

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION: THE ROLE OF COMMUNITY NURSES IN THE REHABILITATION OF PEOPLE WITH SEVERE DISABILITIES

Erna Alant

D. Phil

Director: Centre for Augmentative and
Alternative Communication, Dept of
Communication Pathology,
University of Pretoria

ABSTRACT

This article focuses on the importance of community nurses' involvement in the identification and early referral and intervention of children and adults who have very little or no speech. The use of Augmentative and Alternative Communication strategies with nonspeaking children and adults are described in terms of the different kinds of systems that can be used as well as the general principles involved in working with people with severe disabilities. In conclusion, it is emphasized that close collaboration between community nurses and rehabilitation specialists is vital in ensuring that a difference is made in the lives of people with severe disabilities in this country.

... it is emphasized that
close collaboration
between community
nurses and rehabilita-
tion specialists is vital ...

OPSOMMING

Hierdie artikel handel oor die belang van die betrokkenheid van gemeenskapsverpleegsters in die identifisering en vroeë verwysing en intervensie van kinders en volwassenes wat min of geen spraak het nie. Die gebruik van aanvullende en alternatiewe kommunikasie strategieë met kinders en volwassenes word bespreek in terme van die verskillende soorte stelsels wat gebruik kan word asook die algemene beginsels by implementering. In die finale instansie word noue samewerking tussen gemeenskapsverpleegsters en rehabilitasie spesialiste gesien as noodsaaklik om te verseker dat 'n betekenisvolle verskil gemaak word in die lewens van mense met erge gestremdhede in ons land.



Research

INTRODUCTION

The role of nurses in the caring of people with disabilities has been widely acknowledged, particularly as the philosophy for intervention changed from institutional to community-based care and intervention. In the early history of American nursing, people like Dorothea Dix pressed for special training for children with severe disabilities whilst another nurse reformer Lilian Wald sought to enhance the care of people in the community (Musholt 1995:295). Due to the close involvement of community nurses within community settings, the role of these professionals in the detection and case identification of people with disabilities has been well recognized internationally.

However, the nurse's role in the rehabilitation of people with mental impairments has also become more prominent in recent years (Nehring 1991). It's against this background that this paper aims to discuss the need for community nurses to become more aware and actively involved in the identification and primary level intervention of children and adults who have little or no ability to speak in an attempt to facilitate an awareness of the importance of early intervention.

This is a non-empirical study aimed at exploring the role of community nurses in early intervention of people with severe communication disabilities. The term "nurse or community nurse" as used in this study refers to those primary health care workers who work in generic community settings and are intricately involved in health care and health promotion.

As the custodial care model changed to an educational care model of people with severe disabilities, the role of the nurse in facilitating the development of adaptive life skills also increased. Barnard (1975:1702) stated that the involvement of nurses in the process of lifeskill teaching is "vital to the progress in the field since it is live activities which are germane to nursing practice, but represent the crux of the problem for the handicapped and their families".

This implies that community nurses play a most important role in facilitating the person with severe disability's independent living skills in the com-

munity. Not only do nurses have to identify cases, but to an increasing extent they have become very important facilitators of lifeskill intervention for people with disabilities.

This role change brought with it a whole new set of professional demands for which nurses are not necessarily trained. Musholt (1995:303) stresses that "Unfortunately, nurses in generic community-based health settings, such as outpatient clinics or public health departments often lack the necessary information and training to meet the unique health care needs of persons with disabling conditions".

This need was recognized by the American Nurses Association in 1978 and guidelines for continuing education in developmental disabilities were developed. However, the problem still remains as nursing curriculums have to include an increasing number of medical and technological advances as well as accommodate important health concerns (Nehring 1991).

The need for a new look at nursing education and training to address the increasing need for transcultural nursing in South Africa has been addressed by various researchers (Villiers & van der Wal 1995a; Villiers & van der Wal 1995b). This approach focuses on the importance of socio-cultural understanding to deliver congruent cultural care.

