

**The development of a primary level
communication intervention protocol for
children with severe disabilities**

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Terminology

Adult learning

The literature lists four features that distinguish adults from children in their learning: self-directedness, a rich experience base, the need to address real-life problems and the need to apply learning immediately (Heimlich & Norland, 1994; Shine-Hoff, 1995). In order to facilitate learning in adults a climate of mutual respect (which includes trust, support and caring) must be created (Shine-Hoff, 1995). In the development of this training programme these premises and principles were kept in mind.

Attitudes

Attitudes refer to the affective domain of learning (Bradshaw, 1989). It can be described as “*affect for or against, evaluation of, like or dislike of, or positiveness or negativeness toward a psychological object*” (Heimlich & Norland, 1994, p.36). In the present study community health nurses’ attitudes towards disability and their perception of their role in providing services to this population are important. Attitude is a complex construct as it is based on a set of beliefs and guided by underlying principles (resulting from an individual’s own culture and unique context related to, and apart from the teaching-learning process)(Heimlich & Norland, 1994). Consequently attitudes do not form or change in a short time. Although attitudes form an important component of learning and strongly influence behaviour, it was not included as one of the focus areas of the study.

Augmentative and Alternative Communication (AAC)

The field of clinical/educational practice to improve the communication skills of individuals with little or no functional speech (Lloyd, Fuller & Arvidson, 1997, p.524). This can be done by using aided symbols which requires a transmission device (e.g. real objects, photographs, graphic symbols, devices with speech output, etc.) or unaided symbols which requires only the body (e.g. gestures, manual signs, fingerspelling, etc.).

Terminology

Beginning communicators

This term refers to individuals across the age range who do not yet demonstrate communicative intentionality and/or who rely primarily on prelinguistic communication means and/or who are learning to use aided or unaided communication means to represent basic communication functions (e.g. rejecting, requesting, etc.) and/or who use low technology communication systems (e.g. communication boards) for participation (Beukelman & Mirenda, 1998).

Children with severe disabilities

In this study severe disability does not rely on the particular systems that are affected, the medical diagnosis, or the intellectual status. Rather, it attempts to describe the functional limitations induced by the severity of the disability and/or the range of disability (i.e. the different areas of involvement that result in limited participation of the individual). This term therefore includes all individuals who have to rely on others in their environment to support them to some extent in order to ensure functional participation in their communities. Children with little or no functional speech (which is typical of beginning communicators) would thus be incorporated in the term “*severe disabilities*” as this is an aspect with causes and maintains limited social participation. All beginning communicators can thus be regarded as having a severe disability due to the severity of the communication deficit and its impact on general functioning. “Children” in this study refers to all children younger than 18 years of age.

Community health nurse

Nurses with training in the field of community health nursing which can be described as a synthesis of nursing practice and public health practice, applied to promoting and preserving the health of communities. This practice is general and comprehensive and not

Terminology

limited to a particular age group or diagnosis and is continuous, not episodic. The dominant responsibility is to the population as a whole; nursing directed to individuals, families or groups contributes to the health of the total population (Thomas, 1999a).

Knowledge

This refers to the cognitive domain of learning, and is associated with an understanding and/or reproduction of facts (Bradshaw, 1989). However, Bloom's taxonomy broadened this definition, and also included the application of knowledge (the ability to apply knowledge to new situations) analysis of knowledge (ability to break information down into its component parts in order to clarify meaning), knowledge synthesis (being able to combine components to make a new whole) and evaluation (the ability to make judgements using relative criteria)(Wilson, Lanza & Barton, 1988). In the present study the knowledge domains that were tapped using Response Forms I & II included reproduction of knowledge, comprehension, application, analysis and evaluation.

Multiskilling

Multiskilling is a form of role diversification which refers to the cross training of a service provider to perform procedures and functions in two or more disciplines (Salvatori, 1997). It does not necessitate the loss of a person's professional identity nor does it imply the demise of specialists, but rather offers opportunities for job expansion and job enrichment in the form of new or expanded roles, knowledge and skills. ASHA (1996) identified four dimensions of multiskilling, namely the cross-training of basic patient care skills, cross training of professional, nonclinical skills, cross-training of administrative skills and the cross-training of clinical disciplines. These four dimensions are discussed at length in Chapter 2. In the present study multiskilling was used as the strategy through which community health nurses were equipped with the knowledge and skills to provide services to children with severe disabilities and their primary caregivers.

Terminology

Primary caregivers

In the present study, “*primary caregiver*” refers to the individual who is responsible for the rearing of the CSD and who performs the majority of caregiving tasks (e.g. feeding, hygiene, ADL, discipline, etc.). The role of primary caregiver is predominantly a female one, and society may view this as a natural role for women (Hitchcock, 1999). In the specific context where the study was conducted this usually refers to the parents (in particular the mother) or a grandmother or older sister. The caregiver burden experienced by primary caregivers of CSDs that can lead to social isolation, exhaustion, financial hardship and despair, should not be overlooked.

