

THE HEALTH CARE NEEDS OF THE PHYSICALLY DISABLED PATIENT IN A HOME-BASED CARE ENVIRONMENT: IMPLICATIONS FOR THE TRAINING OF ANCILLARY HEALTH CARE WORKERS

Authors:

Karien Jooste¹
Mary Chabeli¹
Monica Springer¹

Affiliations:

¹Department of Nursing,
University of Johannesburg,
South Africa

Correspondence to:

Karien Jooste

email:

kjooste@uj.ac.za

Postal address:

University of Johannesburg,
PO Box 100477, Moreleta
Plaza 0167, South Africa

Keywords:

experiences; guidelines;
health care worker;
nursing; training needs

Dates:

Received: 18 Oct. 2009

Accepted: 01 July 2010

Published: 09 Nov 2010

How to cite this article:

Jooste, K., Chabeli, M.,
Springer, M., 'The health
care needs of the physically
disabled patient in a home-
based care environment:
Implications for the
training of ancillary health
care workers', *Health SA
Gesondheid* 15(1), Art. #486,
8 pages. DOI: 10.4102/hsag.
v15i1.486

This article is available at:

<http://www.hsag.co.za>

© 2010. The Authors.
Licensee: OpenJournals
Publishing. This work is
licensed under the Creative
Commons Attribution
License.

ABSTRACT

According to existing literature, ancillary health care workers (AHCWs) often do not meet the health care needs of patients with physical disabilities (physically disabled patients) in a home-based environment, because of inadequate training programmes. The purpose of this research study was to explore the health care needs of physically disabled patients in long-term, home-based care in the northern suburbs of Johannesburg and, based on results, to offer recommendations for the training of AHCWs. Qualitative, exploratory, descriptive and contextual means were employed in data collection and analysis. The population consisted of eight physically disabled participants who employed an AHCW to assist them with their long-term home care. Purposive sampling was used with subsequent snowballing to identify further participants for the study. Individual interviews were conducted, where participants had to answer the questions (1) 'What are your health care needs?' and (2) 'How should these be met?' Data saturation was ensured, after which Tesch's method of data analysis was followed. Three categories of health care needs were identified (1) physical health care needs, (2) interpersonal relationship needs and (3) social needs, and 12 themes were derived from these categories. These categories of health care needs should be addressed in the training of AHCWs. From the themes, recommendations were described for the training of AHCWs on the health care needs of the home-based physically disabled patients. The AHCW should assist in the adaptation of the environment to the patient's individual needs, and should use knowledge and critical thinking skills to ensure a patient-centred care setting.

OPSOMMING

Volgens die literatuur kan assistentgesondheidsorgwerkers (AGWs), as gevolg van ontoereikende opleiding, nie altyd aan die behoeftes van fisies gestremde pasiënte in 'n tuisopset voldoen nie. Die doel van hierdie navorsingstudie was om die gesondheidsorgbehoefte van langtermyn, tuisgebaseerde fisies gestremde pasiënte in die noordelike voorstede van Johannesburg te verken en te beskryf, en om hieruit aanbevelings vir die opleiding van AGWs voor te stel. Kwalitatiewe, verkennende, beskrywende en kontekstuele metodes is gebruik om die data in te samel en die analise te doen. Die studiepopulasie het uit agt fisies gestremde deelnemers bestaan wat 'n AGW aangestel het om hulle met hul langtermyn tuisversorging by te staan. Doelbewuste steekproefneming met die daaropvolgendesneebalmetode is gebruik om verdere deelnemers vir die studie te identifiseer. Individuele onderhoude is gevoer waartydens deelnemers die volgende vrae moes beantwoord (1) 'Wat is jou gesondheidsorgbehoefte?' en (2) 'Hoe behoort hieraan voldoen te word?' Datasaturasie is verseker, waarna Tesch se data-analisemetode gevolg is. Drie kategorieë van gesondheidsorgbehoefte is geïdentifiseer (1) fisiese gesondheidsorgbehoefte, (2) interpersoonlike verhoudingsbehoefte en (3) sosiale behoeftes, en 12 temas is van hierdie kategorieë afgelei. Hierdie gesondheidsorgkategorieë behoort aandag tydens die opleiding van AGWs te kry. Aan die hand van die temas is aanbevelings gemaak vir die opleiding van AGWs in tuisgebaseerde sorg van fisies gestremde pasiënte. AGWs behoort ondersteuning te bied om die omgewing by die individuele behoeftes van die pasiënt aan te pas, en moet hul kennis en kritiese denkvaardighede kan toepas om 'n pasiëntgesentreerde omgewing te verseker.

INTRODUCTION

Many situations exist where ancillary health care workers (AHCWs) are being employed to assist patients with their health care needs in a long-term, home-based care environment. Home-based care (HBC) is a continuum of comprehensive health care at the place of residence of the patient, for the purpose of promoting health or maximising the level of independence, while simultaneously minimising illness. Services according to the needs of the patient and the family are planned, coordinated, and made available by service providers. These service providers ensure the delivery of home care by means of employing AHCWs through a contractual arrangement with patients (Smith & Maurer 2000:844). Patients can therefore expect that AHCWs are trained to meet their health care needs in the home-based environment.

An AHCW is a person who has undergone some form of training that enables them to render basic care of the patient and to assist patients and their families with the performance of activities of daily living in the home environment (Ancillary Health Care Unit Standards 2003). Due to today's high costs of hospitalisation, patients are being discharged earlier and sent home for HBC, as it is known in South Africa. Therefore, patients require health care in their home environments sooner, which creates an increasing need for more AHCWs. Long-term, physically disabled patients also need trained AHCWs to tend to their specific health care needs.

