Psycho-Social and Economic Burden on People with Physical Disabilities and Their Caregivers of Vijayapura District.

By

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Under the guidance of

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I, **Dr. Bhoomika. N,** hereby declare that this dissertation entitled **"Psycho-Social and Economic Burden on People with Physical Disabilities and Their Caregivers of Vijayapura District."** is a bonafide and genuine research work carried out by me under the guidance of **Dr. M. C. Yadavannavar.,** M.D., Professor and Head, Department of Community Medicine, B.L.D.E.(DU), Shri. B. M. Patil Medical College Hospital and Research Centre, Vijayapura.

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LIST OF ABBREVIATIONS

WHO	World Health Organisation
ICF	International Classification of Functioning
PSS	Perceived Stress Scale
CBI	Caregiver Burden Inventory
FIS	Financial Impact scale
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ESCAP	Economic and Social Commission for Asia and the Pacific
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
LMIC	Low- or Middle-Income Country
CDC	Centers for Disease Control and Prevention
DDRC	District Disability Rehabilitation Centre
SPSS	Statistical Package for The Social Sciences.
PwD	Persons with Disabilities
BMD	Benchmark disability
RPwD	Rights of Persons with Disabilities
IDEAS	Indian Disability Evaluation and Assessment Scale

WHODAS	World Health Organization Disability Assessment Schedule
ICD	International Classification of Diseases
AI	Artificial Intelligence
UNESCO	United Nations Educational, Scientific and Cultural Organization

❖ ABSTRACT

- Introduction

The International Classification of Functioning, Disability, and Health (ICF) defines disability as impairments, activity limitations, or participation restrictions due to interactions between a health condition and environmental and personal factors. Disabilities, which can be cognitive, physical, mental, sensory, emotional, or developmental, affect approximately 10% of the global population, or 650 million people, with 26.8 million individuals in India according to the 2011 Census. Disabilities significantly impact psychological, social, and economic dimensions, often leading to marginalization and affecting both individuals with disabilities and their families. Caregivers play a crucial role but often face emotional and financial challenges, particularly in developing countries with inadequate healthcare services. This study aims to evaluate the quality of life of individuals with disabilities and caregivers in the Vijayapura district.

- Objectives:

1. To explore the psychological stress on the physically disabled persons and their caregivers (>18 years) using Perceived Stress Scale (PSS) questionnaire.

2. To assess the social burden on the Caregivers of physically disabled persons using the Caregiver Burden Inventory (CBI).

3. To assess the Economic burden on family & caregivers of physically disabled persons by using the Financial Impact Scale (FIS).

- Materials and Methodology:

A cross-sectional study was conducted at the DDR Centre of BLDE (DU) Shri B M Patil Medical College, Hospital & Research Centre, Vijayapura, Karnataka, focusing on physically disabled individuals and their caregivers. Ethical clearance was obtained from the Institutional Ethical Committee before commencing the study. Participants were interviewed using a pretested semi-structured questionnaire to gather socio-demographic information. The Perceived Stress Scale (PSS) was employed to evaluate psychological stress among physically disabled individuals, the Caregiver Burden Inventory (CBI) was used to assess the social burden on caregivers, and the Financial Impact Scale (FIS) was utilized to measure the economic burden on families and caregivers of the physically disabled individuals.

- Statistical Analysis:

The data were compiled into an Excel spreadsheet and analyzed using SPSS version 20. Descriptive statistics such as frequencies, percentages, and diagrams were utilized for analysis. The statistical association between depression and other independent variables was assessed using chi-square tests and logistic regression analysis.

- **Results:**

Out of 400 participants, 40.3% experienced high levels of stress, while 51.5% reported moderate stress levels according to the PSS scale. On the CBI scale, 56% indicated a greater need for respite and services, and 73.8% agreed that caregiving strained their family and social life based on the FIS scale. Binary logistic regression showed significant associations between caregivers' burden and several independent variables like low income and lower educational level ($p<0.001$).

- **Conclusion:**

Improving the quality of life for physically disabled individuals and their caregivers to alleviate their stress and burden is crucial. Effective communication techniques and regular counselling are needed to identify subtle signs of distress and prompt timely help.

Keywords: *Persons with Disability, caregivers, burden, Perceived stress Financial burden.*

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INTRODUCTION

Disability is not just a personal challenge but a significant public health issue affecting individuals' health outcomes, social integration, and economic participation on a broad scale. Disability is not solely a biological condition or a social construct but arises from the interactions between health conditions and environmental and personal factors.[1] According to the World Health Organization, disability encompasses three main dimensions:

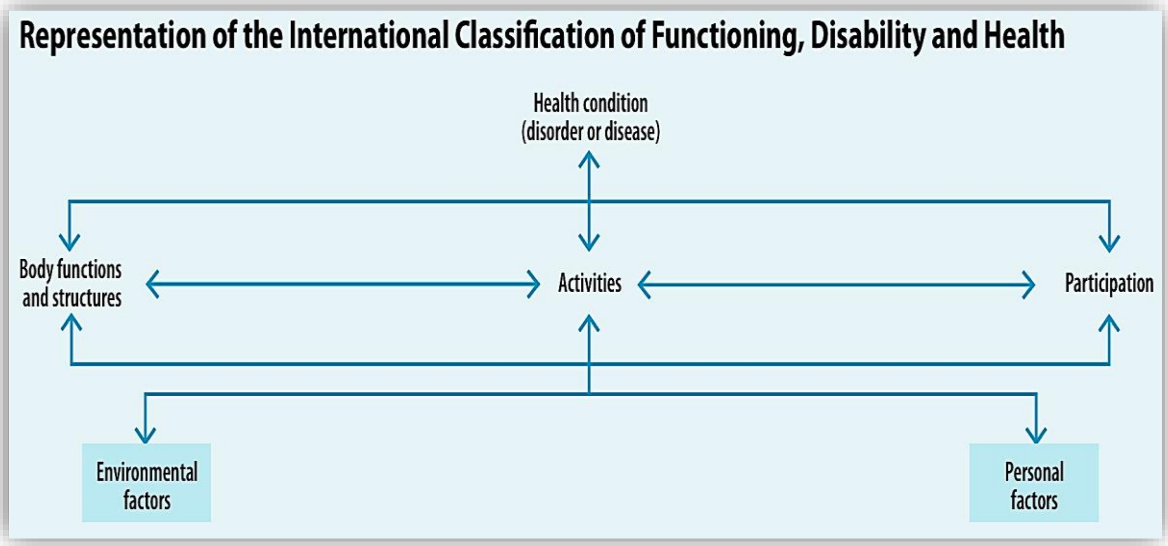
1. Impairment: This refers to deviations or losses in a person's body structure or function, or in their mental functioning. Examples include the loss of a limb, vision impairment, or memory loss.
2. Activity Limitation: This describes difficulties individuals face in carrying out tasks such as seeing, hearing, walking, or problem-solving.
3. Participation Restrictions: These denote the barriers individuals encounter in fully engaging in everyday activities such as work, social interactions, recreational pursuits, and accessing healthcare and preventive services.[2]

The understanding of disability has evolved through various models: initially, the dispensation model perceived disability as a divine punishment, resulting in social exclusion. This was followed by the medical model, which focused on individual impairments as the root causes of disability. In contrast, the social model shifted attention to societal barriers that hindered participation.[3]

Acknowledging the limitations of these models, the International Classification of Functioning, Disability, and Health (ICF) introduces a bio-psycho-social framework. It recognizes disability as a dynamic interaction between health conditions and contextual factors—both personal and environmental. This approach integrates impairments, activity limitations, and participation restrictions, highlighting the intricate interplay between individuals and their surroundings.[4]

The Convention on the Rights of Persons with Disabilities (CRPD) defines disability as a dynamic concept influenced by the interaction between people with impairments and societal attitudes and environmental barriers. It stresses the necessity of creating inclusive environments that promote equal participation in society for everyone, regardless of disability.[5]

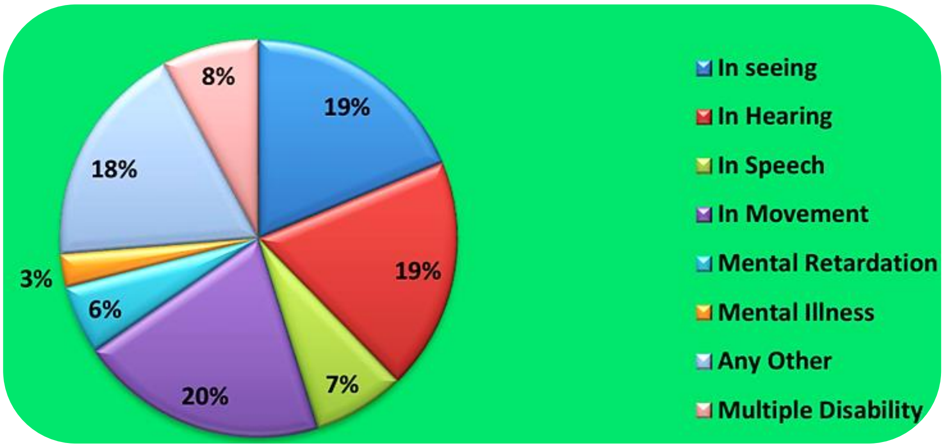
Figure 1: Representation of International Classification of Functioning, Disability and Health.[4]



The World Health Organization (WHO) estimates that around 1.3 billion people worldwide live with significant disabilities. This constitutes roughly 16% of the global population, indicating that about 1 in 6 individuals face challenges related to disability.[6]

In India, the 2011 Census reported that approximately 26.8 million people, or 2.68 crore individuals, are living with some form of disability. This accounts for about 2.21% of India's total population of 1.21 billion at the time. Among these individuals, 20% have movement-related disabilities, 19% have visual impairments, 19% have hearing disabilities, and 8% live with multiple disabilities.[7,8]

Figure 2: Percentage representation of various disabilities in India.



In Karnataka, individuals with disabilities make up about 4.94% of the state's total population, according to the same census data.[9]

Society frequently marginalizes people with disabilities, affecting their social identity, psychological well-being, and economic stability. Limited social interactions and decreased community involvement result from societal barriers and stigma, leading to increased isolation and hindering full participation in everyday life.[10]

People with disabilities often suffer from low self-esteem, feeling unworthy or unable to fully participate in activities and events. Families may view disability as shameful, discouraging social engagement for their disabled members. Community attitudes can be prejudiced, with beliefs that individuals with disabilities defile holy places or are incapable of certain roles. Physical barriers such as inaccessible transportation and buildings further limit social participation, including access to community centers, sports venues, and cinemas. These challenges create significant social issues for people with disabilities, affecting their access to essential services like healthcare, education, vocational training, and employment opportunities. Addressing these complex barriers is crucial for improving the quality of life for individuals with disabilities and ensuring inclusive access and opportunities within communities.[11,12]

Additionally, individuals with disabilities often rely heavily on caregivers for support. Caregiver burden includes feelings of heavy responsibility, constant worry, and uncertainty about meeting the needs of the person they care for. This burden often restricts caregivers' social lives and personal freedom, leading to stress, fatigue, and emotional exhaustion.[13]

Caregivers often prioritize the care of their disabled family members over their own health, potentially neglecting their personal well-being. This tendency is worsened by the increasing duration and severity of the illness or disability they are managing. Caregivers may experience negative emotions such as self-blame, guilt, shame, and embarrassment, further impacting their quality of life.[14,15]

Building on this background, this study explores the burden on caregivers, including the stress experienced by family caregivers while caring for disabled individuals, and examines its impact on the quality of life for both the caregiver and the disabled person. In recent years, there has been a significant societal push towards deinstitutionalizing the care of disabled individuals, promoting initiatives that enable them to live in regular family environments. This shift underscores the need to explore and improve the support mechanisms available to both disabled individuals and their caregivers. Understanding these dynamics is crucial for developing effective interventions and policies that enhance the overall well-being and quality of life for families affected by disability.

OBJECTIVES OF THE STUDY

- To explore the psychological stress on physically disabled persons and their caregivers (>18 years) using the Perceived Stress Scale (PSS) questionnaire.

- To assess the social burden on the Caregivers of physically disabled persons using the Caregiver Burden Inventory (CBI).

- To assess the Economic burden on family & caregivers of physically disabled persons by using the Financial Impact Scale (FIS).

REVIEW OF LITERATURE

History:

- Disability and Historic Perceptions Across Cultures:

In ancient and medieval periods, the theological perspective attributed disabilities to the "wrath of God" for sins, apathy, estrangement, and transgressions from one's current or previous lives.[16]

The Greeks viewed the sick as inferior, with Plato suggesting in his Republic that deformed children of the superior and inferior should be hidden away in "mysterious unknown places." In contrast, early Christian doctrine held that disease was neither a disgrace nor a punishment for sin, but rather a means of purification and a path to grace.[17]

In the sixteenth century, Christian figures like Luther and John Calvin claimed that people with mental illnesses and other infirmities were under the influence of demonic spirits. To expel these spirits, monks and other religious leaders of the time often inflicted physical and emotional suffering on those with impairments.[18]

Advocates of social Darwinism in the 1800s opposed government assistance to the underprivileged and disabled. They believed that preserving the "unfit" would hinder natural selection and affect the selection of the "best" or "fittest" traits for future generations.[19]

The acceptance of individuals with disabilities within a society does not necessarily correlate with the level of financial resources or technological expertise of that society. According to Lippman, people with impairments are more accepted in several European countries, such as Denmark and Sweden, compared to the US. He also found that the rehabilitation programs in these countries were more successful. In Scandinavian nations, the prevailing mindset is to accept social responsibility for all members of society, regardless of the type or severity of disability.[20]

In Africa, people with disabilities are often viewed as helpless and hopeless.[21] African culture and values have not made things any easier. Abosi and Ozoji (1985) found that Africans in general, and Nigerians in particular, attribute the causes of disability to sex-related issues, witchcraft, juju, God, or supernatural powers.[22] Disability is associated with evil, leading to negative attitudes toward persons with disabilities, driven by the desire to avoid anything linked to evil. Many of these unfavourable views stem from misconceptions due to a poor understanding of disability and its impact on functioning. These misconceptions arise from traditional systems of thought, which replicate magical-religious philosophies that can be safely called superstition.[23]

- **Evolution of the Term Disabled:**

The historical development of the word "disabled" reflects significant changes in societal attitudes and understanding of physical and mental impairments.

Originating in the late 16th century, "disabled" combined the Latin prefix "dis-" (meaning separation or negation) with "ability" (from Latin "habilitas," meaning capability or skill) to describe legal disqualification or deprivation of certain capacities.[25]

From the 17th to 19th centuries, the term was primarily used in legal contexts, referring to individuals or entities unable to perform specific acts due to legal restrictions or physical impairments. By the late 19th to early 20th centuries, "disabled" expanded to encompass physical and mental impairments more broadly, reflecting a growing recognition of these conditions' impacts on abilities. Meanwhile, "handicapped" originated from the mid-17th century game "hand in cap" in the UK and evolved to mean equalization in various contexts, particularly in sports. By the early 20th century, "handicapped" described individuals with physical or mental impairments, implying the need for special support. Over time, however, it acquired connotations of dependency, leading to a preference for "disabled."[24,25]

In the late 20th to early 21st centuries, the social model of disability distinguished between impairment (the condition) and disability (societal barriers), emphasizing the need for societal change rather than focusing on individual limitations. Current trends favor inclusive and respectful language, such as "people with disabilities," reflecting a person-centered approach. Advocacy and increased awareness continue to shape the discourse, promoting inclusivity and respect. This evolution highlights the shift from viewing disability as a personal limitation to recognizing the role of societal barriers, contributing to ongoing dialogue about disability language and its implications.[24,25]

- **Models of Disability:**

Two primary conceptual models of disability have historically been used to explain the origins of abnormal physiological and psychological functioning. The medical model views disability as an intrinsic characteristic of the individual, directly caused by diseases, disorders, traumas, or other health conditions, necessitating medical treatment or intervention to "correct" the problem within the person.[26,27]

In contrast, the social model sees disability not as an attribute of the individual, but as a problem created by society. According to this model, the issues needing resolution lie within the unaccommodating social environment rather than the individual. The social model suggests that disability is imposed by society through isolation and exclusion from daily activities, influenced by negative societal perceptions and a reluctance to remove environmental barriers.[28]

However, both the medical and social models fail to fully capture the complex nature of disability. As a result, an integrated approach has emerged in the form of the biopsychosocial model, which considers disability as an interplay between biological, psychological, and societal factors, each contributing to the limitation of the individual’s functioning. According to this model, the World Health

Organization defines disability as “the outcome or result of a complex relationship between an individual’s health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives.” Thus, the degree to which impairment translates into disability is influenced not only by the severity of the impairment but also by the individual’s capacity for social participation.[29,30]

The biopsychosocial model can be seen as an application of ecological systems theory (Bronfenbrenner, 1992; Bronfenbrenner et al., 1994) in the realm of disability. This theory explores how the interaction between individual characteristics and environmental features shapes behaviour and development. Factors affecting the functioning and societal perception of individuals with disabilities include the type and severity of the disability, individual personality traits, available environmental adaptations, financial resources, social inclusion practices, parental attitudes, inclusive education availability, teacher attitudes, cultural beliefs, and historical context.[29,30]

- **Disability Law:**

A comprehensive "human rights model" of disability will promote legislation recognizing the human rights of people with disabilities, defined as "the fundamental concepts that are both universal and indivisible, allowing all people to achieve equality and justice".[31]

The first international convention on disability, the CRPD, was founded on the human rights perspective of disability. Different conceptualizations and cultural contexts can lead to varied legal responses to disability. These legal remedies, though distinct, often coexist within legal systems; welfare, affirmative action, anti-discrimination, and human rights-based legal methods are all combined in some countries for people with disabilities. Most nations adopt and implement these various legal strategies through a range of legal processes, including criminal law, civil rights law, and constitutional law.[32]

Many agreements and treaties demonstrate the United Nation’s commitment to ensuring that people with disabilities have full and meaningful involvement in all facets of society. These include the International Covenant on Civil and Political Rights (ICCPR, 1966), the International Covenant on Economic, Social, and Cultural Rights (ICESCR, 1966), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, 1979), the Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment (CAT, 1987), and the International Covenant on the Elimination of All Forms of Racial Discrimination (CERD, 1969). The first disability-specific document was the Declaration on the Rights of Mentally Retarded Persons (1971), followed by the Declaration on the Rights of Disabled Persons (1975). The UN proclaimed 1981 the "International Year of the Disabled" and 1982 to 1993 the "International Decade of Disabled Persons." Additionally, the United Nations' endorsement of the 1982 World Programme of Action and the "Standard Rules on the Equalization of Opportunities for Persons with Disabilities" has had a significant global impact in safeguarding the fundamental human rights of people with disabilities. While all of these efforts have human rights-related requirements, none specifically address the issues faced by people with disabilities or have legally binding provisions.[33]

The Indian government has passed several laws to address various issues related to disability, welfare, and the empowerment of those with impairments. These include the Mental Health Act of 1987, the Rehabilitation Council of India Act of 1992, the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act of 1999, and the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995. The primary aim of these Acts is to enable and integrate individuals with disabilities into society by affording them equal opportunities. The PWDs Act of 1995 was the primary law offering certain rights in employment, education, affirmative action, and the early identification and prevention of impairments. It was enacted to implement the Asian and Pacific region's declaration on the full participation and equality of people with disabilities.[34,35]

The Indian government replaced the PWDs Act of 1995 with the Rights of Persons with Disabilities (RPWD) Act in 2016 to better meet the needs and aspirations of people with disabilities.[34,35]

