities, their struggles, attitude of society, family, employer etc. Through phenomenology we can focus on the life experiences of educated persons with disabilities wherein experiences of persons with disabilities in various domains such as their personal, professional and social life need to be understand in better way.

The Nature of Disability

The most immediate impression of disability, therefore, is paradoxical. On the one hand there is the appearance that disability implies a personal tragedy, passivity and dependency. On

the other hand disability can be seen as a form of group discrimination, involving constant struggles and independent action. The paradox of disability confounds any attempt to discover uniform attitudes towards disabled people. It is also a challenge to helpers to face squarely their role in a conflictual social relationship. Epistemologically, phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasize the importance of personal perspective and interpretation. In the human sphere this normally translates into gathering 'deep' information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation.

Understanding Phenomenology

Phenomenology is concerned with the study of experience from the perspective of the individual, taken-for-granted assumptions and usual ways of perceiving. These experiences are called lived experiences. This type of research is used to study areas in which there is little knowledge (Donalek, 2004). Due to little knowledge about persons with disabilities there are many stereotypes or images associated to PWDs and these stereotypes labeled on PWDs have had very negative influences on the way they are educated. Some stereotypes of disabled people portray them as being: pitiable and pathetic, sinister or evil, tragic but brave, laughable, aggressive, burdens/outcasts, non-sexual and incapable of fully participating in everyday life. In the field of education, perceptions towards children and adults with disabilities have changed significantly.

Phenomenological research has overlaps with other essentially qualitative approaches including ethnography, hermeneutics and symbolic interactionism. Pure phenomenological research seeks essentially to describe rather than explain, and to start from a perspective free from hypotheses or preconceptions (Husserl 1970). Phenomenological methods are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore at challenging structural or normative assumptions. Adding an interpretive dimension to phenomenological research, enabling it to be used as the basis for practical theory, allows it to inform, support or challenge policy and action.

Types of Phenomenology

In order to accurately describe the scaffolding or staging of phenomenology, it is appropriate to begin with its different types and classes, namely Hermeneutical phenomenology, where it refers to the study of personal experience and requires a description or interpretation of the meanings of phenomena experienced by participants in an investigation. Transcendental phenomenology is analyzes the essences perceived by consciousness with regard to individual experiences and Constitutional phenomenology is refers to the analysis of the self as a conscious entity. This type of phenomenology appeals to universal consciousness.

Methods

Phenomenological research methods are very different from the methods used in quantitative research. Although phenomenological research has sometimes been viewed as so-called soft science, Streubert and Carpenter (2002) contended that this research method is rigorous, critical, and systematic. Phenomenological and associated approaches can be applied to single cases or to serendipitous or deliberately selected samples. While single-case studies are able to identify issues which illustrate discrepancies and system failures - and to illuminate or draw attention to 'different' situations - positive inferences are less easy to make without a small sample of participants. In multiple participant research, the strength of inference which can be made increases rapidly once factors start to recur with more than one participant. In this respect it is important to distinguish between statistical and qualitative validity: phenomenological research can be robust in indicating the presence of factors and their effects in individual cases, but must be tentative in suggesting their extent in relation to the population from which the participants or cases were drawn.

A variety of methods can be used in phenomenologically-based research, including interviews, conversations, participant observation, action research, focus meetings and analysis of personal texts. If there is a general principle involved it is that of minimum structure and maximum depth, in practice constrained by time and opportunities to strike a balance between keeping a focus on the research issues and avoiding undue influence by the researcher. The establishment of a good level of rapport and empathy is critical to gaining depth of information, particularly where investigating issues where the participant has a strong personal stake. Interview methods and issues are discussed in Gorden (1969), Measor (1985), Oakley (1981), Plummer (1983) and Spradley (1979) among others.

Data Collection Strategy in Phenomenology

The samples or participants in phenomenological research are generally chosen according to what is known as "purposive sampling". Purposive sampling is characterized by the incorporation of specific criteria met by the participants at the moment of selection. The most appropriate data collection strategy for a phenomenological research is the profound interview. Existing literature (Kyale & Brinkman, 2009; Marshall & Rossman, 2010) coincides in that the phenomenological interview should be open or semi-structured.

Analysis

Data analysis in phenomenology is characterized by the following procedures: identifying common meanings and essences, "horizontalization" of data, textual and structural analysis (Moustakas, 1994). The 'problem' for many researchers with phenomenological research is that it generates a large quantity of interview notes, tape recordings, jottings or other records all of which have to be analysed. Analysis is also necessarily messy, as data doesn't tend to fall into neat categories and there can be many ways of linking between different parts of discussions or observations. As per my views following two methods are describe below.

Where the data is fairly disorganized - interview transcripts, unstructured notes or personal texts - the first stage is to read through and get a feel for what is being said, identifying key themes and issues in each text. These points - from all the texts for a small-scale project, or a sample of different ones where there are more than 10-15 - can then be aggregated and organised with the aid of a mind-map or set of 'post-it' notes. The resulting list is used as a set of points to interrogate the texts and structure and summarize them ("what is this participant saying about..."). Points which aren't brought out through this process need to be added. A more detailed description of this process is provided by Hycner (1985).

In a small-scale project looking across themes between participants is likely to be easy to do with physical documents, but an alternative useful where there are larger numbers of participants is to enter the data into a database according to the analysis headings, and use a mail merge facility to extract and compare entries. This also enables data entered under different headings to be juxtaposed and compared, particularly useful to identify relationships between different themes and factors.

Discussion and Conclusions

Phenomenology has become an useful and meaningful design among special education, disability rehabilitation and social sciences researches. Most of them, have understood that phenomenology is a genuine manner of representing the realities that participants experience in their lives. Although this premise is true, one of the biggest misconceptions about phenomenology (as a research design) is that it can be applied to all qualitative approaches. Indeed, perception is an element in all qualitative research designs, however, it is very important to consider the intention of the research and the problem to be resolved, before selecting phenomenology as a design.

Usually, the type of problem best suited for this design is the study of lived/common experiences. Bracketing is another aspect that

the researcher might employed while conducting a phenomenological research. The main aspect of phenomenology is to understand the essence of the experience that participants share within a common ground. It is important to understand that participants will bring out subjective and objective experiences. Phenomenology research can be considered directive as its sampling method is purposive. However, it is important to comprehend that all qualitative research has a Phenomenological aspect to it, but the phenomenological approach cannot be applied to all qualitative researchers.

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