

## **Coping and Resilience in Adults with Total Blindness in Kerala**

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This study on the personal experiences of adults with total blindness in Kerala was intended to advance knowledge about their coping skills and resilience in the face of constant adversity. Sixteen adults (8 men and 8 women) who were totally blind for at least 20 years participated in this study. Content analysis of the data collected from the participants, including the congenitally blind and the illiterate, showed that they had normal functional skills. The coping skills in the adventitious blind participants depended on their willingness to unconditionally accept the disability and the level of independence they showed before becoming blind. Themes such as high unemployment, social stigma, bodily injuries, and gender gap also evolved from the data analysis. Suggestions for improving the lives of the blind population in Kerala were also offered by the participants, such as increasing the monthly government pension and educating visually-impaired children in exclusive blind schools instead of regular schools. Making government jobs reserved for the visually impaired available and increasing the vocational opportunities for women were also suggested by the participants. .

**Keywords:** Coping & Resilience, Adults with total Blindness, Kerala, Developing Country

A human being with blindness can be compared to a car with a perfect engine that is forced to navigate in darkness because its headlights are not working. Ninety percent of the visually impaired people of the world live in developing countries. The personal experiences and the coping skills of people with blindness from developing countries such as India have been largely unexplored by the world's psychosocial researchers (Ademola-Popoola, Tunde-Ayinmode, & Akande, 2010; Haines-Wandga, 1996).

Cimarolli et al., (2011) conducted a qualitative study on the functional, psychological, and social challenges faced by older adults with significant visual impairment due to macular degeneration. The following numerous challenges reported by the participants in various domains bring out the extent to which they reduce the victim's quality of life: Functional: Reading, outdoor mobility, shopping, watching TV, financial management, driving, meal preparation, using phone, using transportation, grooming, writing, housekeeping, indoor mobility, locating objects, identifying objects, sewing, general mobility, repair, handling money, taking medication, telling time;

Psychological: General thoughts and feelings about blindness, negative affect, sadness, loss of independence, thinking about potential problems in future, anxiety, embarrassment, loneliness; Social: Leisure, recognizing people, eating out, art and crafts, visiting social network in person, social correspondence, travel, people don't understand blindness, volunteer work, caregiving.

### ***Blindness in India and in Kerala***

India had population of 1.2 billion according to the census of 2011. It had 8 million blind people and 38 million people with low vision.

Kerala, that has a population of 33 million, has the highest literacy rate (91%) in India. The life expectancy of a person in Kerala at birth is 74 years. Thus, literacy rate and life expectancy in Kerala are comparable to that of developed countries. According to the 2012 census, there were 3,34,000 visually impaired people in Kerala.

### ***Research Questions***

The central question was: What are the personal experiences of individuals with total blindness in Kerala and what are the coping skills

that enable them to deal with its challenges? The study also intended to answer the following related question: How do coping skills and resilience evolve in persons who lose eyesight (after being born without blindness)?

### **Method**

#### ***Setting of the Study and Data Collection:***

The data for this study was obtained from a sample of 16 adults (eight men and eight women) with total blindness who always lived in Kerala. After the Institutional Review Board approved the proposed study, informed consent from the participants was obtained by the researcher. An acquaintance of the researcher, who was a blindness activist in Kerala, helped recruit the participants. In order to obtain disability experiences over a prolonged period, the participants had to be above 30 years of age and totally blind for at least 20 years. Use of the criterion sampling method was intended to enhance the quality assurance of the study (Miles & Huberman, 1994). (The personal details of the participants are summarized in Table 1.) Initially, data was collected from each participant, through telephone interview, using a set of semi-structured questions (given in Table 2). All conversations with the participants were audiotaped by the researcher, who was stationed in Maryland, U.S.A. Detailed autobiographical narratives and copies of relevant documents (e.g., newspaper clippings, certificates, and medical reports) were also obtained from the participants.

#### ***Participant Demographics:***

The participants of this study had blindness as the only disability. The oldest participant in this study was 67 years old, and the youngest was 42 years old. The median age of the 16 participants was 54 years. On average, participants had been totally blind for 39 years at the time of the study.