As discussed in de Villiers and van der Wal (1995b: 61) socio-cultural understanding also refers to a sensitivity towards the perceptions of the community regarding health and disease. Of vital importance, however, is also the nurse's understanding of the perceptions and attitudes of the community towards children and adults with disabilities.

Perhaps one of the most neglected areas of awareness and intervention in the South African context relates to the problems of people with severe disabilities, i.e people who extensively rely on others for help due to either mental, sensory and/or physical problems, or a combination of disabilities.

In particular, there is a lack of awareness of the impact of severe communication difficulties on the psychological and physical well-being of the individuals with disabilities and their families.

THE INCIDENCE OF SEVERE DISABILITY IN SOUTH AFRICA

It is estimated that roughly 10-12% of the population is disabled and at least 20% of these people have severe disabilities. This population who is dependent on extensive environmental support in order to function, is most heterogeneous and includes from people with severe physical impairment who are cognitively normal to people who are severely mentally and sensory impaired (Alant & Emmett 1995).

As these people can be a tremendous drain and a burden on family and community resources it is important to expose people with severe disabilities to intervention as early as possible to prevent the development of total dependence due to lack of intervention. In a study conducted by Stein, Belmont & Durkin (1987) it was found that developing countries have a much larger incidence of people with severe disabilities than Western countries.

On closer scrutiny however, it became clear that people labelled as severely disabled in developing countries are often only mildly impaired, but due to lack of intervention and early detection are labelled as severely disabled. This situation is particularly prevalent in South Africa in relation to the incidence of people who are nonspeaking.

In a recent study (Alant & Emmett 1995) it was found that 39% of children in schools for children with severe disabilities in the Pretoria metropolitan area can be described as nonspeaking (thus less than 15 functional words). This incidence is very high in relation to studies in the USA (Burd, Hammes, Bornhoeft et al 1988; Matas, Mathy-Laikko, Beukelman et al 1985), Europe (Coon, Kremer & Hildebrand-Nilshon 1992) and Australia (Bloomberg & Johnson 1990) which indicated a 4 - 6 % incidence of nonspeaking children in the same population.

As in the South African study all these international studies excluded children who are primarily sensory impaired (e.g. deaf or blind) as the area of deaf education has not traditionally been included within the field of AAC. This is important, particularly in view of the comments made in the

rest of the article, all of which will not necessarily apply to Deaf people. When referring to nonspeaking people, reference is therefore made to all those people who can hear (or have some hearing ability) but have no or very little speech.

Nonspeaking people in South Africa are mostly home-bound, have no access to education and training and therefore have very little opportunity of becoming independent in our community or to learn to participate meaningfully in society, even though the vast majority of these people have the ability to do so. This is particularly significant as 20% of all nonspeaking people are cognitively normal (Matas et al 1985), but due to negative attitudes of people in the community these nonspeaking children are often not exposed to learning opportunities. The impact of being nonspeaking cannot be overemphasized as it is often associated with total isolation from family members and the community in which they live. Speaking people experience great difficulty in developing a relationship with nonspeaking people as having no way in which to communicate with each other greatly limits interaction, and thus also mutual understanding. Being nonspeaking often carries the additional label of "being stupid" and therefore "written off" by society. It is against this background that it is vitally important that nurses and other professionals seriously address their own biases in working with these people. In supporting them in society we have to challenge our own beliefs about safety and protection, human dignity and self-esteem, medical care necessity and innovative health care (Musholt 1995: 294).

Community nurses therefore not only need to identify nonspeaking people in the community, but also start the process of active involvement and intervention to facilitate the development of communication.

To achieve this aim implies that the nurse needs sufficient information

and training to cope with these situations. "Nurses need to: consider allied medical needs that accompany specific syndromes, consider alternative ways of communicating when a person is unable to verbalize...and to create new ways of interacting with people whose developmental level is complicated by cognitive impairments" (Musholt 1995: 303).

It is against this background that the community nurse's knowledge of augmentative and alternative communication (AAC) strategies becomes relevant.

