Augmentative and alternative communication practice in the pursuit of family quality of life: a review of the literature

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CRD summary
The authors concluded that augmentative and alternative communication practice (AAC) should take family perspectives into consideration and address problems in the joint contexts of child, family, school and community. Although the data presented appeared to support these broad conclusions, they should be interpreted cautiously due to lack of controlled evidence, heterogeneity between the studies and poor reporting of review methods.

Authors' objectives
To evaluate the effects of augmentative and alternative communication (AAC) practice on family quality of life.

Searching
ERIC, PubMed, PsycINFO and WilsonWeb were searched for studies published between 1985 and 2005. Search terms were reported. Augmentative and Alternative Communication journal was handsearched, as were reference lists of articles retrieved.

Study selection
Qualitative and quantitative studies of AAC practices for children with disabilities were eligible for inclusion provided they reported family perspectives, either on AAC practices used with their children or on the impact of such practices on their own family life. Most AAC users in eligible studies were required to be aged less than 21 years. Studies were excluded if they focused on the effects of specific AAC interventions and only marginally addressed family outcomes, or if they were conducted outside the United States. AAC was defined as “an integrated group of components including the symbols, aids, strategies and techniques used by individuals to enhance communication” (among other definitions).

Participants in studies in the review were families, caregivers, parents, individuals who used AAC and/or associated professionals. Children who used AAC had a variety of physical and intellectual disabilities ranging from mild to severe. The type of AAC device used varied, as did data collection methods. Outcomes reported in the review related to five domains of family quality of life (FQOL): family interaction; parenting; physical/material wellbeing; disability-related support; and emotional wellbeing (Hoffman 2006). The indicators associated with each domain were outlined in the review.

The authors stated neither how the papers were selected for the review nor how many reviewers performed the selection.

Assessment of study quality
Methodological limitations in the primary studies were assessed and reported descriptively. The authors did not state how the assessment was performed.

Data extraction
Outcomes data relating to FQOL were extracted and classified according to the five domains of the FQOL framework.

The authors stated neither how the data were extracted for the review nor how many reviewers performed the data extraction. One reviewer generated several themes that related to the data in each FQOL domain, then refined and finalised them in discussion with the second reviewer. Overall findings for each domain were summarised.

Methods of synthesis
Studies were combined in a narrative synthesis organised by domains and themes.
Results of the review
Thirteen observational studies were included in the review. Sample types and sizes varied (for example, from six to 165 individuals and from four to 114 families). Methodological quality was limited and common problems were: small sample size; low response rate; unrepresentative population (such as predominantly white middle class); selective outcomes reporting; and lack of rigour in statistical analysis.

Family interaction (seven studies): Some studies reported that AAC had a positive impact on aspects that related to relationships with nuclear and extended family, and on family communication styles and preferences. However, a need was identified for extended family members to be included in the process of planning for AAC and for the affected family's preferred communication style to be taken into account, especially among ethnic minorities.

Parenting (eight studies): Two studies reported that AAC devices helped ease some aspects of parenting tasks; other studies indicated an increased parenting workload, especially for mothers, that required time, energy and advocacy. They perceived a need for more information and training, especially on integrating AAC into family and community life (such as accessing support groups).

Physical/material well being (six studies): Introduction of AAC had a substantial financial impact on families, who expressed a need for information about funding mechanisms, vendor support and warranties available on devices.

Disability-related support (seven studies): Families requested partnership with professionals in AAC use and for attention to be given to their specific family needs. AACs needed to fit in to a child's social and community life and be adaptable to changing communication requirements over time. Parents needed to be made aware of their child's educational and social rights to permit informed parental choices.

Emotional well being (seven studies): AAC devices had both positive and negative impact in this domain. Professional insensitivity to family concerns during AAC implementation was identified as a source of frustration, but professionals were also identified as a primary source of social support.

Authors' conclusions
AAC practice should take family perspectives into consideration and address problems in the joint contexts of child, family, school and community.

CRD commentary
The review objectives and inclusion criteria were clear and relevant sources were searched for studies. The apparent limitation to published articles may have caused some studies to be missed. It was unclear whether there was a restriction by language. Steps were taken to minimise the risk of error and bias by having more than one reviewer involved in selecting qualitative themes in analysing the data, but the processes of study selection and validity assessment were not adequately described. It was unclear whether validity assessment was conducted systematically using predefined criteria. There was marked clinical and methodological heterogeneity in the review. The narrative synthesis of studies was appropriate, given the heterogeneity, but the findings were not supported by quantitative data that might indicate their clinical significance. Although the data presented appeared to support the authors' broad conclusions, they should be interpreted cautiously due to lack of controlled evidence, heterogeneity between the studies and poor reporting of review methods.

Implications of the review for practice and research
Practice: The authors stated that professionals should offer partnership to families of children using AAC, be sensitive to family goals, educate and assist family members to take responsibility for device use, and assist them in accessing social support. The FQOL framework was recommended as a useful tool.

Research: The authors stated that research on AAC should consider family, school and community members as stakeholders and consider using social validation procedures. Experimental and quasi-experimental study designs should be used and participants should represent a diverse range of families.
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This is a critical abstract of a systematic review that meets the criteria for inclusion on DARE. Each critical abstract contains a brief summary of the review methods, results and conclusions followed by a detailed critical assessment on the reliability of the review and the conclusions drawn.