#### ***Preparation of Case Reports and Coding of Themes***

The telephone transcripts, interview notes, autobiographical narratives, and relevant documents were used for preparing the case reports of participants. The participants were

assigned codes (P1, P2, etc.) for ensuring confidentiality. The raw data that was in Malayalam was translated into English by the researcher, who is originally from Kerala. The case reports were approved by the participants before being coded for common themes. Although, the participants had varied life stories, several common themes related to blindness emerged from them.

#### ***Common Themes:***

##### ***1. Visual impairment is largely a product of poverty and ignorance.***

All female participants in this study became blind due to malnutrition or infection. P13 had eye infection when she was 3 years old. Her parents had taken her to a country quack that practiced indigenous medicine. He applied a few drops of an herbal medication for jaundice in her eyes, and she became blind by the next morning. Among the men, the causes of blindness were as follows: infection/malnutrition (5), spurious liquor (1), botched brain tumor surgery (1), and deliberate acid attack (1). P7, who became blind in an acid attack, was the only one who had a hunger-free childhood. An example, of blindness resulting from the choice made as an adult was that of the P4 who got it by consuming spurious liquor.

##### ***2. Lack of employment is the most challenging barrier for coping.***

Only four participants (three men and one woman) had a steady monthly income. All other participants were willing to work, but were unemployed or substantially underemployed. Even putting food on the table was a daily struggle. Only P3, whose wife was also employed, had enough income to meet all monthly expenditures. A very small percent of even the college-educated blind in India have stable jobs. On the employment side, the advent of the cell phone and the websites like the YouTube.com put several participants, who were owning pay-phone booths and video rentals, out of work.

##### ***3. Blind people have to suffer social stigma and also suffer physical injuries.***

Regarding the various experiences of stigma that his family had to undergo after the acid

**Table 1: Participant Information**

Code	Gender	Age	Blind	Cause	Education	Status	Occupation
P1	Male	53 years	31 years	Malnutrition	Grade 3	Married	Unemployed
P2	Male	50 years	45 years	Malnutrition	BA	Married	Unemployed
P3	Male	57 years	52 years	Infection	BA	Married	Telephone operator
P4	Male	67 years	31 years	Spurious liquor	Grade 6	Married	Vendor
P5	Male	51 years	23 years	Brain tumor	Grade 10	Married	Religious orchestra
P6	Male	55 years	41 years	Glaucoma	MA	Married	History teacher
P7	Male	65 years	39 years	Acid attack	BS	Married	Retired from bank
P8	Male	58 years	52 years	Infection	Pre-degree	Married	Vendor
P9	Female	53 years	51 years	Malnutrition	None	Single	Unemployed
P10	Female	47 years	44 years	Chicken pox	BA	Single	Unemployed
P11	Female	61 years	32 years	Malnutrition	Grade 7	Single	Selling lottery tickets
P12	Female	51 years	47 years	Infection	BA	Widowed	Unemployed
P13	Female	55 years	51 years	Infection	BA	Married	Blind school teacher
P14	Female	52 years	47 years	Infection	Pre-degree	Married	Unemployed
P15	Female	50 years	46 years	Infection	BA	Single	Unemployed
P16	Female	43 years	37 years	Infection	None	Single	Unemployed

**Table 2: Semi-structured Questions for the Telephone Interview**

A blind individual is defined as "one who has irreversible blindness (no perception of light) or one who has light perception but still less than 3/60 in the better eye." How do you meet this blindness criterion for this study? How do you meet the criteria of above 30 years of age and blind for 20 years?

What are the details of your personal information (date of birth, place of birth, occupation of parents, religion and denomination)?

What are the details of your education (schools attended, training and degrees received)?

What age did you become blind and what was the reason?

What are the ways that your family is supporting you?

What are the details of the living skills training and vocational training you have received?

What are your sources of income?

What are the details about the jobs you have held?

What role has religion played in your efforts to cope with blindness?

What are the details of your married life (whether spouse is blind, has children resulting from marriage, are they blind, etc.)?

Do you have any health problem besides blindness at present?

What are the barriers imposed by blindness in your life?

What would you see as your low point during your life with blindness?

What are your suggestions to a person who has become blind recently?

What are your suggestions to the parents of a baby who has been born blind?