Curricula of recognised training programmes should address the health care needs of the home-based patient. Formal recognised training of AHCWs in HBC currently does not exist in South Africa,

although there are policies and documents that make provision for it. South Africa has a national policy that recognises the importance of HBC and the training of AHCWs, as described by the Primary Health Care Principles (Department of Health 2000a). In an educational drive, the *Primary Health Care Package for South Africa – a set of norms and standards* (Department of Health 2000b) was introduced. It describes the ‘Batho Pele – people first’ principles and provides for communities to have access to the services that they are entitled to. This in turn has training implications for health staff, including the AHCWs, because it is becoming increasingly important to provide services of a high level of competency and professional ethics to the community (Department of Health 2000c).

In the urban areas of South Africa, some training courses are being offered to AHCWs in order to assist them in the long-term care of patients at home. The researcher is aware that courses are offered by a variety of organisations, such as nursing agencies, which provide some assistance to AHCWs to become more acquainted with basic nursing skills. Candidates who have completed these courses can then apply for employment within the organisation or agency that provides the training (e.g. a hospice).

Against the background of a lack of recognised training for AHCWs and courses that vary in content, these workers are expected to fulfil the needs of home-based patients. The content of many AHCWs’ courses does not indicate an acknowledgement of the patients’ perspective on their health care needs. The experiences of home-based patients, with regard to how their health care needs are met by AHCWs, has not previously been studied in the South African context. The needs of the patient, as perceived by the patient, are an important factor in the delivery of adequate health care in the home environment. The researcher therefore explored these health care needs and how the training of AHCWs, on these health care needs, could assist the AHCWs in playing a pertinent role as home-based health care professionals.

The need for HBC is a complex one: people who are in the process of dying cannot always afford long hospital stays, hospitals and clinics are often not within easy reach of the home, hospitals are often overcrowded, and people feel better when they are cared for at home in a well-known environment (Anon 2000). At home, the patient is able to interact with the environment in an integrated manner (University of Johannesburg 2009:4). However, at home, the patients are often cared for by AHCWs who are, according to John and Salvini (1996:723), inadequately trained to address the health care needs of the frail. In order to provide a healthy and safe environment for the patient, the AHCW should be adequately trained and equipped to deal with the health care needs of the patient.

While some work has been done on the training and education aspects of health care workers, the researcher was particularly interested in the patients’ perspective with regard to their health care needs. In the researcher’s experience, as a private professional nurse practitioner involved in assisting long-term, home-based patients, even AHCWs with some training appear not to meet the expectations of their patients. Conflict could arise due to unmet expectations of either the patient needing basic health care or the employee taking on the role of an AHCW.

PROBLEM STATEMENT

An acute shortage of bed space in hospitals has led to patients often being discharged earlier, or not even being admitted to hospitals for treatment. Owing to the lack of capacity in the public sector hospitals for the care of long-term patients, the community is being increasingly asked to become more involved in HBC of people who are aged, frail and terminally ill, HIV/AIDS patients, patients that are physically disabled, and patients in palliative care. The community members and/or

semi-trained persons within the community are expected to take on the role of AHCWs to assist such patients. Sometimes the AHCWs are unable to cope with the health care demands they have to deal with, as has been experienced by the researcher in her role as a professional nurse practitioner. The researcher has witnessed high levels of frustration by both the patient and the AHCW.

The researcher’s concern was the lack of inclusion of the long-term, home-based patients’ perspective in the training of AHCWs. Patients who are assisted by AHCWs are entitled to quality care as described in the Patient’s Rights Charter (Department of Health 2000d). Patients expect certain nursing abilities when they employ someone to assist them in their home environment. The health care needs of patients include all aspects of activities of daily living, as described by Brunner and Suddarth (1986:62).

The patients’ perspectives on their health care needs could highlight the need for relevant training of the AHCWs as primary caregivers to physically disabled patients in a home-based environment.

RESEARCH OBJECTIVES

The purpose of the research was to explore the health care needs of physically disabled patients in long-term HBC in the northern suburbs of Johannesburg.

The objectives of the research were to:

- Explore and describe the experiences of the physically disabled patient cared for by an AHCW in a long-term HBC environment, in terms of their health care needs.
- Describe recommendations for the training of AHCWs, in terms of the health care needs of physically disabled patients in long-term HBC.

RESEARCH METHOD AND DESIGN

Burns and Grove (1995:394) define qualitative research as research being conducted to generate knowledge that is concerned with meaning and discovery. By means of primary data collection, an empirical study was conducted to present the researcher with textual data, which could then be used to develop guidelines for the training of AHCWs on the health care needs of physically disabled patients in long-term HBC (Babbie & Mouton 2002:76–78). Qualitative, exploratory and descriptive means were employed in data collection and analysis, to establish the physically disabled, home-based patients’ health care needs and how they could be met. The study focused on patients in the northern suburbs of Johannesburg, thus the data were contextual in nature.

Population and sampling

The population studied in the empirical phase was patients with physical disabilities, living in the northern suburbs of Johannesburg who employed AHCWs to assist with their long-term HBC. The population had no existing sampling framework, where all cases were represented and from which the actual sample would have been taken (Mouton 2002:135), because not all physically disabled persons are reflected by any association or register.

For the empirical study of the research, non-probability sampling methods were used – more particularly purposive sampling, with subsequent snowball sampling as described by Babbie and Mouton (2002:166). All eight participants were restricted to the use of wheelchairs and had minimal arm movement abilities. The participants in the study were over the age of 18 years, had completed their initial rehabilitation programmes, and had been home based for at least three months. Since the study was primarily exploratory and contextual in nature, this sampling method was considered appropriate (Babbie & Mouton 2002:167).



Data collection

In this study, the data were collected by unstructured, in-depth, face-to-face interviews, using open-ended questions, which enabled the patients to express their views freely. The patients were encouraged to narrate their health care needs and how they thought the AHCWs should be trained to assist them in terms of meeting these needs.

Data were gathered up to a point of saturation, when no new information was gathered from the participants. The researcher used unstructured observation and communication to gather data and no attempts were made to control the interaction (Burns & Grove, 1995:395). The research questions asked were (1) 'What are your health care needs?' and (2) 'How could your health care needs be met?' The interviews were taped and transcribed by the interviewer. All participants preferred to be interviewed in English.

