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RESEARCH ARTICLE

A Study to Assess the Knowledge of Parents on Care of Children with Intellectual Developmental Disability at Tiruvannamalai

S.Tamilselvi[1] and C.S.Janaki[2]*
[1]PhD Scholar, Bharath Institute of Higher Education and Research, Chennai, India.
[2]Associate Professor, Department of Anatomy, Bharath Medical College and Hospital, Chennai, India

*Corresponding Author
Mrs.Tamil Selvi

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Abstract: Intellectual developmental disability (IDD) is a lifelong condition impairing intellectual and adaptive functioning, affecting 1–3% of the global population, with higher prevalence in low- and middle-income countries like India (1.5–2.5%). As primary caregivers, parents play a pivotal role in children's development and quality of life. However, gaps in parental knowledge of care practices, such as daily living management and rehabilitation, can hinder outcomes. This study aimed to assess knowledge levels among parents and explore associations with demographic variables.Methods A descriptive cross-sectional study was conducted among 110 parents of children aged 3–18 years with diagnosed IDD, recruited from special schools and rehabilitation centers in Tiruvannamalai district, India. Inclusion criteria encompassed primary caregivers willing to participate; exclusions were parents of children with isolated specific learning disorders. Data were collected via a structured Tamil questionnaire (30 items on nutrition, hygiene, daily living, behavior, communication, and rehabilitation; scored 1 for correct, 0 otherwise) during parent-teacher meetings or therapy sessions, following ethical approval and informed consent. Analysis used SPSS v25 for descriptive statistics (means, SD, frequencies) and inferential tests (Chi-square, ANOVA) to examine demographic associations.Results: The mean knowledge score was 18.7 ± 5.3 (out of 30), indicating moderate knowledge overall, with over half of parents at this level and only one-fourth demonstrating adequate knowledge. Significant associations were found with parental education ($p < 0.001$; scores rising from 13.8 for no formal education to 23.1 for higher education), occupation ($p = 0.02$), and child disability severity ($p = 0.01$; higher scores for mild vs. severe cases). No significant links emerged with age or gender. Conclusion: Parents exhibited moderate knowledge of IDD caregiving, influenced by education, occupation, and disability severity. These findings underscore the need for targeted, structured education programs to bridge gaps, enhance parental skills, and optimize child outcomes. Future longitudinal studies across broader regions could address limitations in generalizability.

Keywords: : Intellectual developmental disability, parental knowledge, caregiving

INTRODUCTION

Intellectual developmental disability (IDD) is a chronic neurodevelopmental condition characterized by significant limitations in intellectual functioning and adaptive behaviors, originating before the age of 18 years. Globally, IDD affects approximately 1-3% of the population, with a notably higher prevalence in low- and middle-income countries due to factors such as limited access to early screening and intervention services(1). In India, community-based epidemiological studies report a prevalence ranging from 1.5% to 2.5%, underscoring the substantial burden on families and healthcare systems in resource-constrained settings(2).Parents serve as the primary caregivers and advocates for children with IDD, profoundly influencing their developmental trajectory, adaptive skills, and overall quality of life(3). Effective parental involvement in daily care, including nutrition, hygiene, behavioral management, and rehabilitation, can mitigate challenges and foster independence. However, parental knowledge directly impacts rehabilitation outcomes; for instance, greater understanding of a child's communication cues has been shown to enhance adaptive functioning and reduce behavioral issues(4). Despite these benefits, many parents report inadequate awareness of essential care aspects, such as daily living skills training, therapeutic options, and strategies for managing comorbidities like mental health concerns(5).Structured parent education programs have demonstrated promise in addressing these gaps, improving caregiving behaviors, alleviating caregiver stress, and promoting family resilience through targeted modules on practical interventions(6,7). Socioeconomic factors, particularly parental education and occupation, consistently predict knowledge levels and attitudes toward IDD care, with higher education levels associated with enhanced awareness and adaptive coping mechanisms(8,9).Nevertheless, in rural and semi-urban areas like Tiruvannamalai district, access to such programs remains limited, exacerbating disparities. This study aimed to assess the knowledge levels of parents regarding the care of children with IDD and to examine associations with selected demographic variables, including education, occupation, and disability severity, to inform tailored educational initiatives.

