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Anjali K. G Ms

Manipal College of Nursing, anjalikg88@gmail.com

Tessy Treasa Jose Dr

Manipal College of Nursing, tessy.j@manipal.edu

Blessy Prabha Valsaraj Dr

Sultan Qaboos University, Muscat

Asha K. Nayak Ms

Manipal College of Nursing

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Cover Page Footnote

We greatly acknowledge all the authors of the original research articles that have been found useful to write this review article. Extend our thanks to the Manipal University's health sciences library for providing facilities to retrieve relevant studies from various online databases. We also express our sincere gratitude to the reviewers, who gave their valuable suggestions in preparing this article and analysis

Quality of life of mothers having intellectually disabled children: A systematic review

Anjali K G*, Tessy Treesa Jose, Blessy Prabha Valsaraj, Asha K Nayak, Savitha, Renjula Yashodaran

Email: anjalikg88@gmail.com

Abstract

Introduction: Parents with children having intellectual disability experience more stress compared to their counterpart who have children with no intellectual disability. Disabilities of children may burden their family members, especially their parents, who are their long term caregivers. Mother act as the primary caregiver within the family. **Purpose:** This systematic review is intended to bring out pooled evidence on quality of life (QOL) of parents with children having the intellectual disability which will affect the rehabilitation of the affected child. **Method:** Databases such as CINAHL, Pub Med/Medline were searched to identify the potential studies. **Results:** A variety of survey methods were used by the researchers. Studies also focused on various domains of QOL such as financial wellbeing, family support and community interactions, etc. and findings showed a QOL ranging from good to excellent. But, most of the studies used purposive sampling technique and had missing data. Meta-analysis is out of the scope of this review. **Conclusion:** There is a need for more studies related to this topic. The studies reviewed were from Australia, Kenya, Ireland, and the UK. Hence, there is scope for further review. There is an evidence gap in the area of QOL of mothers living with children having intellectual disability.

Key words: Intellectual disability, mothers, quality of life, systematic review

Introduction

Prevalence of mental illness has a significant impact on the global burden of diseases. Among the urban population of developing countries, 5.3% are suffering from mental illness (Deswal, & Pawar, 2012). Intellectual

Anjali K G¹, Tessy Treesa Jose², Blessy Prabha Valsaraj³, Asha K Nayak⁴, Savitha⁵, Renjula Yashodaran⁶

¹Former Lecturer, Department of Psychiatric/Mental Health Nursing, Manipal College of Nursing Manipal, MU, Manipal

²Professor and HoD, Psychiatric/Mental Health Nursing, Manipal College of Nursing Manipal, MU, Manipal

³Assistant Professor, Department of Community and Mental Health Nursing, Sultan Qaboos University, Muscat

⁴Assistant Professor (Senior Scale), Department of Psychiatric/Mental Health Nursing, Manipal College of Nursing Manipal, MU, Manipal

⁵Assistant Professor, Department of Psychiatric/Mental Health Nursing, Manipal College of Nursing Manipal, MU, Manipal

⁶Lecturer, Department of Psychiatric/Mental Health Nursing, Manipal College of Nursing Manipal, MU, Manipal

*Corresponding Author

disability or mental retardation as it persists throughout lifetime adds on to these rates. It contributes to 1.2% of the mental illness in Kerala (Celine, & Antony, 2014). Intellectual disability is the most prevalent childhood psychiatric disorder. Among them, majority of the cases (85%) belong to mild mental retardation (Harris, 2009), (Ganguly, 2000).

A Meta-analysis on the prevalence of intellectually disabled children shows that 10.37/1000 population are affected (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Parents with children having intellectual disability use various coping strategies, which are ineffective most of the time. Parents with children having intellectual disability experience more stress compared to their counterparts, who have children with no intellectual disability ($t=2.46, p<.01$) (Gupta, & Kaur, 2010).

Stress is a factor which seriously affects the QOL of parents. This systematic review is intended to bring out pooled evidence on QOL of parents with children

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having an intellectual disability, which influences the rehabilitation of the affected child.