THE USE OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION STRATEGIES (AAC)

AAC can be defined as the use of less frequently used modes of communication to facilitate the interaction of the person who has very little or no speech. These strategies include both aided communication strategies (the use of aids, for example communication boards or communication devices) as well as unaided communication strategies (the use of gestures in communication). In most cases the individual will use a combination of these strategies to enable him/her to cope in different communication situations.

For example, the individual may be able to use gestures with the family, but will be dependent on a communication board when communicating with others in the community. This implies that any communication system should be personalized to ensure that it addresses the variety of communication needs of the individual and his/her family. Although communication devices can be expensive, most of the low technological options only require minimal resources and the initiative to start!

Some basic principles of AAC intervention will be discussed to facilitate an understanding of the underlying philosophy of these strategies.

BASIC AAC INTERVENTION PREMISES

Four main principles of AAC intervention can be identified:

- Communication means access to life. Without a communication system the individual is unable to participate in those activities which form an integral part of human existence. Everybody can communicate - the way in which people communicate, may however differ.

- How the individual communicates is not important, that he/she communicates is much more important. The best guarantee for a child or adult to learn to speak (if it is at all possible) is for them to be motivated to make contact and to interact with people. Therefore the general principle is to introduce AAC strategies when in doubt; the use of these strategies can always be withdrawn once they seem redundant.

- An individual will only use a communication strategy if it addresses a real need in his/her life. It is therefore of cardinal importance that AAC strategies are introduced within the family and community context. Only by training relevant communication partners (e.g. peers and siblings) can these strategies be used meaningfully.

- A vital part of developing the ability to communicate relates to the expectation that the individual can communicate and needs to do so. It must be accepted that any individual can communicate, but that in order to develop this skill, he/she needs to be given the opportunities to do so. Thus, people in the environment must expect the nonspeaking person to communicate. Rich Creech, an AAC user (Musselwhite 1988:ix) expresses it as follows: "The closest simile as to how people treat nonspeech people is how they treat pet dogs...think about it for a minute.

How much difference is there? People take good care of pet dogs. They give them love, food, warm homes,

A vital part of developing the ability to communicate relates to the expectation that the individual can communicate...

attention when they are not busy. And people don't expect much out of their pet dogs. Just affection and obedience. This is the sad part. People just don't expect much from nonspeech people".

The role of the community nurse in facilitating the development of communication in people with severe disabilities.

It is clear that with a shortage of nurses and the range of abilities required of community nurses it is unrealistic to expect specialist knowledge of these professionals. However, as Musholt (1995: 307) states, "With the advent of people living in the community who have complex health care needs, the generalist nurse will need to draw on many new resources to provide quality care. As more technological information unfolds concerning specific health conditions or syndromes, nurses will need to know the implications of these conditions on their nursing assessment, plan, interventions and evaluations".

This implies that the nurse needs to be aware of intervention possibilities in order to refer clients and to encourage them to create learning opportunities for people with special needs.

In the South African context, where access to speech and language therapists is generally poor, contact with a community nurse could be the decisive factor in whether a person who is severely disabled will have any opportunity of developing his/her ability to communicate. Only by identifying the problem can intervention be started. The important role of the nurse in the process of detection and identification of nonspeaking people can thus not be overemphasized. Children and adults who are not speaking or have a very limited speech output, should be identified and referred to speech therapists to facilitate the development of communication skills. In addition, however, the nurse who has some specialized knowledge would be in a very favourable position to facilitate the process of intervention in contexts where other professional help might be unavailable.

It is within this framework that some information on the use of AAC strategies in the training curriculum of community nurses may not only have a

significant effect on the nonspeaking person and his family, but also contribute to a reduction in the incidence of people with severe disabilities in our country.

The knowledge and skills of AAC and severe disabilities that is included in such a curriculum needs to be well defined to ensure optimal practical use and application.

