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ORIGINAL ARTICLE

Intellectual disability in children and teenagers: Influence on family and family health. Systematic review[☆]

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KEYWORDS

Family health;
Intellectual disability;
Family;
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Abstract

Objective: To examine the influence of a child or adolescent with intellectual disabilities on the family unit.

Method: A systematic review of the literature, following the recommendations of the PRISMA statement, was carried out on the PubMed, Scopus, CINAHL, PsycINFO and Psycodoc databases. Original articles were found, published in the last 5 years, in Spanish, English, Portuguese, Italian or French, with summary and full text and satisfactory or good methodological quality. Two independent researchers agreed on their decisions.

Results: In general, care is provided in the family, mothers assume the greater responsibility, and their wellbeing is lower than that of fathers. Having the support of the husband improves their quality of life. The fraternal subsystem can be affected, with regard to the warmth and the status/power of the relationship, and behavioural problems. Family health may be affected in all its dimensions: family functioning and atmosphere due to increased demands and changes in the organisation and distribution of roles; family resilience and family coping, due to rising costs and dwindling resources; family integrity could be strengthened by strengthened family ties. Quality of family life is enhanced by emotional support.

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Conclusions: These families may need individualised attention due to the increased demand for care, diminishing resources or other family health problems. Nurses using a family-centred care approach can identify these families and help them to normalise their situation by promoting their family health and the well-being of its members.

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PALABRAS CLAVE

Salud familiar;
Discapacidad
intelectual;
Familia;
Enfermería

Discapacidad intelectual en niños y adolescentes: influencia en la familia y la salud familiar. Revisión sistemática

Resumen

Objetivo: Analizar la influencia en la unidad familiar de la existencia de un hijo en edad infantil o adolescente, con discapacidad intelectual.

Método: Revisión sistemática de la literatura, siguiendo las recomendaciones de la declaración PRISMA, en PubMed, Scopus, CINAHL, PsycINFO y Psycodoc. Se localizaron artículos originales, publicados en los últimos 5 años, en español, inglés, portugués, italiano o francés, con resumen y texto completo y calidad metodológica satisfactoria o buena. Dos investigadores independientes consensuaron decisiones.

Resultados: Generalmente el cuidado se presta en la familia, asumiendo las madres la mayor responsabilidad, presentando menor bienestar que los padres. El apoyo del cónyuge mejora su calidad de vida. El subsistema fraternal puede afectarse en la calidez de la relación, el estatus/poder y los problemas comportamentales. La salud familiar puede afectarse en todas sus dimensiones: clima y funcionamiento familiar por las mayores demandas y modificaciones en la organización y distribución de roles; resistencia y afrontamiento familiares por el aumento de gastos y disminución de recursos; la integridad familiar puede reforzarse al fortalecerse los lazos familiares. El apoyo emocional favorece la calidad de vida familiar.

Conclusiones: Estas familias pueden necesitar atención diferenciada por su mayor demanda de cuidados, disminución de recursos o problemas de salud familiar. Las enfermeras, desde un enfoque de atención centrado en la familia, pueden identificarlas y ayudarlas a normalizar su situación, fomentando la salud familiar y el bienestar de sus miembros.

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What is known?

Illness and disability are phenomena which can form part of family life, leading to structural, procedural and emotional changes. Care for children with intellectual disability mostly falls on their families. Depending on the degree of intellectual disability, the care demands for these children may be a huge burden for the family and significant changes occur to their quality of life, affecting the family system as a whole.

What does this article contribute?

The disability of a child or teenager may alter the well-being and quality of family life of each of its members, as well as the family health which, depending on the family unit characteristics, may be affected in different dimensions, particularly with regard to family social

life, how the family functions, and the resistance and coping strategies of that family. An improvement in family integrity may be appreciated in those families who actively participate in caring for a disabled child. The importance of mutual helps groups for these families and the need for nurses to intervene stand out. They would be aimed at caring for the family unit, contributing to normalising the situation of these families and to improving their family health.

Introduction

Illness or disability is generally unpredictable phenomena, which may become part of family life leading to structural, procedural and emotional changes. They may impose huge burdens on the family, affecting their different sub-systems and the family health, which is understood to be the family's ability to function and to adapt to stressful life events, among which are the illness or disability of some of its members.^{1,2}

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