Why is it important to have this review?

Mothers with children having mental retardation always pass through a difficult experience. It affects various aspects of their life negatively. Government entrusts various supporting schemes for these children and parents, but this does not have an impact on stress and QOL of parents. This review will aid in identifying the domains of QOL which are affected negatively by their children’s disability. By considering the findings of this review, suggestions to modify supporting schemes can be put forward. It was found from initial review that no systematic reviews were conducted specific to this area and this project aims to study the aspect of QOL of mothers with intellectually disabled children.

Methods

A review protocol was established and electronic databases like PubMed, Ind-Med, CINHALL, and Proquest were searched for potential studies. Language

limitation of studies published in English in the period 2009 to 2015 was included. Case control studies and descriptive studies were included for the review. Studies on mothers of children having an intellectual disability and studies related to the QOL of mothers with intellectually disabled children were considered. The reviewed papers on studies conducted at home, school, community, organizations, and rehabilitative setting were included. The primary outcome of the study was QOL of mothers and secondary outcomes were wellbeingness and stress.

Results

PRISMA 2009 guideline was used for summarizing the data (Figure 1). Initial search resulted in 43 hits with a limiter of studies from 2009-2014. Six articles were found repeating between the databases. Eligibility assessments of 37 articles were done and 17 were found appropriate. Among them, only eight articles were full text available and those were reviewed. Out of which four studies were conducted in India (Table 1).

