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## **Caregivers' and nurses' perceptions of the responsibilities of community nurses in the management of infant developmental needs in a primary healthcare clinic in South Africa**

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### **Abstract**

By virtue of their access to infants and their families, community nurses in South Africa are provided with an important window of opportunity to assess and positively influence infant health and development. Hence, developmental surveillance should be incorporated into the ongoing healthcare of the child. Such routine child development services are not consistently provided by community nurses and if at all these services are provided, significant inadequacies hamper the delivery thereof. A single holistic case study design was used to explore the perceptions of caregivers and community nurses about the responsibilities of community nurses regarding the management of infant developmental needs in a primary healthcare clinic in one of the provinces in South Africa. Semi-structured interviews were conducted with five nurses and eleven caregivers of infants. Data were analysed by means of content analysis. Community nurses do not focus adequately on infant development, as stipulated in their scope of practice. The caregivers indicated that they receive limited emotional and appraisal support. The only interventions indicated by the community nurses were that of referral and limited anticipatory guidance. This study highlights the importance of community nurses living up to their responsibility regarding the management of infant developmental needs to ensure optimal outcomes for both the infant and the family.

**Keywords:** Caregivers' and nurses' perceptions, responsibilities of community nurses, management of infant developmental needs, primary healthcare.

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### **Introduction**

Despite the fact that children are the most vulnerable members of society and that their wellbeing is an important measure of the overall health of a society (Guyer, Grason, Frick, Perry, Sharkey & McIntosh, 2009), many children do not receive the services and interventions that they need (Halfon, Stanley & Du Plessis, 2010). The first years lay a crucial foundation for the health and

development of children. It is critical not just to maintain, but also to optimise the development and health of infants, as investments in infant development are fundamental for the future of every individual and for the wealth of society. A distinct goal in caring for infants is to identify, as early as possible, developmental delays and disabilities and to provide appropriate services and support (Maulik & Darmstadt, 2009).

Although South Africa has some of the most comprehensive legislation and policies protecting and promoting the rights of children with disabilities (Philpott & McLaren, 2011), developmental screening is not required by law (Samuels, Slemming & Balton, 2012). Hence, many gaps in service delivery remain due to limited implementation, weak capacity and procedural hindrances (Philpott & McLaren, 2011). In spite of community nurses in South Africa having access to infants and their families to assess and positively influence infant health and development (VanLandeghem, Curtis & Abrams, 2002), a high proportion of children miss out on being identified and receiving the necessary help at an early stage (Aly, Tai & Ibrahim, 2010).

To ensure that the window of opportunity does not become a missed opportunity, the responsibilities of community nurses regarding the management of the developmental needs of infants in a primary healthcare (PHC) clinic in the North West province in South Africa were explored in this study.

## **Methodology**

### *Research design*

A qualitative, single holistic case study (Yin 2009) was used to gain in-depth insight into the participants' perceptions of the responsibilities of community nurses in the management of developmental needs. According to Yin (2009), a single-case study is an appropriate design especially when it is a representative or typical case where the objective is to learn from the circumstances and conditions of an everyday situation in an institution and the lessons learned are assumed to be informative regarding the experiences at the average institution. The rationale for using a single case is that in South Africa, health care is rendered according to the principles of the primary health care (PHC) approach. Implementation of the PHC approach requires a decentralised management and the major locus of implementation is the district. In South Africa a "District Health System based on PHC is a more or less self-contained segment of the national health system ..." (National Department of Health, 2001). As the functioning of primary health care clinics is sanctioned by national/district health policies, the information obtained from one clinic could be applicable to other clinics functioning within the district health system.

### *Setting and participants*

This study was conducted in an urban PHC clinic; the site was chosen by means of purposive sampling. The eight community nurses working at this site were invited to participate in the study and five agreed to do so. Eleven caregivers (mothers or grandmothers) were selected by case type, specifically reputational case sampling, meaning that the researcher obtained recommendations from knowledgeable experts for the best examples (McMillan & Schumacher, 2001). Ethical approval was obtained from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria.

