

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION INTERVENTION: A LIFESPAN ISSUE

ABSTRACT: *The purpose of this article is to reflect on the needs of people with little or no functional speech and the difficulties they experience throughout their lives. The mismatch between the needs of Augmentative and Alternative Communication (AAC) users and intervention provided is explored by firstly addressing the need for AAC users to become an integral part of the intervention team and in this way to professionalise consumer input. Secondly, the need for a more collaborative approach to team work is highlighted to ensure more effective problem-solving of lifespan issues. Finally some brief comments are made about the role of the physiotherapist as part of the AAC intervention team.*

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INTRODUCTION

In the past there has been increasing awareness of the importance of communication for daily living. Consequently, there has been a growing realisation of the limitations and restrictions of service-delivery models in addressing the needs of individuals - and in particular the needs of those who have very little or no functional speech. This realisation has to a large extent contributed to the fast development of the field of Augmentative and Alternative Communication (AAC) over the last 30 years. AAC refers to the use of different modes of communication in order to supplement or extend an individual's verbal communication, thereby enabling him to convey messages more effectively. AAC strategies could include the use of aided systems (e.g. the use of communication boards and technology) as well as unaided systems (e.g. the use of gestural systems and vocalisations). These strategies are thus intended to facilitate communication by extending the range and quality of the messages.

The anxiety that the inability to communicate creates for people who have very little or no speech, has however been ill understood as professionals tended to focus on current needs and requirements without a lifespan orientation towards intervention. This means that individuals with severe disabilities

are relatively well catered for as long as they attended school, but once they leave school, they are left on their own without any infrastructure for support except their immediate family. A lifespan approach to planning and intervention focuses on the facilitation of activities of daily living (ADL) as well as the encouragement of individuals and their families to develop resources and coping mechanisms for the future. This approach therefore emphasises aspects such as:

- Functional living and the modification of current skills to address future needs
- Empowerment of the individual and the family to cope with difficulties on an ongoing basis by, for example, teaching skills in problem solving, networking, and how to access resources in the community
- Involvement of the person with disability and the family as vital role players in the decision-making and intervention processes

The significant impact of the lack of focus on lifespan issues in intervention can be seen by the difficulties adults with disabilities experience in coping in the community. This situation is emphasised by Richard Fosler (1998:7) who described his anxiety in facing his dete-

riorating physical condition, without a secure support system "My greatest fear about my deteriorating health was being trapped in my body with no way to communicate."

The present paper intends to explore a source of information that has always been neglected - listening to AAC users and their stories to guide the direction of interventions. Secondly, this paper addresses the importance of a lifespan approach to intervention and emphasises the role of teamwork. Finally some comments are made about the role of the physiotherapist in AAC implementation.

AAC USER PERSPECTIVES

The need to involve AAC users more directly as part of the intervention process has been identified by various experts in the field of AAC. Although some studies have been attempted to describe AAC intervention from the perspective of the user, most of these seem

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limited in providing clear perspectives. McCall, Markova, Murphy, Moodie & Collins (1997) identified a shortage of systematic evidence concerning the impact of communication devices on the quality of communication of the individual in daily life. They identified a void in the knowledge of the perceptions of AAC users particularly in relation to the impact of technological advances. Studies conducted to investigate the perspective of the AAC users have often been limited to the description of AAC users' particular preferences in relation to devices e.g., the case study conducted by Soto, Belfiore, Schlosser and Haynes (1993) in which the individual was asked to express his preference in relation to an electronic system or a low technology communication board with an identical overlay. Huer and Lloyd (1990) produced a summary of 165 AAC users' perspectives gleaned from articles published between 1982-1987. From this analysis common themes emerged e.g. feelings of frustration, attitudes towards professionals and issues concerning communication partners. Users often commented on professionals' insensitivity to the suggestions of AAC users. Their contributions were often regarded as less important due to the strong emphasis on professional input and values during the rehabilitation process.