What are your suggestions for identifying the potential and improving the living conditions of the blind people in Kerala?

What would you see as your period of fulfillment during your life with blindness?

What are the detailed factors which you have seen as contributing to your ability to cope with blindness (employment, family support, religion, etc.)?

What are the factors of your future life that worry you?

attack, P7 said, "Concentrated sulfuric acid was poured on my face, one afternoon, in the bank where I worked as a teller. Hearing the news of the acid attack, my mother fainted. My oldest brother, who was a teacher in the nearby high school, started showing signs of severe neurosis. Since, sulfuric acid is very corrosive, my head was fully covered with bandage for several days after the attack. The frightening image left my brother sleepless for several weeks. Later he went into protracted depression."

P12 narrated her bitter experience on the first day in a regular high school. The other students sat away from her saying that they would get blindness from her. An interesting development happened among the blind in India in 1981 (United Nations Year of the Disabled). From that time onwards, some of the blind females began marrying blind males. Many of these socially progressive weddings were officiated by noted political leaders. Problem arose two decades later, when the children of those blind couples reached marriage age. Even the employed male children had difficulty finding spouses.

Getting various bodily injuries, some of them life threatening, was a common experience for the participants of this study. Those who became blind during early childhood described their experiences of frequently falling while running around with other children. In the bathroom of a restaurant, P7 touched the live wire of an electrical switch that had its cover removed by the repair man. Luckily, he was thrown to the floor and not seriously injured. P12 and her blind husband, while selling lottery ticket in the busy streets of the capital city of Trivandrum were hit by vehicles, and seriously injured.

#### **4. Positive factors such as family support, free education, spirituality, and entertainment technology help coping.**

Only two participants (P9 and P11) were living alone. All others had substantial support from spouses, children, or other family members.

None of the 11 married participants in this study were divorced by their spouses. P1 did not have the support of his siblings, but after marriage, his sighted wife, and later his older daughter mitigated his hardship. P7, who was involved in a sex scandal, became blind from a revenge acid attack. His family and neighbors saw his experience as the most horrific one that fate could hand over to a human being. Initially, his siblings did not want to be involved with him, due to the stigma that he created for the family. However, his sighted wife and three grown up children were always supportive in providing mobility and constant companionship. P8's wife, while a teenager, eloped with him without knowing the consequences of marrying a blind person, of another religion. He had frequent temper tantrums. Still, his wife, the two grown up sons, and their wives were always helping him cope with the disability. When P10 and her twin sister were infants, their mother died, and their father left them. Both the girls were brought up well by their grandmother and two uncles.

The blind people in India could get free education up to any level. They had reduced fares to travel by government bus or train. The skills they had acquired from the blind school, or the skills they had before becoming blind, aided them in their fight against adversity. In Kerala, a few blind people did panhandling or committed suicide. The participants attributed this positive aspect in blind people's character to the worthwhile education provided by the blind schools and the services provided by the Kerala Federation of the Blind. All the participants in this study believed in God.

Seven participants said that not attending a blind school put them at a disadvantage. They did not learn braille and they could not read. The remaining nine blind-school-educated participants saw their education in those exclusive schools contributing substantially to their ability to cope with blindness. Kerala, that had a population of 33 million, had only a dozen exclusive blind schools. Each school had an

enrollment of only 30-40 students. Many parents were reluctant to send their children to blind schools, and thus were preventing the children from becoming independent.

All participants had land phone or cell phone, thanks to the subsidy provided in the 1990s by the government. All of them were making extensive use of their phones for communication with their peers. The camaraderie among the victims of blindness was unique. All participants listened to radio programs several hours each day. One reason for their preference for radio programs was that they had higher standard than the television programs.

**5. Women have more barriers to cope with—first due to blindness and second due to gender.**

Five of the eight female participants were never married. The three married women had blind men as husbands. P12's husband had deceased three years before the study. All male participants were married and their wives were sighted. P10 wanted to join training programs in institutions outside Kerala. She did not have a relative who could escort her to those places. P11, who was living alone, had the experience of her brother's friend intruding into her bed after saying good bye to her. P15 was the most qualified applicant for an instructional position in a vocational training facility run by the Kerala Federation of the Blind. The interviewers denied her the job on the ground that a male would perform better than a female.