Patients who were potential participants for the study were contacted by the researcher and asked to take part. Those patients who were willing to be interviewed were made aware of their role in the research by means of the informed consent form that they were required to sign. The interviews were tape recorded and field notes were made during the interview.

Data analysis

On completion of the interview transcripts, a qualitative, open-coding data analysis method was employed, using Tesch's protocol as described in Creswell (1994:155). This process resulted in the identification of categories, sub-categories and themes of health care needs. Once a number of interviews were conducted, the transcripts were read to gain a sense of the responses. During the reading of the transcripts, notes were made on a separate sheet of paper or on the transcript itself. After a general idea of the content of the interviews was gained, a random transcript was chosen from all the transcripts. The researcher attempted to determine the underlying meanings and noted them in the margins of the document. A list of topics emerged, which could then be sorted into clusters of similar topics, categories, sub-categories and themes, and others that did not fit.

For the sake of simplicity, the categories were abbreviated and then written into the appropriate sections of the text and

using these abbreviations, the researcher then developed a scheme. During this phase, some new themes emerged, which led to the refinement of categories and sub-categories. The next step entailed the use of descriptive wording to categorise the themes. Once the categories were finalised, an abbreviation was created for each category in order to identify each category in the transcriptions. Using segments of the text marked in the previous steps, the data were analysed within these categories. This system facilitated the development of categories, sub-categories and themes. The final step included recoding existing data when it became evident that it was necessary.

RESULTS AND DISCUSSION

After exploring the data generated by the interviews with patients in a long-term, home-based situation, the information was classified into three main categories (1) *physical health care needs*, (2) *interpersonal relationship needs* and (3) *social needs*, as portrayed in Figure 1.

Physical health care needs

Because the patients interviewed during the research project were all quadriplegics or paraplegics, certain physical health care needs or aspects of activities of daily living (Brunner & Suddarth 1986:62) were predominant.

A therapeutic environment that ensured the safety and security of both themselves and the AHCWs was found to be the participants' greatest concern. From the comments made by participants it emerged that a *therapeutic environment* in which they would feel safe and secure had, as main features (1) awareness of their unique physical environmental needs, (2) management of hygiene and elimination, (3) assistance with nutrition and hydration, (4) assistance with mobilisation and (5) administration of medication. This required education and training of the AHCW. 'Environment' pertains to the external surroundings of a person (Freshwater & Maslin-Prothero 2005:211). Orem (1995) uses the term 'therapeutic' to mean supportive of life processes, either remedial or curative, when relating to disease processes, and contributing to personal development and maturing. The therapeutic environment included the entire context in which the management and care of the patient took place, as presented in Figure 2.

The patient's *external environment* was viewed as the home situation of the physically disabled patient in a long-term HBC situation, which included the relevant social aspects. The patient's *internal environment* (personal health) incorporated the spiritual and mental aspects of the patient (University of Johannesburg 2009). The patient should be assured of safety (in the external human environment) and feel secure (internal personal health) (Eliopoulos 2005:536).

Awareness of the unique physical environmental needs of the disabled person, including injury prevention

The interviews established that all participants regarded their situation and circumstances as being unique, even though disabled persons face similar problems or needs. Two participants noted that, while all quadriplegics have certain common needs, '... no two people who are paralysed are exactly identical ...' and '... every person's needs are different ...' Collins (2004:1777) describes the term unique as 'being the only one of a particular type'. Patients in HBC face situations that are particular to their situation and different from those of all other patients. Smart and Smart (2006:29) describe disability as an intervention between the individual, the individual's incapacity, and the environment. Rimmer (2002:337) mentions that disabled persons are unable to access some health-promoting behaviours due to environmental barriers, which may be traced to a lack of knowledge of the unique needs of disable persons.

The participants described awareness of the physical environmental needs as a responsibility of the AHCW to ensure

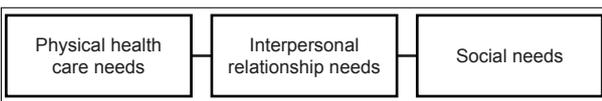


FIGURE 1
The three main categories of needs as stated by participants

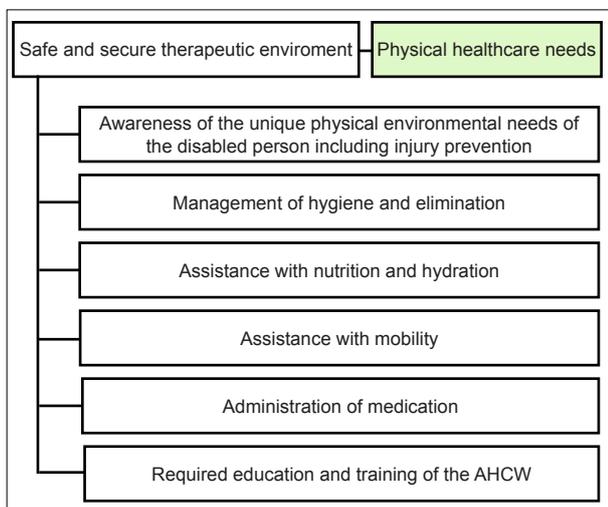


FIGURE 2
Physical health care needs of participants

the safety and security of the patient. One patient described 'being aware' as follows, while shaking his head slightly:

'I think one of the most important words in life is a small word called "aware" ... So, that is one of the things; to find people who are really aware in all circumstances, is really difficult.'

Blackwell (2005:65, 145) describes awareness as consciousness, and being cognisant of one's self and one's surroundings, which might be experienced as a thought, perception, idea, sensation or emotion.