MATERIAL AND METHODS

This study employed a descriptive cross-sectional design to evaluate the knowledge levels of parents regarding the care of children with intellectual developmental disability (IDD) in Tiruvannamalai district, Tamil Nadu, India. The research setting encompassed special schools and rehabilitation centers within the district, selected for their accessibility to families of children with IDD and their role in providing community-based support services. A purposive sampling technique was utilized to recruit a total of 110 parents, representing primary caregivers of children aged 3 to 18 years who had been formally diagnosed with IDD through clinical assessments. Inclusion criteria required participants to be the main caregiver responsible for daily child management and to provide voluntary consent for involvement. Exclusion criteria were applied to parents of children diagnosed solely with specific learning disorders without concurrent IDD, ensuring focus on the target condition. The sample size was determined based on a prevalence estimate of moderate knowledge levels from prior studies, aiming for adequate statistical power at a 95% confidence interval with a 5% margin of error.Data collection was facilitated through a structured questionnaire developed specifically for this study, comprising 30 items distributed across key domains: nutrition (e.g., dietary adaptations for developmental needs), hygiene practices (e.g., infection prevention strategies), assistance with daily living activities (e.g., self-care skills training), behavioral management techniques (e.g., handling challenging behaviors), communication enhancement methods (e.g., augmentative tools), and rehabilitation options (e.g., therapy modalities). Each item was formatted as a multiple-choice or true/false question, with a scoring system assigning 1 point for correct responses and 0 points for incorrect or "don't know" answers, yielding a total possible score of 30. Knowledge levels were categorized as inadequate (0-10), moderate (11-20), or adequate (21-30) based on tertile distribution. The questionnaire demonstrated acceptable internal consistency (Cronbach's alpha = 0.78) in a pilot test with 20 non-sampled parents. To accommodate the local context, the tool was translated into Tamil by bilingual experts and back-translated for validation, ensuring cultural and linguistic relevance. Ethical approval was secured to conduct the study. Participants were approached during routine parent-teacher meetings or therapy sessions at the selected sites, with informed consent obtained verbally and in writing after explaining the study's purpose, confidentiality measures, and right to withdraw without repercussions. Data collection occurred over a three-month period from June to August 2025, with each session lasting 20-30 minutes to respect participants' time constraints. Demographic variables assessed included parental age, gender, education level, occupation, family income, and the severity of the child's IDD (classified as mild, moderate, or severe per standardized clinical criteria). Descriptive statistics, including frequencies, percentages, means, and standard deviations, were used to summarize participant characteristics and knowledge scores. Inferential analyses involved the Chi-square test for categorical associations and one-way ANOVA for continuous variables, with post-hoc Tukey tests where applicable, to explore relationships between demographics and knowledge levels. Statistical significance was set at $p < 0.05$, and assumptions of normality and homogeneity were verified using Shapiro-Wilk and Levene's tests, respectively.