- **Types of Disabilities:**

A) Physical Disability

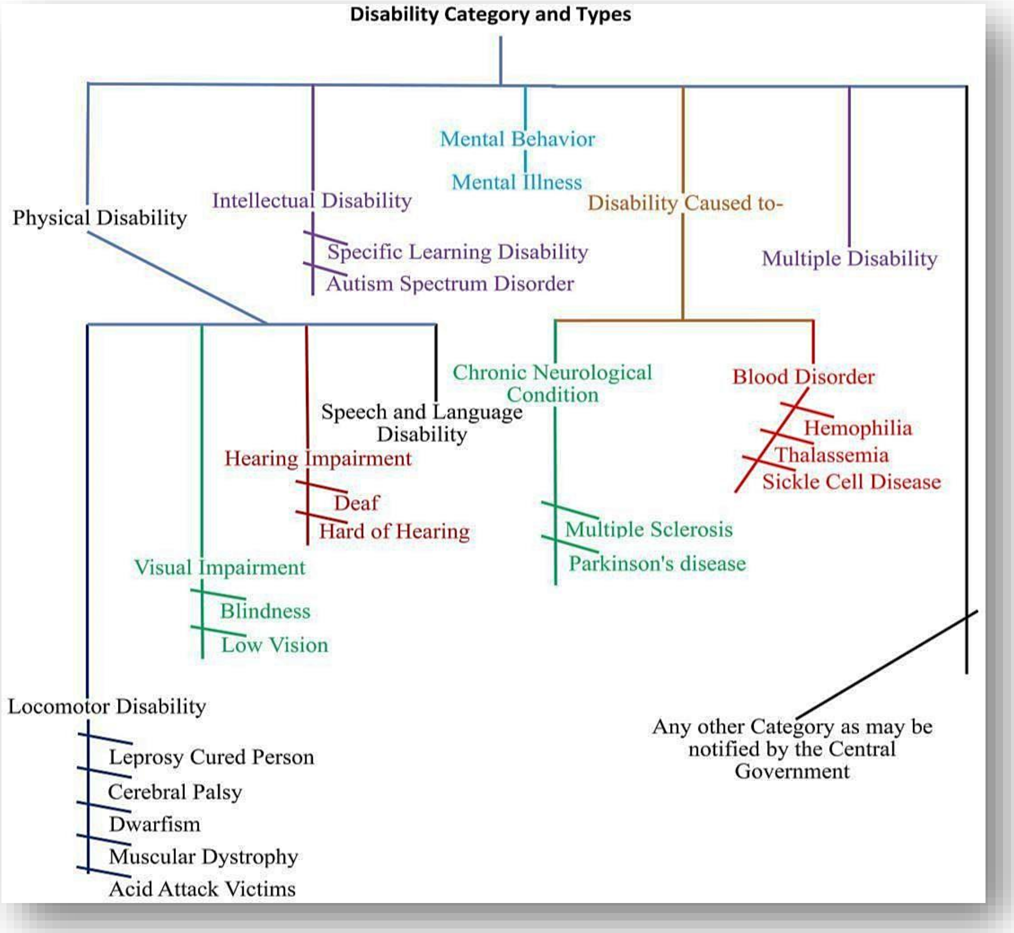
B) Intellectual Disability

C) Mental behaviors

D) Disability caused by condition/disorder

E) Multiple Disability

Figure 3: Disability category and types.[36]



A) Physical Disabilities:

Physical disability arises from conditions affecting the body's physical components. These conditions can encompass ailments such as amputations, multiple sclerosis, cerebral palsy, brain and spinal cord damage, and spina bifida. Severe heart and respiratory conditions can also impact mobility.

- **Locomotor disability:** A person with a locomotor disability cannot perform certain tasks related to moving themselves and objects due to a musculoskeletal, neurological, or combined condition. (Vikaspedia, 2021).
- **Leprosy-cured persons:** Persons who have been cured of leprosy may experience the following symptoms: extreme physical deformity, advanced age preventing gainful employment, loss of sensation in hands or feet, loss of sensation and paresis in the eyes and eyelids without deformity, or manifest deformity and paresis, with sufficient mobility in hands or feet for normal economic functions (Vikaspedia, 2021).[36]
- **Cerebral palsy:** Cerebral palsy refers to a group of non-progressive neurological conditions characterized by impaired muscle coordination and body movements. These conditions result from injury to one or more specific brain regions and typically manifest before, during, or shortly after birth.[37]
- **Dwarfism:** Dwarfism is a medical or hereditary condition that results in adults being no taller than 4 feet 10 inches (147 centimeters).[38]
- **Muscular dystrophy:** Muscular dystrophies comprise a group of inherited

genetic muscle diseases that weaken the muscles responsible for human body movement. Individuals with various forms of dystrophy have defective or absent gene information, preventing the production of proteins necessary for strong, healthy muscles. This condition involves the deterioration of muscle cells and tissue, leading to the progressive weakening of skeletal muscles and abnormalities in muscle proteins.[38]

- **Acid attack victims:** An acid attack victim is someone who has been violently assaulted with acid or another corrosive chemical, resulting in severe disfigurement.
- **Visual impairments:** Visual impairment can vary widely among individuals. Some may have no eyesight at all, while others may experience low or distorted vision. Learning is more significantly impacted by visual impairment that is present from birth compared to impairment that develops later in life.[39] There are two types:
    - **Blindness** – A person is considered blind under the following conditions after optimal correction:

      Complete loss of vision; or

      Visual acuity in the better eye of less than 3/60 or less than 10/200 (Snellen) after optimal correction; or

      Field of vision limited to less than ten degrees.
    - **Low vision**- A person with low vision may experience any of the

following conditions:

Visual acuity in the better eye, even with the best possible corrections, not exceeding 6/18, less than 20/60 down to 3/60, or up to 10/200 (Snellen);

Field of vision limited to less than 40 degrees down to 10 degrees.[40]

- **Hearing impairments**: Many hearing-impaired students often learn most effectively through visual means. Hearing impairments can be congenital or acquired, with some individuals retaining residual hearing while others experience complete hearing loss. The extent of impairment and the underlying cause of the hearing loss dictate its impact on learning.[41]

  There are two types:

  a) Deafness: A person is classified as deaf if they have a hearing loss of 70 dB or more in both ears at speech frequencies.

  b) Hard of hearing: A person who is considered hard of hearing has a hearing loss of between 60 and 70 dB in both ears at speech frequencies.

- **Speech and language disabilities:** A speech and language disability is a lifelong condition caused by factors such as aphasia or laryngectomy, which impair one or more aspects of speech and language due to neurological or biological factors.[42,43]

- **Specific learning disabilities:** The term "specific learning disabilities" encompasses a diverse range of conditions, including perceptual disabilities, dyslexia, dysgraphia, dyscalculia, dyspraxia, and developmental aphasia. These conditions are marked by challenges in processing language, whether spoken or written, and may manifest as difficulties in understanding, speaking, reading, writing, spelling, or performing mathematical calculations.[44,45]

- **Types of specific learning disabilities**

- Perceptual disorders
- Dyslexia
- Dyscalculia
- Dysgraphia
- Dyspraxia
- Aphasia

Table 1: Types of learning disabilities.[45]

Type of Learning Disability	Problem
Dyslexia – Difficulty with reading	Problems reading, writing, spelling, speaking
Dyscalculia – Difficulty with math	Problems doing math problems, understanding time, using money

Dysgraphia – Difficulty with writing	Problems with handwriting, spelling, organizing ideas
Dyspraxia (sensory integration disorder) – Difficulty with fine motor skills	Problems with hand-eye coordination, balance, manual dexterity
Dysphasia/Aphasia – Difficulty with language	Problems understanding spoken language, poor reading comprehension
Auditory Processing Disorder – Difficulty hearing differences between sounds	Problems with reading, comprehension, language
Visual Processing Disorder – Difficulty interpreting visual information	Problems with reading, math, maps, charts, symbols, pictures

- **Mental behaviors:**

Mental illness does not encompass retardation, which is characterized by arrested or incomplete development of intellectual abilities, specifically marked by subnormal intelligence. Instead, mental illness refers to significant disorders affecting thinking, mood, perception, orientation, or memory, severely impairing judgment, behavior, ability to perceive reality, or meet the ordinary demands of life.[46]

There are varying levels of symptoms for mental illnesses and behaviors. Effective learning outcomes can be enhanced through well-designed and implemented social and emotional programs. It is crucial to consider individual learning styles—whether auditory, visual, tactile, or a combination of techniques—because each person is unique. Incorporating diverse educational activities can contribute to improved learning outcomes.[46]

- **Mental illness:**

The term "mental illness" refers to a significant disorder affecting thinking, orientation, perception, mood, or memory, severely impairing one's ability to recognize reality, make decisions, behave appropriately, or meet daily needs. It does not include retardation, which is characterized by arrested or incomplete mental development and marked by subnormal intelligence. Mental illness impacts behavior, emotions, and thoughts.[46]

Anxiety conditions, mood disorders, attention deficit disorder, attention deficit hyperactivity disorder, personality disorders, psychotic disorders (such as schizophrenia), eating disorders, stress disorders, substance abuse disorders, obsessive-compulsive disorder (OCD), and other psychotic disorders.

B) Disability caused by chronic neurological conditions

A chronic neurological condition originates in a person's nervous system and is characterized by long-lasting effects or recurrent episodes. Since every case of chronic neurological illness is unique, it is crucial to identify each individual's learning style and address various learning preferences (auditory, visual, kinesthetic, or a combination).[47,48]

- **Multiple sclerosis:** Multiple sclerosis is an inflammatory disease of the nervous system characterized by damage to the myelin sheaths surrounding the axons of nerve cells in the brain and spinal cord. This damage leads to demyelination, which impairs the ability of nerve cells in the brain and spinal cord to communicate with each other.[47]

- **Parkinson's disease:** Parkinson's disease is a degenerative neurological condition marked by tremors, muscle rigidity, and slow, jerky movements. It mainly affects middle-aged and older adults and is associated with dopamine deficiency and degeneration of the brain's basal ganglia.[48]

Students with juvenile Parkinson's disease, which begins before age 20 and is typically an inherited form of the disease, will face educational challenges.[47,48]

C) Multiple Disabilities:[49]

As specified in the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, multiple disabilities refer to a combination of two or more disabilities, specifically:

I. Locomotor disability, including leprosy cured

II. Low vision or blindness

III. Deficit in speech and hearing

IV. Mental illness

V. Mental retardation.

- **Benchmark Disability:[49]**

According to the RPwD Act, a "Benchmark Disability" (BMD) is defined as having at least 40% of a specified disability. This criterion determines eligibility for various social welfare programs aimed at persons with disabilities. The Act outlines that individuals with disabilities must be certified by the appropriate authority to qualify under this benchmark. Countries like India use standards such as the International Classification of Functioning and Health (ICF) to assess functioning, disability, and health-related data for such certifications, although approaches may vary internationally, some relying solely on clinical judgment.

According to Section 2 of the Rights of Persons with Disabilities (RPwD) Act 2016, an individual classified as having Benchmark Disability (BMD) is someone who meets the criteria of having at least 40% of a specified disability. This definition applies whether the disability is explicitly quantifiable or not. Additionally, individuals with disabilities who have been formally certified by the appropriate authority in accordance with the provisions of the RPwD Act 2016 are also considered under the BMD classification. This certification process ensures that those eligible can access benefits and protections outlined in the Act.[49]

A person certified with Benchmark Disability (BMD) is eligible to participate in any social welfare program or scheme specifically designed for people with disabilities. This certification ensures that they can access the benefits and provisions outlined by the government or relevant authorities.

In some countries, such as India, the International Classification of Functioning, Disability and Health (ICF) is adopted as the standard for reporting data related to functioning, disability, and health. This standardized approach helps in consistent assessment and classification of disabilities based on globally accepted criteria. In contrast, other nations may rely primarily on clinical judgment to determine disability status and eligibility for benefits, which can vary in consistency and application depending on local practices and policies.[50]

IDEAS evaluates disabilities in domains such as employment, activities of daily living (ADL), interpersonal interactions, communication and comprehension, and self-care. The tool demonstrates robust concept validity and internal consistency.[51]

Despite India's adoption of the ICF, the Indian Disability Evaluation and Assessment Scale (IDEAS) continues to be utilized due to prevailing government regulations. IDEAS is employed in India for assessing disability arising from mental illness.[52] Within IDEAS, a score of 7 correlates with a 40% baseline impairment.[53]

India's endorsement of the ICF indicates a potential shift towards adopting the World Health Organization Disability Assessment Schedule (WHODAS 2.0). WHODAS 2.0 is a comprehensive tool used worldwide to evaluate health and disability stemming from mental, physical, and/or substance use disorders. This culturally adaptable scale aims to standardize disability assessment across different populations.

WHODAS 2.0: The 12-item interview-administered version of WHODAS 2.0 is crafted to align with the ICF framework, covering all domains of functioning. It is applicable for assessing mental, physical, and substance use disorders. This scale is designed to be universally applicable, transcending contexts, diseases, and cultural differences. WHODAS 2.0 offers four variations: self-reported, proxy, 36-item, and interviewer-administered.[54]

The creation of a Swavalamban card, or unique disability identity, for individuals with Benchmark Disabilities (BMD) is a recent initiative by the DEPWD. However, it is currently in the planning stages, and there is no published national data available yet on individuals with BMD.[55]

The concept of disability has evolved from a charitable perspective to a medical one, with significant changes in how disabilities are classified and assessed moving towards rights-based models. The adoption of WHODAS 2.0 by DSM-5 illustrates this shift, aligning with the International Classification of Functioning, Disability and Health (ICF) and the International Classification of Diseases (ICD-11). This integration provides a unified platform that offers comprehensive insights into illness and its impact on an individual's functioning.[56] This trend reflects a gradual move towards standardization in diagnostic frameworks, with WHODAS emerging as a prominent tool for disability assessment. Other assessments like the Global Assessment of Functioning and surveys based on Activities of Daily Living also play roles in evaluating disability.[56]

- Barriers faced by Disabled persons

In the 21st century, special needs services play a crucial role in advancing sustainable development by addressing the barriers faced by people with disabilities (PWDs) worldwide. The rise of artificial intelligence (AI) has ushered in significant social, economic, political, cultural, and technological changes over the years. However, alongside these advancements, there have also been disruptions in religious and intertribal communities, negatively impacting the psychological well-being and overall quality of life for many individuals, especially PWDs who often face isolation and unmet needs. This situation underscores the increasing demand for specialized education and counselling services tailored to the unique challenges faced by PWDs.

Four fundamental aspects of equity concerning individuals with disabilities are delineated in this context (OECD 2004, p. 17):[57,58]

1. Equity of access or equality of opportunity: This pertains to the accessibility of a comprehensive range of resources and services (such as healthcare, social welfare, transportation, and income-generating opportunities) necessary for enrolling in school.

2. Equity in production or equality of achievement (or results): This focuses on the direct outcomes of education, including diplomas and the development of occupational, political, and recreational skills essential for activities after school.

3. Equity in terms of learning environment or equality of means: This refers to the quality of teaching, curriculum, and instructional methods provided to facilitate participation in education.

4. Equity in terms of results realization or exploitation: This involves the social, cultural, and economic capital that creates opportunities for community engagement and productivity throughout life.

- Social Barriers

Social barriers are common for people with disabilities, significantly impacting their well-being and social integration. Employment rates for individuals with disabilities are notably lower compared to those without disabilities. In 2017, those without disabilities constituted 76.5% of the workforce, while those with disabilities made up only 35.5% of the 18–64 age group.[57] Additionally, adults with disabilities have lower high school completion rates (10.1% versus 22.3% for those without disabilities) and are more likely to earn less than $15,000 annually (22.3% versus 7.3%) compared to their peers without disabilities.[58] These disparities highlight ongoing challenges in achieving equity and inclusion for people with disabilities in various aspects of life.

- Educational Barrier

Perceptions of people with disabilities in education have evolved significantly over time. Birch and Johnstone (1975) underscored the importance of ensuring equal and complete accessibility of schools for individuals with disabilities, likening it to one of the foremost challenges in education today.[59] This perspective emphasizes the national interest in serving all children equally, irrespective of human rights, economic efficiency, or social desirability.

Education, recognized as a fundamental right by international organizations and national governments alike, forms the cornerstone of personal and national development. Despite this recognition, accessing education remains a daunting task for many individuals with disabilities, especially in developing countries. UNESCO (2009) reports that globally, 18% of children lack access to schooling, with South Asian children representing a significant portion of this figure. Shockingly, over 90% of the estimated 120 to 150 million disabled children under 18 in developing nations do not attend school, underscoring the profound barriers faced by individuals with disabilities in education.[60]

Even with historical missionary and state-driven educational initiatives, disparities persist in the quality of education received by individuals with disabilities compared to their peers without disabilities. Factors contributing to this disparity include familial neglect, poverty, and inadequate educational infrastructure (Musa, 2016).[61]

In many parts of Africa, educational institutions remain ill-equipped to accommodate and educate willing students with disabilities in inclusive settings. Consequently, many individuals with disabilities are relegated to isolated "special" institutions lacking the resources necessary to equip them with the skills needed for employment or independent social lives as adults (Elwan, 2017).[62]

Tororei (2019) highlights governmental inertia in addressing the educational challenges faced by people with disabilities, attributing the persistence of barriers not to overcrowding or resource shortages in mainstream schools, but to the systemic failure to prioritize and address these issues.[63]

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) marks a significant step forward by affirming inclusive education as the primary vehicle for realizing the right to education for persons with disabilities. Inclusive education systems are characterized by teaching methods, resources, and learning environments designed to accommodate boys and girls of all abilities, enabling participation in mainstream classes within their local communities (Ubani, 2022).[64]

- **Economic Barrier**

The economic inclusion of people with disabilities presents significant disparities compared to their non-disabled counterparts. They experience lower employment rates, earn significantly less, often work in precarious jobs, face challenges in obtaining workplace accommodations, may conceal stigmatized identities, and report higher incidences of discrimination. These difficulties are exacerbated by intersecting injustices faced by marginalized groups, including higher rates of poverty and limited access to banking, food, housing, healthcare, and education.[64,65]

The relationship between disability and poverty is intricate and cyclical. Poverty increases vulnerability to disability, while disability can reinforce and deepen poverty. This dual causality highlights how disability serves both as a cause and an effect of poverty (Osakwe, 2018).[65] Without improved access to the workforce, people with disabilities will continue to face negative social and economic consequences.

The United Nations has established guidelines for equal opportunities for individuals with disabilities, with economic rehabilitation identified as crucial for achieving maximum independence and self-reliance (Osakwe, 2018). This recognition is grounded in understanding the vicious cycle between poverty and disability.[65]

Research by Filmer (2008), analysing household survey data from 13 low- and middle-income countries (LMICs), found that being an adult with a disability significantly correlates with a higher likelihood of belonging to the poorest segments of the population in eight of these countries.[66]

Individuals born with disabilities or who acquire them often face social marginalization and encounter significant barriers to accessing employment, healthcare, and education. This exclusion contributes to poverty, further limiting their access to essential resources like housing, food, and healthcare, thus impacting overall family well-being.

Further evidence of wage disparities comes from Mitra and Sambamoorthi (2008), who demonstrate that adults with disabilities earn considerably less than their non-disabled peers, even when performing comparable work.[67] This disparity underscores the economic challenges faced by people with disabilities and emphasizes the need for inclusive economic policies and practices to address these inequities.

- **Physical Barriers**

Physical barriers refer to structural obstacles that hinder access or mobility in both natural and man-made environments. While everyone faces occasional adversity and challenges, these barriers can disproportionately affect individuals with disabilities. According to the World Health Organization (WHO), barriers encompass more than just physical impediments:

"A person's environment may contain elements that, whether present or absent, restrict functioning and create disability. These include things like an inaccessible physical environment, lack of assistive technology, negative attitudes towards people with disabilities, and services, systems, and policies that hinder full participation in all aspects of life."

Examples of physical barriers include stairs, curbs, outdoor surfaces, parking lots, building entrances and exits, internal and external doors, gates, restrooms, public facilities like phone booths or service counters, lighting, ventilation, elevators, escalators, floor coverings, signage, furniture, and movable items like equipment and display racks.