To further enrich our understanding of the perspectives of AAC users, the life stories of three AAC users were analysed in order to identify common themes that could guide intervention. The three individuals were Richard Fosler, a banker (Fosler, 1998); Jim Renuk a lecturer (Renuk, 1998); Lake Kissick, a writer (1984). The following common themes emerged from their autobiographical descriptions:

- A late start to communication in their lives; difficulties with physical problems and / frustration with inadequate communication systems
- An intense struggle to communicate
- The key role of parents in solving general problems and more specifically those related to communication
- The important role of technology in their lives

- The long wait for access to a computer
- The difficulties in acquiring literacy skills
- The difficulties with technology and requirements (knowledge and skills) to keep up with changes
- The anxiety when having to cope on their own after having been dependent

From the above it is clear that most of their frustrations revolved around predictable issues namely, access to communication and literacy skills, dependency on technology, dependency on family and caregivers and lack of independence. Although one could argue that all people have to cope with change throughout their lives, accommodating change is much more difficult for people with severe disabilities due to their dependence on others. In fact, this implies that intervention needs to be orientated toward dynamic changes in the life of the individual, rather than focusing only on the current needs of the individual. This kind of intervention would aim at advancing the concept of promoting the development of the skills for self-advocacy in preparation for the day when a student faces a learning difficulty without the safety net of special education programs. One needs to see each person with little or no functional speech as a lifelong learner and develop a lifespan approach to problem solving that not only provides an immediate service, but also supports the long-term goals of self-advocacy for learners with little or no functional speech. Intervention then becomes focused on the concept of implementation for change, thus preparing the individual and the family for the transitions that need to be made throughout life. The question arises as to what a lifespan orientation towards intervention would entail? This kind of approach to intervention would imply focusing on the improvements or deterioration in abilities of the individuals, improvements or changes in technology relevant to the person as well as temporary or permanent contextual changes that might take place in the person's environment, for e.g. moving from the parents' home into a group home. In addition, it is also

important to consider the different rates of change that can occur as deterioration accelerates or retards as well as the changes that could occur in the partners over time, for example, the impact of age on parents' ability to support a young adult with severe disabilities.

IMPLICATIONS FOR INTERVENTION

The challenge, therefore, is how to plan intervention to ensure that it becomes more lifespan orientated and thus provides the individual with severe disabilities with the skills to cope with changes. A lifespan approach needs to be team driven to ensure systematic and goal directed intervention. This entails the inclusion of the family members and the AAC users themselves as major decision-makers in the process. Although the principle has been accepted in theory, the practical application of including the AAC users and their families as full members of the intervention team has been less successful. Although the reasons for this lack of success could be most complicated, Geb Verburg (1995), an AAC user, has some ideas on how this process can be facilitated. He poses the following question "How can we expect to treat people as invalids, as lesser beings, to ignore them or to barely listen to them when they are in our "care" and expect them to do the right things the minute they step out of our hospital (rehab centre, etc)?"

He maintains that much more power needs to be given to the consumer as the field of disability is removed from health care into the jurisdiction of social justice. According to him three issues are central namely, the dilemma of power in the helper/helpee relationship, attitudes or kindness and help, and lastly the professionalisation of consumer input.

Although much has been written about the doctor/patient or helper/helpee relationship, it is clear that relevance and appropriacy of intervention to a large extent depends on the mutual understanding between professional and client during intervention. A persistent imbalance of power between the provider and the receiver of the service largely contributes to the counter-productive attitudes, which prevail so often during the process of intervention. Clients should

be encouraged to make decisions about their own intervention and health and in this way they need to be encouraged to take responsibility for their own life. "If we really want people to take responsibility for their own body, their own health, their own lifestyle then surely we must not treat them as if they are less competent, less responsible, ignorant, and unable to make decisions regarding their own life" (Verburg, 1995).

A second issue identified by Verburg relates to the belief that subjects of services, for example people with disabilities, are being done a favour. Helping has the connotation of "doing good" and whilst this might be true, the expectation is that the subject of this process needs to be grateful and is certainly not expected to "hate the people who did the "good"" (Verburg, 1995). He explains that the professionals themselves get much reward from this relationship as they don't only benefit financially, but also socially as they are seen to be providing services to sufferers. He emphasises the need to do away with the helping, do away with the patient and let health care and rehabilitation become a service provided to paying customers by professionals. People with disabilities need to be the principle decision-makers in their own health and lifestyle decisions and exercise these abilities in the relative "safety" or supportive environment of the rehabilitation centre or hospital in preparation for independence.

