

Critical Review: What are the barriers to augmentative and alternative communication (AAC) use in developing countries around the world?

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ABSTRACT

This critical review examines the published literature regarding barriers to AAC use in developing countries around the world. Study designs include three grounded theory designs and one case series design. Overall, the results indicate commonalities between barriers to AAC use in the countries of study. They include (a) funding, (b) time requirements, (c) access to AAC tech (d) lack of skills, knowledge and training of service providers and (e) lack of support from the AAC user's team. Results are limited to 3 developing countries in Africa. The articles reviewed have limited trustworthiness; future research is warranted.

Introduction

Augmentative and alternative communication (AAC) services are under-recognized and under-prioritization for individuals with complex communication needs, globally (Muttiah, Mcnaughton, & Drager, 2015). For individuals living in developing countries, accessing and implementing AAC is especially challenging (Muttiah et al, 2015). In these countries, people with all types of communication difficulties experience socioeconomic and sociodemographic based barriers to equal access to services; these barriers include living in rural versus urban settings, having less economic means, identifying with minority groups, and being a part of transient, migrant and indigenous populations, etc. (Wylie, Mcallister, Davidson, & Marshall, 2013). These individuals are also likely to have poorer health and education outcomes (Wylie et al, 2013).

Speech-language pathologists play a primary role in providing AAC services (Dada, Murphy, & Tönsing, 2017), but the number of SLP's practicing in developing countries is very small (Muttiah et al, 2015). The current research on SLP practices in AAC is also limited, especially in regard to AAC services in developing countries (Dada et al, 2017). In order to move forward with best practices, SLP's working in developing countries need to identify and understand the barriers that exist to AAC implementation.

Objectives

The primary objective of this paper is to critically evaluate existing literature regarding barriers to AAC use in developing countries around the world. The secondary objective is to provide recommendations for clinical practice and future research for SLP's specifically working in these developing economies.

Methods

Search Strategy: A variety of computer databases, including EBSCO, Science Direct, PubMed and Google Scholar were searched using the following terms:

(Augmentative and Alternative Communication) OR (AAC) AND (Barriers) AND (Developing Countries) OR (Low-and-Middle-Income Countries) OR (LAMI Countries). The search was limited to articles written in English between 2010 and 2019.

Selection Criteria: Studies were required to address barriers to AAC use; have participants from a developing economy as per the United Nations country classification document; and participants were required to be either AAC users, caregivers of AAC users or AAC professionals. No other limits were set.

Data Collection: Results of this literature search yielded 4 articles that adhered to the selection criteria. Three of the studies employed a grounded theory design for qualitative research. One article employed a single case series design.

Results

Grounded Theory Design

A grounded theory study design focuses on theory construction through the use of inductive qualitative research. The researcher collects data that is relevant to their topic of interest and identifies core theories or themes relative to the topic through methods of inductive content analysis. Therefore, the researcher's objective is to collect data rather than to prove or disprove a theory or hypothesis. This is an appropriate design choice for researchers interested in the perspectives and experiences of AAC users, their caregivers and their service providers (i.e. the studies reviewed below). Although the design choice is not explicitly discussed in each of the articles, it can be inferred via the researchers' study objective, method

of data collection, inductive analyses, and presentation of themes and subthemes.

Focus Groups

Focus groups are an appropriate qualitative method for researching barriers to AAC use in developing countries. They allow for the expression of multiple viewpoints and responses on a topic from a specific population. Participants can build discussions around ideas presented by group members; this leads to a more in-depth exploration of the topic. The disadvantages of focus groups include the potential constraints a group setting can place on an individual (i.e. social desirability effects) and the challenge of ensuring each participant is given an equal opportunity to contribute.