Individuals with disabilities encounter various obstacles in their physical environments, such as structural limitations that hinder their participation in social, cultural, and occupational activities. A truly inclusive society must prioritize accessibility to promote their engagement and mobility, facilitating their full integration and enjoyment of rights alongside fellow citizens.[68]

Research by Medeiros (2017) highlights the challenges faced by people with visual impairments in accessing healthcare services, including difficulties with transportation, physical access to facilities, receiving care, and communicating with medical professionals. These challenges undermine accessibility principles and contribute to lower standards of care for individuals with disabilities.[69]

Additionally, studies like Sousa et al. (2014) underscore the systemic challenges within healthcare systems, such as inadequate consultations and specialized exams, long wait times, limited and unwelcoming access, high demand coupled with a shortage of medical professionals in primary care, and poor communication across different levels of healthcare services.[70]

Transportation and natural environments are identified as major obstacles in people's daily lives, particularly in African contexts. Factors like rugged terrain, flooding, poor road infrastructure, long distances, costly or inadequate public transportation, and declining vehicle ownership contribute to significant transportation challenges in the region.[71] Addressing these barriers is crucial for enhancing the quality of life and societal inclusion of individuals with disabilities worldwide.

- Psychological Barriers

The statistics reveal a stark reality for individuals with disabilities, particularly regarding their mental health. According to a CDC study, an estimated 17.4 million persons with disabilities reported experiencing at least 14 mentally unhealthy days in the previous 30 days in 2018, marking frequent mental distress. This level of emotional anguish is associated with mental disorders, chronic illness, poor health behaviours, increased use of healthcare services, and limitations in daily functioning. Comparatively, individuals with disabilities report higher levels of mental distress than those without disabilities.[72]

The challenges faced by persons with disabilities are not merely limited to their impairments but are exacerbated by systemic and societal barriers. These barriers contribute significantly to poor mental health and mental illness among this population. Addressing these issues requires focusing on strategies that support both impairments and mental health to mitigate these challenges.

People with disabilities are especially susceptible to the adverse impacts of mental illness and poor mental health. They report experiencing mental distress approximately five times more frequently than adults without disabilities, with a substantial number reporting frequent mental distress in 2018.[72]

Frequent emotional anguish has multifaceted negative consequences, including exacerbating mental health conditions, influencing health behaviours negatively, imposing restrictive limitations, and contributing to chronic illness. Daily hurdles such as physical barriers, societal stereotypes, and restricted community access further compound their vulnerability to mental health issues and mental illness.

Moreover, employment outcomes for individuals with incapacitating mental illnesses are notably poorer compared to those without such conditions. Surveys conducted between 1989 and 1998 indicated lower employment rates (ranging from 22 to 40 percent) for individuals with diagnoses associated with high disability levels like schizophrenia, compared to higher rates (ranging from 76 to 87 percent) for those without mental illness.[73] These disparities highlight the profound impact of mental health on employment opportunities and underscore the need for comprehensive support systems to address these challenges effectively.

- Caregivers and their Burdens

Caregivers play a crucial role in providing informal support and taking responsibility for individuals who are chronically ill, disabled, or elderly, often without financial compensation.[74] While caregiving is seen as a necessary service to fill gaps in healthcare, it exacts a significant emotional toll on caregivers.[75]

The term "carer burden" refers to the stress and strain experienced by individuals who provide care to their family members. Originally conceptualized by Hoenig and Hamilton, this burden can be divided into objective and subjective components: objective burden relates to the practical challenges and negative experiences associated with caregiving, while subjective burden encompasses the emotional and psychological impact on the caregiver.[76,77]

Zarit, Reever, and Bach-Peterson define burden in terms of caregivers' perceptions of its effects on their emotional well-being, physical health, social life, and financial status, emphasizing the personal and non-objective nature of this experience.[78] Collins et al. further elaborate on carer burden, noting its negative psychological effects, health issues, financial strains, and disruptions to social and familial relationships.[79]

Nijboer et al. (1999) describe carer burden as a complex concept that includes both positive and negative aspects of caregiving, highlighting the dual role of caregiving as both a duty and a source of difficulty or hardship.[80]

The intensity of caregiver burden varies over time and is influenced by factors such as the duration of caregiving, availability of social support, and progression of the care recipient's illness. Longitudinal studies, such as those conducted in Taiwan, illustrate how caregiver burden fluctuates with changing care demands and support dynamics within the family.[81]

Financial strain is a significant aspect of carer burden, as many caregivers may reduce their work hours or quit their jobs entirely to provide care, impacting their economic stability.[82] Studies indicate that caregiving contributes to financial difficulties for a substantial portion of caregivers.[83]

Caregivers often neglect their own health needs due to the demands of caregiving, leading to higher rates of chronic health conditions like hypertension and heart problems among caregivers.[84,85,86]

Melon emphasizes that carer burden encompasses both subjective evaluations of caregiving difficulty and objective aspects related to the practical challenges of caregiving.[87] Given et al. suggest that caregiver burden can diminish the quality of care provided, as stressed caregivers may have reduced coping abilities and lack emotional support for the care recipient.[88] Goldstein et al. highlight the role of social networks, noting that caregivers with limited social support are more likely to experience burden.[89]

Overall, understanding and addressing caregiver burden is essential for supporting both caregivers and care recipients, ensuring that caregivers receive adequate support and resources to manage their responsibilities effectively while maintaining their own well-being.

MATERIALS & METHODS

Figure 4: Map of Karnataka state showing Vijayapura district.

- Background details:

The research took place at the District Disability Rehabilitation Centre (DDRC) in Vijayapura district, located at BLDE (Deemed to be University) Shri B. M. Patil Medical College Hospital & Research Centre, Vijayapura. DDRC operates as a community-based rehabilitation program aimed at identifying, screening, and providing extensive rehabilitation services to individuals with disabilities, particularly those living in rural regions.

Figure 5: District Disability Rehabilitation Centre (DDRC). Vijayapura

- **Study setting:** District Disability Rehabilitation Centre (DDRC), BLDE (DU) Shri B M Patil Medical College, Hospital & Research Centre, Vijayapura, Karnataka
- **Study population:** Physically disabled persons and their caregivers visiting the DDR Centre aged above 18 years.
- **Sampling method**: Convenient sampling was utilized, including all physically disabled individuals and their caregivers who consented and met the study's inclusion criteria.
- **Interview method:** Face-to-face interviews were conducted using semi-structured questionnaires, and the PSS, CBI, and FIS scales were administered while ensuring privacy and without disrupting the purpose of the visit.
- **Study design**: Cross-sectional study.
- **Study duration**: January 2023 to December 2023

Inclusion criteria:

- Diagnosed cases of benchmark physically disabled persons aged more than 18 years who are enrolled in the District Disability Rehabilitation Centre (DDRC).
- Caregivers of physically disabled persons who are more than 18 years (Family members, relatives and friends)
- Physically disabled persons through a duration of disability of more than 1 year.

Exclusion criteria:

- Physically disabled people who are suffering from any mental disability and with serious comorbidities.
- Patients who are not willing to participate in the study.

Sample size:

With an anticipated proportion of economic burden on caregivers of people with physical disability of 37%,[12] the study would require a sample size of 359 subjects with a 95% level of confidence and 5% absolute precision. (Using: Statulator software http://statulator.com/Sample Size/ss1P.html) Formula used

- $n = \frac{Z^2 \, p*q}{D^2}$

Where Z= Z statistic at α level of significance

D2= Absolute error

P= Proportion rate

q= 100-p

Dropout rate=10% of Sample size=359+36 = **395**

Rounding it off, **400** people with physical disabilities will be included in the study

Study tool: A semi-structured, pre-tested questionnaire was used to collect the data from study participants.

A. Socio-demographic profile of the study participants which includes:

a) Name, age, gender, marital status, religion, residence.

b) Information about education, occupation income, Socioeconomic status, Type of family, Type of disability, cause for the disability, and barriers.

B. Perceived stress scale (PSS) Questionnaire:

The Perceived Stress Scale (PSS)[90] is utilized as a tool to evaluate psychological stress among individuals with physical disabilities. Comprising 10 questions, the PSS questionnaire assigns scores ranging from 0 ("never") to 4 ("very often") for each item. This results in a total score that spans from 0 to 40, reflecting the level of perceived stress experienced by the respondent.

Interpretation of PSS is as follows:

- Scores ranging from 0-13 would be considered low stress.
- Scores ranging from 14-26 would be considered moderate stress.
- Scores ranging from 27-40 would be considered high perceived stress.

C. Caregiver Burden Inventory scale (CBI)[91] Questionnaire:

The Caregiver Burden Inventory (CBI)[91] is a comprehensive 24-item questionnaire designed to evaluate caregiver burden across five dimensions: time dependence, developmental, physical, social, and emotional. Each dimension consists of a specific number of items: time dependence and developmental dimensions each have 5 items, while the physical dimension includes 4 items. The social and emotional dimensions also contain 5 items each. This structured approach allows for a detailed assessment of the various facets of the burden experienced by caregivers of individuals with disabilities.

Each of the 24 items in the Caregiver Burden Inventory (CBI) can be scored on a scale from 0 (“never”) to 4 (“nearly always”). Higher scores, especially those near or above 36, indicate a higher level of caregiver burden and suggest a greater need for respite and additional support services to alleviate caregiver stress and enhance well-being.

Time Dependency Items	
He/she needs my help to perform many daily tasks	⓪①②③④
He/she is dependent on me.	⓪①②③④
I have to watch him/her constantly.	⓪①②③④
I have to help him/her with many basic functions.	⓪①②③④
I don't have a minute's break from his/her chores.	⓪①②③④
He/she needs my help to perform many daily tasks	⓪①②③④
Development Items	
I feel that I am missing out on life.	⓪①②③④
I wish I could escape from this situation.	⓪①②③④
My social life has suffered.	⓪①②③④
I feel emotionally drained due to caring for him/her.	⓪①②③④
I expected that things would be different at this point in my life.	⓪①②③④
Emotional Health Items	
I feel embarrassed over his/her behavior	⓪①②③④
I feel ashamed of him/her.	⓪①②③④
I resent him/her	⓪①②③④
I feel uncomfortable when I have friends over	⓪①②③④
I feel angry about my interactions with him/her.	⓪①②③④
Physical Health Items	
I'm not getting enough sleep.	⓪①②③④
My health has suffered.	⓪①②③④
Caregiving has made me physically sick.	⓪①②③④
I'm physically tired.	⓪①②③④
Social Relationships Items	
I don't get along with other family members, as well as I, used to	⓪①②③④
My caregiving efforts aren't appreciated by others in my family.	⓪①②③④
I've had problems with my marriage (or other significant relationship)	⓪①②③④
I don't get along as well as I used to with others.	⓪①②③④
I feel resentful of other relatives who could but do not help.	⓪①②③④

D. Financial Impact Scale (FIS)[92] Questionnaire:

The Financial Impact Scale (FIS)[92] is designed to evaluate the economic burden experienced by families caring for physically disabled individuals. Each of the 20 statements in the scale is followed by a range of responses from "Strongly Agree" to "Strongly Disagree." This tool helps assess how financial challenges affect families who provide care for disabled individuals, offering insights into the extent of economic strain experienced by caregivers and their households.

- **Data Collection:**

After obtaining Institutional Ethical Clearance, the study was conducted on physically disabled persons and their caregivers attending the DDR Centre of BLDE (DU) Shri B M Patil Medical College, Hospital & Research Centre, Vijayapura, Karnataka and to achieve the desired sample size in stipulated time, the house visits were also done by taking the list of physical disabled persons and their caregivers from DDR Centre. Participants who met the inclusion criteria were enrolled after explaining the study's purpose, and written informed consent was obtained from both the disabled persons and their caregivers. Data collection utilized a semi-structured questionnaire to gather sociodemographic information. The Perceived Stress Scale (PSS) was employed on physically disabled persons and their caregivers to assess the stress levels, Caregiver Burden Inventory (CBI), and Financial Impact Scale

(FIS) were employed on caregivers to assess caregiver burden, and financial impact. Participants with higher scores on these scales were identified after completing data collection.

- **Statistical Analysis:**

The data was compiled into an Excel spreadsheet and analyzed using SPSS version 26. Descriptive statistics such as frequencies, percentages, and diagrams were utilized for initial data exploration. Results were presented as Mean (Median) ± SD for continuous variables and counts with percentages for categorical variables, supplemented by diagrams where appropriate. A significance level of $p < 0.05$ was chosen to determine statistical significance. Statistical associations between depression and other independent variables were assessed using chi-square tests for categorical variables and logistic regression analysis for exploring predictive relationships.

- **Study variables:**
  - **Age**: Age was recorded in completed years based on the information provided by the subjects, which was verified using identification cards such as Aadhar or voter ID belonging to each participant.
  - **Marital status** [93]: The marital status of each participant was recorded under the following categories:

1. Married: Individuals currently married, whether for the first time or subsequent times, with marriages still valid under applicable

regulations at the time of the study.

2. Widowed: Individuals whose spouse has passed away and who have not remarried since the death during the study period.
3. Separated: Individuals whose marriage has been legally terminated.

- **Type of family**:
  - *Nuclear family:* typically comprises a married couple and their dependent children.
  - *Joint family:* It consists of several married couples and their children living together in the same household. All the men are related by blood, and the women in the household include their wives, unmarried sisters, and other female family members.
  - *Three Generation family:* It is a multi-generational family where representatives of three generations live together. This includes young married couples who continue to reside with their parents while also raising their children.

- **Education**:
  - Never attended school/illiterate: Individuals who are not able to read, write, or understand any language.

- Primary school: Those who completed studies up to the 7th standard.
- High school: Individuals who completed studies from 8th standard to SSLC (Secondary School Leaving Certificate).
- PUC/Diploma: Those who completed studies up to Pre-University Course (PUC) or any diploma.
- Graduate and above: Individuals who completed graduation or any higher education beyond that level.

- **Occupation:**

  - Unemployed: Individuals who are currently not engaged in any employment.
  - Self-employed: Individuals who run their own businesses or own factories.
  - Government employees: Individuals who hold permanent positions and receive a monthly salary from government institutions.
  - Private employee: Individuals who work in private companies or organizations, whether in skilled or unskilled positions.
  - Retired: Participants who have formally retired from their occupations upon reaching the age of 60 years.

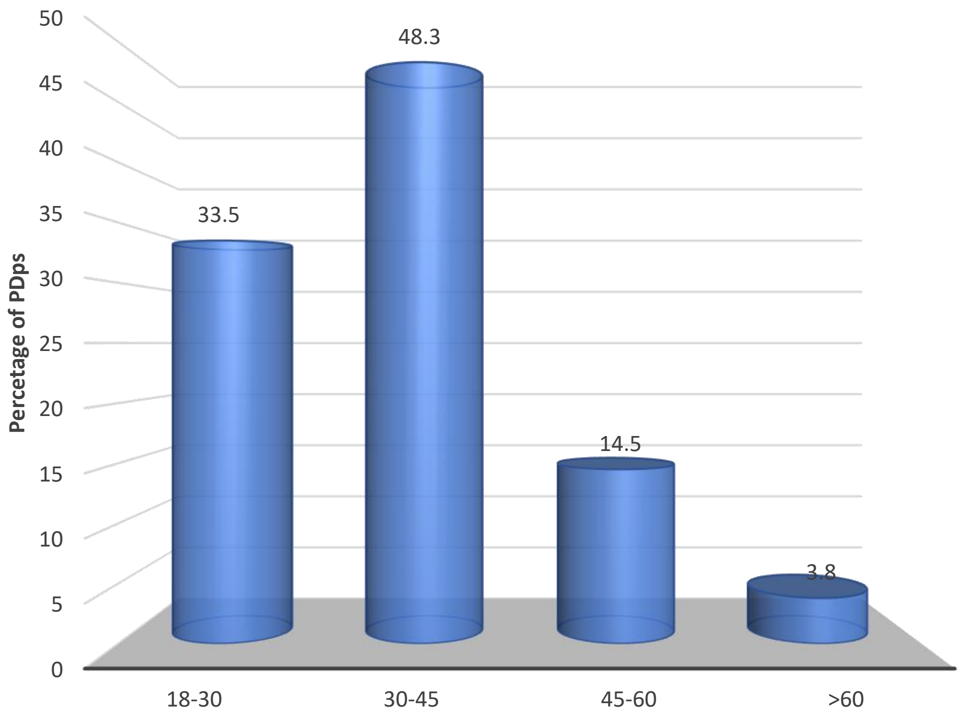
- **Type of disability:**
  - Mobility impairment: Difficulty in using hands, feet, arms, or legs, resulting in challenges with movement or physical coordination.
  - Vision impairment: Partial or total inability to see, leading to limitations in visual perception or complete lack of vision.
  - Hearing impairment: Partial or total inability to hear, resulting in challenges with auditory perception compared to those with normal hearing.
  - Others: Any disability not categorized under mobility impairment, vision impairment, or hearing impairment.
- **Cause for disability:**
  - Congenital: Refers to a condition or trait that is present at birth, whether inherited genetically or occurring during fetal development.
  - Acquired: Describes a disability that develops during a person's lifetime, typically as a result of an accident, injury, illness, or other external factors after birth.

RESULTS

Socio-demographic profile of the study participants:

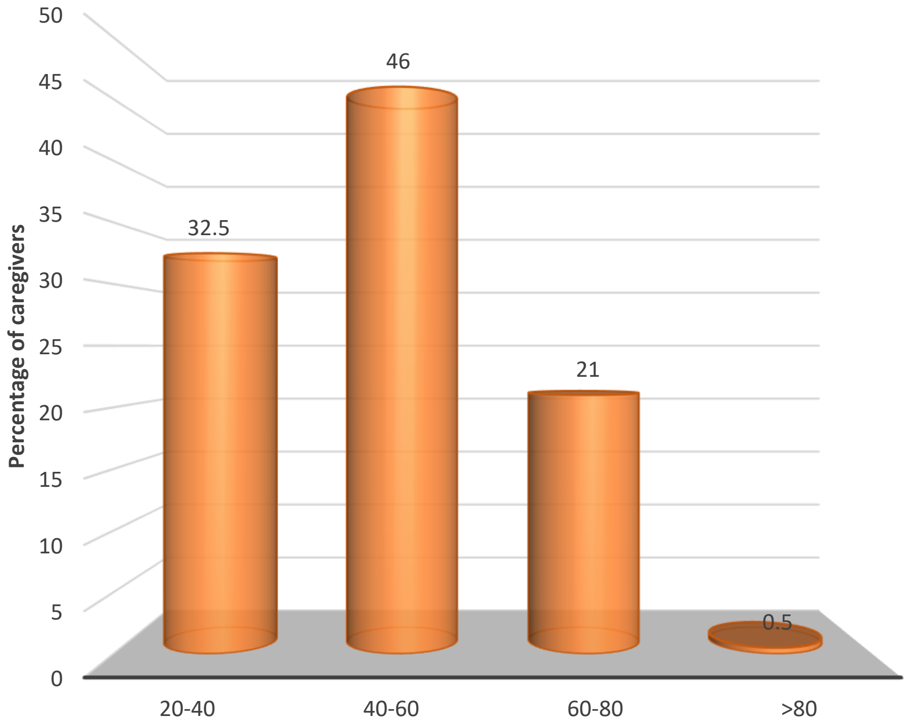
A total of 400 participants who gave consent were included in this study. This study included Physically disabled persons and their caregivers.