Topics for training could include firstly, the identification of attitudinal barriers in the community and the importance of information-giving in facilitating attitudinal change; secondly, the basic use of gestures and graphic symbol systems (pictures, line drawings) in getting a nonspeaking person to express him/herself and finally, minor adaptations that can be made to the environment or equipment to facilitate the individual's exposure to learning opportunities or participation in the community.

This aspect could include:

- showing parents how to handle and position a child with severe physical problems (i.e. the use of boxes, paper technology)
- the making of simple adaptations to toys to enable a child with severe physical disabilities to play by for example using velcro. Also, the making of simple adjustments to eating and drinking utensils to facilitate independence in daily living activities.
- practical changes in and around the house to facilitate the individual's independence in mobility

CONCLUSION

This article stresses the need for community nurses to become more involved in the identification and intervention of people with very little or no speech in South Africa. The need for intervention of children with no or very little speech was described in a survey conducted in 19 schools for children with severe disabilities in and around Pretoria (Alant & Emmett 1995).

The findings of this survey indicated a very high incidence of nonspeech in this group of children. Lack of intervention due to poor access to and availability of speech-language therapists as well as other rehabilitation professionals necessitates the in-

volvement of community nurses to facilitate this process.

As the community nurse in many instances constitutes the disabled person's only contact with intervention, her awareness and knowledge of specific communication systems that can be used can be critical in starting the process of communication intervention.

To cope with these demands, however, require the inclusion of specific knowledge and skills relating to severe disabilities and augmentative and alternative communication strategies in the curriculum for training of community nurses.

This knowledge and skills should be well defined and relevant to ensure practical implementation within community settings.

This kind of transdisciplinary approach towards intervention, however implies a close interaction between rehabilitation specialists and community nurses to ensure a supportive framework that promotes a realistic and meaningful work situation. Professionals (nurses and rehabilitation workers) need to operationalize their joint commitment towards positive change in the communities.

Only by collaborative team work between communication therapists, other rehabilitation experts and community nurses can a difference be made in the lives of people with severe disabilities in this country.

References

- Alant, E. & Emmett, A. B. (1995).** Breaking the silence: communication and education for nonspeaking children. Pretoria: HSRC publishers.
- Barnard, K. (1975).** Trends in the care and prevention of developmental disabilities. *American Journal of Nursing*, 75, 1700-1704.
- Bloomberg, K & Johnson, H (1990).** A statewide demographic survey of people with severe communication impairments. *Augmentative and Alternative Communication*, 6,1, 50-60.
- Burd, L ; Hammes, K; Bornhoeft, D & Fisher, W. (1988).** A North Dakota prevalence study of nonverbal school-age children. *Language, Speech and Hearing Services in Schools*, 10, 4, 371-383.
- Coon, R; Kremer, G & Hildebrand-Nilshon, M (1992) .** A demographic analysis of people with speech impairments in West Berlin, Germany. *International Society for Augmentative and Alternative Communication: fifth biennial international conference: Philadelphia.*
- De Villiers, L & Van der Wal, D. (1995a).** Putting Leininger's nursing theory "culture care diversity and universality" into operation in the curriculum - part 1. *Curationis*, 18, 1, 56 - 60.
- De Villiers, L & Van der Wal, D. (1995b).** Including transcultural nursing content in the curriculum - part 2. *Curationis*, 18, 4, 61 - 64.
- Matas, J; Mathy-Lalkko, P; Beukelman, D & Legresley, K. (1985).** Identifying the nonspeaking population: a demographic study. *Augmentative and Alternative Communication*, 1, 1, 17-31.
- Musselwhite, C R. & St Louis, K. (1988).** *Communication Programming for persons with severe handicaps.* Boston: College-Hill.
- Musholt, M. (1995).** *Nursing Services.* In Karan, O & Greenspan, S (eds). *Community rehabilitation services for people with disabilities.* Boston: Butterworth-Heinemann.
- Stein, Z; Belmont, L & Durkin, M. (1987).** Mild mental retardation and severe mental retardation compared: Experiences in eight less developed countries. *Upsala Journal of Medical Science*, 44, 88-96.