Tönsing et al (2018) conducted a series of focus groups with AAC service providers across South Africa to determine the current methods of negotiation for AAC services to multilingual clients. In addition, the study set out to discover how possibilities and limitations of available AAC systems influence the practice of service providers. In total, 15 AAC service providers (i.e. SLPs, OTs, PTs) took part in one of three focus groups; two were held face-to-face and one was held online. Each focus group was recorded, transcribed, coded and analysed. The following three themes were identified and discussed;

Current practice: current practices ranged from focusing exclusively on L1 or exclusively on L2 to a multilanguage approach.

Influences on current practices: service providers identified the following influential factors to service provision; (a) South African language context, (b) service provider's skills and knowledge, (c) language choice made by families, and (d) AAC technology.

Access to multiple languages through AAC: though many of the service providers viewed access to AAC in multiple languages as desirable and beneficial, there were concerns and reservations about providing these multilingual services.

The selection criteria employed in this study is appropriate and well defined. Participants were purposively selected for being registered with the Health Professional Council of South Africa and for offering clinical AAC intervention services in various settings. One weakness of the study is a very small sample size; the achievement of redundancy in data is not addressed by the authors. A limitation of the study is that the participants' language profiles were not representative of the South African population as a whole. There was an over representation of participant

with English and Afrikaans language backgrounds and an underrepresentation of participants with African language backgrounds. To expand on this limitation, it should be noted that the selection criteria may have resulted in a biased "status quo", as it excluded sectors of the population who do not receive services and therefore do not factor into service providers opinions (i.e. clients from African language backgrounds). The potential influence of a post-apartheid bias should also be considered.

The procedures were well defined for both the face-to-face and online focus group, but supplementary material used by researchers was not included (i.e. background questionnaire, scripts and questions). Two different execution methods were implemented to include participants from a larger geographical area, but the varied experiences of the participants may influence the trustworthiness of the data.

The data analysis was done using inductive descriptive coding process, but the process was not adequately described, and an audit trail was not clearly outlined. A serious weakness is that the initial coding scheme used in the analyses of the transcriptions was solely developed by one author; this lack of triangulation limits the credibility of the findings. Involvement of traditional authors in the initial stage of coding would have increased credibility.

This study provided a low level of trustworthiness resulting from low evidence of credibility, moderate evidence of transferability, low evidence of dependability and moderate evidence of confirmability.

Interviews

Interviews are an appropriate method for this type of research because they can be done with relatively low resources (i.e. quick and inexpensive) and are useful for exploring a specific issue in-depth. A disadvantage, however, is that the types of questions asked in the interview frame the participants responses and, therefore, question selection requires great attention. In addition, the information collected may be specific to an individual's experience and, therefore, not generalize to a larger population.

Singh et al. (2017) conducted one-on-one interviews with parents of AAC users in Malaysia to investigate caregiver perception of AAC and caregiver experience supporting children who use AAC. Twelve parents fit criteria (i.e. child with developmental disability, 3-12 years old, inadequate natural speech, AAC user >6m) and participated in a 30-60-minute interview consisting of a set of 11 open-ended questions.

Responses were transcribed and analysed using qualitative content analysis. The results of the analysis indicated three main themes;

Impact of the use of AAC: the majority of participants indicated that AAC had a positive impact on their child's communication and allowed the parents to better understand their child. Their children's AAC use did, however, lead the parents to worries about the child's future.

Challenges faced: internal challenges identified in AAC use included the children's a) lack of motivation and interest in AAC, b) lack of understanding the importance of AAC use, c) physical limitations in accessing AAC system, and d) influence of poor literacy skills on AAC use. External challenges identified in the use of AAC included a) time requirements, b) specific components of the AAC system, c) restrictive use of AAC in settings outside the home, d) cost, and e) support.

Hopes for the Future: results indicated that parents hope to see an increase in professional support for AAC use with their child, more information from professionals about AAC including information to help teach their child about AAC use, and resources for non-English speaking families.