In being aware of the unique physical environment, it was expected of the AHCW to adapt the home environment to address the needs of the patient and to reduce risks. Adaptation is defined as 'something that is changed or modified to suit new conditions' (Collins 2004:16). Falls potentially could be serious accidents and might be prevented by using appropriate mechanical restraints like bed rails (Uys 2004:241-243). The researcher noted that the home situation could be adapted to reduce environmental dangers like loose carpets on smooth floors, uneven ground, and furniture obstructing the patient's movements.

Certain procedures for bathing and pressure sore prevention were expected to be performed by the AHCW in a specific manner. One participant indicated how the AHCW should adapt the situation for assisting with bathing:

'The wheelchair I use has a tilt mechanism so you can tilt back over the bath or basin or whatever, so you just use a shower attachment [shows lever on wheelchair that controls this electronically].'

The AHCW should reflect a person-centred approach (Farvis 2003:2). The patient's individual needs should be considered when adapting the home environment, relative to the kind of disability present (Bromley 1998:76). Bromley (1998:111) states that special lifting techniques are to be used when assisting patients, like the cervical lift.

In another instance, particular attention was required for prevention of pressure sores by ensuring correct positioning of limbs and regular mobilisation. One participant said the following, while turning slightly from side to side with the upper body:

'Turn me to make me comfortable and see that my legs and my pressure points don't touch and I don't get other bedsores because I am so vulnerable for [to] bedsores now.'

Pressure sores might be prevented by regular movement of the affected body parts, ensuring adequate nutrition and hydration, as well as keeping the skin clean and dry (Nicol *et al.* 2000:247). AHCWs could be required to adapt certain procedures to suit specific situations (according to data on the procedures) in order to ensure the safety of the patient.

Participants mentioned numerous incidences where they were exposed to pain and injuries inflicted by the AHCWs because of incorrect handling techniques. While lifting his shoulders slightly and moving forwards and backwards, one participant said:

'I need someone who has been taught the correct way to lift a person ... who is not going to aggravate the pain by either not supporting me or, you know, bumping me or inflicting pain.'

Patients found that provision of comfort is related to injury prevention. Here comfort is defined as 'to bring physical ease to' a person or thing (Collins 2004:322).

The health status of the AHCW, specifically the HIV/AIDS status, was identified as being of concern to the patients. This aspect was mentioned by two participants with regard to the health status of the AHCW, specifically the 'declaration of HIV status'. According to the Employment Equity Act (SA Government 1998), the employer does not have a right to demand to know the AHCW's HIV status unless they get prior permission from the Labour Court.

As part of the therapeutic environment, the participants identified the need for availability of assistance, 24 hours a day. The participants required assistance with activities of daily living, like personal hygiene. Being unable to perform activities of daily living independently, a participant stressed the fact that 'I need help "now" because I cannot do things myself "now"'. A practical solution needs to be found in each case to maximise the availability of assistance to best meet the needs of the patient. When the AHCW was unavailable, the role of the family members was crucial. This is supported by the World Health Organization (WHO 2003:4) which states that the family forms a central role in the care of long-term dependency.

Management of hygiene and elimination

The patients were more secure in the knowledge that with adequate personal and environmental hygiene many health problems, like bladder infections, could be avoided or minimised. Eliopoulos (2005:536) describes hygiene as a part of the most basic level of needs, which also includes physiological needs and assurance of safety in the physical environment. Basic survival depends on these needs being fulfilled. Hygiene extended to the immediate environment where it was necessary. One patient stated the following, while drawing attention to a pile of clean towels on a chair in the corner of the room:

'... for example, they need to keep me clean when I have soiled [on] the towels or something, and that means to get the towels washed.'

The patient should be assured of safety in the human environment, for example, during interactions with AHCWs (Eliopoulos 2005:536). Patients described the personal hygiene of the AHCW as another aspect of hygiene management. 'Their personal hygiene when they are working with me must also be good'. Patients required the AHCWs to participate in maintaining the patient's personal and environmental hygiene.

Assistance with nutrition and hydration

Nutritional needs impact on the health and the functional capacity of the patient by influencing the body's ability to defend itself against disease, maintaining anatomic and structural normality, assisting the patient to think clearly, and generating energy and desire to engage in social activities (Eliopoulos 2005:193).

The participants described their nutritional needs as covering a wide variety of dietary habits in relation to a wide variety of health care needs. Some participants required the AHCW to be able to cook and prepare foods: 'I have a maid with special cooking skills'. Others merely indicated that the food would need to be cut up into manageable sizes and the rest they could do themselves. With a tinge of embarrassment, one participant stated: 'Then I need someone to butter a piece of bread and toast'. Cutting food into manageable sizes, assessing the temperature of the meal, and taking time to prepare the meal are all important aspects of meeting the nutritional needs of the disabled person (Du Gas 1983:289).

In terms of needs for hydration, the patients concurred that the AHCW should assist in making fluids freely available and offering fluids frequently - 'I am not drinking enough water for one thing'. - thereby preventing dehydration of the patient with its subsequent problems of bladder infections, constipation and feeling weak. Patients might experience a lack of access to fluids because of immobility, fear of incontinence, reduction in thirst sensation, lack of motivation to acquire drinks, or due to suffering from nausea (Eliopoulos 2005:197).

Assistance with mobility

Exercise is defined as a planned, structured and repetitive bodily movement performed to maintain or improve one or more physical fitness components (Edelman & Mandle, 2006:262), and can be either active or passive.

AHCWs had to assist with the mobility of the participants. Active and/or passive exercises should be administered by the



AHCW because the patients had limited capacity to do so by themselves, as expressed by one participant: *'Sometimes, I use an exercise bicycle'*. It could help to prevent further degeneration of joints and muscles. Because of spinal cord injuries, people with disabilities are especially susceptible to musculoskeletal decline as well as rapid bone demineralisation, resulting in a permanently heightened susceptibility to femur fractures and joint deterioration. Subsequently, injury might be caused by even trivial or imperceptible trauma (Jacobs & Nash, 2004:734).