Figure 6: Age-wise distribution of Persons with disability (n=400)



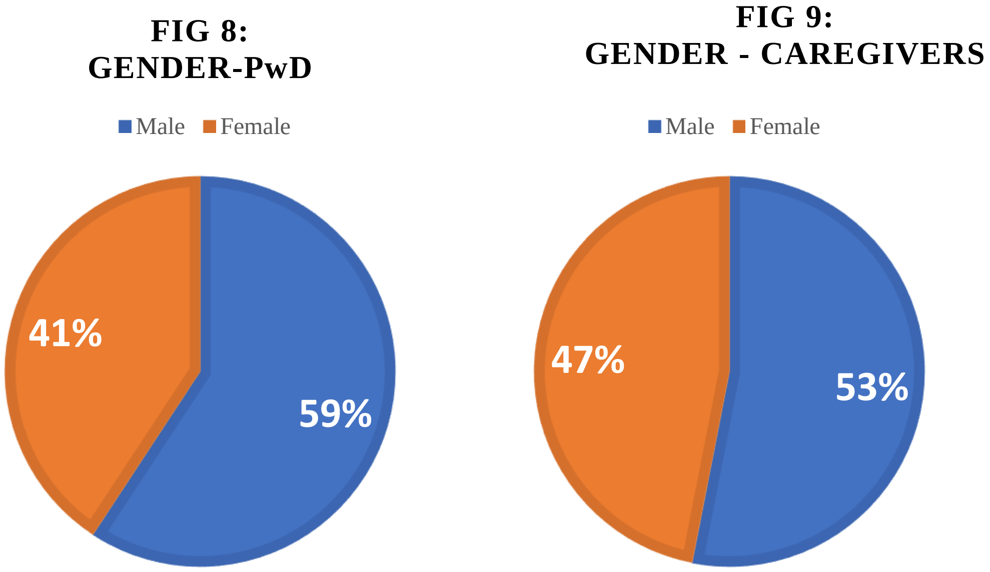
Among 400 participants, 48.3% were in the age group of 30 to 45 years and 33.5% were in the age group of 18-30 years.

Figure 7: Age-wise distribution of caregivers (n=400)



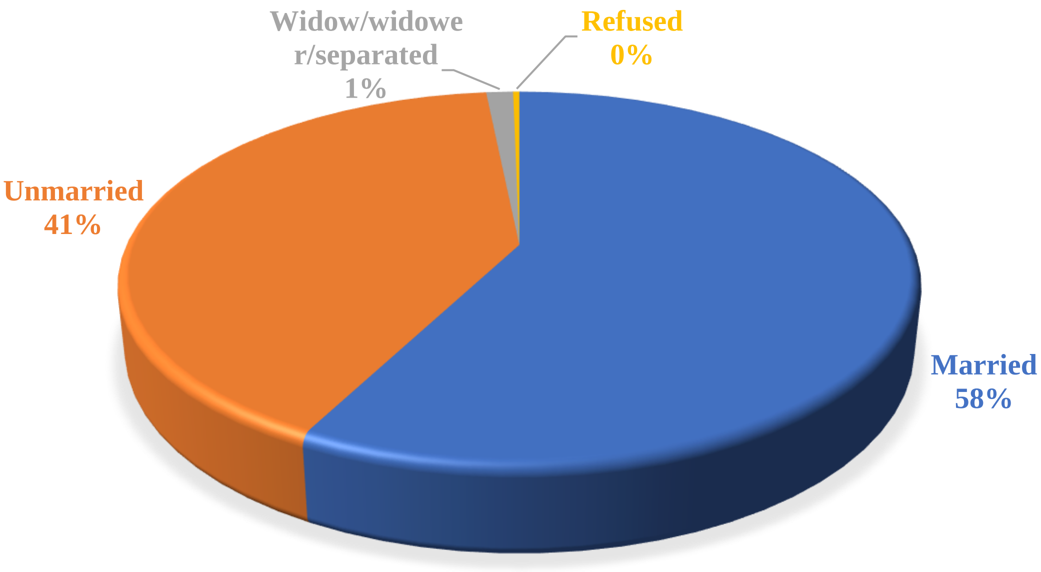
46% of caregivers were in the age group of 40 to 60 years and 32.5% were in the age group of 20-40 years.

Figure 8 & 9: Gender distribution among Persons with disability and their caregivers



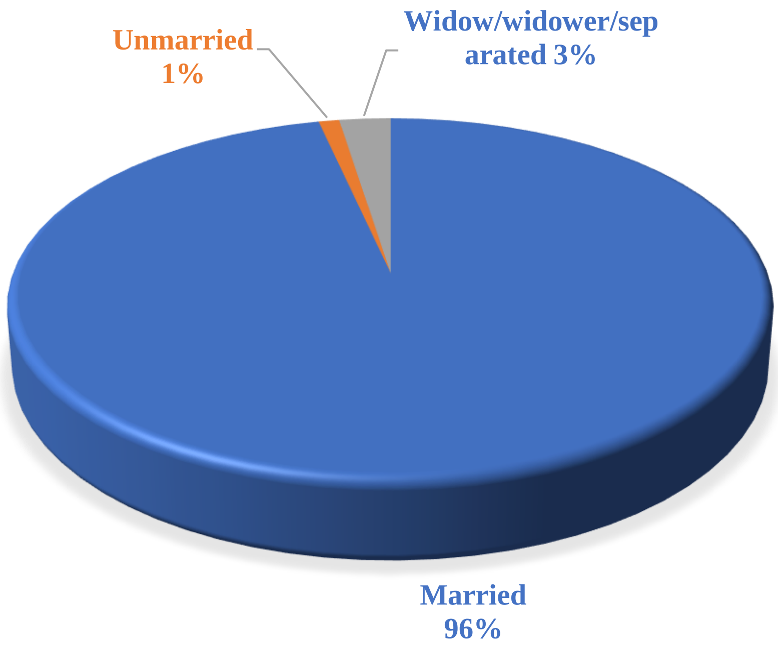
Among 400 participants of people with Disability, majority of 59% were Male and 41% were female. Similarly, among caregivers 53% were male and 47% were female respectively.

Figure 10: Marital status of Persons with disability



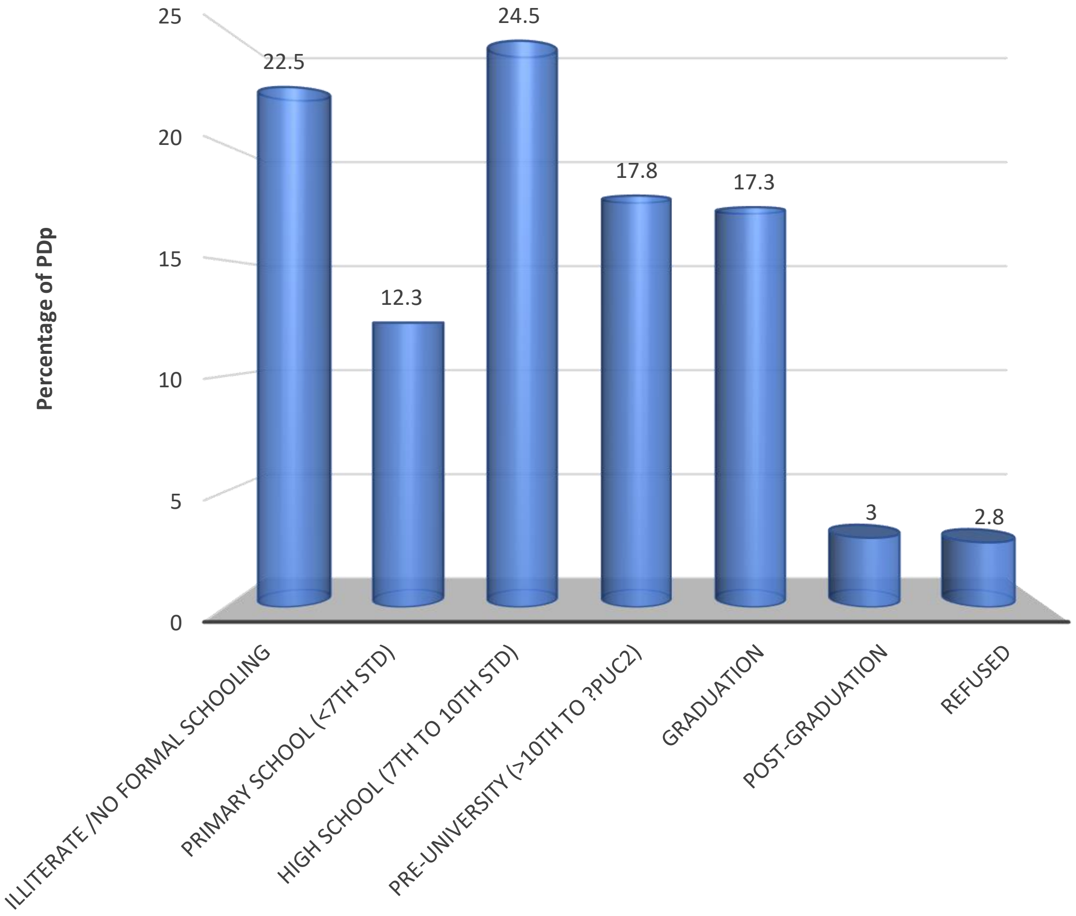
We found that 58% of the participants with disability were married and 41% were unmarried among persons with disability.

Figure 11: Marital status of caregivers



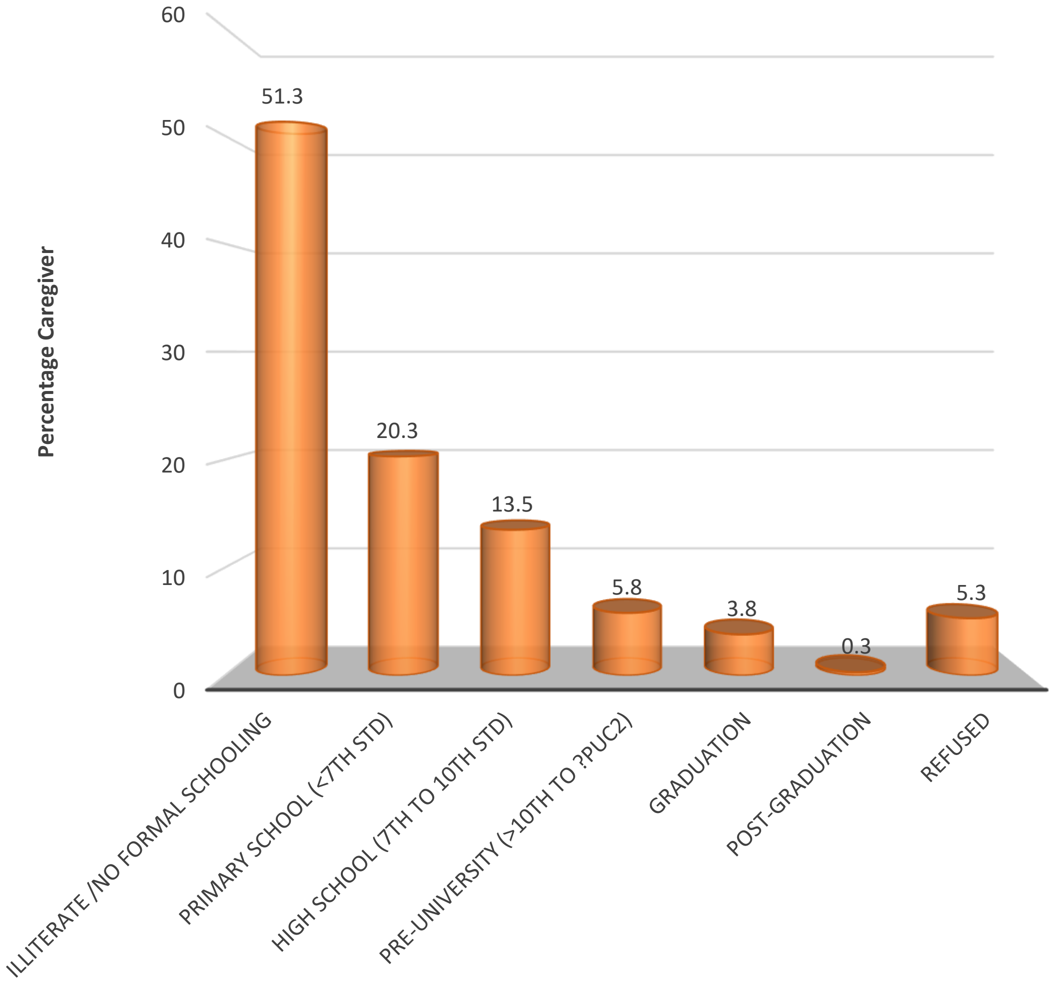
And among caregivers, we found 96% were married and 1% were unmarried.

Figure 12: Distribution of Persons with disability according to their education.



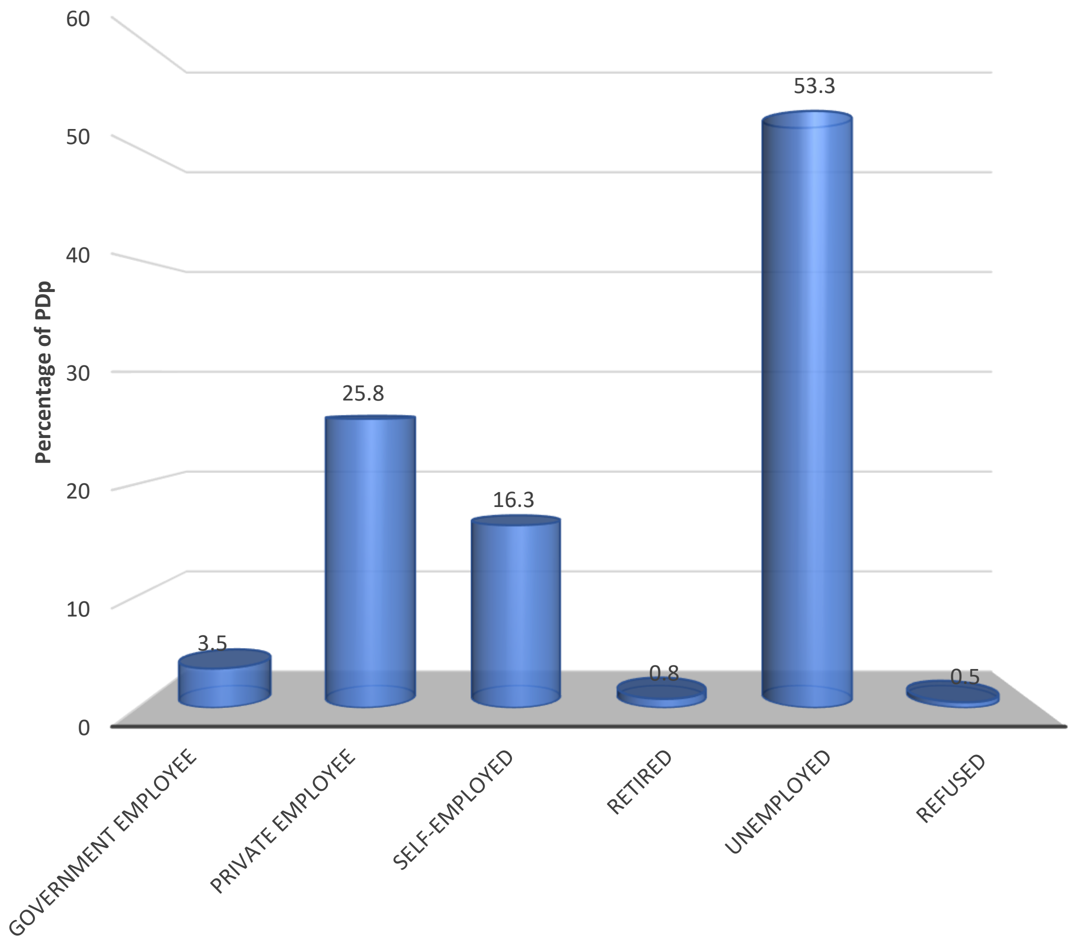
The result shows that 24.5% of the participants had studied from 7th std to 10th std, while mostly 22.5% were illiterates or had no formal schooling.

Figure 13: Distribution of caregivers according to their education.



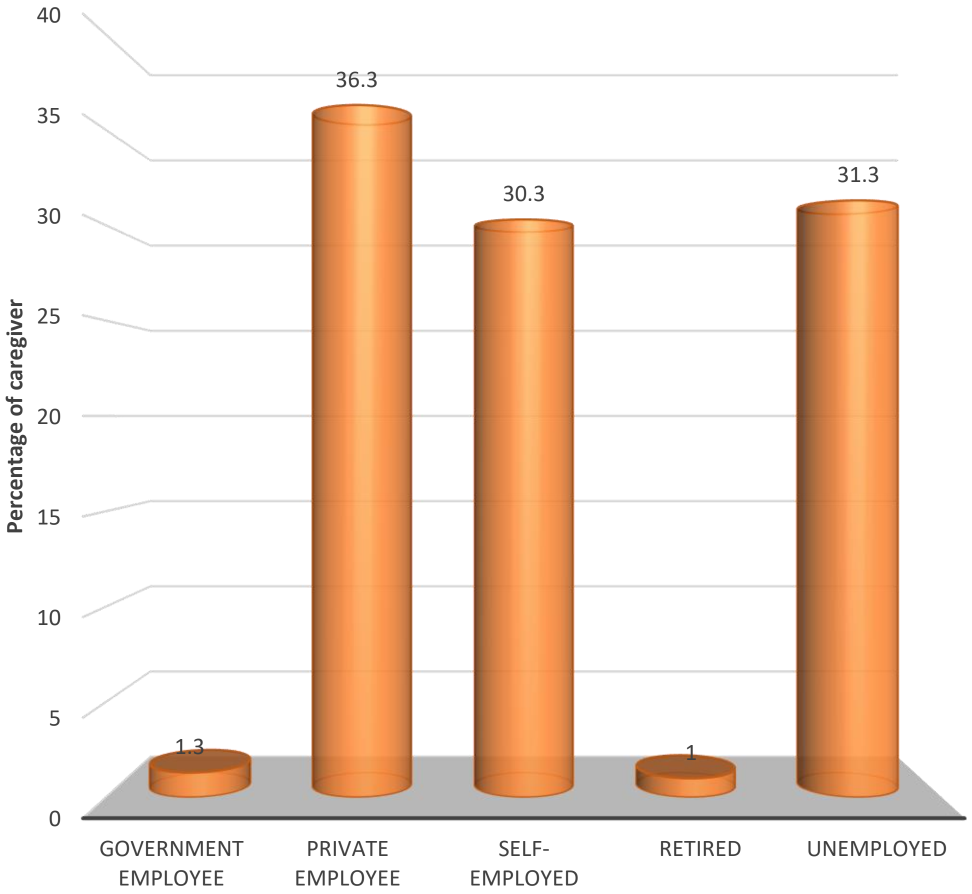
The study claims that the majority of caregivers were illiterates and had no formal schooling (51.3%) and around 20.3% had studied till primary school (<7th std)

Figure 14: Distribution of Persons with Disability according to their Occupation



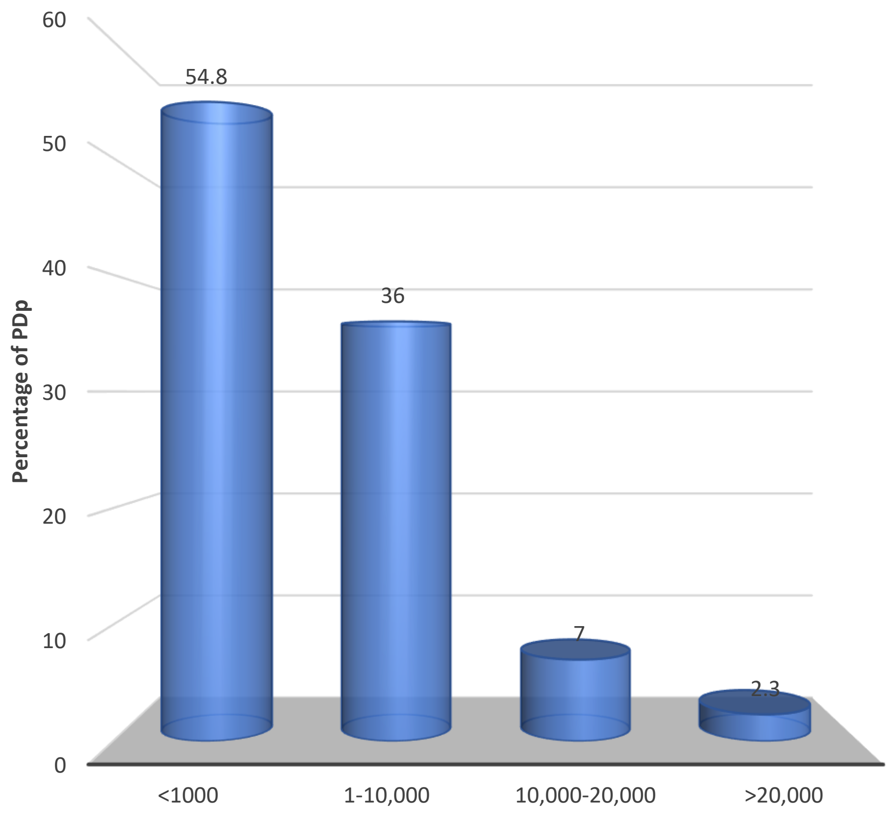
Among the participants, the majority were unemployed (53.3%), while 25.8% worked in private firms, 16.3% were self-employed, and 3.5% were government employees.