### *Data collection*

Data from a larger qualitative, single case study were used for the current study. Semi-structured interviews were conducted with five nurses. Five caregivers of children with optimal development were interviewed as well as six caregivers of children with an identified developmental delay or disability. Data were collected over a period of five months in 2005. The participants could choose to have the interview conducted either in their own home or at the PHC clinic. The duration of the interviews varied between 45 and 90 minutes, and they were audio-taped with the permission of the participants. Before the interview, the researchers guided the participants through the process of informed consent by explaining the purpose of the study, the voluntary nature of participation, that they could withdraw at any time during the interview and that data reported would be used in a confidential manner.

A preliminary literature review was used for the development of the semi-structured interview guides for the different groups of participants. Questions included in the interview guide for the community nurses focused on: the perceived responsibilities of community nurses relating to infant development; barriers preventing the nurses from focusing on infant development; eliciting of caregiver concerns; social support; and available resources in the community for families with infants with special development needs. Questions for the caregivers focused on: knowledge about growth and development; satisfaction with care at the clinic; eliciting of parental concerns; relationship between caregiver and nurse; anticipatory guidance; social support; and referral to available resources in the community and barriers to effective service. In addition, the researchers kept field notes to record any personal responses to events that could influence her interpretation thereof.

### *Data analysis*

The recorded interviews were transcribed verbatim and reviewed for accuracy and discrepancies were corrected. The researchers used content analysis to sort

data according to key issues and themes. The researcher became familiar with the data, focused the analysis, categorised the information, identified patterns and connections within and between categories, and then interpreted it (Taylor-Powell and Renner, 2003).

## **Results**

Analysis of the data revealed several categories. However, for the purpose of this article, only the following categories are discussed:

### *Focus on infant developmental needs*

The community nurses agreed that it is their responsibility to focus on the developmental needs of infants. However, when they do focus on infant developmental needs, it is inconsistent and not according to a specific guideline or protocol. Their focus is mainly on growth and nutrition, as stipulated in the priority programmes, and possibly a review of the milestones. The following excerpts from the transcriptions are reflections of one community nurse and one caregiver about their perceptions of community nurses' focus on infant developmental needs:

*"On the illnesses, but not the development ... it's rare that I assess the developmental process."* [CN].

*"[The community nurses focus more on] the growth than ... on the other [domains of development], no."* [CG].

The caregivers realised the importance of having their infants' development assessed. They indicated that it was either not done or that the focus had been only on the growth of the child, as indicated by two different caregivers:

*"They don't examine the babies, they only weigh them and that is most probably why most of our children's problems are not identified."* [CG].

*"We normally take them for injections, immunisations and it is then that they can detect if there is [anything] wrong with the child."* [CG].

Some of the caregivers were not aware of the fact that developmental care should actually be part of infant healthcare. Most of them felt that the nurses did not give enough attention to their infants' development, as indicated by the following excerpts:

*"I don't know if it is part of the service ...."* [CG].

*"I feel it shouldn't be purely medical[ly] focused, but also around my child's development. Because ... a mother don't naturally know these things ...."* [CG].

All the nurses indicated that imparting information is important. However, none indicated that the information should be set at a level the caregivers could understand. The following are two quotes from different community nurses:

*“... to teach the very same mother as ... the child is developing ....” [CN].*  
*“Give education to the mother ... know that he will go through different stages, so you give education about that to them ....” [CN].*

The caregivers expressed their need for information. Unfortunately, they never voiced this need during consultations and the community nurses never anticipated this need. Most of the caregivers were very frank about the fact that they did not receive any guidance or advice and if they received any, it was very basic, as indicated by the following excerpts:

*“I very much would like to hear about all these things [infant development], but ... we can't ... expect that they [community nurses] ... individually must give attention, because then what will happen to their work ....” [CG].*  
*“Advice is always welcome especially about where to get help and how to manage your child as well as where to get support groups.” [CG].*

The nurses viewed comprehensive service delivery as a barrier and felt that if they could focus exclusively on a specific field for a given period, they could enlarge their knowledge base about that specific field. The following is a quote from one of the community nurses:

*“... because we [community nurses] must do a comprehensive service ... because the government's policy is that everyone, every day, must do everything. So you [the CN] must [attend to different types of clients]; from a broken foot and plantar warts ... [to] a baby. [The CN] ... must work [only] with babies, then she can fix her attention on one thing, then she can equip her and do research ... but it can't happen like that ....” [CN].*

The clients were mostly Setswana-speaking and not all the nurses were proficient in this language. Language was therefore a very valid barrier to the delivery of a quality infant developmental service, as it impeded the provision of information, as indicated by this community nurse:

*“... you must sometimes call an interpreter and the interpreter that is willing to come and help you is sometimes a cleaner that also now [has] a lack of knowledge, you know, you tell her what to say, but I think if she interprets, then I wonder how much is left out and how much is added ....” [CN].*

### *Family care*

The nurses reported that it is important to build trusting relationships with the caregivers. Through this process, they can gain insight into family dynamics and the caregivers will be more willing to reveal their needs, as denoted by the following excerpt:

*“... you must establish rapport, a good rapport ... to show the parent that the child can still lead a normal life ... the parents must be supported and encouraged ....” [CN].*

The following quotations indicate several characteristics that caregivers felt should be part of a nurse–parent relationship:

*“I feel there must be comfortableness from her to share things with me, irrespective [of] whether I’ve asked ....” [CG].*

*“... warmth, genuine interest and time, and that the patient experience[s] there is time for me ....” [CG].*

*“... very kind and calm and I could talk and ask questions ....” [CG].*

Contradicting responses were obtained from the nurses and the caregivers when asked whether nurses elicit parental concerns. The nurses indicated that they do, whereas the caregivers, for various reasons, felt that they did not get any or sufficient chance to voice their concerns.

*“I usually want to find out how the child is at the home ....” [CN].*

*“They [the community nurses] only say the necessary ... they only tell about immunisation and nothing further.” [CG].*

The caregivers commented that they did not receive any information pertaining to available resources in the community and felt that it was the nurses’ responsibility to assist them in gaining access to the necessary resources in the community. The nurses openly stated that they do not know of resources and the informal network did not really feature as a resource in their responses.

*“Not at the clinic, there they indeed ask nothing.” [CG].*

*“No we don’t have the specific places that we know of.” [CN].*

*“I don’t know ... if there is any provision for resources for infants ....” [CN].*

### *Caregivers’ views and expectations of community nurses*

In general, the caregivers indicated that they were satisfied with the service delivery, yet it was mostly related to their interpersonal relationship with the nurse, as indicated by a caregiver:

*“The nurses and everyone are sensible and they help nicely, therefore I’ve never encountered any problems.” [CG].*

In addition, the researcher wanted to know whether the caregivers perceived the community nurses as communicative and open, and whether they were treated with kindness.

*“I want them to be open with me.” [CG].*

*“You know I was really satisfied with them, they were very, very kind and calm and I could talk and ask questions and so forth.” [CG].*

All caregivers were of the opinion that community nurses should be knowledgeable about infant development. As one grandmother indicated, “... they are nurses, they know it”. Although caregivers are not experts when it comes to evaluating community nurses’ knowledge, their perception of the level of knowledge is important, as this could have a negative impact on their trust relationships with community nurses.

*“No, I don’t think they really have the necessary knowledge and skills unless otherwise if they are neglecting some of the things ... they should really get enough training on ... the child’s development.” [CG].*

The caregivers furthermore reported that a ‘running commentary’ about findings while the community nurse is assessing their infants would be reassuring to them. Several caregivers stated that there was no explanation of the procedures/assessment that the nurse carried out and identified it as another shortcoming. As one caregiver stated:

*“... everyone measures his head but no one tells ... why they are doing it ... when I got home I measured his head, now I’ve got a size, but I’ve got no idea what it means.” [CG].*

#### *Intervention for infant developmental delays and disabilities*

The only interventions expressed by the nurses were that of referral and limited anticipatory guidance. The community nurses chose to refer infants to a doctor at the paediatric clinic at the local district hospital; their reason being that they cannot bypass the doctor. The responsibility to refer the baby for therapy then rested with the doctor at the paediatric clinic:

*“The first that we refer, it’s to paed, the paediatric department ....” [CN].*

The caregivers reported that they themselves took action or if the nurses referred them, they went from pillar-to-post to get to somebody who could diagnose what

is wrong with the infant and refer them for the proper treatment or therapy. This could indicate that community nurses are not aware of the role and functions of the different therapists; hence the preference to refer to the paediatric clinic. One of the caregivers also mentioned that funds are also preventing them from accessing the necessary resources:

*“No, I thought I must go and fetch that money of the child ... said it myself ... I went to the commissioner to do those things ... but I haven’t been back to the commissioner, because I don’t have that eight Rand that I can again go to town.” [CG].*

When asked whether they use anticipatory guidance as a means of offering guidance to the caregivers, the nurses indicated that they do. However, in contrast, the caregivers indicated that they never received any guidance or assistance on how to take care of their infants. The following extracts from one community nurse and one caregiver portray the contrast:

*“I must start teaching the mother, finding out how is she bringing up this child and help to teach her maybe where I can see she is lacking and also if there is something that she need me to refer ....” [CN].*

*“... she did not, she only mentioned it is not her field ... and that one refers to an expert ....” [CG].*

The nurses and caregivers alike reported that follow-up was minimal. The community nurses expected the caregivers to keep them informed about the situation, as they have no means of contacting the caregivers as indicated in the following excerpts:

*“You know most of the times, to say the truth, we don’t try to keep track, but if that family come[s] to the clinic again, we do ask them ....” [CN].*

*“... with my next visit to the clinic she asked me ... do I remember we spoke about it and asked what happened ... with the problem, did I get someone and what were the results.” [CG].*

Community nurses must be able to either support the caregivers themselves, or see to it that they are referred to professionals who can assist them with the acceptance of the infant’s condition. As indicated by the following extract, some of the caregivers have not yet accepted or worked through their emotions regarding their child’s developmental delay or disability:

*“You know, very upset and angry. Angry at the people who never noticed it and who worked with him and never made us aware of it.” [CG].*



The nurses focused more on emotional support and appraisal support than any other type of support. Only one nurse expressed that she would employ support groups and sharing of information as means of support. Community nurses can help caregivers to identify and build informal networks to ensure emotional support and enhance wellbeing:

*“We only reassure the parent at primary level. We refer them to ... the different departments at the hospital ... if we’re to ... support parents here I don’t think you’ll have ample time to do that ....” [CN].*

*“I congratulate the mother in the first place on how well the baby is being taken care of and then encourage the mother to keep up ....” [CN].*

*“... if there is a support group for mothers with a child, children like that [children with developmental disabilities], at least if you involve them they will know that I’m not alone, at least we share information with the mothers.” [CG].*

The caregivers reported that information will help the family better understand the disability and make adjustments accordingly:

*“You know information at any stage, I can’t tell you ... you get this terrible shock and no one can tell you ....” [CG].*

*“She just told me that I must accept it; my baby will not be like other babies ....” [CG].*

## **Discussion**

The findings of this study support the notion that the importance of early identification and intervention for infants with developmental delays and disabilities is unquestionable (Barbaro, Ridgway & Dissanyake, 2011). Despite this evidence, and the fact that community nurses have an important window of opportunity to assess and positively influence infant health and development (Regalado & Halfon, 2001), the participants indicated that this opportunity is not utilised to its fullest extent. Therefore, early childhood interventions that have the potential to alter infants’ development trajectories are not instituted (Doyle, Harmon, Hackman & Tremblay, 2009).

The nurses in the present study indicated that lack of time due to a high workload, language barriers, and inadequate knowledge regarding infant development prevent them from focusing on the developmental needs of infants. Chung, Lee, Morrison and Schuster (2006) also identified a lack of clinician skill, limited English proficiency and lack of time as barriers that may interfere with preventive care, such as developmental surveillance. Linked to these barriers is the limited use of anticipatory guidance as a means to promote optimal infant development due to a lack of time, as indicated by the nurses.