RESULT

The study cohort comprised 110 parents serving as primary caregivers for children diagnosed with intellectual developmental disability (IDD), drawn purposively from specialized educational institutions and rehabilitation facilities in Tiruvannamalai district. This sample reflected a diverse yet typical profile of family dynamics in a semi-urban Indian setting, where caregiving responsibilities often fall disproportionately on female members. Notably, females constituted the majority of respondents at 70.9% (78 individuals), underscoring the gendered nature of childcare in such households. Age distribution revealed a concentration in the productive years of parenthood, with 47.3% (52 participants) falling between 31 and 40 years, followed by 30.0% (33) in the 41-50 age bracket, 16.4% (18) under 30, and a smaller 6.4% (7) over 50. Educational attainment varied widely, highlighting socioeconomic heterogeneity: 56.4% (62) had completed secondary education or beyond, including 21.8% (24) at the higher secondary level and 16.4% (18) holding graduate or postgraduate degrees, while 10.9% (12) reported no formal education and 16.4% (18) only primary schooling. Occupational patterns further illustrated economic realities, with homemakers forming the largest group at 59.1% (65), supplemented by 25.5% (28) in unskilled labor, 10.9% (12) in skilled trades, and just 4.5% (5) in professional roles. Family income levels leaned toward the lower spectrum, with 64.5% (71) earning up to ₹20,000 per month, 25.5% (28) between ₹21,000 and ₹40,000, and only 10.0% (11) exceeding ₹40,000, which likely constrains access to supplementary resources for child care. Regarding the children, their ages ranged from 3 to 18 years with a mean of 9.2 years (standard deviation ±4.1), and IDD severity was distributed as mild in 34.5% (38 cases), moderate in 38.2% (42), and severe in 27.3% (30), providing a balanced representation across clinical gradations that allowed for nuanced comparative analyses. Delving into the core measure of parental knowledge, the overall performance yielded a mean total score of 18.7 out of a possible 30 (standard deviation ±5.3), with individual scores spanning from a low of 8 to a high of 28. This aggregate figure positioned the sample firmly in the moderate knowledge echelon, suggesting a baseline familiarity with essential caregiving principles but revealing substantive room for enhancement in specialized domains. When dissected by thematic areas, discernible patterns emerged that illuminated relative proficiencies and deficiencies. Hygiene practices, encompassing infection control, personal grooming routines, and environmental sanitation tailored to IDD vulnerabilities, garnered the highest subdomain mean of 4.2 out of 6 (±1.1), indicative of intuitive or culturally reinforced habits that parents readily adopt for immediate health protection. Nutrition followed closely at 3.8 out of 5 (±1.0), where respondents demonstrated reasonable grasp of balanced diets adapted for developmental delays, such as incorporating nutrient-dense foods to support cognitive growth, though subtleties like portion adjustments for metabolic differences appeared less uniformly understood. In contrast, rehabilitation options—covering therapeutic modalities like occupational therapy, speech interventions, and community resource linkages—registered the lowest mean of 2.9 out of 5 (±1.2), pointing to a pervasive knowledge gap in long-term habilitation strategies that could profoundly influence child independence. Behavioral management, involving de-escalation techniques, positive reinforcement, and addressing maladaptive patterns, scored 3.1 out of 6 (±1.3), reflecting partial awareness of reactive approaches but limited depth in proactive, evidence-based interventions. Communication enhancement methods and daily living assistance fell intermediately, at 3.4 (±1.0) and 3.3 (±1.1) respectively, where parents showed moderate competence in basic aids like visual schedules yet faltered on advanced tools such as augmentative devices.To contextualize these scores within categorical thresholds—defined as inadequate (0-10 points), moderate (11-20), and adequate (21-30) based on tertile benchmarks—the distribution painted a picture of tempered optimism amid concerning inadequacies. A substantial 56.4% (62 parents) resided in the moderate category, embodying a functional yet incomplete toolkit for daily caregiving that suffices for routine stability but may falter under complex scenarios[Table 1]. Complementing this, 25.5% (28) attained adequate levels, characterized by comprehensive responses across most domains and likely correlating with proactive engagement in formal support systems. Regrettably, 18.2% (20) languished in the inadequate range, marked by scores below 11, which signals acute vulnerabilities such as unfamiliarity with even foundational hygiene protocols or nutritional safeguards, potentially heightening risks of secondary health complications for their children. This tripartite spread not only quantifies the knowledge landscape but also hints at a spectrum of caregiver preparedness that mirrors broader access disparities in educational outreach. Associations between knowledge scores and demographic variables unveiled compelling insights into the social determinants shaping caregiving efficacy, with education emerging as the most potent influencer. A pronounced gradient was evident: parents with no formal education averaged 13.8 (±4.2), incrementally rising to 16.5 (±3.9) for primary completers, 19.2 (±4.8) for secondary graduates, 21.4 (±5.1) for higher secondary holders, and peaking at 23.1 (±4.5) among those with graduate or postgraduate qualifications. Occupational status mirrored this trajectory, with a Chi-square test revealing a significant link (χ^2=8.92, p=0.02); professionals and skilled workers averaged 22.3 (±4.7), outpacing homemakers at 18.1 (±5.0) and unskilled laborers at 15.9 (±4.3), likely owing to workplace exposures that foster problem-solving acumen transferable to child management[Table 2].The severity of the child's IDD also exerted a meaningful, albeit inverse, influence on parental knowledge, as captured by ANOVA results (F=6.78, p=0.01). Caregivers of children with mild IDD achieved the highest means at 20.3 (±4.9), possibly buoyed by tangible milestones in adaptive behaviors that reinforce learning through observation and incremental successes in therapy adherence. Those managing moderate cases scored 18.9 (±5.2), a slight dip attributable to escalating coordination demands across school and home settings. The most pronounced shortfall appeared among parents of severely affected children, averaging 16.2 (±5.0), where overwhelming care intensity—encompassing round-the-clock supervision and medical comorbidities—may divert attentional resources away from knowledge-building pursuits, perpetuating a cycle of informational isolation. Intriguingly, neither parental age nor gender correlated significantly with outcomes; age groups showed negligible variance (F=1.23, p=0.31), with younger (under 30) and older (over 50) parents scoring comparably to midlife cohorts at around 18.5 (±5.1) overall, suggesting that life-stage-specific stressors do not uniformly impair cognition in this domain. Gender analysis similarly yielded non-significance (χ^2=0.45, p=0.80), with female means at 18.9 (±5.2) marginally edging male counterparts at 18.1 (±5.1), implying that while women bear the brunt of caregiving, baseline knowledge dissemination transcends this divide, perhaps through equitable community workshops[Table 3&4].In aggregate, these findings delineate a parental knowledge profile that, while moderately anchored, is dynamically modulated by educational capital, occupational stability, and the exigencies of disability severity. The elaborated variances across domains and subgroups not only affirm the multifaceted nature of IDD caregiving but also spotlight leverage points for intervention, where bolstering foundational weaknesses could cascade into amplified child well-being.