The selection criteria for this study is well defined. Participants were purposefully selected from intervention programs for children with disabilities. A limitation to the sampling is that all participants were recruited from one major city in Malaysia. As a result, participants had better access to speech language pathologists and other professionals and were more likely to receive AAC support in comparison to elsewhere in the country. This limits the transferability of the findings. A weakness of the study is a small sample size; the achievement of redundancy in data was not addressed by the authors. There was also limited demographic information about the children involved in the study, with the exception of their developmental disability and age. This is important for building content in qualitative data.

The methods and procedures of this study were clearly described. One strength of the procedures is that the interviewer was fluent in both Malay and English, and interviews were conducted in participant's preferred language. In addition, the interview questions were developed based on a literature review and included by the authors. Face-validation was also conducted, and a pilot study was implemented with two caregivers who met selection criteria. These factors indicate good transferability.

Appropriate inductive analyses were conducted. The interviews were transcribed and analyzed using qualitative content analysis based on the procedures outlined by Graneheim and Lundman. This comprised of a detailed four-stage approach to determining themes and subthemes of the data. Graphics were included to assist in the understanding of these stages. Throughout the process various levels of crosschecking and peer checking occurred, which strengthens the credibility of the study. At the second stage the percentage agreement was calculated between the researchers and the independent reviewer and there was 88% agreement. The detailed decision trail developed for this analysis strengthens the dependability of this study and minimizes researcher bias. One limitation to the study is that no analyses were done to compare and contrast themes and subthemes between caregivers of children with ASD and caregivers of children with cerebral palsy. They are two very different developmental disabilities with different communication characteristics and needs; the caregiver demands, perspectives and challenges may vary.

This study provided a moderate-high level of trustworthiness resulting from moderate evidence of credibility, moderate evidence of transferability, good evidence of dependability and good evidence of confirmability.

Surveys

The primary intent of a survey is to listen to participants opinions and experiences in order to learn about a topic of interest. This is similar to focus groups and interviews, as previously discussed. Surveys tend to be limited and constrain participants in ways other qualitative methods do not. This is especially true if surveys include a limited opportunity to answer open ended questions. Therefore, it is difficult to ensure that the extent of a participants' experiences is conveyed in a survey. Other challenges of surveys include rating level inconsistencies, inadequate response options, assumptions of prior knowledge, etc. Although it may not be the strongest research method, it is still an appropriate design for researching barriers to AAC use in developing countries.

Dada et al. (2017) conducted online surveys to investigate current trends in AAC practice from the perspective of speech language therapists delivering AAC services in South Africa. A total of 77 registered speech language therapists, working in AAC in South Africa for at least a year, completed the online survey which consisted of 59 questions pertaining to biographical data; AAC assessment and intervention

practices; and practices in the selection and use of AAC symbols and devices. Both open and closed questions were included. Results were extensive but included that the major challenges to AAC implication are funding (86%), availability of AAC devices (80%), time constraints (77%), staying up-to-date with AAC developments (66%), low expectations for the individual who uses AAC (64%), and slow progress (62%). Results of the open-ended questions indicated a lack of current evidence based training; lack of support from the AAC users team (i.e. family, teacher, therapists, AAC professionals); lack of adaptation of the school curriculum to accommodate AAC user; difficulty creating useful low-tech AAC options; limited familiarity and availability of AAC systems/devices in other languages; and lack of trial equipment as challenges to implementation. Further results indicated that speech language therapists in South Africa use a limited variety of assessment and intervention approaches for AAC, current best practices are informed by previous experience, and primary caseloads do not appear to inform specific approaches to assessment and AAC implementation.