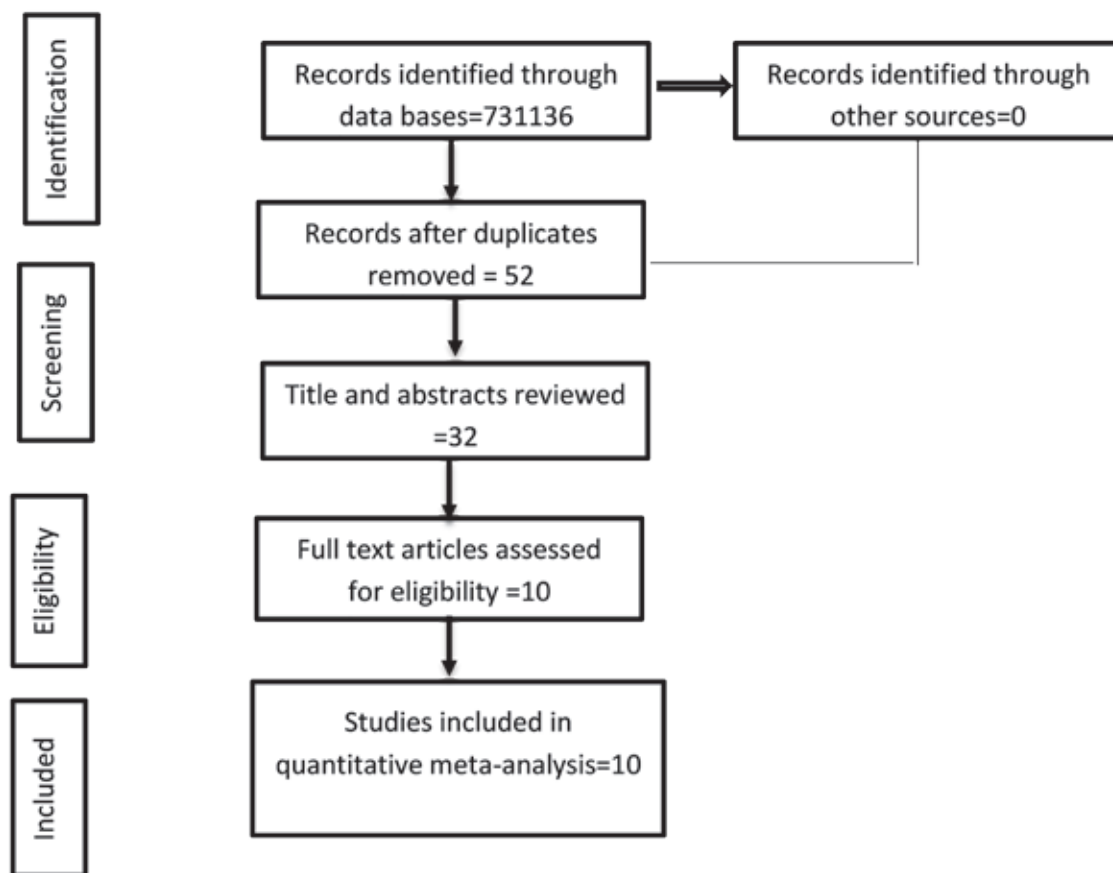


Figure 1: PRISMA flow diagram in summarizing the data

Table 1:
Study Characteristics

Study	Type of study	Sampling technique	Age in years	N	Outcome	Tool used	Results
Norlin, & Broberg, 2013	Descriptive Survey	Purposive sampling	33-39	236	QOL and Well being	Self reported questionnaire on couple QOL and individual wellbeing	Mothers with children having intellectual disability showed low wellbeing and poor marital and couple QOL.
Norizan, & Shamsuddin, 2010	Descriptive Survey	Purposive sampling	23-59	147	QOL and Parental stress	DASS21, COPE, Pediatric symptom checklist	Poor QOL and increased parental stress
Lloyd, & Hastings, 2010	Descriptive Survey	Purposive sampling	23-57	138	QOL, Parental hope, and depression	Self-reported questionnaire on Hope, Affect and psychological well-being	Low level of QOL and hope. High levels hope correlated with low level of depression scores
Yoong, & Koritsas, 2012	Qualitative	Purposive sampling	55-77	12	QOL Caring	Structured interview	Caring for adult intellectually disabled children has both positive and negative effect on QOL
Caples, & Sweeney, 2011.	Comparative study	Purposive sampling	33-81	49	QOL	WHO QOL questionnaire	Good to the excellent QOL among parents of children with intellectual disability availing respite care.
Boehm, Carter, & Taylor, 2015	Descriptive Survey	Purposive sampling	64-80	27	QOL	Family QOL questionnaire	Family have low QOL with support from others, lowest QOL in the aspect of spiritual being
Ravindran, & Raju, 2008	Comparative study	Purposive sampling	25-50	200	QOL and emotional Intelligence	QOL Scale, emotional intelligence scale	Low QOL among parents of children with intellectual disability There is no gender difference in emotional intelligence among parents irrespective of the condition of the child.
Paliwal & Paliwal, 2014	Comparative study	Convenient sampling	Not mentioned	100	Subjective wellbeing Caregiver stress Perceived social support	Subjective wellbeing scale, COPE inventory, caregiver stress test, multidimensional test for perceived social support	No significant difference in subjective wellbeing, social support and stress level among mothers of male and female intellectually disabled children
Kumar & Santhosh, 2013	Comparative study	Purposive sampling	30-37	240	QOL	WHO QOL questionnaire	Poor QOL is seen among mothers of intellectually disabled children
Malhotra Khan & Bhatia, 2012	Comparative study	Purposive sampling	Not mentioned	240	QOL	WHO QOL questionnaire	Mothers in MR group had highly significantly impaired QOL in all the four domains as compared to mothers of normal healthy children

A variety of survey methods were used by various researchers. Studies specifically focusing on mothers of intellectual disability were limited. The review shows that majority of the participants in the reviewed papers were parents of intellectually disabled children. Studies specifically done among mothers were limited, even though the experiences of both the parents were different. Studies also focused on various domains of QOL like financial wellbeing, family support, and community interactions etc. and findings showed a QOL ranging from good to excellent (Caples & Sweeney, 2010). But most of the studies used purposive sampling technique and had missing data. Meta-analysis is out of the scope of this review.