Figure 15: Distribution of caregivers according to their Occupation



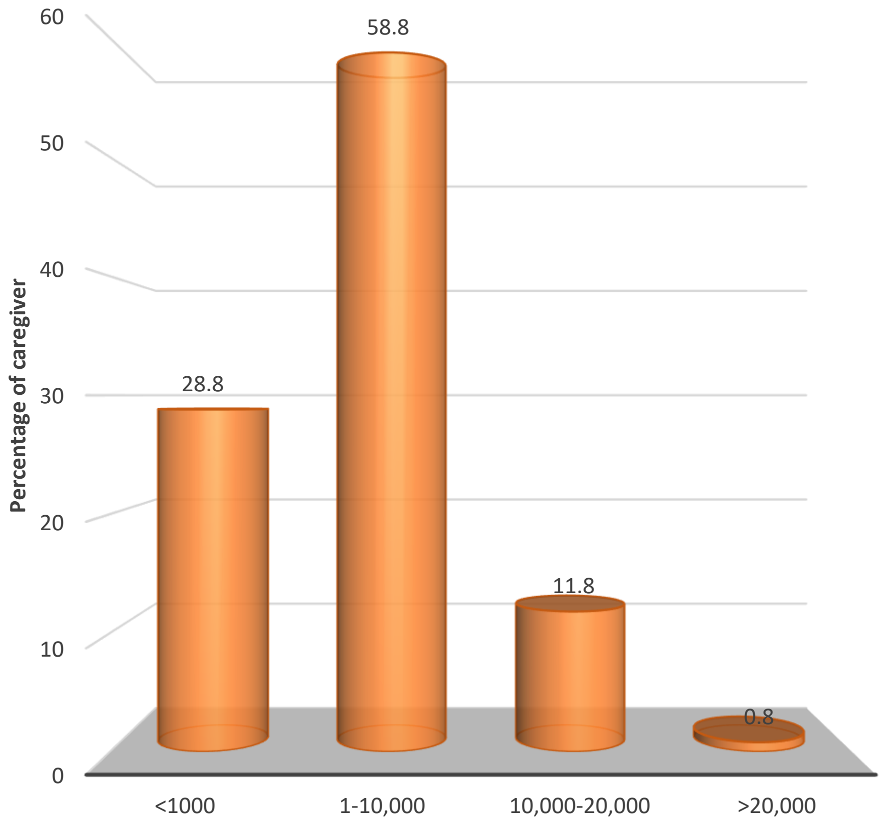
The caregiver occupations reveal that 36.3% were employed in private firms, 30.3% were self-employed, and 1.3% were government employees.

Figure 16: Distribution of Persons with Disability according to their income



Among the participants, the majority of them declared their income to be less than Rs 1000 (54.8%) and 36% of participants reported that their income was around Rs 10,000.

Figure 17: Distribution of caregivers according to their income



Among the participants, the majority of them reported their income to be around Rs 10,000 (58.8%) and 28.8% declared that their income was less than Rs 1000.

Table 2: Stress level of Person with Disability (n = 400)

Sl No	Stress level	Range	Frequency	Percent
1	Low	0-13	33	8.3
2	Moderate	14-26	206	51.5
3	High	27-40	161	40.3

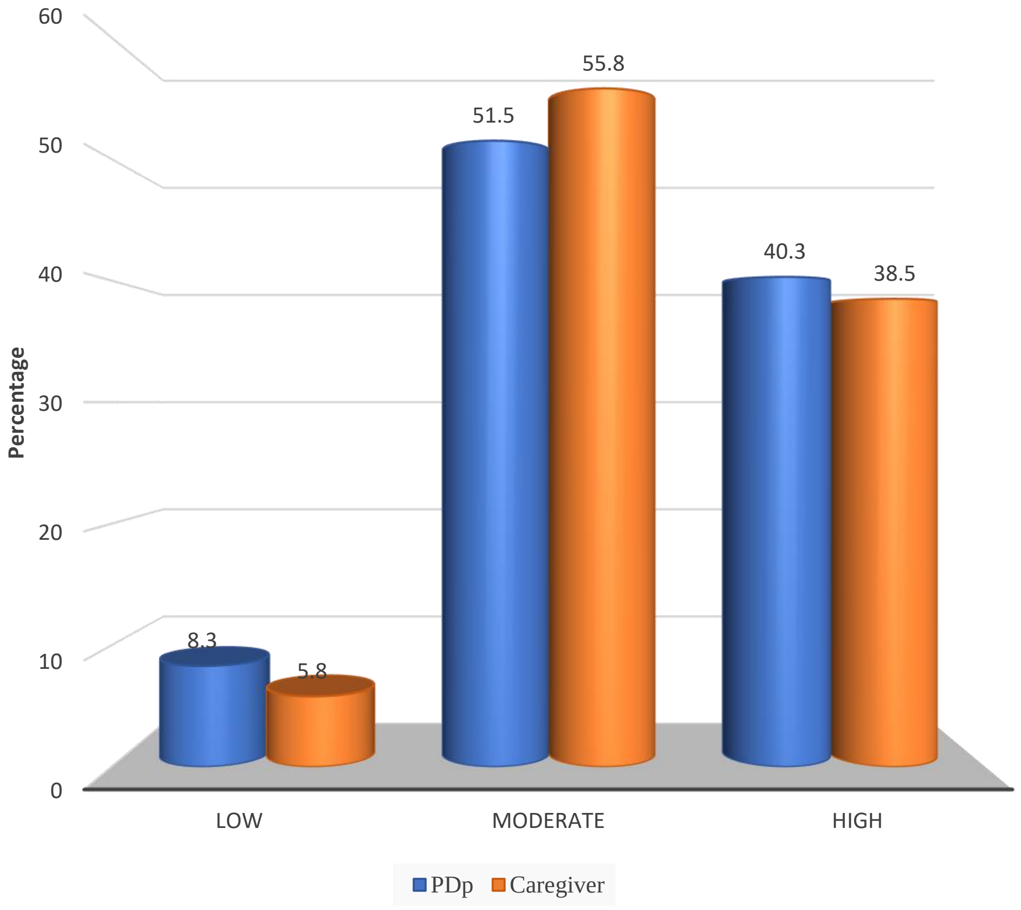
According to Perceived Stress Scale (PSS),[90] it was observed that 161 (40.3%) participants suffered high levels of stress, and 206 (51.5%) participants suffered from moderate stress levels.

Table 3: Stress level of Caregiver (n = 400)

Sl No	Stress level	Range	Frequency	Percent
1	Low	0-13	23	5.8
2	Moderate	14-26	223	55.8
3	High	27-40	154	38.5

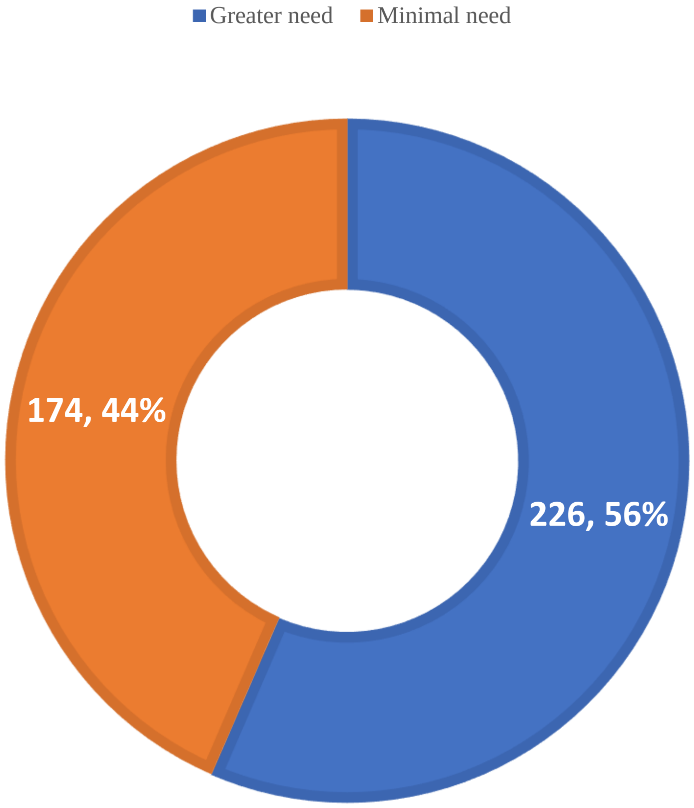
According to the Perceived Stress Scale (PSS)[94], it was observed that caregivers reported a high-level stress of 154 (38.5%), and 223 (55.8%) participants exhibited moderate stress levels.

Figure 18: Comparative representation of stress levels of persons with disability and caregivers



The comparative analysis of the stress level of both persons with disability and caregivers using the PSS scale showed that both persons with disability and caregivers underwent high levels of stress with 40.8% and 38.5% respectively. While the majority of the participants showed moderate levels stress of at 51.5% and 55.8% respectively.

Figure 19: Level of Caregiver Burden



According to the Caregiver Burden Inventory (CBI) analysis, 56% of 400 caregivers indicated a significant need for respite and other support, as they had higher burden of providing care to the disabled. In contrast, 44% reported a minimal need for these services.

Table 4: Correlation between caregiver stress and caregiver burden (n=400)

		Caregiver burden
Caregiver stress	Spearman rho Correlation Coefficient	0.591
	Sig. (2-tailed)	**0.001***

The Spearman rho correlation showed significant positive correlation between caregiver stress and caregiver burden with p-value <0.001 (Spearman rho correlation coefficient, r = 0.591). This positive correlation between caregiver stress and caregiver burden was statistically significant (P < 0.001). When there is significant amount of stress among the caregivers there is positive increase in the level of caregiver burden.

Table 5: Association between socio-demographic data and stress levels of PwDs

Sl No	Socio-Demographic Characteristics		Stress						Chi square	p value
			Low		Moderate		High			
			n	%	n	%	n	%		
1	Age (in years)	15-30	16	48.50	62	30.10	56	34.80	12.153	0.059
		30-45	15	45.50	111	53.90	67	41.60		
		45-60	1	3.00	26	12.60	31	19.30		
		>60	1	3.00	7	3.40	7	4.30		
2	Gender	Male	26	78.80	123	59.70	88	54.70	6.641	**0.036***
		Female	7	21.20	83	40.30	73	45.30		
3	Marital status	Married	20	60.60	126	61.20	85	52.80	6.72	0.348
		Unmarried	13	39.40	79	38.30	71	44.10		
		Widow/widower/separated	0	0.00	1	0.50	4	2.50		
		Refused	0	0.00	0	0.00	1	0.60		
4	Religion	Hindu	19	57.60	110	53.40	63	39.10	9.861	**0.043***
		Muslim	14	42.40	96	46.60	97	60.20		
		Christian	0	0.00	0	0.00	1	0.60		
5	Education	Illiterate /No formal schooling	0	0.00	36	17.50	54	33.50	62.543	**<0.001***
		Primary school (<7th std)	3	9.10	31	15.00	15	9.30		
		High school (7th to 10th std)	6	18.20	50	24.30	42	26.10		
		Pre-university (>10th to ≤PUC2)	6	18.20	40	19.40	25	15.50		
		Graduation	17	51.50	39	18.90	13	8.10		
		Post-graduation	1	3.00	8	3.90	3	1.90		
		Refused	0	0.00	2	1.00	9	5.60		

6	Occupation	Government employee	2	6.10	10	4.90	2	1.20	27.786	**0.002***
		Private employee	14	42.40	62	30.10	27	16.80		
		Self-employed	6	18.20	36	17.50	23	14.30		
		Retired	1	3.00	1	0.50	1	0.60		
		Unemployed	10	30.30	96	46.60	107	66.50		
		Refused	0	0.00	1	0.50	1	0.60		
			2	6.10	10	4.90	2	1.20		
7	Income (Rs)	<1000	11	33.30	96	46.60	112	69.60	34.071	**<0.001***
		1-10,000	14	42.40	87	42.20	43	26.70		
		10,000-20,000	7	21.20	17	8.30	4	2.50		
		>20,000	1	3.00	6	2.90	2	1.20		

*P value <0.05 are considered statistically significant, (n- no of participants)

- Among socio-demographic factors, education and income show a statistically significant association with stress severity at a p-value of <0.001.
- Participants who were illiterate or had no formal schooling reported a high-stress level of 33.5%, followed by those who had studied up to 7th to 10th standard, showing 26.1%. Participants with education up to post-graduation exhibited the lowest stress levels compared to others in terms of education.
- Participants whose income is less than Rs 1000 exhibited the highest stress levels, approximately 69.6%, followed by those with incomes up to Rs 10,000, showing a stress level of 26.7%. Participants with incomes greater than Rs 20,000 reported lower stress levels.
- The majority of persons with disabilities (66.5%) who were unemployed showed

high-stress levels, followed by 16.8% of PWDs who worked for private firms.

- Participants aged between 30-45 years reported a high stress level of 41.6%, followed by 34.8% in the age category between 18-30 years.
- Male participants exhibited high-stress levels at 54.7%, while females showed 45.3%.
- Married participants reported moderate stress levels at 61.1%, while unmarried participants showed high-stress levels contributing to 44.1%.

Table 6: Association between socio-demographic data and stress levels of Caregivers

Sl No	**Socio-Demographic Characteristics**		**Stress**						**Chi-square**	**p-value**
			Low		**Moderate**		**High**			
			n	**%**	**n**	**%**	**n**	**%**		
1	Age	20-40	8	34.80	81	36.30	41	26.60	4.279	0.639
		40-60	11	47.80	96	43.00	77	50.00		
		60-80	4	17.40	45	20.20	35	22.70		
		>80	0	0.00	1	0.40	1	0.60		
2	Gender	Male	9	39.10	125	56.10	91	59.10	3.248	0.197
		Female	14	60.90	98	43.90	63	40.90		
		Others								
3	Marital status	Married	21	91.30	216	96.90	149	96.80	4.736	0.315
		Unmarried	0	0.00	3	1.30	1	0.60		
		Widow/widower/separated	2	8.70	4	1.80	4	2.60		
4	Religion	Hindu	14	60.90	116	52.00	61	39.60	8.613	0.072
		Muslim	9	39.10	107	48.00	92	59.70		
		Christian	0	0.00	0	0.00	1	0.60		
5	Education	Illiterate /No formal schooling	5	21.70	104	46.60	96	62.30	27.785	**0.006***
		Primary school	7	30.40	47	21.10	27	17.50		
		High school	5	21.70	39	17.50	10	6.50		
		Pre-university	2	8.70	12	5.40	9	5.80		
		Graduation	3	13.00	9	4.00	3	1.90		
		Post-graduation	0	0.00	1	0.40	0	0.00		
		Refused	1	4.30	11	4.90	9	5.80		
6	Occupation	Government employee	0	0.00	3	1.30	2	1.30	9.859	0.275

		Private employee	7	30.40	71	31.80	67	43.50		
		Self-employed	5	21.70	77	34.50	39	25.30		
		Retired	0	0.00	2	0.90	2	1.30		
		Unemployed	11	47.80	70	31.40	44	28.60		
7	Income (Rs)	0	10	43.50	64	28.70	41	26.60	10.921	0.091
		1-10,000	9	39.10	125	56.10	101	65.60		
		10,000-20,000	4	17.40	31	13.90	12	7.80		
		>20,000	0	0.00	3	1.30	0	0.00		
8	Family income (Rs)	0	0	0.00	1	0.40	0	0.00	30.346	**<0.001***
		1-10,000	4	17.40	74	33.20	80	51.90		
		10,000-20,000	11	47.80	115	51.60	66	42.90		
		>20,000	8	34.80	33	14.80	8	5.20		
9	Total number of family members	1-4	9	39.10	70	31.40	39	25.30	12.242	0.057
		5-8	11	47.80	148	66.40	110	71.40		
		9-12	2	8.70	2	0.90	3	1.90		
		>12	1	4.30	3	1.30	2	1.30		
10	Type of family	Nuclear	15	65.20	145	65.00	110	71.40	5.407	0.493
		Joint	7	30.40	60	26.90	31	20.10		
		Extended	0	0.00	4	1.80	6	3.90		
		Third generation	1	4.30	14	6.30	7	4.50		

*P value <0.05 are considered statistically significant

- Among socio-demographic factors, education and family income have shown a statistically significant association with stress severity at a p-value <0.005.
- Illiterate participants or those with no formal schooling reported a high stress level of 62.3%, followed by participants who had studied up to less than 7th standard, showing 17.5%. Participants who had completed education up to post-graduation exhibited the lowest level of stress compared to others in terms of education.
- Participants with family incomes up to Rs 10,000 exhibited the highest stress levels, about 51.9%, followed by those with incomes between Rs 10,000 and Rs 20,000, showing a 42.9% stress level. Participants whose income was >Rs 20,000 reported lower stress levels.
- A majority of caregivers (43.5%) employed in private jobs showed high stress levels, followed by unemployed caregivers at 28.6% and self-employed caregivers at 25.3%.
- Participants aged between 40-60 years reported high stress levels, contributing to 50%, followed by 26.6% in the age category between 20-40 years.
- Male participants exhibited high stress levels at 59.1%, while females showed 40.9%.
- Married caregivers reported high stress levels significantly, at 96.8%, while widowed/separated caregivers reported up to 2.6% experiencing high stress. Unmarried caregivers showed the lowest stress levels.
- 59.7% of Muslim participants exhibited high stress levels, while Christians exhibited little or no stress at 0.60%.
- Caregivers who had 5-8 members in the family reported high stress levels up to

71.4%, followed by those with 1-4 members at 25.3%.

- Caregivers living in nuclear family setups reported high-stress levels (71.4%) compared to those in joint family setups (20.1%).