In the study conducted by Chung et al. (2006), patient-level data suggest substantially less delivery of anticipatory guidance than that indicated by the physician data. According to Reich (2005), interventions designed to increase parental (caregiver) knowledge of typical child development and effective parenting strategies have been associated with overall improved child outcomes. Therefore, caregivers that are more knowledgeable are more likely to notice problems in their infant's development and attend to it sooner, thereby minimising the possibility of late identification.

To be effective in delivering anticipatory guidance to empower caregivers, nurses need to build a relationship with the caregivers. This relationship should be characterised by mutual acceptance, trust, respect and openness (Brotherson, Summers, Naig, Kyzar et al. 2010), otherwise it may impede positive outcomes for the caregivers and infants (Dunst & Dempsey, 2007). Overall, the caregivers in this study were satisfied with their relationship with the nurses and the service in general at the clinic. However, some of the caregivers indicated that the nurses did not elicit their concerns or provided them with a 'running commentary' of the procedures they carried out when attending to the infant. Asking caregivers about their concerns regarding their infant's development can provide valuable information when assessing the infant's development (Glascoe & Marks, 2011; Sheldrick, Neger & Perrin, 2012).

Not eliciting parental concerns properly can be a significant factor leading to missed early identification, and it could be linked to inadequate training regarding developmental issues, as the nurse's skills in early identification is then compromised (Rydz, Shevell, Majnemer & Oskoui, 2005). The nurses in this study felt hampered by their inadequate knowledge to assess infant development and identify those infants requiring further evaluation and referral. Earls, Andrews and Hay (2009) also indicate the need for improved referral and follow-up when assessment results are indicative of risk for delay.

The findings indicated that the reactions of caregivers after receiving the diagnosis of impairment in a child can range from fear, denial, anger and frustration to guilt, grief and mourning. These are just the beginning of chronic stress, sadness and consequently ongoing distress and dysfunction in the family (Kearney & Griffin, 2001). Boström, Broberg and Hwang (2009) suggested that the concept of caregivers' reaction to the diagnosis could be seen as an ongoing process, and they may vary in degree of resolution on a continuous scale. This emphasises the importance of nurses being aware of the enormous effect the disability may have on each member of the family, and being able to provide the necessary support. The responses from both groups of participants indicated that support was minimal and mainly focused on emotional and appraisal support. The caregivers expressed a need to receive more information, thereby indicating

that caregivers and families might benefit from being offered a range of support systems, as indicated by Freeman, O'Dell and Meola (2003).

In summary, both the community nurses and the caregivers indicated that they regard early identification of developmental delays and disabilities as the responsibility of community nurses. The community nurses also need to be able to provide appropriate services and support. Early intervention can be a positive experience for the caregivers, as it can assist in strengthening the relationship between the caregiver and child. In addition, the caregivers' confidence in their ability to care for the child can be increased (Edwards & Sarwark, 2005).

### **Conclusion**

In this research, caregivers and community nurses provided their perceptions of the responsibilities of community nurses regarding the management of infant developmental needs in a PHC clinic.

The findings indicated that both community nurses and caregivers agree that it is the responsibility of community nurses to manage the development of infants whenever they have contact with infants in the PHC clinic. Although there is consensus that community nurses can play a central role in developmental surveillance and that early identification of developmental delays and disabilities is the first step to facilitate referral and specialised intervention, it is still an unrealised goal. If intervention is instituted early enough, it can serve to move the child towards a more positive developmental outcome (Barbaro et al., 2011).

The recommendation derived from the research is that community nurses should be empowered to integrate developmental surveillance into their daily care with infants. Therefore, community nurses should receive the necessary training on typical and atypical development of infants, how to raise concerns with caregivers, referral for further assessment and intervention to the appropriate healthcare professional, and how to support caregivers and be more emotionally responsive.

Caution is needed in using and applying the study findings to other settings. The research was confined to one PHC clinic, in one province of South Africa; therefore, the research findings may not be generalised to similar settings. To improve the continuity of developmental care provided to infants and their families, research could be conducted on referral and management procedures that would aid communication between healthcare professionals, thereby assisting service providers to improve the quality of developmental care to infants and their families.

Overall, this study has highlighted the importance of community nurses living up to their responsibility regarding the management of infant developmental needs to ensure optimal outcomes for both the infant and the family.

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