The patients indicated that mobility was an important feature of their physical health care needs. In order to assist a patient when mobility was needed an AHCW required a basic understanding of the structure of the body and should have some training in how to mobilise joints and to perform activities as required and instructed by the patient.

Administration of medication

All the participants were on a selection of medications, ranging from antispasmodics, diuretics, antidepressants, antibiotics and laxatives, to drugs treating various underlying conditions like pain, hypertension or hypercholesterolaemia. Some patients related the consequences of being given the incorrect medication, for example, as one participant exclaimed angrily: *'She put(s) in a scheriproct suppository instead of a dulcolax and didn't know why my stomach wouldn't work'*. To assist the patient in taking medication it is important that the AHCW be guided by the patient regarding the medication regimen, the purpose for which each medication is used and, where possible, the potential side-effects and complications of the medicines (Stanhope & Lancaster 1988:643).

The AHCWs were required to dispense and administer the daily medication as instructed by the patients. AHCWs are not regulated by the *Nursing Act 33 of 2005*, and therefore perform their duties outside of its jurisdiction. As a result, this area remains problematic because the issue of accountability and responsibility has not been clarified.

The study results indicate that long-term, home-based physically disabled patients are faced with a unique situation at home, for which the AHCW should be trained. They expected the AHCW to be sensitive to their situations. Awareness of the physical environment of the patient was needed, and it was expected that the AHCW should use knowledge of past experience, and critical thinking skills to ensure a patient-centred care setting, by anticipating the unique needs that might arise. The AHCW was required to help adapt the environment to the patient's individual needs and to ensure access and manoeuvrability throughout the house. AHCWs were required to anticipate environmental needs, focusing primarily on the prevention of injuries. This included managing the extrinsic and intrinsic risk factors and using the appropriate equipment, to anticipate and prevent pressure sores, fractures, burns, falls or other injuries.

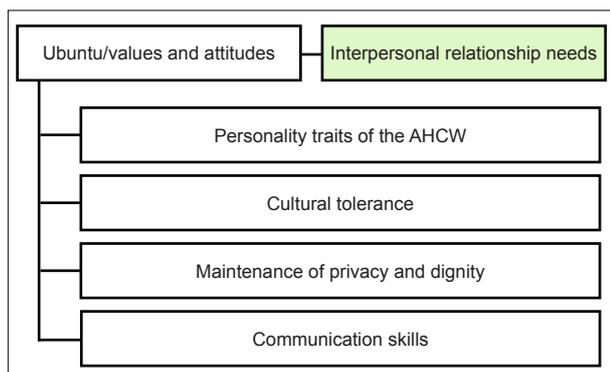


FIGURE 3
Interpersonal relationship needs of participants

Interpersonal relationship needs

The participants indicated that they all had specific needs with regard to interpersonal relationship needs (Figure 3). Many of the participants were not part of a stable family relationship because of their personal health circumstances. This may explain the importance they placed on interpersonal relationship needs in relation to the AHCW.

Personality traits of AHCW

The ideal personality of an AHCW, as described by the participants, would be a person who was caring, honest, could be trusted, and had a sense of humour. While folding his hands in his lap, one participant responded: *'Personality-wise you expect somebody who is friendly, honest and kind. I would expect a bit more love and care'*.

Chabeli (2004:43) describes caring as one of six pillars of character. Empathy is a concern for others and arises out of compassion and sharing experiences (Sadock & Sadock 2003:32). The concept of Ubuntu helps to attain good human relationships and to increase human value, trust and dignity (Venter 2004:151).

Cultural tolerance

Cultural tolerance appeared to be a topical issue within the South African socio-political context. It was expressed emphatically and swiftly by a participant: *'I think the party has got to be socially adaptable to the situation you are going to place her (in).'* In a tired voice, one response was:

'Attitude can become a problem; it all depends on their perception of what is required ... if they consider it to be just a job, you won't get very far'.

Patients in the home environment might need to display cultural tolerance, but they also expected the AHCW to reciprocate.

According to Leininger and McFarlane (2002:47), culture relates to the learned, shared and transmitted knowledge of values, beliefs and way of life of a particular group; generally transmitted intergenerationally. This knowledge influences thinking, decisions and behavioural patterns. The AHCW should be able to demonstrate cultural tolerance in making decisions about the health care needs of the home-based physical disabled patient.

Maintenance of privacy and dignity

In general, the participants were very aware of their privacy and dignity being invaded for purposes of personal health care and they would like to perceive sensitivity to be displayed by anyone dealing with them. Their physical disabilities necessitated an intrusion of their personal space. Although the patients accepted that this 'invasion' was necessary, they also unanimously expressed the desire to have their privacy respected and their dignity maintained at all times.

The AHCW *'would have to be exceptional – because you are invading that person's space'*. One patient explained that assistance was required, but she wanted time alone as well. *'I need to find a bit of space and time for myself, which is what I try and do during the day'*. Maintaining privacy and dignity can be achieved by a number of means like *'... seeing that my body is closed with (indicating a blanket) ...'*, limiting the number of persons performing a procedure, and being aware of and respecting a person's preferences with regard to the execution of procedures.

The concept of Ubuntu contains an element pertaining to dignity, known as *isidima* (a Xhosa word), which describes a person as being divine and therefore to be respected and valued (Mnyaka & Motlhabi 2005:219). Baillie (2001:148) includes the concept of maintenance of privacy and dignity in all procedures being performed on a patient. The AHCW should be trained in this regard.

Communication skills

Participants indicated the need for appropriate communication between the patient and the AHCW. Both verbal and non-verbal

communication needs were described. Communication is a way of sharing thoughts and is a cornerstone of human relationships (Edelman & Mandle 2006:81).

The AHCW was required to be competent at listening to, understanding, and correctly interpreting what was being communicated by the patient. One patient emphatically stated the following:

'When they understand, when communication is good, they are able to follow instructions ... if they misunderstand they don't follow instructions and that has resulted in injury (patient emphasises this by moving her hands). I would expect them to understand English and also to be able to apply what has been heard to the work situation, to understand this is the way it needs to be done, and to actually do what they are told.'