Table 7: Association between socio-demographic data and caregiver burden among caregivers

Sl No	Socio-Demographic Characteristics		Need for respite				Chi-square	p-value
			Greater need		Minimal need			
			n	%	n	%		
1	Age	20-40	81	35.80	49	28.20	4.325	0.228
		40-60	94	41.60	90	51.70		
		60-80	50	22.10	34	19.50		
		>80	1	0.40	1	0.60		
2	Gender	Male	117	51.80	108	62.10	4.237	**0.04***
		Female	109	48.20	66	37.90		
3	Marital status	Married	219	96.90	167	96.00	0.249	0.883
		Unmarried	2	0.90	2	1.10		
		Widow/widower/separated	5	2.20	5	2.90		
4	Religion	Hindu	111	49.10	80	46.00	1.626	0.444
		Muslim	115	50.90	93	53.40		
		Christian	0	0.00	1	0.60		
5	Education	Illiterate /No formal schooling	92	40.70	113	64.90	26.156	**<0.001***
		Primary school (<7th std)	57	25.20	24	13.80		
		High school (7th to 10th std)	38	16.80	16	9.20		
		Pre-university (>10th to ≤PUC2)	14	6.20	9	5.20		
		Graduation	12	5.30	3	1.70		
		Post-graduation	1	0.40	0	0.00		
		Refused	12	5.30	9	5.20		

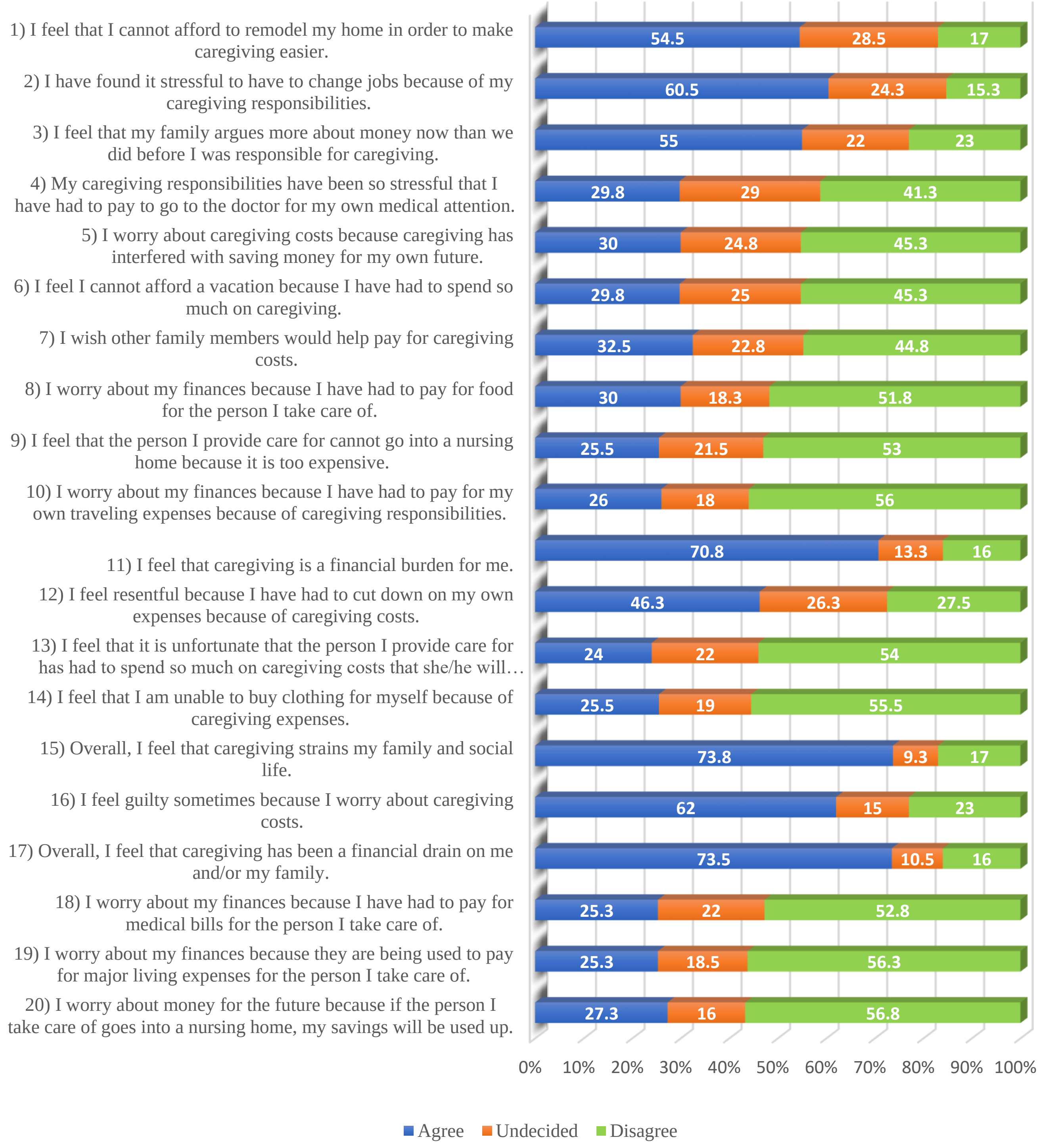
6	Occupation	Government employee	4	1.80	1	0.60	3.985	0.408
		Private employee	74	32.70	71	40.80		
		Self-employed	70	31.00	51	29.30		
		Retired	2	0.90	2	1.10		
		Unemployed	76	33.60	49	28.20		
7	Income (Rs)	<1000	73	32.30	42	24.10	7.506	0.057
		1-10,000	121	53.50	114	65.50		
		10,000-20,000	29	12.80	18	10.30		
		>20,000	3	1.30	0	0.00		
8	Family income (Rs)	<1000	1	0.40	0	0.00	31.719	**<0.001***
		1-10,000	64	28.30	94	54.00		
		10,000-20,000	122	54.00	70	40.20		
		>20,000	39	17.30	10	5.70		
9	Total number of family members	1-4	59	26.10	59	33.90	3.783	0.286
		5-8	160	70.80	109	62.60		
		9-12	3	1.30	4	2.30		
		>12	4	1.80	2	1.10		
10	Type of family	Nuclear	149	65.90	121	69.50	2.735	0.434
		Joint	56	24.80	42	24.10		
		Extended	5	2.20	5	2.90		
		Third generation	16	7.10	6	3.40		

*P value <0.05 are considered statistically significant

- Among socio-demographic factors, education, and income have shown a statistically significant association with caregivers' burden at a p-value <0.001.
- Illiterate participants or those with no formal schooling reported a greater need for respite at 64.9%, followed by participants who had studied up to less than 7th standard, showing 13.8%. Participants who had completed education up to post-graduation exhibited no need for respite compared to others in terms of education.
- Participants with family incomes up to Rs 10,000 exhibited a greater need for respite of about 54%. Participants whose income was >Rs 20,000 reported minimal need.
- A majority of caregivers (40.8%) working for private firms showed a greater need for respite, followed by self-employed and unemployed caregivers at 29.3% and 28.2%, respectively.
- Participants aged between 40-60 years reported a greater need for respite, contributing to 51.7%, followed by 28.2% in the age category between 20-40 years.
- 62.1% of male participants showed a greater need for respite, while females exhibited 37.9%.
- Married caregivers reported a significantly greater need at 96%, while widowed/separated caregivers reported up to 2.9% experiencing a greater need.
- Caregivers who had 5-8 members in the family reported a greater need for respite, up to 62.6%, followed by those with 1-4 members at 33.9%.

- Caregivers living in nuclear family setups reported the greatest need for respite and other services at 69.5%, compared to those in joint family setups at 24.1%.

Figure 20: Financial impact scale



According to the FIS (Financial Impact Scale)[92] scale:

- 295 participants (73.8%) agreed that caregiving strains their family and social life, while 68 (17%) disagreed.
- 294 participants (73.5%) agreed that caregiving has been a financial drain on them and/or their families, while 16% disagreed.
- 228 participants (56.8%) disagreed that they worry about money for the future if the person they care for goes into a nursing home and their savings are used up, while 27.3% agreed.
- 283 caregivers (70.8%) agreed that caregiving is a financial burden for them.
- 242 caregivers (60.5%) agreed that it is stressful to have to change jobs because of caregiving responsibilities.
- 224 caregivers (56%) disagreed that they worry about finances due to having to pay for their own travel expenses because of caregiving responsibilities.

Table 8: Association between demographic data and stress levels among PwDs by using Binary logistic Regression analysis: Unadjusted and Adjusted Odds Ratios

Sl No	Socio-Demographic Characteristics		Odds ratio (OR)	95% CI of OR p-value	Adjusted Odds Ratio (AOR)	95% CI of AOR
1	Gender	Male	0.738	(.492-1.109) p=.144	1.049	(.642-1.715) p=.848
		Female ®				
2	Religion	Hindu	0.554	(.369-.832) **p=.004***	0.637	(.403-1.006) p=.053
		Muslim ®				
3	Education	Illiterate /No formal schooling	0.333	(.068-1.633) p=.175	0.31	(.062-1.537) p=.152
		Primary school (<7th std)	0.098	(.019-.510) **p=.006***	0.102	(.019-.539) **p=.007***
		High school (7th to 10th std)	0.163	(.033-.793) **p=.025***	0.189	(.038-.933) **p=.041***
		Pre-university (>10th to ≤PUC2)	0.121	(.024-.603) **p=.010***	0.143	(.028-.724) **p=.019***
		Graduation	0.052	(.010-.268) **p=0.001***	0.079	(.014-.430) **p=.003***
		Post-graduation	0.074	(.010-.555) **p=.011***	0.153	(.018-1.269) p=.082
		Refused ®				

4	Occupation	Government employee	0.167	(.007-3.890) p=.265	1.345	(.039-46.274) p=.870
		Private employee	0.355	(.021-5.880) p=.470	2.108	(.079-56.176) p=.656
		Self-employed	0.548	(.033-9.169) p=.675	2.533	(.096-66.512) p=.577
		Retired	0.5	(.013-19.562) p=.711	0.723	(.013-40.599) p=.875
		Unemployed	1	(.062-16.197) p=1.000	0.715	(.030-17.310) p=836
		Refused ®				
5	Income/month (Rs)	<1000	3.631	(.738-17.872) p=.113	5.445	(.496-59.779) p=.166
		1-10,000	1.49	(.297-7.466) p=.628	0.87	(.138-5.497) p=.883
		10,000-20,000	0.583	(.088-3.880) p=.577	0.558	(.075-4.121) p=.567
		>20,000 ®				

***-Statistically significant**

The binary logistic regression method was applied to independent variables that showed significant association with stress in univariate analysis. Among these variables, persons with disabilities who were unemployed or had less income, and those with income up to Rs 10,000/month exhibited odds ratios (OR) more than 1 (3.3 and 1.5 respectively). This suggests that unemployment and less income are significant risk factors for stress levels among PwDs. However, adjusted Odds ratio estimation showed that people who are employed, either government, private or self-employed and people with lower income

(<Rs. 1000/month) experienced more stress.

Table 9: Association between caregivers' demographic data and stress by using Binary logistic Regression analysis: Unadjusted and Adjusted Odds Ratios

Sl No	Socio-Demographic Characteristics		Odds ratio (OR)	95% CI of OR p-value	Adjusted Odds Ratio (AOR)	95% CI of AOR
1	Education	Illiterate /No formal schooling	0.563	(.140-2.264) p=.418	0.502	(.123-2.048) p=.337
		Primary school (<7th std)	0.135	(.031-.589) **p=.008***	0.134	(.030-.589) **p=.008***
		High school (7th to 10th std)	0.185	(.046-.743) **p=.017***	0.204	(.050-.831) **p=.027***
		Pre-university (>10th to ≤PUC2)	0.217	(.053-.889) p=.217	0.25	(.060-1.037) p=.056
		Graduation	0.123	(.029-.515) **p=.004***	0.171	(.040-.734) **p=.018***
		Post-graduation	0.125	(.019-.805) **p=.029***	0.195	(.029-1.309) p=.092
		Refused ®				
2	Family income (Rs)	<1000	0	0 p=1.000	0	1
		1-10,000	5.256	(2.317-11.926) **p<0.001***	3.558	(1.471-8.606) **p=.005***
		10,000-20,000	2.644	(.171-5.970) **p=.019***	2.187	(.937-5.102) p=.070
		>20,000 ®				

***-Statistically significant**

The binary logistic regression method was applied to the independent variables which showed significant association with stress in univariate analysis. In this, independent variables except for caregivers with income up to Rs 20000, rest all the variables had a lower odd, (OR<1)

In both the univariate analysis and the models adjusting for education, financial status, social support, and demographics (OR = 5.256, 95% CI: 1.471-8.60, P = <0.001), (AOR = 0.134.4, 95% CI: 0.30-0.589, P = 0.008). Higher the level of education and good financial status are suggestive of having a protective impact on stress which was statistically significant (P value <0.05).

Table 10: Association between caregivers demographic data and burden by using Binary logistic Regression analysis: Unadjusted and Adjusted Odds Ratios

Sl No	**Socio-Demographic Characteristics**		**Odds ratio (OR)**	**95% CI of OR p value**	**Adjusted Odds Ratio (AOR)**	**95% CI of AOR**
1	Gender	Male	1.524	1.020-2.279 **p=.040***	1.715	(1.107-2.656) **p = .016***
		Female ®				
2	Education	Illiterate /No formal schooling	1.638	(.661-4.056) p=.286	1.546	(.605-3.947) p = .363
		Primary school	0.561	(.209-1.507) p=.252	0.596	(.216-1.645) p = .318
		High school	0.561	(.198-1.593) p=.278	0.779	(.263-2.306) p = .652
		Pre-university	0.857	(.257-2.856) p=.802	1.139	(.328-3.962) p = .837
		Graduation	0.333	(.072-1.543) p=.160	0.405	(.083-1.966) p = .262
		Post-graduation	0	0 p=1.000	0	0 p = 1.000
		Refused ®				
3	Family income (Rs)	<1000	0	0 p=1.000	0	0 p = 1.000
		1-10,000	5.728	(2.668-12.296) **p<0.001***	4.426	(1.967-9.962) **p<0.001***
		10,000-20,000	2.238	(1.052-4.758) **p=.036***	1.92	(.873-4.222) p=.105
		>20,000 ®				

***-Statistically significant**

The binary logistic regression method was applied to the independent variables which showed a significant association with caregivers' burden in univariate analysis. In this, several independent variables had lower odds (OR<1)

In both the univariate analysis and the models adjusting for gender, education, financial status, social support, and demographics (adjusted AOR = 1.715, 95% CI: 1.107-2.65, P = 0.016), (AOR = 4.4, 95% CI: 1.11-1.16, P ≤ 0.001) providing care is a risk factor. Lower the education and lower the income, higher is the level of burden among caregivers.

DISCUSSION

This study aims to evaluate the psycho-social and economic burden on people with physical disabilities and their caregivers in the Vijayapura District. There is a scarcity of research on the stress and burden experienced by people with physical disabilities and their caregivers. Our study attempted to assess the prevalence of stress among people with physical disabilities and their caregivers, finding rates of 40.8% and 38.5%, respectively. Previous studies on this topic have shown varying stress prevalence rates, ranging from 30% to 80%. The methodology and scales used to estimate these prevalence rates also differ among studies. The Perceived Stress Scale (PSS) is widely recognized as the gold standard instrument for measuring stress perception.[94]

Dharamveer Chaudhary et al. reported that perceived stress and severity of disability were 61.29%.[95] Similarly, studies on groups with autism spectrum disorder showed high stress levels of 29.38% using the PSS scale, as reported by Tatja Hirvikoski and My Blomqvist.[96]

The participants were 196 elderly individuals with visual and physical disabilities residing in nursing homes in Shanghai. They were assessed using the PSS, with results indicating that 27.2% reported high stress.[97] Similarly, a study by Cohen S. et al. stated that a significant degree of perceived stress is indicated by a score of 56, while the lowest attainable score is zero, indicating no perceived stress. [98]

These findings are consistent with those reported by Iwasaki and Mactavish[99] regarding the perspectives of people with disabilities on stress. To quantify stress associated with wheelchair use and physical disability, the Physical Disability Stress Scale identified four primary components of stress through factor analysis of PSS items, with 33.7% of stress attributed to access issues. The findings suggest that the PSS variables are reliable indicators of stress associated with disabilities, which may be useful in clinical and scientific settings, as noted by Michele Furlong and Jason P. Connor.[100]

Socio-demographic profile of study participants

Among 400 participants, 48.3% of individuals with disabilities were aged 30 to 45 years, and 33.5% were aged 18 to 30 years. Additionally, 46% of caregivers were aged 40 to 60 years, and 32.5% were aged 20 to 40 years. A similar study by Jenni Kulmala et al., a 28-year prospective cohort study, showed relationships between midlife stress and old age impairment at baseline, with participants aged 44 to 58.[101]

Sumner LA et al. also reported similar findings in participants aged 18 to 81 years, assessing socioeconomic status, depression, disability, and perceived stress in adults with systemic lupus erythematosus.[102] Gregorius Abanit Asa et al. published a study on the psychological and financial effects on female caregivers and families raising disabled children, with participants aged 35 to 60 years.[103]

The productive age range of 35 to 54 years is when individuals with disabilities experience a decline in their quality of life (Benner et al., 2017).[104]

In our study, among 400 participants with disabilities, 59% were male and 41% were female. Among caregivers, 53% were male and 47% were female. Similarly, Chan N. et al. reported on disability and symptoms of depression in later life, with 35.5% female participants and 64.5% male participants.[105] Additionally, a study by Soma Sahu et al. on perceived stress in individuals with intellectual disabilities reported that 68.3% of the participants were male.[106]

In contrast, a study on the impact of an elderly person's disability and associated stress levels on their coping mechanisms reported 64% female and 36% male participants.[107] Another study by Nanthamongkolchai et al. (2022), which analyzed Thai adults with physical and mobility disabilities, found that 58.6% were female and 41.4% were male.[108]

In our study, 58% of individuals with disabilities were married, and 41% were unmarried. Among caregivers, 96% were married, and 1% were unmarried. Similarly, a study by Ghazawy ER et al.[109] on determinants of disability and their caregivers reported that 30% of individuals with disabilities were married, while 73% were unmarried. Additionally, 80.7% of caregivers were married, and 19.3% were unmarried. In Canada, a study conducted by Amber Savage and David McConnell on the marital status of disabled women reported that 60.9% of disabled women were married.[110]

Our study found that 24.5% of participants had education ranging from 7th to 10th grade, while 22.5% were illiterate with no formal schooling. The study also revealed that the majority of caregivers were illiterate and had no formal schooling (51.3%), with about 20.3% having studied up to primary school (below 7th grade). Similarly, a study by Ramasubramanian et al.[111] assessed caregiver burden and reported that 19% of caregivers had only primary school education. Additionally, a study by Rana M.S. et al. found that 56.9% of caregivers had not received any formal schooling.[112]

Regarding the educational attainment of the disabled population in India, as of 2011, there were 26.8 million disabled individuals. Of these, 14.6 million (54.5%) were educated, while the remaining 12.2 million (45.5%) were illiterate. Additionally, 26.4% had studied up to the 7th standard, as reported by C. M. Lakshmana and Maruthi (2018).[113]

A study similar to ours found that 37.8% of individuals had no higher education. This study, analyzed by Sachs, D., and Schreuer, N., examined the inclusion of students with disabilities in higher education. In comparison, our report indicated that 24.5% of disabled individuals had studied from 7th to 10th grade.[114]

Luck (2011) conducted an experiment highlighting the significance of knowledge and exposure to disabilities in promoting positive attitudes toward individuals with disabilities.[115] Based on this research, it is recommended to implement improved educational programs. Additionally, studies by Park E-Y and Kim J-H (2021) revealed that 23.4% of individuals with disabilities had education levels below high school.[116]

Chao HL reported that patients with colorectal cancer showed greater acceptance of their disability when they were more educated and had fewer serious health issues. The interaction between these factors led to reduced variation in disability acceptance among IWPD employees, based on their health conditions and educational attainment.[117]

A cross-sectional descriptive study conducted in Kenya on caregivers, as reported by Margaret Njeri Mbugua et al., found that 15.8% had not attended formal schooling, 57.9% had attended primary school, and 26.3% had attended secondary school.[118]

Among the participants, the majority were unemployed (53.3%), while 25.8% were employed by private firms, 16.3% were self-employed, and 3.5% worked for the government. Regarding the caregivers' occupations, 36.3% worked for private firms, 30.3% were self-employed, and 1.3% were government employees.