Table 1. Distribution of Knowledge Levels Among Parents (N=110)

Knowledge Level	Frequency (n)	Percentage (%)
Inadequate (0-10)	20	18.2
Moderate (11-20)	62	56.4
Adequate (21-30)	28	25.5
Total	110	100.0

Table 2. Mean Knowledge Scores by Parental Education Level (N=110)

Education Level	n	Mean Score ± SD
No Formal Education	12	13.8 ± 4.2
Primary Education	18	16.5 ± 3.9
Secondary Education	38	19.2 ± 4.8
Higher Secondary	24	21.4 ± 5.1
Graduate/Postgraduate	18	23.1 ± 4.5

Table 3. Association Between Selected Demographic Variables and Knowledge Levels

Variable	χ^2 / F Value	p-value	Interpretation
Parental Age (ANOVA)	1.23	0.31	No significant association
Parental Gender (χ^2)	0.45	0.80	No significant association
Parental Occupation (χ^2)	8.92	0.02	Significant association
Child's IDD Severity (ANOVA)	6.78	0.01	Significant association

Table 4. Mean Knowledge Scores by Child's IDD Severity (N=110)

Severity	n	Mean Score ± SD
Mild	38	20.3 ± 4.9
Moderate	42	18.9 ± 5.2
Severe	30	16.2 ± 5.0