The selection criteria implemented in this study was well defined, but the recruitment strategies had limitations. The online recruitment approach made it difficult to determine a true response rate. Surveys were sent out via email distribution lists and social media platforms to increase sample size; this made it difficult to track recipients. The authors estimated there were 3111 initial recruits; if true, this indicates a low response rate and a small sample size (i.e. 77). In addition, the criteria called for SLTs to have a minimum of one-year experience providing AAC services but there is no way to verify this experience in South Africa. The majority of participants worked in higher resource provinces of South Africa, which limits the transferability of the findings. This may have been a result of the use of an online delivery method which could have posed a barrier to access for practitioners working in more rural areas of a developing country such as South Africa. Participants did, however, come from a wide range of work settings (public hospitals, private practices, universities, public schools, etc.), had varied amounts of experience working in AAC, and worked with adults, children, or both. This is a strength of the study.

The methods and procedures of this study were clearly described. The survey was developed based on credible pre-existing surveys and customized for the South African context. The survey was piloted on a group of experienced AAC SLT's in South Africa and, based on their feedback, it was changed to improve clarity, fix inconsistent terminology, refine definitions,

and restructure the survey in a more logical way. This strengthens the dependability of the study. A weakness of the study, however, is the number of eligible SLT's who started the survey but didn't finish it (i.e. 44). The authors attribute this to survey fatigue. Only completed surveys were included in the study but the results should be interpreted with caution.

Appropriate analyses were conducted. Descriptive methods of data analysis were used to analyze close ended questions (i.e. frequency tables). Chi-square analysis, with Cramer's phi used as a post test, was used to determine associations between SLTs' native language and the language of service delivery. A one-way ANOVA was used to determine if ratings between SLT groups differed depending on different primary caseloads. Inductive content analyses were conducted for open ended question responses. Data was organized and coded for common themes using Braun and Clarke's method. The first and second author independent identifies themes and subthemes until data saturation was reached. The third author then checked the other two authors codes and cycle of consensus coding between all three authors. This analyses approach strengthens the dependability and credibility of the of the study.

This study provided a moderate level of trustworthiness resulting from a moderate evidence of credibility, moderate evidence of transferability, good evidence of dependability and moderate evidence of confirmability.

Single Case Series

A single case series is a study design where data is collected on a series of participants with common characteristics, before and after an intervention, and without the presence of a control group. It is an observational, descriptive study design and, as with the grounded theory design, does not involve hypothesis testing. Rather, it is used to describe the participants experience and effectiveness of an intervention. Though it is an appropriate design method for the research topic, it is important to note that single case series are typically vulnerable to selection bias.

Gona et. al (2013) conducted a single case series to examine caregiver experiences of children with complex communication needs before and after the introduction of home-based AAC intervention in rural Kenya. Nine caregivers took part in the study. Each participant was a caregiver of a child age 4-12 years old, with limited or no functional communication, and with a recognised condition (i.e. cerebral palsy, cognitive impairment, deafness, ASD). Interviews

were conducted with the caregivers before intervention occurred and 6 months after the intervention was implemented. The interviews were qualitative in manner and focused on the child's communication with the caregiver and other people, the caregiver communication with child, available support and the caregivers view of the future. Interviews were translated, transcribed and analysed. Four main themes emerged from the data;

Communication process: in the pre-treatment interviews caregivers expressed that they relied on their own familiarity with the child (i.e. personal knowledge and experience) when interpreting the child's behaviours, inferring basic wants and suppling basic needs. In addition, caregivers expressed their reliance on the trial-and-error approach to decoding their child's communication attempts. In the post treatment interview, caregivers expressed an *opening up* of the communication context, and now capture new ways of understanding and communicating with the child.

Normality: in both the pre- and post-intervention interviews, caregivers expressed a strong desire for their child to be a normal (i.e. develop similarly to their peers) talker. A subtheme of wanting their child to be cured resonated throughout the interviews, as well as a desire for learning and academic achievement.

Struggle: caregivers identified feeling isolated from others, the financial burden of caring for the child, and the pain associate with caring for a child with complex needs as struggles prior to intervention. After intervention occurred, these struggles remained, but new perspectives were formed as noted by a positive shift in the language used by nearly all caregivers.