The General Authority for Statistics (2023) reports that in 2022, the employment rate for individuals with disabilities aged 16 to 64 was approximately 14.6%, compared to 84.6% for those without disabilities. In contrast, in the United States, the global employment rate for individuals with disabilities within the same age range was about 34.8% in 2022, while the rate for those without disabilities was 74.4%.[119]

Previous studies have investigated the attitudes of recruiting managers towards hiring individuals with disabilities. Lindsay et al. (2018) found that employers' positive perceptions were associated with increases in their profit margins.[120] The opportunity costs of informal care are often tied to paid employment, as the time devoted to informal care competes with time that could be spent on paid work when potential caregivers are of working age (Becker, 1965).[121]

The self-employment rates for individuals with disabilities in Greece (10.52%), Portugal (8.64%), and Ireland (8.14%) were reported, showing significant self-employment differentials favoring men with disabilities, while the differentials for women were less pronounced. Greece (13.54%) and Portugal (10.32%) had the largest differentials, followed by Austria (8.21%) and Spain (7.68%).[122] Notably, our studies indicated a 16.3% self-employment rate among persons with disabilities.

The study related to our data reported the employment status of disabled individuals across three sectors: government (25.9%), private (9.9%), and self-employment (64.2%).[123] Pamela Doty et al. found that 32.8% of caregivers were unemployed, whereas our study reported a higher unemployment rate of 53.3% among caregivers.[124]

In contrast, a study by G. Magoulios and A. Trichopoulou found that among those currently employed, 70.6% work full-time, 18.3% work part-time, and 10.7% are self-employed. Approximately 27% of the sample is employed in the public sector, while a significant majority (72%) works in the private sector.[125]

Among the participants, the majority of individuals with disabilities reported having income of less than Rs 1000 (54.8%), and 36% reported an income of around Rs 10,000. In comparison, most caregivers reported an income of around Rs 10,000 (58.8%), while 28.8% declared having no income.

A similar study found that 0.9% of respondents earn more than 10,000 rupees per month, with the majority (68.8%) earning between 1,001 and 5,000 rupees from all sources. Approximately 18.3% of participants earn less than 1,000 rupees, while 10.1% receive no personal compensation, as reported by Lloyd Vicky D'Souza and Dr. Mohan S. Singhe.[126] Similarly, another study reported that among individuals with disabilities, 30% had an income of up to 5,000 rupees, 24.8% had an income of up to 10,000 rupees, and 2.7% had an income greater than 50,000 rupees.[127]

Stress level of Person with Disability and their caregiver

A comparative analysis of stress levels between individuals with disabilities and their caregivers using the PSS scale showed that both groups experienced high levels of stress, with 40.8% and 38.5% respectively. The majority of participants exhibited moderate stress levels, at 51.5% for individuals with disabilities and 55.8% for caregivers.

A meta-study by Vitaliano et al. (2003) examined the impact of caregiving across 23 samples, revealing significant but moderate differences in various health categories, such as self-reported health, medication use, antibodies, and stress hormones.[128] Similarly, employees in eldercare groups reported worse physical and mental health compared to employees in other groups, with lower life satisfaction (37%) and higher levels of stress (59% high), burnout (36% high), and depression (42% high).[129]

A study by Aarthi Ramachandran et al. reported findings similar to the current study, with 64.3% of caregivers experiencing severe stress, 21.7% experiencing moderate stress, and 13.8% experiencing mild stress.[130] Additionally, a related study by Abirami P. found that 89% of caregivers experienced moderate stress, with a significant correlation between their stress levels and demographic factors such as sex, education, occupation, income, and relationship with the child. The study also explored caregiver burden and its relationship to disabilities.[131]

A study by Abhijit Biswas (2020) reported that 48.57% of individuals with disabilities experienced moderate stress, while 10% experienced severe stress.[132] Families with children who have disabilities exhibit higher levels of stress but are also found to have effective coping mechanisms, as noted by Kazak and Marvin.[133]

Data presented by Sirisha Merla and S. Naveen Kumar indicated that 25% of caregivers of intellectually disabled children experienced moderate stress, and 20% experienced severe stress.[134] Another study by Dr. Thiyam Kiran Singh and Priyanka Panday evaluated stress levels among male and female parents, finding significant differences, with female parents experiencing higher stress levels.[135]

Level of Caregiver Burden Inventory scale

Based on the Caregiver Burden Inventory (CBI) scale, among 400 participants, 56% of caregivers reported a greater need for respite and other services, while 44% (174 participants) indicated a minimal need for these services.

The caregiver burden questionnaire by Kaur and Arora (2010) is a semi-structured scale assessing the burden of raising mentally disabled children, impacting all aspects of the home environment, including family life, emotional issues, and finances.[136] Arasu et al. found the mean score for caregiver burden to be 33.27 ± 13.03, with 56% of caregivers experiencing a mild burden, 25% a moderate burden, and 2% a severe burden.[137] Grunfeld E et al. reported breast cancer caregivers burden ratings to be 26.21.[138]

Our studies found significant positive correlations between caregiver stress and burden (Spearman rho, $P < 0.001$). Similarly, Arun R et al. reported a positive association between the IDEAS global disability score and the spousal carer burden score (Pearson's correlation coefficient, $r = 0.588$, $P < 0.001$).[139]

The Caregiver Burden Inventory (Zarit) reported mean scores of 16 ± 13.9 for the Inventory and 2.1 ± 2.3 for the CSI, with a high correlation between ZCBI and CSI ($r = 0.819$; $P < 0.0001$). Additionally, 9.1% of caregivers had a moderate to severe burden (ZCBI > 40), and 5.8% reported high stress levels (CSI ≥ 7).[140]

Andren, Signe, and Elmstahl's studies showed a link between caregiver burden and age, NHP, and SOC, but not gender. There was a substantial correlation between burden and the NHP's measure of perceived health ($r = 0.540$; $P < 0.001$).[141] Other studies reported that higher levels of perceived stress ($r = 0.57$, $P < 0.01$), depressive symptoms ($r = 0.54$, $P < 0.01$), and neuropsychiatric symptoms ($r = 0.37$, $P < 0.01$) were associated with higher caregiver burden. Perceived stress and depressive symptoms fully mediated the direct effect of neuropsychiatric symptoms on caregiver burden ($r = 0.13$, $P = 0.177$), increasing the variation in caregiver burden by 46% according to this parallel mediation model.[142]

Financial impact scale

According to the Financial Impact Scale (FIS), 73.8% of respondents agreed that caregiving strains their family and social life, while 17% disagreed. Additionally, 73.5% agreed that caregiving has been a financial drain on them and/or their family, with 16% disagreeing. Furthermore, 56.8% of participants disagreed with the statement that they worry about future finances due to the possibility of the care recipient entering a nursing home and depleting savings, while 27.3% agreed. Moreover, 70.8% of caregivers felt that caregiving is a financial burden, and 60.5% agreed that it is stressful to change jobs due to caregiving responsibilities. Notably, 56% disagreed that they worry about finances related to self-travel expenses incurred because of caregiving responsibilities.

All informal long-term caregivers can be assessed using the Financial Impact Scale (FIS), designed specifically for this purpose. The FIS is a validated, one-dimensional scale with a Cronbach alpha value of 0.9384, measuring the overall financial impact of providing long-term care. This tool is instrumental in understanding the financial pressures on caregivers regarding service utilization and budgetary impact.[143]

Studies indicate that the patient's sex does not affect the financial strain on families, disruptions to routine, family leisure, or interactions. This aligns with Lal et al.'s findings, which showed no significant correlation between a child's sex and the socioeconomic burden.[144] Additionally, caregiver stress was found to be negatively correlated with caregivers' wellbeing (0.114, $p = 0.000$) and positively correlated with the financial impact of caregiving (0.105, $p = 0.000$).[145]

Research involving both male and female caregivers revealed that higher perceived financial costs of caregiving were linked to increased caregiving burden, with similar key determinants of burden for both groups. Standardized coefficients suggest that financial expenditures' impact on caregiving strain is comparable for male and female caregivers.[146]

The financial cost dimension of the Cost of Care Index was used to evaluate how providing care for an elderly relative impact financial expenditure (Kosberg & Cairl, 1986).[147] The authors posed the following questions to measure the financial expenses of informal caregiving: (a) Do you agree that spending money intended for other purposes on caring for your aging relative is depleting your savings? (b) Do you agree that the costs of caring for your aging relative force you and your family to forgo necessities? (c) Do you agree that the cost of caring for your aging relative prevents you and your family from affording small extras? and (d) Do you agree that the cost of caring for your aging relative is prohibitive? Participants responded on a 4-point scale: strongly disagree, disagree, agree, and strongly agree, with scores ranging from 1 to 4. The total score, ranging from 4 to 16, was calculated by summing all responses; higher scores indicated greater financial costs.

Association between caregivers' demographic data and stress and burden:

A binary logistic regression method was applied to the independent variables that showed a significant association with stress in the univariate analysis. Except for caregivers with an income up to Rs 20,000, all other variables had lower odds (OR < 1), indicating a protective impact on stress, which was statistically significant ($P < 0.05$).

The family caregiver's adjustment and adaptation to risky, difficult, and vulnerable situations throughout the course of a chronic illness are influenced by various personal, familial, and societal factors. These factors are considered in the psychosocial perspective on the role of the family caregiver. Consequently, high levels of strain and burnout characterize the psychosocial profile of caregivers.[148]

In both the univariate analysis (IRR = 1.14, 95% CI: 1.11-1.16, $P \leq 0.001$) and the models adjusting for long-term illness, financial status, social support, and demographics (adjusted IRR = 1.03, 95% CI: 1.01-1.06, P = 0.019), providing care was identified as a risk factor for more days of worse physical health, as reported by Berglund et al. and Carr D.[149,150]

SUMMARY

- A cross-sectional study was conducted among individuals aged 18 years and above with disabilities and their caregivers at the District Disability Rehabilitation Centre (DDRC), BLDE (Deemed to be University) Shri B. M. Patil Medical College Hospital & Research Centre, Vijayapura from January to December 2023. A semi-structured questionnaire was used in an interview approach to gather data.
- A sample size of 400 participants was determined based on anticipated outcomes of the economic burden on caregivers of persons with physical disability.
- The data collection adhered to ethical guidelines, and informed consent was secured from participants and caregivers.
- The analysis of socio-demographic characteristics revealed that 48.3% of individuals with disabilities were aged between 30 to 45 years, while 33.5% were aged between 18 to 30 years. Among the caregivers, 46% were in the age group of 40 to 60 years, and 32.5% were aged between 20 to 40 years. Of the 400 participants with disabilities, 59% were male and 41% were female. Among caregivers, 53% were male and 47% were female.
- The gender distribution indicated that 59% of individuals with disabilities were male, and 41% were female. Similarly, among caregivers, 53% were male, and 47% were female. In terms of marital status, 58% of persons with

disabilities were married, and 41% were unmarried. Among caregivers, 96% were married, and 1% were unmarried.

- The education status indicated that 24.5% of the participants had completed schooling from 7th standard to 10th standard, while the largest group, 22.5%, were illiterate with no formal schooling. The majority of caretakers (51.3%) were also illiterate with no formal schooling, and approximately 20.3% had completed education up to primary school (below 7th standard).
- The occupation status revealed that the majority of participants (53.3%) were unemployed, while 25.8% worked for private firms, 16.3% were self-employed, and 3.5% were government employees. Among caregivers, 36.3% worked for private firms, 30.3% were self-employed, and 1.3% were government employees.
- Regarding income status among the participants, the majority (54.8%) reported earning less than Rs 1000, while 36% reported an income of around Rs 10,000. Among caregivers, the majority (58.8%) reported an income of around Rs 10,000, and 28.8% stated their income was less than Rs 1000.
- According to the Perceived Stress Scale (PSS), 40.3% (161) of participants experienced a high level of stress, and 51.5% (206) reported a moderate stress level. A comparative analysis using the PSS scale indicated that both persons with disabilities and caregivers experienced high levels of stress, with percentages of 40.8% and 38.5%, respectively. The majority of

participants in both groups reported moderate stress levels, with percentages of 51.5% and 55.8%, respectively.

- According to the Caregiver Burden Inventory scale (CBI), 56.5% of caregivers among the 400 participants experienced indicated a greater need for respite and other services. Conversely, 43.5% of caregivers (174 participants) expressed a minimal need for such services.
- Further study on the association between caregivers and persons with disabilities revealed that socio-demographic factors like education and income are significantly associated with stress severity ($p < 0.001$). Participants who were illiterate or had no formal schooling reported a high stress level of 33.5%, followed by those who had completed schooling up to the 7th to 10th standard, reporting 26.1%. Participants with education up to post-graduation showed the lowest stress levels compared to others.
- In the logistic regression analysis, several independent variables showed significant associations with caregivers' burden. After adjusting for gender, education, financial status, social support, and demographics, providing care was found to be a risk factor (adjusted AOR = 1.715, 95% CI: 1.107-2.65, $p = 0.016$). Male caregivers and higher family income were identified as having a potentially protective impact on stress, which was statistically significant ($p < 0.05$).
- Participants with less than Rs 1000 income exhibited the highest stress level

at 69.6%, followed by those with incomes up to Rs 10,000, who reported a 26.7% stress level. Conversely, participants with incomes exceeding Rs 20,000 reported lower stress levels.

- According to the Financial Impact scale, 73.8% agreed that caregiving strained their family and social life, while 17% disagreed. Additionally, 73.5% agreed that caregiving had been a financial drain on them or their family, with 16% expressing disagreement.

CONCLUSION

The study emphasizes on increased stress, burden, and financial pressure on both people with disability and their caregivers. There is urgent need for enhanced social and psychological support system custom-made to address these challenges effectively among both. Targeted interventions focusing on mental health support and therapy services to improve overall psychosocial well-being of individuals with disabilities and their caregivers is necessary. As, these initiatives may promote resilience and empower individuals to lead meaningful lives amidst their unique challenges.

RECOMMENDATIONS

- Systematic assessment of caregivers and people with disability on stress, caregiver burden and financial strain must be routinely done at a community setup.
- Establishing mental health clinics and helplines to provide counseling & social support for physically disabled individuals, their caregivers, and family members is crucial. These services facilitate early identification of depression among affected individuals, thereby offering timely support and intervention.
- Promoting awareness about Job Clubs, Work Stations, Job Assessment and Work Preparation programs, Selective Placement Job camps, social reinforcement initiatives, and Institutional Placement Services exclusively designed for disabled persons.
- Aiding caregivers in managing stress through lifestyle improvement programs is essential. These efforts will support both disabled individuals and their caregivers by enhancing their capabilities and quality of life.
- Considering the caregivers burden, financial benefit can be considered for caregivers at policy level.

STRENGTHS OF THE STUDY

- It is a new study that contributes valuable data to the limited existing literature on the prevalence of challenges faced by physically disabled individuals and their caregivers across psycho-social, time-dependent, economic, and emotional dimensions.

- This study enhances understanding of the quality of life among disabled persons and their caregivers, identifying the risk factors.

- We utilized validated questionnaires (PSS, CBI, and FIS scales) in the local language, known for their good sensitivity and specificity.

- This study comprehensively explored various aspects of individuals lives, including socio-demographic details, psychological stress, caregiver burden, and financial impacts.

LIMITATIONS OF THE STUDY

- Some variables analyzed in this study relied on self-reported information from participants, potentially introducing recall bias and data masking.

- Verification of the monthly income reported by participants was not feasible in this study.

- The study was limited to patients visiting the DDR Centre in Vijayapura district, which may affect the generalizability of findings beyond this specific population.

- The study used a non-sampling technique, with the sample size derived from a universal sampling approach within one district.

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ANNEXURE – I

QUESTIONNAIRE

A. SOCIO-DEMOGRAPHIC QUESTIONNAIRE

Participant ID

Que code	**Questions**	**Response**
1	Name of the Physically Disabled Person	
2	Address	
3	Age in completed years	………………yrs completed
4	Sex	Male………….. Female………. Others………..
5	Marital status	Married……… Unmarried…. Widow/widower/separated…. Refused ……………………..
6	Religion	Hindu………………. Muslim……………. Christian………… Others(specify)……………

7	Education	Illiterate /No formal schooling……………. primary school (<7th std) ……… High school (7th to 10th std) ……. Pre-university (>10th to ≤PUC2) ………… Graduation………. ….. Post-graduation……………. Refused………………………..
8	Occupation	Government employee…………… Private employee…………………. Self-employed…………………………. Retired………………………………… Unemployed………………………….
9	Income	Rs.
10	Name of the Caregiver	
11	Relationship of the caregiver with the PDp	
12	Age in completed years (Caregiver)	
13	Sex of the Caregiver	Male…………… Female………. Others…………
14	Marital status of the Caregiver	Married……… Unmarried…. Widow/widower/separated…. Refused ……………………..
15	Religion of the Caregiver	Hindu………………. Muslim……………. Christian………… Others(specify)……………

16	Education of the Caregiver	Illiterate /No formal schooling……………. primary school (<7th std) ……… High school (7th to 10th std) ……. Pre-university (>10th to ≤PUC2) ………… Graduation………. ….. Post-graduation……………. Refused………………………..
17	Occupation of the Caregiver	Government employee…………… Private employee…………………. Self-employed…………………………. Retired………………………………… Unemployed………………………….
18	Income of the Caregiver	Rs.
19	Total family income per month	Rs.
20	Total number of family members	
21	Type of family	Nuclear………… Joint………………. Extended……….. Living alone………
22	Type of disability	1. Mobility impairment 2. Vision impairment 3. Hearing impairment 4. Any other specify
23	Percentage of deformity	
24	Disability Certificate issued from Government Under Medical Board	Yes /No

25	Cause for the disability	1. Congenital 2. Acquired If acquired, 2a. Type……. 2b. Cause……
26	Duration of disability	
27	a. Any financial support from the government b. Any other support from the government	**Yes/No** If yes, how much……….. …………………………..
28	Accessing Health care for present disability	**Yes/No**
29	If yes, then preferred facility	1. Primary health care center 2. Government hospital 3. Private hospital 4. DDRC of BLDE
30	If no, what are the barriers in accessing the healthcare	1. Physical barrier………. 2. Medical equipment-related barrier……. 3. Communication barrier 4. Economic barrier……. 5. Geographic barrier…….. 6. Nobody to accompany…
31	In case of Physical barrier	1. Difficulty in transportation 2. Absence of ramps and elevators 3. Narrow corridors and doors entrances 4. Uncomfortable toilets

32	In case of medical equipment-related barrier	1. Lack/inadequate of assistive devices 2. Lack/inadequate of stretchers/wheelchairs 3. Lack/inadequate of patient admission beds 4. Lack/inadequate supply of drugs 5. Long waiting period
33	In case of a communication barrier	1. Unable to explain to the healthcare practitioners 2. Lack of disability assistants 3. Absence of easily readable sign boards
34	In case of Economic barrier	1. High cost 2. unable to afford treatment 3. lack of health insurance
35	Geographic barriers	1. Lack of transport facility 2. location of the healthcare facility 3. Difficulty in transportation
36	If you manage your own care, what has this been like now?	1. Easy 2. Very easy 3. Difficult 4. Very difficult 5. I don’t manage my own care
37	Has anyone ever been very negative towards you because of your disability? a. Family members b. Outsiders	Yes/No Sometimes…… Yes/No Sometimes……

B. SCALE FOR MEASURING PERCEIVED STRESS:

For each question, choose from the following alternatives:

A. 0 - never
B. 1 - almost never
C. 2 - sometimes
D. 3 - fairly often
E. 4 - very often ________

l. In the last month, how often have you been upset because of something that happened unexpectedly? ________

2. In the last month, how often have you felt that you were unable to control the important things in your life? ________

3. How often have you felt nervous and stressed in the last month? ________

4. In the last month, how often have you felt confident about your ability to handle your personal problems? ________

5. In the last month, how often have you felt that things were going your way? ________

6. In the last month, how often have you found that you could not cope with all the things that you had to do? ________

7. In the last month, how often have you been able to control irritations in your life? ________

8. How often have you felt that you were on top of things in the last month? ________

9. In the last month, how often have you been angered because of things that happened that were outside of your control? ________

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Figuring Your PSS Score You can determine your PSS score by following these directions:

- First, reverse your scores for questions 4, 5, 7, and 8.

