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, Renjulal 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 research. 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 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 having intellectual 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).

How to cite this article: Anjali, K.G., Jose, T. T., Valsaraj, B. P., Nayak, A. K., Savitha, & Yashodharan, R. (2017). Quality of life of mothers having intellectually disabled children. Manipal Journal of Nursing and Health Sciences, 3(2), 67-72.
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, CINHAL, 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>
<thead>
<tr>
<th>Study</th>
<th>Type of study</th>
<th>Sampling technique</th>
<th>Age in years</th>
<th>N</th>
<th>Outcome</th>
<th>Tool used</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Norlin, &amp; Broberg, 2013</td>
<td>Descriptive Survey</td>
<td>Purposive sampling</td>
<td>33-39</td>
<td>236</td>
<td>QOL and Well being</td>
<td>Self-reported questionnaire on couple QOL and individual wellbeing</td>
<td>Mothers with children having intellectual disability showed low wellbeing and poor marital and couple QOL.</td>
</tr>
<tr>
<td>Norizan, &amp; Shamsuddin, 2010</td>
<td>Descriptive Survey</td>
<td>Purposive sampling</td>
<td>23-59</td>
<td>147</td>
<td>QOL and Parental stress</td>
<td>DASS21, COPE, Pediatric symptom checklist</td>
<td>Poor QOL and increased parental stress</td>
</tr>
<tr>
<td>Lloyd, &amp; Hastings, 2010</td>
<td>Descriptive Survey</td>
<td>Purposive sampling</td>
<td>23-57</td>
<td>138</td>
<td>QOL, Parental hope, and depression</td>
<td>Self-reported questionnaire on Hope, Affect and psychological well-being</td>
<td>Low level of QOL and hope. High levels hope correlated with low level of depression scores.</td>
</tr>
<tr>
<td>Yoong, &amp; Koritsas, 2012</td>
<td>Qualitative</td>
<td>Purposive sampling</td>
<td>55-77</td>
<td>12</td>
<td>QOL Caring</td>
<td>Structured interview</td>
<td>Caring for adult intellectually disabled children has both positive and negative effect on QOL.</td>
</tr>
<tr>
<td>Caples, &amp; Sweeney, 2011</td>
<td>Comparative study</td>
<td>Purposive sampling</td>
<td>33-81</td>
<td>49</td>
<td>QOL</td>
<td>WHO QOL questionnaire</td>
<td>Good to the excellent QOL among parents of children with intellectual disability availing respite care.</td>
</tr>
<tr>
<td>Boehm, Carter, &amp; Taylor, 2015</td>
<td>Descriptive Survey</td>
<td>Purposive sampling</td>
<td>64-80</td>
<td>27</td>
<td>QOL</td>
<td>Family QOL questionnaire</td>
<td>Family have low QOL with support from others, lowest QOL in the aspect of spiritual being.</td>
</tr>
<tr>
<td>Ravindran, &amp; Raju, 2008</td>
<td>Comparative study</td>
<td>Purposive sampling</td>
<td>25-50</td>
<td>200</td>
<td>QOL and emotional Intelligence</td>
<td>QOL Scale, emotional intelligence scale</td>
<td>There is no gender difference in emotional intelligence among parents irrespective of the condition of the child.</td>
</tr>
<tr>
<td>Paliwal &amp; Paliwal, 2014</td>
<td>Comparative study</td>
<td>Convenient sampling</td>
<td>Not mentioned</td>
<td>100</td>
<td>QOL</td>
<td>Subjective wellbeing scale, COPE inventory, caregiver stress test, multidimensional test for perceived social support</td>
<td>No significant difference in subjective wellbeing, social support and stress level among mothers of male and female intellectually disabled children.</td>
</tr>
<tr>
<td>Kumar &amp; Santhosh, 2013</td>
<td>Comparative study</td>
<td>Purposive sampling</td>
<td>30-37</td>
<td>240</td>
<td>QOL</td>
<td>WHO QOL questionnaire</td>
<td>Poor QOL is seen among mothers of intellectually disabled children</td>
</tr>
<tr>
<td>Malhotra Khan &amp; Bhatia, 2012</td>
<td>Comparative study</td>
<td>Purposive sampling</td>
<td>Not mentioned</td>
<td>240</td>
<td>QOL</td>
<td>WHO QOL questionnaire</td>
<td>Mothers in MR group had highly significantly impaired QOL in all the four domains as compared to mothers of normal healthy children.</td>
</tr>
</tbody>
</table>
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 a 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.

Acknowledgements

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.

Sources of support: None
Conflicts of interest: None declared
Source of support in form of grants: None

References


Cooper, E. (1991). In my opinion... helping parents cope with the reality of parenting a child with a disabling condition. Children’s Health Care, 20(3), 189-190.