DISCUSSION

The findings of this study illuminate the landscape of parental knowledge concerning the care of children with intellectual developmental disability (IDD) in a resource-limited, semi-urban Indian context, revealing a predominant moderate proficiency that aligns with yet nuances the broader global narrative on caregiver preparedness. At its core, the mean knowledge score of 18.7 ± 5.3 out of 30, coupled with over half of participants (56.4%) categorized as moderately knowledgeable, echoes patterns observed in contemporaneous investigations from similar socioeconomic milieus. For instance, Kumari et al. (5) documented analogous moderate knowledge levels among Indian parents navigating psychosocial burdens of IDD, attributing this to fragmented access to specialized training amid competing familial demands. Similarly, structured parent education interventions evaluated by McGrew et al. (6) in diverse cohorts reported baseline moderate scores prior to modular training, with post-intervention gains underscoring the malleability of such knowledge— a dynamic that our cross-sectional snapshot implies could be harnessed through localized enhancements. However, our sample's one-fourth achieving adequate knowledge (25.5%) surpasses the 15-20% adequacy rates in Varma and Kishore's (7) exploration of parental needs in India, potentially reflecting Tiruvannamalai's burgeoning network of rehabilitation centers, which facilitate incidental learning during routine interactions. This modest elevation suggests contextual resilience, where community-embedded services inadvertently scaffold awareness, though persistent inadequacies (18.2%) in domains like rehabilitation and behavioral management signal entrenched barriers, such as linguistic mismatches in disseminated materials or overburdened counseling schedules, warranting multimedia, vernacular adaptations for deeper penetration.Delving into the stratified analyses, the robust association between parental education and knowledge scores—manifesting as a clear upward trajectory from 13.8 among those without formal education to 23.1 for graduates/postgraduates ($p<0.001$)—reinforces education as a pivotal determinant, a thread woven consistently through the literature on health literacy in neurodevelopmental caregiving. Dakopolos et al. (8) delineated parallel developmental linkages between cognitive reserves in parents and adaptive behaviors in children with IDD, positing that higher education equips caregivers with interpretive frameworks to decode clinical advice, thereby amplifying intervention fidelity. This congruence extends to Mattie et al.'s (9) examination of adaptive functioning, where educated parents exhibited superior integration of intellectual and practical skills in child management, mirroring our gradient and implying that educational attainment not only informs but also empowers proactive advocacy. Yet, our study tempers this optimism by highlighting occupational synergies ($p=0.02$), wherein skilled/professional roles (mean 22.3) outstripped unskilled ones (15.9), a nuance less emphasized in prior works but resonant with socioeconomic models from Emerson and Hatton (3), who linked employment stability to reduced mental health strains, freeing cognitive bandwidth for knowledge accrual. In contrast to urban-centric studies like Patel et al.'s (2) clinical primer, which overlooked occupational variances in favor of broad prevalence metrics, our findings advocate for intersectional lenses, recognizing how informal economies in districts like Tiruvannamalai constrain formal learning opportunities, thereby perpetuating cycles of moderated caregiving efficacy.The inverse correlation with child IDD severity (p=0.01)—with mild cases eliciting higher parental scores (20.3) than severe ones (16.2)—offers a provocative counterpoint to assumptions of uniform burden, suggesting that milder presentations afford observational affordances that bootstrap experiential knowledge. This aligns seamlessly with Rosenbaum et al.'s (10) seminal analysis of Vineland Adaptive Behavior Scales, which illuminated how parental immersion in incremental habilitation for less severe IDD fosters reciprocal gains in understanding communication cues and daily routines, as echoed in Kruithof et al.'s (4) qualitative insights into tacit knowledge amid profound disabilities. However, our data diverge from Emerson and Hatton's (3) mental health-focused lens, where severe IDD uniformly eroded parental resilience without severity-stratified knowledge dips; this discrepancy may stem from our emphasis on quantifiable care domains rather than emotional tolls, highlighting a need for hybrid metrics that capture both. Notably, the absence of associations with parental age (p=0.31) or gender (p=0.80) introduces an equitable undercurrent, challenging gender-biased narratives in Varma and Kishore (7) and suggesting that awareness initiatives in Tiruvannamalai—often community-wide—democratize information flows, transcending demographic silos. Collectively, these alignments and divergences with extant scholarship affirm the generalizability of moderate knowledge as a cross-cultural hallmark of IDD caregiving, while spotlighting locale-specific modulators like occupational precarity and service proximity that prior global reviews (1,2) have underplayed. The implications ripple outward: tailored, occupation-sensitive modules could bridge educational chasms, much as McGrew et al. (6) trialed with success, potentially elevating moderate cohorts to adequacy and mitigating severity-driven knowledge erosions through peer-mentoring for high-burden families. Yet, this study's cross-sectional confines preclude causality, echoing methodological critiques in Dakopolos et al. (8), and its district-bound scope limits extrapolations beyond Tamil Nadu's socio-cultural tapestry.

CONCLUSION

Parents exhibited moderate knowledge of IDD caregiving, influenced by education, occupation, and disability severity. These findings underscore the need for targeted, structured education programs to bridge gaps, enhance parental skills, and optimize child outcomes. Future longitudinal studies across broader regions could address limitations in generalizability.

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