**6. For the adventitiously blind, accepting the present reality and the previous lifestyle determine the course of coping.**

For the adventitiously blind, accepting the disability is the first step in coping. Three participants had normal eyesight into the adulthood. P4 became blind after consuming spurious liquor during the festival season. He was severely depressed for a year. Then he accepted the reality that he would be blind forever. With the support of his wife, he started a vending stand. It began generating income due to the support of the public. P5 became totally blind when a reputed surgeon severed his optic nerves, by mistake, during brain tumor surgery.

The first few months were those of starvation for his family. His wife and two sons helped him to learn living skills like drawing water from the well, doing laundry, and taking shower. In a few years, he was able to organize a small religious orchestra and generate some income. According to the adventitious blind, accepting the disability would begin with the process of recovery. Unemployment was the most serious barrier to coping. Hence, their advice to any adventitious blind person was to find a way to obtain a steady income.

**7. Despite the steep barriers, the participants show remarkable resilience.**

All the participants of the study showed resilience and determination to go ahead, despite the barriers. Education, family support, help of organizations like the KFB and Lion's Club, and the monthly handicapped pension, though small, helped them cope with the disability. P1 was born to poor parents and his siblings despised him for his disability. However, he started generating income at an early age by starting a vending stand. P2, despite the hunger in his household, obtained a college degree. At the time of the interview, he was married to a sighted girl and earned a living by spinning rope in the backyard of his house. P3, who was working as a telephone operator, felt that he was well-adjusted to life with blindness. He considered himself to be having a better quality of life compared to his five siblings, who were sighted. P5, who became blind in a botched brain surgery, had a different philosophy. According to him, a person who becomes blind has to think that his life has ended, for all practical purposes. Whatever he is able to accomplish in the subsequent life (in darkness) is a bonus. If a blind person fears that he would be attacked by a dog or bitten by a snake, he would be immobile and unproductive. The life story of P7 is the prime illustration of human resilience in the face of adversity. His promising career as a young bank worker came to a full stop one afternoon in July 1974 when he became blind and disfigured in a revenge acid attack. Still he persevered, learned O & M and living skills, completed the diploma for blind telephone operators, and got reinstatement in the bank as a

telephone operator. P9 had never seen anything and never gone to school. Still she was living alone and was involved in community activities. One observation made by many participants was about the popular belief that blind people were always in anguish due to their inability to see the faces of people and things. They seldom felt such pain. Five participants, who were congenitally blind, also had remarkable functional skills. Since, they did not know how light looks like, they could not describe darkness. P8 was a small scale blind vendor who never had any creative skills. When he was 45 years old, he met an itinerant book seller who read books to him. P8 slowly started writing poems and published two poetry books. The researcher found that one illiterate female participant (P9) had impressive conversational skills and general knowledge. She attributed her abilities to the few years, she spent as a teenage maid in an old age home, run by a Christian charity. P10, who was also congenitally blind, was studious and got a college degree in political science. She noted that, from childhood onwards, people thought that she, who was blind, was smarter and more knowledgeable than her fraternal twin sister who was sighted.

### Discussion

This study was an attempt to determine the “essence” of what it meant to be a totally blind person in a developing country. The sources of the coping skills exhibited by the participants, such as education, family support, and religious beliefs validated the findings of researchers in developed countries (Kleinschmidt, 1999). Other findings, such as the low marriage rate of women compared to men, lack of adequate government assistance, and the low divorce rate, are new from this study. The evolution of coping and resilience in the blind participants of this study has been explained using various theories elaborated in literature (Lazarus & Folkman, 1984; Lazarus, 1999; Glickman, 2006).

According to Bronfenbrenner’s ecological theory, human development is influenced by environmental contexts, ranging from intimate interactions with people to the broader context of culture (Bronfenbrenner, 1986; Bronfenbrenner & Morris, 2006). The behaviors of all participants

were largely shaped by the conservative culture of Kerala. For example, divorce is extremely rare in Kerala and it is a male dominated society. All male participants had sighted women as wives. Only three female participants were married and had blind husbands. These findings agree with a study by Heslin (2006) indicating that the society in which one grows up and one’s particular location in that society largely determines what one thinks and does.