Prior knowledge

Prior knowledge refers to the whole of a person’s knowledge. As such prior knowledge is dynamic in nature, is available before a specific learning task, is explicit and contains conceptual and metacognitive knowledge components (Dochy, 1996). In the present study prior knowledge will thus refer to the specific knowledge of community health nurses before the BCIP training.

Terminology

Skills

This refers to the psycho-motor domain of learning, and encompasses the practical skills in performing a particular task. While skills require a knowledge base, they are easily learnt through the strategies of demonstration and practice under supervision (Bradshaw, 1989). A danger exists when teaching skills without knowledge (as the individual might not understand the rationale for doing something), consequently the present study focused on including both these domains of learning.

List of Acronyms

AAC	Augmentative and Alternative Communication
ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
ALS	Aided Language Stimulation
ASHA	American Speech-language Hearing Association
ASL	American Sign Language
BCIP	Beginning Communication Intervention Protocol
CAAC	Centre for Augmentative and Alternative Communication
CBR	Community-based Rehabilitation
CP	Cerebral Palsy
CSD	Child with a severe disability
CSDs	Children with severe disabilities
DPO	Disabled People/Parent organisation
DPASA	Disabled People South Africa
DiCAG	Disabled Children's Action Group
FAS	Foetal Alcohol Syndrome
HIV	Human Immune Deficiency Virus
ICIDH	International Classification of Impairment, Disability and Handicap
ICIDH-2	International Classification of Functioning and Disability
II	Intellectual impairment
INDS	Integrated National Disability Strategy
LFNS	Little or No Functional Speech
NPA	National Programme of Action
OT	Occupational Therapist
PCS	Picture Communication Symbols

List of Acronyms

PHC	Primary Health Care
PKU	Phenylketonuria
PT	Physiotherapist
2	Rank order
SASL	South African Sign Language
SLP	Speech-language pathologist
TB	Tuberculosis
VOCA	Voice Output Communication Aid
WHO	World Health Organisation

List of South Africanisms

Braai	Barbecue : Outdoor social event at which meat cooked over a charcoal or wood fire is eaten.
Fridge	Refrigerator
Jam	A sweet substance made by boiling fruit with sugar to a thick consistency.
Jellytots	Soft, round jelly-based sweets covered in sugar
Maltabella	Sorghum grain porridge
Mealie porridge	Maize meal porridge
Paraffin	Oil obtained from petroleum or coal that is used as a fuel (in lamps, heating and cooking-stoves)
Simbas	Potato crisps
Smarties	Chocolate-coated sweets in assorted colours
Spaza shop	Small general dealer that usually operates from an individual's house
Takkies	Soft-soled canvas shoes
Zip	Zip fastener

Opsomming

Die ontwikkeling van ‘n primêre vlak kommunikasie-intervensie protokol vir kinders met erge gestremdhede

Dienslewering aan kinders met erge gestremdhede in ontwikkelende lande het sekere kenmerke in gemeen. Dit sluit ontoeganklike dienste as gevolg van die feit dat die meeste dienste in ‘n paar groot stede gelokaliseer is; die fokus van dienste is gewoonlik op skoolgaande kinders (met min vir voorskoolse kinders); baie dienste benodig gespesialiseerde personeel en gevorderde tegnologiese hulpmiddels wat nie altyd beskikbaar is nie, en professionele persone wat in isolasie werk met minimale integrasie tussen dienste. ‘n Besonder weerlose groep in die sfeer van kinders met erge gestremdhede is beginnende kommunikeerders as gevolg van hul onvermoë om hul behoeftes, emosies en regte bekend te maak. Programme wat daarop gemik is om hierdie kommunikasiebehoeftes aan te vul deur sulke kinders van die nodige vaardighede te voorsien, ten einde in die samelewing te kan deelneem, is baie beperk.

Skakeling met die gemeenskapsverpleegkundige is dikwels die eerste kontak wat primêre versorgers van kinders met erge gestremdhede met professionele persone het. Voorts bly die verpleegkundige dikwels die enigste professionele persoon wat deurlopende ondersteuning en hulp aan hierdie versorgers bied. Dit is dus duidelik dat hierdie verpleegkundiges toegerus moet word met die nodige kennis en vaardighede ten einde versorgers in staat te stel om hul kinders met erge gestremdhede te kan hanteer. Dit kan gedoen word deur die opleiding van hierdie verpleegkundiges (deur middel van multi-vaardigheidsopleiding) om as transdissiplinêre professionele persone te funksioneer. Verder bestaan daar ook ‘n behoefte aan toepaslike materiale vir dienslewering aan hierdie populasie. Gevolglik is die BKIP (Beginnende Kommunikasie Intervensie Protokol) ontwikkel. Die BKIP spreek vier belangrike kommunikasiedomeine aan, naamlik kommunikasie metodes (insluitend objekte, fotos, gebare, PCS simbole en ‘n vereenvoudigde 4-opsie digitale spreker), funksies (naamlik versoekfunksies, bv. vra vir nog, vra vir hulp, en sosiale funksies bv. groet, aandag op self vestig, ens.),

Opsomming

gespreksgenote (beide volwassenes en portuurgroep) en die doelbewuste skep van kommunikasiegeleenthede (bv. slegs klein porsies gee, verlangde items buite bereik plaas, ens.). Sorg is gedra om kulturele sensitiwiteit en geldigheid van die BKIP te verseker.