The third issue identified by Verburg relates to the professionalisation of consumer input. He emphasises that although there has been a rise in the philosophy of consumer involvement internationally, there is limited evidence that consumers are directly involved in the process of evolving this participation. He explains that the creation of a small group of consumers and professionals who are involved in research and development of products greatly misguide the role and function of consumer input. "By asserting that the process of extracting "valid data" from focus groups is a very complex process that must be carried out by professionals, this approach re-inserts the professionals back into a segment of the decision-making chain where the consumer ought

to be directly in charge of the input and feedback. The process of development and more so the process of device prescription is already too professional-controlled" (Verburg, 1995).

CONCLUSION

The implications of Verburg's discussion for the intervention process are multiple, but perhaps the most important relates to the collaborative nature of intervention and the need for the person with severe disabilities to take ownership of the process. The notion of collaborative consultation can be described as "an interactive process that enables people with diverse expertise to generate creative solutions to mutually defined problems. The outcome is enhanced, altered and produces solutions that are different from those that the individual team members would produce independently" (Coufal, 1993). To be involved in a collaborative process requires specific skills to ensure a context congenial to include not only professionals, but also AAC users and their families as an inherent part of the process. These skills could include:

- Identification of family's interaction patterns and their perspectives as well as those of the AAC user in terms of coping with disability.
- Application of different strategies in which these perspectives can be integrated to ensure the AAC user and family's inclusion as vital members of the rehabilitation team.
- Flexibility in integrating physical rehabilitation within the framework of transition and future planning.
- More focused attention and training to facilitate the AAC user and family's ability to gain access to community resources to facilitate physical coping in integrated community settings.
- Use of strategies to facilitate transdisciplinary team work between members of the rehabilitation team.

How successful are we in training professionals to become sensitive team players with our clients? For example, what clinical competencies do we expect from speech, occupational and physiotherapy students that could facilitate the

development of these skills? Simuzingili and Amosun (1998:11) described the competencies expected from physiotherapy students at the University of the Western Cape. Although impressive and relevant, it is not clear where in this list the skills related to team building would be included. This comment could probably be extended to most professional training programmes as we build philosophies around the process of teamwork.

The profession of physiotherapy has a significant role to play in the intervention of people with little or no functional speech as a significant percentage of these clients are physically severely challenged. AAC users mentioned in this article focused on their frustrations as they had to not only wait to get access to communication devices and systems but also had to contend with the reality that they had been poorly prepared to function independently in society. To become more effective in intervention requires not only dedicated teamwork, but also the inclusion of all relevant professionals as part of this team. Physiotherapists need to be orientated towards integrated rehabilitation to facilitate function in the community. Strategies aimed at facilitating the development of lifeskills, communication and transitional issues need to be emphasised. In the field of AAC in particular, physiotherapists need to play a more rigorous role in facilitating independent living by identifying ways in which physical difficulties can be accommodated or integrated in daily life activities. Besides utilising their specific skills, such as facilitating functional positioning and purposeful movements, which will give the AAC user access to his communication systems, physiotherapists should have a knowledge and skills to interact using these systems. Internationally, as well as in South Africa, physiotherapists have been slow to become involved in the field of AAC. It is clear, for the field of AAC to develop, we need more involvement from physiotherapists. Only by providing the AAC user with enough support and guidance to become functionally independent can we really move towards meaningful service.

REFERENCES

- Coufal, K. 1993. Collaborative consultation for speech-language therapists. *Topics in Language Disorders*, 14(1): 1-14
- Fosler RH. 1998. Looking for the right communication device. *Communication Outlook*, 18(2/3): 6-8.
- Huer MB, Lloyd LL. 1990. AAC users' perspectives on augmentative and alternative communication. *Augmentative and Alternative Communication*, 6:242-249.
- Kissick LN. 1984. Communication devices and an enriched life. *The exceptional parent*, June: 9-14.
- McCall F, Markova I, Murphy j, Moodie E, Collins S. 1997. Perspectives on AAC systems by the users and by their communication partners. *European Journal of Disorders of Communication*, 32: 235-256.
- Renuk J. 1998. Searching. *Communication Outlook*, 18(2/3): 9-10.
- Simuzingili T, Amosun SA . 1998. What clinical competencies do we expect from physiotherapy students at the University of the Western Cape? *SA Journal of Physiotherapy*, 54(4): 10-14.
- Soto G, Belfiore PJ, Schlosser R, Haynes C. (1993). Teaching specific requests. *Education and training in mental retardation*, 28:169-178.
- Verburg G. 1995. Wouldn't it be nice if.... *Communicating Together*, 12(2):21-22.