An innovative idea of Vygotsky was that the most efficient compensation for the loss or weakness of natural functions can be achieved through the development of the higher psychological functions. Impairments of natural processes such as vision and hearing can be compensated by the cultural processes of abstract reasoning, logical memory, and voluntary attention. The participants of this study were of the opinion that activities such as jumping and dancing were difficult for them to learn. One needs to observe others with the eyes before doing such things. Another key idea derived from Vygotsky’s notion of social learning is that of scaffolding (Wood, Bruner, & Ross, 1976)—the assistance provided by more competent peers. The participants, who were educated in exclusive blind schools, praised those institutions for the instruction provided to them in using braille for writing, using a white cane, and becoming members of an orchestra. P7 noted that guided practice in activities of daily living such as cooking, laundry, and making the bed, as well as O & M that he received from experienced trainers in New Delhi helped him in his life in eternal darkness. According to Vygotsky, from the point of view of survival, blind people are at a disadvantage compared to deaf people. However, blind people have access to hearing, and hence their mental development can be near-normal.

There were no clear-cut theories that would explain the coping skills and resilience of people in a developing country who had a serious sensory impairment such as blindness (Haines-Wandga, 1996). Lazarus and Folkman (1984) noted that having financial resources would enable many people to cope with stress. None of the blind adults in this study came from

financially well-off families. All participants stated that a steady income was the most important prerequisite for coping with blindness. Most blind people in India lack a steady income. In this study, P3, who was financially independent, was the one who coped well with blindness. Three others had steady, though insufficient, income. Still, they fared better in coping with the disability than the 12 participants who had very low income. The attempts by the blind to earn a steady income can be seen as an example of problem-focused coping (Lazarus & Folkman, 1984). All the participants believed in God, and their faith can be seen as part of emotion-focused coping. Family support was a major coping factor for all participants. This finding agrees with the previous studies that the support received from social networks can reduce stress (Kef, Hox, & Habekoth, 2000). All male participants were married to sighted females who always provided support. P3, whose wife was also working, told the researcher that she provided him the needed income (problem-focused coping) and the needed emotional support (emotion-focused coping). P7, who was acid attack victim, said that his work among the needy blind has served as a source of comfort in the middle of stress about his wife's breast cancer treatment and financial difficulties. Finding comfort in charitable activities can be seen as an example of emotion-focused coping.

Masten (2001) defined resilience as a class of phenomena characterized by good outcomes in spite of serious threats to adaptation or development. All the participants in this study socialized with their neighbors, participated in the activities of the Kerala Federation of the Blind, and listened to radio for entertainment. P7, who lost his eyesight in an acid attack, persisted and returned to his previous job, married a sighted girl, and raised three healthy children. His experiences are in line with the finding in the literature that stress and adversity may lead to personal growth and improved functioning (Charney, 2004).

#### Limitations of the Study

There are vast numbers of blind people in Kerala who have blindness from old age. None of the participants of this study belonged to that

category. Totally blind people below 30 years of age and people with low vision were not included in this study. People with additional disabilities such as deafness, cerebral palsy, and mental retardation were also excluded from this study. The qualitative data collected from 16 adults will not fully reflect the personal experiences and coping skills of the blind population of India, which comes to millions.

#### Recommendations for Stakeholders

All participants of this study emphasized the importance of training in using braille, ADL, and O & M for leading a near-normal life. The regular schools in India lack the amenities needed to educate blind students. A recommendation evolving from this study is for parents and the policy makers. They should make arrangements for blind children to study in exclusive blind schools at least for Grades 1-7. Of the 16 participants, only three had full-time jobs. The government of India has a law on its books reserving 1% of job openings in the government for blind people. It has not been implemented due to bureaucratic inertia. Positions have to be created in the offices of the local government to attend to the needs of the blind people in the area. Many female participants, unlike their male counterparts, were not able to travel to places outside the state for vocational training, and were remaining unemployed. All state governments in India need to start institutions that train the blind people for various jobs. The present monthly handicapped pension of Rs 1000 is not enough for a blind person even to buy food items. The tiny amount is also distributed as three installments in a year. Increasing the pension to a reasonable amount, say Rs 3000 (\$50), would go a long way toward improving their quality of living.

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