On these 4 questions, change the scores like this: 0 = 4, 1 = 3, 2 = 2, 3 = 1, 4 = 0.

- Now add up your scores for each item to get a total. My total score is ___________.

- Individual scores on the PSS can range from 0 to 40, with higher scores indicating higher perceived stress.

► Scores ranging from 0-13 would be considered low stress.

► Scores ranging from 14-26 would be considered moderate stress.

► Scores ranging from 27-40 would be considered high perceived stress

C. CAREGIVER BURDEN INVENTORY SCALE

The Case Manager will administer the inventory by reading the statement and marking the responses.

Choose the number that best represents how often the statement describes your feelings.

0 - Never

1 - Rarely

2 - Sometimes

3 - Quite Frequently

4 - Nearly Always

Client Name______________________

Caregiver Name ____________________ **Date**___________

Time Dependency Items	
He/she needs my help to perform many daily tasks	⓪①②③④
He/she is dependent on me.	⓪①②③④
I have to watch him/her constantly.	⓪①②③④
I have to help him/her with many basic functions.	⓪①②③④
I don't have a minute's break from his/her chores.	⓪①②③④
He/she needs my help to perform many daily tasks	⓪①②③④
Development Items	
I feel that I am missing out on life.	⓪①②③④
I wish I could escape from this situation.	⓪①②③④
My social life has suffered.	⓪①②③④
I feel emotionally drained due to caring for him/her.	⓪①②③④
I expected that things would be different at this point in my life.	⓪①②③④
Emotional Health Items	
I feel embarrassed over his/her behavior	⓪①②③④
I feel ashamed of him/her.	⓪①②③④
I resent him/her	⓪①②③④
I feel uncomfortable when I have friends over	⓪①②③④
I feel angry about my interactions with him/her.	⓪①②③④

Physical Health Items	
I'm not getting enough sleep.	⓪①②③④
My health has suffered.	⓪①②③④
Caregiving has made me physically sick.	⓪①②③④
I'm physically tired.	⓪①②③④
Social Relationships Items	
I don't get along with other family members, as well as I, used to	⓪①②③④
My caregiving efforts aren't appreciated by others in my family.	⓪①②③④
I've had problems with my marriage (or other significant relationship)	⓪①②③④
I don't get along as well as I used to with others.	⓪①②③④
I feel resentful of other relatives who could but do not help.	⓪①②③④

Total Score:

Scores near or above 36 indicate a greater need for respite and other services.

It is important to look at any item on the burden scale where the answer was scored as a 3 or 4 ('quite frequently' or 'nearly always). If you have a 3 or 4 as an answer, give careful thought to why the Caregiver scored so high on the question and see if you can find a way to reduce the stress.

Comments:____

D. FINANCIAL IMPACT SCALE

Each statement is followed by five responses. Please circle the response (one for each statement) that best represents your caregiving situation

Strongly Agree- Agree- Undecided - Disagree - Strongly Disagree

1. I feel that I cannot afford to remodel my home in order to make caregiving easier.
   Strongly Agree - Agree- Undecided - Disagree - Strongly Disagree

2. I have found it stressful to have to change jobs because of my caregiving responsibilities.
   Strongly Agree- Agree - Undecided - Disagree- Strongly Disagree

3. I feel that my family argues more about money now than we did before I was responsible for caregiving.
   Strongly Agree- Agree - Undecided - Disagree - Strongly Disagree

4. My caregiving responsibilities have been so stressful that I have had to pay to go to the doctor for my own medical attention.
   Strongly Agree - Agree- Undecided - Disagree- Strongly Disagree

5. I worry about caregiving costs because caregiving has interfered with saving money for my own future.
   Strongly Agree - Agree - Undecided - Disagree - Strongly Disagree

6. I feel I cannot afford a vacation because I have had to spend so much on caregiving.
   Strongly Agree - Agree - Undecided -Disagree - Strongly Disagree

7. I wish other family members would help pay for caregiving costs.
   Strongly Agree- Agree - Undecided - Disagree - Strongly Disagree

8. I worry about my finances because I have had to pay for food for the person I take care of.
   Strongly Agree - Agree - Undecided - Disagree - Strongly Disagree

9. I feel that the person I provide care for cannot go into a nursing home because it is too expensive.

Strongly Agree - Agree- Undecided - Disagree - Strongly Disagree

10. I worry about my finances because I have had to pay for my own traveling expenses because of caregiving responsibilities.
    Strongly Agree -Agree -Undecided - Disagree - Strongly Disagree

11. I feel that caregiving is a financial burden for me.
    Strongly Agree - Agree - Undecided - Disagree - Strongly Disagree

12. I feel resentful because I have had to cut down on my own expenses because of caregiving costs.
    Strongly Agree - Agree - Undecided - Disagree- Strongly Disagree

13. I feel that it is unfortunate that the person I provide care for has had to spend so much on caregiving costs that she/he will be unable to leave much of an estate to his/her family.
    Strongly Agree-Agree- Undecided - Disagree- Strongly Disagree

14. I feel that I am unable to buy clothing for myself because of caregiving expenses.
    Strongly Agree - Agree-Undecided-Disagree - Strongly Disagree

15. Overall, I feel that caregiving strains my family and social life.
    Strongly Agree -Agree - Undecided - Disagree -Strongly Disagree

16. I feel guilty sometimes because I worry about caregiving costs.
    Strongly Agree -Agree - Undecided - Disagree -Strongly Disagree

17. Overall, I feel that caregiving has been a financial drain on me and/or my family.
    Strongly Agree- Agree - Undecided - Disagree -Strongly Disagree

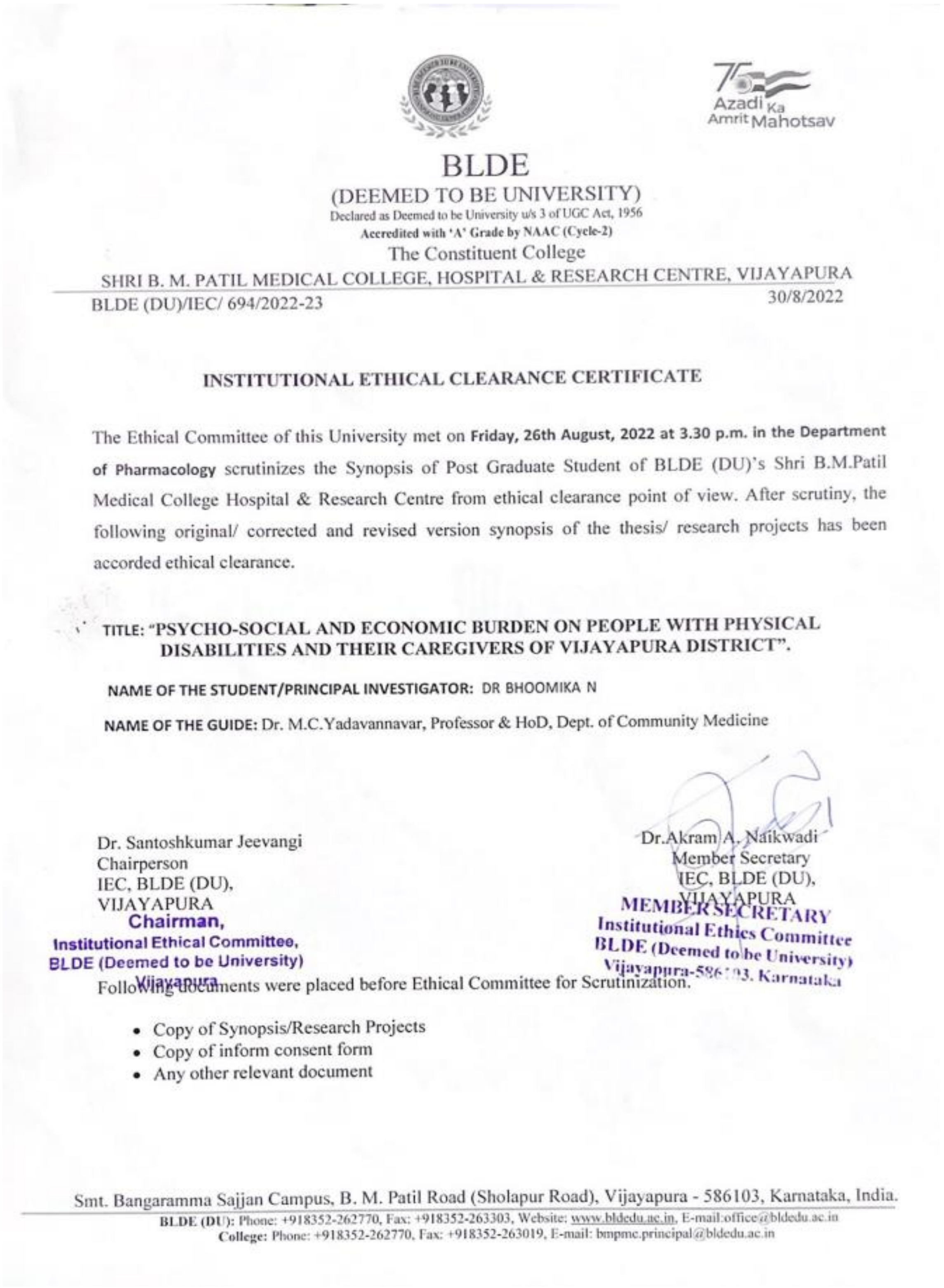
18. I worry about my finances because I have had to pay for medical bills for the person I take care of.
    Strongly Agree - Agree - Undecided - Disagree - Strongly Disagree

19. I worry about my finances because they are being used to pay for major living expenses for the person I take care of.
    Strongly Agree - Agree - Undecided - Disagree - Strongly Disagree

20. I worry about money for the future because if the person I take care of goes into a nursing home, my savings will be used up.
    Strongly Agree - Agree - Undecided - Disagree - Strongly Disagree

ANNEXURE – II

ETHICAL CLEARANCE CERTIFICATE



Azadi Ka Amrit Mahotsav

BLDE
(DEEMED TO BE UNIVERSITY)
Declared as Deemed to be University u/s 3 of UGC Act, 1956
Accredited with 'A' Grade by NAAC (Cycle-2)
The Constituent College
SHRI B. M. PATIL MEDICAL COLLEGE, HOSPITAL & RESEARCH CENTRE, VIJAYAPURA

BLDE (DU)/IEC/ 694/2022-23

30/8/2022

INSTITUTIONAL ETHICAL CLEARANCE CERTIFICATE

The Ethical Committee of this University met on **Friday, 26th August, 2022 at 3.30 p.m. in the Department of Pharmacology** scrutinizes the Synopsis of Post Graduate Student of BLDE (DU)'s Shri B.M.Patil Medical College Hospital & Research Centre from ethical clearance point of view. After scrutiny, the following original/ corrected and revised version synopsis of the thesis/ research projects has been accorded ethical clearance.

TITLE: "PSYCHO-SOCIAL AND ECONOMIC BURDEN ON PEOPLE WITH PHYSICAL DISABILITIES AND THEIR CAREGIVERS OF VIJAYAPURA DISTRICT".

NAME OF THE STUDENT/PRINCIPAL INVESTIGATOR: DR BHOOMIKA N

NAME OF THE GUIDE: Dr. M.C.Yadavannavar, Professor & HoD, Dept. of Community Medicine

Dr. Santoshkumar Jeevangi
Chairperson
IEC, BLDE (DU),
VIJAYAPURA

Chairman,
Institutional Ethical Committee,
BLDE (Deemed to be University)
Vijayapura

Dr.Akram A. Naikwadi
Member Secretary
IEC, BLDE (DU),
VIJAYAPURA

MEMBER SECRETARY
Institutional Ethics Committee
BLDE (Deemed to be University)
Vijayapura-586103. Karnataka

Following documents were placed before Ethical Committee for Scrutinization.

- Copy of Synopsis/Research Projects
- Copy of inform consent form
- Any other relevant document

Smt. Bangaramma Sajjan Campus, B. M. Patil Road (Sholapur Road), Vijayapura - 586103, Karnataka, India.
BLDE (DU): Phone: +918352-262770, Fax: +918352-263303, Website: www.bldedu.ac.in, E-mail:office@bldedu.ac.in
College: Phone: +918352-262770, Fax: +918352-263019, E-mail: bmpmc.principal@bldedu.ac.in

ANNEXURE – III

INFORMED CONSENT FORM

B.L.D.E. (DEEMED TO BE UNIVERSITY)
SHRI B.M. PATIL MEDICAL COLLEGE HOSPITAL AND RESEARCH
CENTER, VIJAYAPURA-586103

INFORMED CONSENT FOR PARTICIPATION IN DISSERTATION/RESEARCH

TITLE OF TOPIC: Psycho-Social and Economic Burden on People with Physical Disabilities and their Caregivers of Vijayapura District

GUIDE : Dr. M.C. Yadavannavar

PG STUDENT : Dr. Bhoomika N

PURPOSE OF RESEARCH:

I have been informed that this study will help in understanding the burden on physically disabled persons and their caregivers.

I have explained the reason for doing this study and selected DDR Centre as a subject for this study. I have also been given the free choice of either being included or not in the study

PROCEDURE:

I understand that this is a cross-sectional study. In this procedure, I will be asked a series of questions by the researcher regarding the topic.

RISKS AND DISCOMFORTS:

I understand that I may experience some discomfort during this procedure. This is mainly the result of conditions. The procedures of this study are not expected to exaggerate these feelings, which are associated with the usual course of study.

BENEFITS:

I understand that my participation in the study as one of the study subjects will help the researcher to assess Psycho-social and economic burden on people with physical disability and their caregivers.

CONFIDENTIALITY:

Your answers are kept secret. Your name and contact information will never be identified to anyone outside of the study.

If the data are used for publication in the medical literature or for teaching purposes, no names will be used, and other identifiers such as photographs and audio or video tapes will be used only with my special written permission. I understand that I may see the photograph and videotapes and hear audiotapes before giving this permission.

REQUEST FOR MORE INFORMATION:

I understand that I may ask more questions about the study at any time. Dr. Bhoomika N at the department of community medicine to answer my questions or concerns. I understand that I will be informed of any significant new findings discovered during the course of the study, which might influence my continued participation. A copy of this consent form will be given to me to keep for careful reading.

REFUSAL OR WITHDRAWAL OF PARTICIPATION:

I understand that my participation is voluntary and that I may refuse to participate or may withdraw consent and discontinue participation in the study at any time without prejudice. I also understand that Dr. Bhoomika N may terminate my participation in the study at any time after she has explained the reasons for doing so.

(Guide / Principal Investigator) (Date)

(Investigator) (Date)

STUDY SUBJECT CONSENT STATEMENT:

I confirm that Dr. Bhoomika N has explained to me the purpose of the research, the study procedure that I will undergo & the possible discomfort as well as benefits that I may experience in my own language. I have explained all the above in detail in my language and understand the same.

Therefore, I agree to give consent to participate as a subject in this research project.

____________________________ Date:

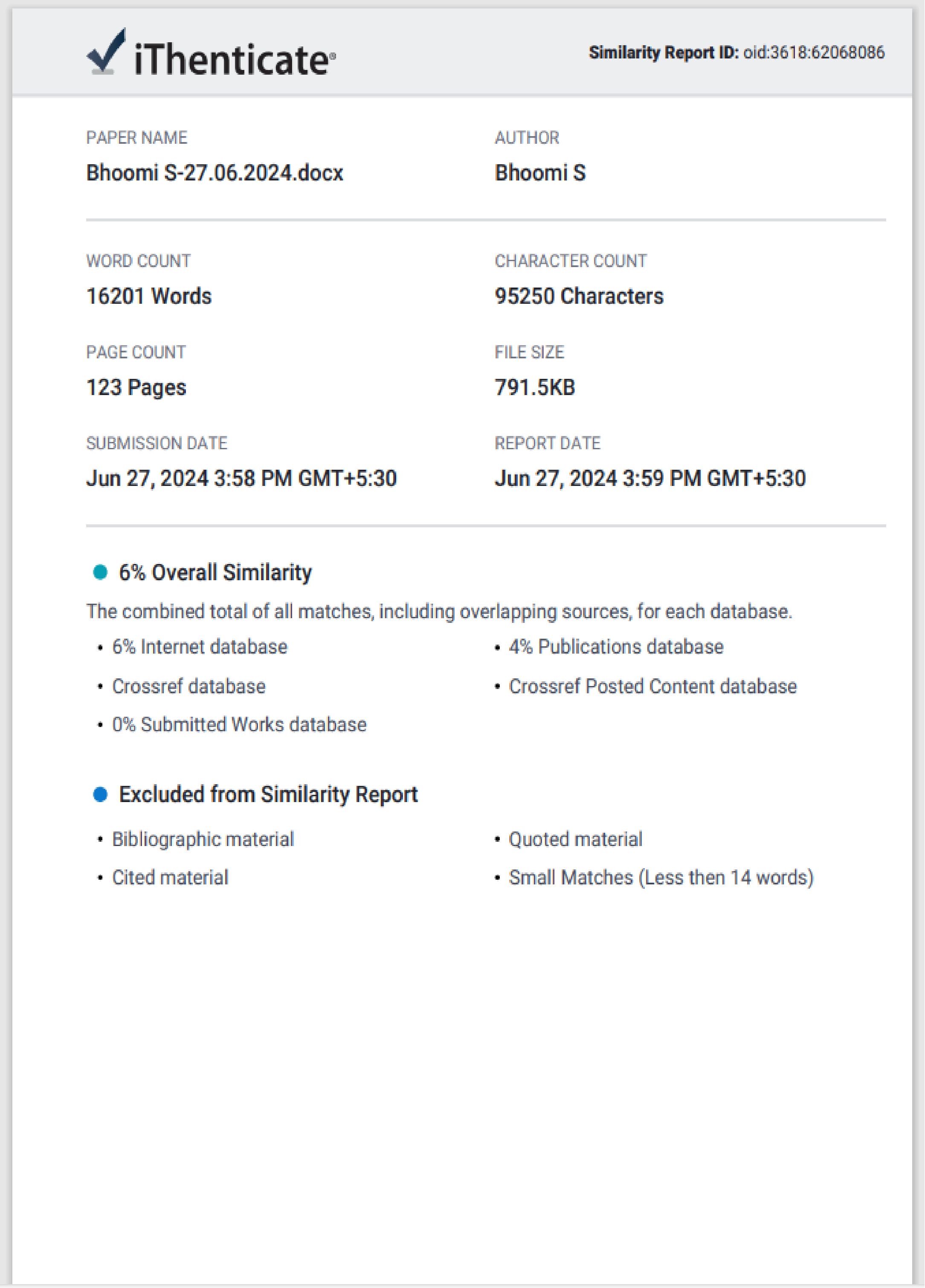
(participant signature)

__________________________________ Date:

(Witness signature)

ANNEXURE – IV

PLAGIARISM REPORT



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ANNEXURE – V

GANTT CHART

In Years	**2022**							**2023**												**2024**					
Activity	Jun	July	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
Topic selection	■	■																							
Synopsis preparation and submission			■	■																					
Review of literature					■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■					
Preparation ofProforma							■	■	■	■															
Data collection									■	■	■	■	■	■	■	■	■	■	■	■					
Data analysis																			■	■	■				
Dissertation writing																■	■	■	■	■	■	■	■	■	
Dissertationsubmission																									■

ANNEXURE – VI

DATA COLLECTION PHOTOGRAPHS