All forms of communication would assist in binding individuals together as set out in the tenets of Ubuntu (Venter 2004:153).

Verbal and non-verbal communication is the backbone of the relationship between the AHCWs and patients. Factors that contribute to effective communication as identified by Edelman and Mandle (2006:85) include listening, being flexible, utilising silence, having a sense of humour, and using touch and space. These factors should be incorporated into a training programme for AHCWs in order to enhance the communication skills and establish sound interpersonal relationships with fragile persons, such as home-based physically disabled patients.

Social needs

The social needs of the participants could be described under the sub-category of social encounter, with the themes of companionship and promotion of independence of the patient (Figure 4). According to Collins (2004:1542) the word 'social' means to relate to or have the purpose of promoting companionship or communal activities.

The disabled person in the home environment often faced situations where the AHCW was required to assist with aspects of care that might not necessarily be part of the job description. Once the patient was settled in the wheelchair and was ready for the day, a variety of additional tasks might need to be performed. It ranged from the AHCW preparing meals, to

'helping with the shopping – I take her with me, basically it is the mobility in outside areas' [the patient stated while pointing at the door]. 'I don't focus on the wheelchair, but the general public awareness is not there'.

In addition, the AHCW might have to assist with looking after the children or driving the patient around. *'If they did driving duties, it would definitely constitute a better pay opportunity'.* Many patients required the AHCW to also *'Take care of the other area where I need help, which is the house'.*

The relationships of the patient with family members and caregivers are redefined within the home spaces because of a rearrangement of the most intimate spaces in the home (Angus et al. 2005:178). Hence, from the patients' perspective, the AHCW may be required to perform additional tasks, such as domestic work, child-minding and shopping.

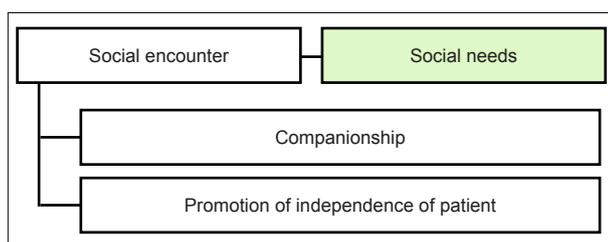


FIGURE 4
Social needs of participants

Companionship

Factors that could lead to social isolation of a person include changes in health status, location in sparsely situated rural areas, and fear of crime; all of which could affect the frequency of patients venturing into the community (Eliopoulos 2005:44). A physically disabled person is to a certain extent isolated from the community and the health care worker then becomes their companion.

The AHCW was required to provide companionship to the patient and sometimes also to the family members or significant others close to the patient. The participants in this research described how AHCWs were required to be companions to them and significant others in their life: *'She (also) spends time with my mom.'* The need for companionship was expressed by one participant as: *'I can have any kind of conversation with them'.* Time alone was also valued by one participant, *'When will I get time for myself? I just need that break'.* Patients could appreciate times of being alone. Eliopoulos (2005:44) supports this opinion by describing how being alone is not necessary synonymous with being lonely.

The results indicated that the AHCW should be trained to care for the long-term, home-based physically disabled patients that are faced with a unique situation at home. The patients expected a trusting and safe relationship with the AHCW as their companion, as well as the AHCW's sensitivity towards people near to them.

Promotion of independence of the patient

From the interviews it became clear that the participants felt very strongly about their independence. Being dependent on others *'is a very frustrating place to be in, being of an independent mindset'*, one participant said, with a grimace. For the participants, dependency on others was one of the most difficult things to cope with, and therefore AHCWs needed to show particular awareness in this regard. AHCWs should encourage patients to be as independent as possible to increase their confidence in their own ability (Larner 2005:37).

The patients ideally would have liked to be as independent as possible within their means and therefore required the AHCW to assist them in this regard by showing awareness of the unique circumstances while promoting independence. All patients indicated that specific training in the home environment was required. One participant stated, with a nod of the head, the following:

'If I take a domestic and train her up, I find that sometimes it is a bit of a problem in trying to train them. So, for me to try and train somebody who has had a bit of training is much, much easier, because they do have a better understanding of what is actually expected.'

The nature of an AHCW's work is very practical, and numerous motor skills are required. A person's motor skills need to be practised for that person to become proficient in certain skills (Quinn 1991:95). Apart from formal training, Quinn (1991:96) also endorses on-the-job training, stating that the best place to learn skills is in a real setting.

ETHICAL CONSIDERATIONS

Anonymity, confidentiality, informed consent, privacy and the need for self-respect were observed during all phases of the research. By not publishing their personal details, patients were assured of confidentiality. Any personal details that could identify a patient were excluded from the study, and each interviewee was given an identifying number (Babbie & Mouton 2002:529–531).

The planning of the research complied with all recognised standards and ethical clearance was obtained from the ethics committee of the particular university. In order to ensure accuracy of the data, the researcher conducted all the interviews



personally. The researcher obtained informed consent from all participants, after the purpose, importance and research method were shared.

Patients were made aware that they could withdraw their consent and from the research at any phase of the research project. No adverse consequence would arise from their withdrawal or refusal to participate. As the participants were all more than 18 years old, they were able to give their own informed consent. If the patient could not sign the informed consent, a verbal consent was obtained and noted on the consent form. Permission to tape-record the interviews and to make field notes was obtained. The tapes were kept secure for 2 years, and destroyed after publication of the results.

The privacy of the patient was respected throughout the research process. The patient's physical comfort was assured by conducting the interview at the patient's home. No inherent risks for the patient as participant were evident in this study. The participant could indicate at any time whether they were too tired to continue and appropriate arrangements would have been made. In order to minimise the invasiveness of conducting the interview in the home environment, consent to conduct the interview at home was obtained prior to the interview.