Twintig gemeenskapsverpleegkundiges is opgelei in die toepassing van die BKIP. Opleiding het gebruik gemaak van die beginsels van volwasse leer en het ‘n week geduur, met drie in-situ opvolgbesoeke (onderskeidelik twee weke, ses weke en vyf maande na opleiding). Veelvuldige metings is gemaak om die verworwe kennis en vaardighede na opleiding te evalueer, naamlik gestruktureerde onderhoude, vaardigheidsdemonstrasies (wat deur middel van ‘n video opgeneem is en deur die navorser en ‘n onafhanklike evalueerder geëvalueer is) en ‘n fokusgroep.

Resultate het aangetoon dat die BKIP opleiding relevant is om ‘n betekenisvolle verandering in die teikenareas, naamlik kennis en vaardighede, teweeg te bring. Perifere gedrag (naamlik houdings, werkstevredenheid en tipe dienslewering) het aan die begin van die projek reeds ‘n hoë telling getoon, dus het kwalitatiewe data nie ‘n verbetering weerspieël nie. Kwalitatiewe data vanuit die fokusgroep het egter wel op ‘n verbetering gedui.

Sleutelsterme: Aanvullende en Alternatiewe Kommunikasie (AAK); Beginnende kommunikeerders; Gemeenskapsverpleegkundige; Houdings; Kennis; Kinders met erge gestremdhede; Multi-vaardigheidontwikkeling; Primêre gesondheidsorg; Primêre versorgers; Trans-dissiplinêre dienslewering; Vaardighede; Volwasseleer.

Abstract

The development of a primary level communication intervention protocol for children with severe disabilities

Service delivery to children with severe disabilities (CSDs) in developing countries share some common characteristics. These include inaccessible services due to the fact that the majority of services are located in a few large cities, the focus of services are usually on school-age children (with few for pre-schoolers), many services require specialised staff and high technology equipment that is not always available and professionals who tend to work in isolation with minimal integration between services. A particularly vulnerable group within the sphere of CSDs are beginning communicators because of their inability to articulate their needs, feelings and rights. Programmes to specifically address these communication needs by equipping them with the necessary skills to interact and participate in society, are very limited.

Often the first contact that primary caregivers of a CSD have with professionals, is with the community health nurse. Furthermore, they often remain the only professionals who provide continuous support and assistance to these caregivers. It is therefore clear that these nurses need to be equipped with the necessary knowledge and skills in order to assist caregivers in dealing with their children with severe disabilities. This can be done by training these nurses (through multiskilling) to function as transdisciplinary professionals. Furthermore, a need for appropriate materials for service delivery to this population also exists. Consequently the BCIP (Beginning Communication Intervention Protocol) was developed. The BCIP addresses four important communication domains, namely communication means (including objects, photographs, manual signs, PCS symbols and a simplified 4-option digital speaker), functions (namely informational functions e.g. requesting more, requesting help, etc. and social functions, e.g. greeting, drawing attention to self, etc.), partners (both adults and peers) and the deliberate creation

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of communication opportunities (e.g. by providing small portions, placing desired items out of research) etc. Care was taken to ensure culture sensitivity and the authenticity of the BCIP.

Twenty community health nurses were trained in the application of the BCIP. Training employed adult learning principles and was one week long, followed by three follow-ups that were conducted in situ (at two weeks, six weeks and five months post-training). Multiple measurements were used to evaluate the knowledge and skills acquired after training, namely questionnaires, structured interviews, skill demonstrations (which were video recorded and rated by the researcher and an independent rater) and a focus group.

Results indicated that the BCIP training is relevant in bringing about a significant change in the targeted domains, namely knowledge and skills. Peripheral behaviours (namely attitudes, job satisfaction and type of service delivery provided) were all rated high at the onset of the research and thus quantitative data failed to show improvement. On the other hand, qualitative data from the focus group suggested improvement.

Key terms: Adult learning; Attitudes; Augmentative and Alternative Communication (AAC); Beginning communicators; Children with severe disabilities; Community health nurses; Knowledge; Multiskilling; Primary caregivers; Primary health care; Skills; Transdisciplinary service delivery.