Supernatural power: caregivers frequently expressed their beliefs that supernatural powers were both the source and the potential answer to their child's condition.

The selection criteria for this study is well defined. The child participants were purposefully selected from the Educational Assessment and Resource Centre's (EARC) register using a purposive-convenience sampling procedure. The resulting sample represented all four categories of primary conditions outlined in the study (i.e. CP, CI, ASD and deafness), included a balanced age range, and a balanced male to female ratio. The caregivers were all committed to implementing the AAC home-intervention and taking part in the interviews. One weakness of the study is the small sample size (i.e. 9).

All caregivers were interviewed by one researcher. This researcher conducted the interviews in the participants local language, and he was unknown to the participants and their families. These are strengths of the study. The study did not provide detailed information about specific questions addressed in the pre- and post-intervention interviews and provided relatively little information on the post-intervention interview process. This is a weakness of the study.

The procedures used to create the individualized intervention plans were thorough and clearly outlined. Information regarding the children's speech and language skills, the family dynamic, and environmental factors were collected and used to determine an appropriate intervention approach. Individual goals were developed based on the International Classification of Functioning, Disability and Health for Children and Young People and each intervention program was developed to be technically valid, economically feasible, and socially and culturally acceptable. Although the Communication Profile was administered pre- and post-treatment, associated data is not included this study.

Appropriate qualitative content analyses were applied and included text familiarization, topic organization, theme and subtheme identification, connection forming and data interpretation. A strength of the study is that a second, independent, analysis of the data was conducted to enhance the validity of the research findings and the two analyses were cross-checked to identify and discuss any conflicting ideas until a consensus was met. One limitation of the study is that the positive changes indicated by the data cannot be attributed to a specific component of the home-based AAC intervention.

This study provided a moderate level of trustworthiness resulting from a moderate evidence of credibility, moderate evidence of transferability, good evidence of dependability and moderate evidence of confirmability.

Recommendations

The results indicate that there are commonalities in barriers to AAC use within the developing countries studied (i.e. South Africa, Kenya, Malaysia). These barriers include (a) funding; (b) time requirements; (c) access to AAC tech; (d) lack of skills, knowledge and training of service providers; and (e) lack of support from the AAC user's team. Less common, but important, challenges identified in the studies include the physical restrictions of the AAC user, the lack of adoption of AAC use in environments outside of the home, and the presence of supernatural influence.

An important idea explored throughout the research is the role that the diverse African language context plays on AAC use and availability. There is a lack of available language and cultural appropriate AAC technology options for users (i.e. AAC tech equipped with African language options and graphics that represent the cultural needs and realities of the user). There is a need for multilingual AAC device options for individuals whose language of use in the home differs from their language of use at school or work.

It is important to note that all of the studies reviewed were conducted in developing countries in Africa, and most took part in urban areas where education levels are higher, economies are stronger, and resources are more plentiful. Not only does this limit the scope of the review to the African continent, it also limits the ability to generalize the finding to population with reduced resources in rural areas of these countries.

Future research is warranted to better understand the barriers to AAC in diverse socioeconomic, sociodemographic and cultural contexts found within the developing countries of the world. To improve the level of trustworthiness provided by the existed literature and increase confidence for clinical implementation, it is recommended that future research take the following into consideration:

- a. Future research should employ study designs that lend stronger levels of evidence and incorporate larger sample sizes
- b. Future publications should provide more in-depth demographic information for participants.
- c. Research should be conducted in developing countries outside of the continent of Africa.
- d. Research should target both rural and urban demographics to account for changes in socioeconomic and sociodemographic factors within a country.
- e. Future research should be representative of the language context in the country of study.

Clinical Implications

Although the level of evidence provided by the articles reviewed has limited trustworthiness, they did provide important findings for which to direct future research. Based on the findings of the review, it is suggested that clinicians use caution when applying and/or generalizing the findings to demographics that fall outside of those explored in the studies.

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