The participants were informed that any data gathered would be shared with the supervisors of the study and other relevant people aiding in the transcription of the interviews, analysis of the data and compilation of the research findings. The participants would receive a copy of the research findings upon request once the study was completed.

TRUSTWORTHINESS

Trustworthiness was established by adhering to the guidelines of the process as described by Lincoln and Guba (1985:301–320).

Credibility

The researcher ensured credibility by member checking (Lincoln & Guba 1985:301). Sufficient time was allowed in order to build a trust relationship with each patient and also to explore all the relevant health care needs of each patient, and ensured achievement of scope for the study. Member checking was performed to confirm data analysis with the participants of the study.

Transferability

The researcher included patients with physical disabilities in a long-term HBC situation. Participants were engaged from the direct field of work of the researcher and included patients with various degrees of physical disability. All participants were using the services of AHCWs in order to meet their requirements for activities of daily living. At the time of the interviews, all patients were residing in the northern suburbs of Johannesburg. This context provided a data base for other, similar situations, for example, the health care needs of HIV/Aids patients could be investigated (Lincoln & Guba 1985:316).

Dependability

Dependability involved an enquiry audit during which the process and the product were examined by an outsider to check the acceptability and therefore, dependability, of the process, and the internal cohesion and hence, confirmability, of the inquiry (Lincoln & Guba 1985:318).

Confirmability

Confirmability included the confirmability audit in comparison with the audit trail and the audit process. In this study, raw data were generated by the interviews and underwent the auditing process (independent coder) as described by Lincoln and Guba (1985:319–320).

LIMITATIONS OF THE STUDY

The results of this study cannot be generalised, as the research was contextual in nature and only eight physically disabled persons in long-term, home-based environments in the northern suburbs of Johannesburg participated in the study. To enable transferability, a thick description of the context was given (Lincoln & Guba 1985:316).

RECOMMENDATIONS

The results indicated the expectations of patients and the requirements for training of the AHCW through recounting the experiences that the physically disabled patients shared about their health care needs in the home-based environment. The AHCW should be trained in specific competencies related to physical health care needs of patients, and their interpersonal relationships and social encounters with them.

Training in physical health care needs of the patient

The AHCW should:

- Be aware of the unique physical environmental needs of the physically disabled person, including injury prevention. The physical environment must be adapted to prevent injuries by using appropriate equipment, anticipating needs and preventing pressure sores.
- Manage the hygiene and elimination of the patient through adequate health care assistance. The AHCW is required to assist in ensuring the personal and environmental hygiene of the patient, maintaining high standards of personal hygiene, and assisting in the management of urinary and faecal elimination.
- Assist with nutrition and hydration in the environment of the bedridden patient as supported by the Standards for Community Level HBC, which describes diet as part of caring for a patient (Department of Health 2000b).
- Assist with mobility to promote circulation that could prevent bedridden complications, such as deterioration of the musculoskeletal system. Passive and active exercises can promote circulation, maintain or improve fitness levels and mobility, and prevent pressure sores and contractures.
- Assist the patient with the administration of medication under the patient's supervision, and according to the instructions of the patient. This ensures continuity of care as per the Patient's Right Charter (Department of Health 2000d).
- Be encouraged to embark upon further education and training. In-service training should be expected, because each patient has unique needs and requires individualised care.

Training in the interpersonal relationship with the patient

The AHCW should:

- Demonstrate certain personality traits in caring for the long-term patient, which include caring, trust and empathy.
- Be sensitive to cultural differences in the HBC environment.
- Maintain the privacy and dignity of the patient in the home-based environment. Respect, courtesy and dignity are interrelated, and indicate a sharing of values.
- Focus on verbal and non-verbal communication skills to form the basis of the relationship between the patient and the AHCW.

Training in social encounters with the patient

The AHCW should:

- Fulfil the role of a companion to the patient and the family in line with norms described for Community Home-based Rehabilitation (Department of Health 2000a).
- Assist the patient with becoming as independent as possible within the home environment.

Further research projects need to be conducted to examine the affordability of employing adequately trained AHCWs to assist physically disabled persons in meeting their health care needs. The role of private and public medical funding in financing the training of AHCWs for this category of patients needs to be explored, as well as possibilities for a viable, long-term strategy for all health care users in South Africa. In addition, intensive discussion needs to take place, and input obtained from relevant stakeholders regarding the accountability of AHCWs for their actions.

CONCLUSION

A qualitative study was conducted that explored and described the experiences of the home-based physically disabled patient, in terms of their health care needs. Three themes emerged from the data obtained during eight individual interviews and were described in detail, (1) physical health care needs, (2) interpersonal relationship needs and (3) social needs. Although the participants had widely differing ideas about some aspects of their health care needs they all agreed that, although they were dependent on assistance for activities of daily living, they required the AHCW to be able to adapt to the unique circumstances of individual situations.

The participants differed in their experiences as far as the training and education of the AHCWs were concerned. Their needs ranged from wanting a highly skilled and multi-tasked individual to the other extreme of the AHCW having minimum prior training.

A literature search was completed to conceptualise the three identified categories of health care needs (physical needs, interpersonal relationship needs and social needs) with their sub-categories and themes. The researcher's own experience was included in the interpretation of the data, and their relevance to the training of AHCWs was established. It was concluded that the AHCW should be trained regarding the health care needs of the home-based, physically disabled patient. Recommendations for training of AHCWs on the health care needs of the home-based, physical disabled patient were described. The AHCW is required to anticipate the environmental needs of the patient, to help to adapt the environment to the patient's individual needs, and to ensure access and manoeuvrability throughout the house. A greater focus should be placed in training AHCWs on verbal and non-verbal communication skills, to form the basis of the relationship between the patient and the AHCW.