Quality of life

Having a child with an intellectual disability is the highly demanding situation for the parents. As the caregivers are responsible for meeting the needs of the child with a disability, it overburdens them in the aspect of rearing a child. This, in turn, can impair the QOL of parents. Mothers of children with intellectual disability showed to have deteriorated physical health, psychological state, the perception of the environment, and impaired social relationship while comparing to the mothers of healthy children (Malhotra, Khan, & Bhatia, 2012).

Overall QOL of mothers with intellectually disabled children is significantly impaired than their counterparts. The domain of social relation was the major area which was negatively affected in mothers of these children (Mothers: 44.61 ± 18.12 , Fathers: 51.81 ± 19.71). The difference in this QOL may be the result of the mother being the primary caregiver and father performing the financial support role. The mother spends her maximum time with the child in meeting the daily needs. When the socio-economic factor is being considered, parents with lower socioeconomic status shown to have a poor QOL and require immediate intervention (Kumar, Santhosh, & Joseph, 2013).

Caring a child with a disability is a demanding effort irrespective of the type of disability such as attention deficit hyperactive disorder, mental retardation, autism, or learning disability. Both the parents of an intellectually disabled child will have a poor QOL but mothers are more affected by the lack of personal support network. Mothers also experience a perception

of stress in parenting associated responsibilities of a disabled child (Ravindranadan & Raju, 2008).

Need to be cared for a long time or throughout the life of their offspring create a negative impact on QOL of parents. Thoughts about their child's future - financial and frustrations about health care system, contribute to deteriorated QOL (Yonng, & Koritsas, 2012). Supportive services, accessible health care system, and residential set up for caring these children can aid in resolving this issue.

The transition from childhood to adulthood is a crisis not only for an individual but also for the family he/she belongs to. The QOL of parents with intellectually disabled children will have to face a major challenge during their child's transition from childhood to adulthood. High demand for caring needs, support services, and low spiritual faith can result in poor QOL of parents. (Bertelli, & Bianco, 2015).

Even though much resource is allocated to support the parents of intellectually disabled children, demand is much higher than what is provided. Parents may experience a good QOL but they always seek for supportive services on which they can rely upon. Care of their disabled child is their primary responsibility but the supportive services such as easy access to health care, vocational training, and social care are reported to improve the QOL (Caples, & Sweeney, 2010).

Well-being and stress

Children with intellectual disability are indicated risk factor for poor parental wellbeing. The relationship between the couple affects their wellbeing as supporting each other in caring the child has an effect on wellbeing. Marital quality and coparenting have a significant role in sense of wellbeing. Mothers of children with intellectual disability have a poor individual wellbeing, while compared to mothers of normal children (Norlin & Broberg, 2013).

Mothers of children with intellectual disability experience a moderate to high stress because of their child's behavior problems. There is a strong positive correlation between the lack of acceptance that the child is having disability and stress. Spiritual supports and use of adaptive coping skills have a negative correlation with parenting stress. Negative maternal

psychological wellbeing compensates the stress in parenting (Norizan, & Shamsuddin, 2010).

Dimensions of psychological wellbeing such as anxiety, depression, and stress of mothers are affected by lower levels of hope and more behavioural problems of the child. Higher hope will help in developing a positive effect and enhanced psychological wellbeing. Developing a hope among the mothers will aid improving the psychological wellbeing (Lloyd & Hastings, 2009).

A comparison on the subjective wellbeing and stress of the mothers of male and female intellectually disabled children shows that mothers of female children lie in a lower range in wellbeing and higher range in stress. The feeling of hope was found to be significantly good among mothers of male intellectually disabled children. Mothers of female intellectually disabled were more worried about their child's future, but the study shows that, mothers cared their children in the same way irrespective of their gender (Paliwal & Paliwal, 2015).

Conclusion

Review suggests that mothers of intellectually disabled children experience a poor QOL. Even though social support services are available, they are not sufficient to meet the exceeding demands. Services in social care, financial assistance, and easy access to health care services should be the focus of support. Intervention on developing hope, enhancing wellbeing, and stress management are crucial and is the immediate need for mothers with intellectually disabled children. While planning interventions for this population, economic status and longterm availability need to be considered.

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