REFERENCES

- Ancillary Health Care Standards Unit, 2003, *Government Gazette* 455(24815), viewed 02 May 2003, from www.saga.org.za
- Angus, J., Kontos, P., Dyck, I., Mckeever, P. & Poland, B., 2005, 'The personal significance of home: Habitus and the experience of receiving long-term home care', *Sociology of Health and Illness* 27(2), 161–187.
- 'Choose a career in home care', *The Teacher/Daily Mail and Guardian*, 03 August, 2000, n.p.
- Babbie, E. & Mouton, J., 2002, *The practice of social research*, Oxford University Press, Southern Africa.
- Baillie, L., 2001, *Developing practical nursing skills*, Arnold, London.
- Blackwell, M., 2005, *Journal of Consciousness Studies* 7(11–12), 145–176.
- Bromley, I., 1998, *Tetraplegia and paraplegia – a guide for physiotherapists*, 5th edn., Edinburgh, Churchill Livingstone.
- Brunner, L.S. & Suddarth, D.S., 1986, *The Lippincott manual of nursing practice*, 4th edn., Lippincott Co., Philadelphia.
- Burns, N. & Grove, S.K., 1995, *The practice of nursing research: Conduct, critique & utilization*, 2nd edn., WB Saunders, Philadelphia.
- Chabeli, M.M., 2004, 'Character – a virtue and moral foundation for the nursing profession', *Nursing Update*, 28(5), 42–43.
- Collins, W., 2004, *Collins English dictionary – desktop edn + CD-ROM*, HarperCollins, Glasgow.
- Creswell, J.W., 1994, *Research design: qualitative and quantitative approaches*, Simon & Shuster, London.
- Department of Health, 2000a, *Policy statement: The primary health care package for South Africa – a set of norms and standards: Community based rehabilitation*, Government Printer, Pretoria.
- Department of Health, 2000b, *Policy statement: The primary health care package for South Africa – a set of norms and standards: Community level home-based care*, Government Printer, Pretoria.
- Department of Health, 2000c, *Policy Statement: The primary health care package for South Africa – a set of norms and standards. Part 1. Norms and standards for health clinics: Batho Pele – people first*, Government Printer, Pretoria.
- Department of Health, 2000d, *Policy statement: The primary health care package for South Africa – a set of norms and standards: Patient's Rights Charter*, Government Printer, Pretoria.
- Du Gas, B.W., 1983, *Introduction to patient care – a comprehensive approach to nursing*, 4th edn., Saunders, Philadelphia.
- Edelman, C.L. & Mandle, C.L., 2006, *Health promotion throughout the lifespan*, 6th edn., Mosby Inc., St. Louis.
- Eliopoulos, C., 2005, *Gerontological nursing*, 6th edn., Lippincott Williams & Wilkins, Philadelphia.
- Farvis, M., 2003, 'Residential aged care and a home-like environment', *Australian Nursing Journal* 11(5), 19–21.
- Freshwater, D. & Maslin-Prothero, S.E., 2005, *Blackwell's nursing dictionary*, 2nd edn., Prentice Hall International, New Jersey.
- Jacobs, P.L. & Nash, M.S., 2004, 'Exercise recommendations for individuals with spinal cord injury', *Sports Medicine* 34(11), 727–751.
- John, R. & Salvini, M.L., 1996, 'Training in support of the American Indian Eldercare campaign: replication of an American Indian homecare training program', *Educational Gerontology* 22(8), 723.
- Larner, S., 2005, 'Common psychological challenges for patients with newly acquired disability', *Nursing Standard* 19(28), 33–38.
- Leininger, M. & Mcfarlane, M.R., 2002, *Transcultural nursing*, 3rd edn., McGraw-Hill, Toronto.
- Lincoln, Y.S. & Guba, E.G., 1985, *Naturalistic inquiry*, Sage, London.
- Mnyaka, M. & Motlhabi, M., 2005, 'The African concept of Ubuntu/Botho and its socio-moral significance', *Black Theology* 3(2), 215–237.
- Mouton, J., 2002, *Understanding social research*, 3rd edn., Van Schaik, Pretoria.
- Nicol, M., Bavin, C., Bedford-Turner, S., Cronin, P. & Rawlings-Anderson, K., 2000, *Essential nursing skills*, Mosby, Edinburgh.
- Orem, D.E., 1995, *Nursing: concepts of practice*, 5th edn., Mosby, St Louis.
- Quinn, F.M., 1991, *The principles and practice of nurse education*, 2nd edn., Chapman Hall, London.
- Rimmer, J.H., 2002, 'Health promotion for individuals with disabilities: The need for a traditional model in service delivery', *Disease Management and Health Outcomes* 10(6), 337–343.
- Sadock, B.J. & Sadock, V.A., 2003, *Synopsis of psychiatry: Behavioral sciences/clinical psychiatry*, 9th edn., Lippincott Williams & Wilkins, Philadelphia.
- SA Government, 1998, *Employment Equity Act*, Act No. 55 of 1998, Chapter II: Prohibition of unfair discrimination, 7, Medical Testing, Government Printer, Pretoria.
- SA Government, 2005, *The Nursing Act*, Act No. 33 of 2005, Government Printer, Pretoria.
- Smart, J.F. & Smart, D.W., 2006, 'Models of disability; implications for the counseling profession', *Journal of Counseling and Development* 84, 29–40.
- Smith, C.M. & Maurer, F. A., 2000, *Community health nursing theory and practice*, WB Saunders Co., Philadelphia.
- Stanhope, M. & Lancaster, J., 1988, *Community health nursing – process and practice for promoting health*, Mosby, St Louis.
- Uys, L.R., 2004, *Fundamental nursing*, Maskew Miller, Cape Town.
- Venter, E., 2004, 'The notion of Ubuntu and communalism in African educational discourse', *Studies in Philosophy and Education* 23, 149–160.
- University of Johannesburg, 2009, Department of Nursing Paradigm, Johannesburg.
- World Health Organization (WHO), 2003, *Long-term care in developing countries: ten case studies*, ed. J. Brodsky, J. Habib & M. Hirschfeld, WHO, Geneva.