

ORIGINAL RESEARCH

# WHAT ROLES DO INDONESIAN NURSES PLAY IN THE EARLY IDENTIFICATION AND INTERVENTION OF CHILDREN WITH DEVELOPMENTAL DISABILITIES? A QUALITATIVE STUDY

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Abstract

**Background:** Developmental delays can be a basis for identifying children who may experience a disability. Accordingly, developmental screenings and monitoring are implemented to facilitate early identification of developmental disabilities

**Objective:** To explore Indonesian's community nurses' perceptions regarding their roles in the early identification and intervention of developmental disabilities

**Method:** This was a descriptive phenomenological study. Eleven community health nurses participated in a multiple semi-structured interview. Thematic analysis was used to analyse data.

**Findings:** Four themes of nursing roles emerged, these include parents' expression of need, a focus on curative management, provision of nursing care and being alert to discuss a possible developmental delay. Indonesian nurses describe their roles as focusing on curative management and include monitoring child growth and nutritional status because they perceive these roles as the main program of the centres and as to fulfilling parents' expressions of needs, however they will raise concern when it is suspected or observed, that the child has delayed development.

**Conclusion:** Child's developmental surveillance has been implemented in developed countries as the basis to identify developmental disabilities earlier in children, however Indonesian nurses focus more on nutrition and eradicating communicable diseases rather than child's developmental monitoring. More investigation is needed to find barriers of implementation of developmental screenings.

KEYWORDS

child; developmental disabilities; nurses; Indonesia

## BACKGROUND

Developmental disabilities refers to a group of chronic, lifelong disability characterised by physical and/or mental impairment which manifested before the individual attains age 22 and result in substantial functional limitations in day to day activities such as self-care, communication, learning, mobility, independent living and self-direction ([American Association on Intellectual and Developmental Disabilities, 2020](#)). Some common type of developmental disabilities are Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorders (ASDs), learning disabilities, behavioural and emotional disorders, communication disorders, cerebral palsy and Down syndrome ([Patel et al., 2010](#)).

According to [WHO \(2012\)](#) developmental delays can be a basis for identifying children who may experience a developmental disability ([Batshaw et al., 2013](#); [Patel et al., 2010](#)). Current practice of early identification of developmental delays has been addressed through developmental surveillance (known as developmental monitoring) and developmental screening programs targeting young children between

birth and preschool age ([Hamilton, 2006](#); [Pizur-Barnekow et al., 2010](#); [Rydz et al., 2005](#); [Squires et al., 2002](#)). The programs are usually delivered by general practitioners (in European countries) or paediatricians (in United States) through well-child check-ups or health supervisions ([Guevara et al., 2013](#); [King et al., 2010](#)). Other groups delivering the program are public health, community health nurses ([Armstrong & Goldfeld, 2008](#); [Barbaro et al., 2011](#); [Fraser et al., 2016](#)), general practice nurses ([Walsh & Mitchell, 2013](#)), child educators and other professionals in child care or early intervention ([Pizur-Barnekow et al., 2010](#)). Moreover, child development monitoring and screenings have been mandated as a national service in the majority of developed countries (e.g. Child Find and Oregon Healthy Start in the US; Universal Child and Family Health Service (UCFHS) in Australia) ([Australian Health Ministers' Advisory Council, 2011](#); [Macy et al., 2014](#)). Therefore, a nationwide initiative of child development monitoring and screenings is critical to support the implementation of early identification of developmental disabilities.

However, this mandate for early identification of developmental delay may not be the case in developing countries where poverty, poorly sustained health and education systems and lack of expertise remain high ([Charema, 2012](#)). Moreover, developing countries like Indonesia still have a high number of health problems in terms of infectious diseases, maternal and neonatal mortality rate, under-five mortality rate, malnutrition including iron and iodine deficiency and severe growth stunting ([Ministry of Health, 2015, 2019](#)). As a result, early intervention for children with disabilities may not be a major concern and readily available.

The aim of this study was to explore Indonesian nurses' perception regarding their roles in the early identification of developmental disability and their intervention. By investigating their perceptions, the roles of the nurses and how they perform their roles would be revealed.

## METHODS

### Study Design

A descriptive phenomenology approach with semi-structured interviews have been employed to collect data. Phenomenology is "an approach to exploring and understanding people's everyday life experiences through hearing, seeing, believing, feeling, remembering, deciding and evaluating" ([Polit & Beck, 2010](#)). Through in-depth interviews, the informants are helped to describe their working experiences without leading the discussion.

### Participants

Eleven participants were recruited from four community health centres in Banten Province Indonesia. According to [Polit and Beck \(2010\)](#) a phenomenological study involve a small number of study participants-often 10 or fewer. However, this study recruited eleven participants as an effort to experience the phenomenon in the same way. The inclusion criteria included nurses who worked in the community health centres and who had work experience in the centres for a minimum of 12 months. The exclusion criteria were to exclude those nurses who had not had any experience in child health service.

The participants were recruited after receiving approval from the Health Department of the City (*Dinas Kesehatan*) and after receiving ethics permission (Project number 6460) from Flinders University Social and Behavioural Research Ethics Committee. The researcher met the managers of the centres to introduce the study and hand out the research package (letter of introduction, informed consent form and information sheet). The managers then introduce the head of child health services and asked her to introduce the researcher to the nurses who met the criteria of the study. During introduction of the study, researcher met the nurses in the health centres and took part in friendly conversation to build rapport with them prior the scheduling of interviews. Semi-structured interviews were conducted in an informal conversation which often started with an idea in mind, open-ended questions were put to the informants, and the conversation followed these to gain greater understanding.

### Data Collection

Data collection were gathered from field notes and in-depth interview with 11 nurses and five of them were followed into second interview. The interviews were conducted in a quiet room in the centres that the

informants chose. All of the interviews were conducted in working hours when the informants available. The main researcher of this study did all the interviews which mostly run for approximately an hour. All of the interviews were audio-recorded and transcribed by the researcher. In the first interview, the researcher asked questions guided by the interview protocol to remain focused but without a rigid structure. After the first interview, the researcher added some notes to explain the situation and highlighted important issues or unclear statements that needed a clarification in the next interview. The second interview was focused on the main issues that emerged in the first interview and also to ask if there were any additional responses from the first interview the participant wish to provide. Due to time limitations, the second interview was not successfully conducted with all participants. Only five out of eleven participants participated in the second interview. The remainder of the participants reported they were too busy.

### Data Analysis

Thematic analysis was used to analyse data. Thematic analysis refers to "a method of identifying, analysing and reporting patterns (themes) within data" ([Braun & Clarke, 2006](#)). Thematic analysis is applied by reading the interview transcripts line by line, underlying the key words, creating codes (sub-themes) and then themes or categories (thematic structures) to see patterns ([Munhall, 2007](#); [Taylor et al., 2006](#)). Refinements of the codes and themes requires the researcher to read the text several times before then being able to see what the participants actually felt was important to highlight. The data were translated from Bahasa Indonesia into English version by the main researcher as she originally come from Indonesia. An Australian editor also helped the main researcher to proof-read the research report.

### Trustworthiness

To gain the rigor for this study the researcher established trustworthiness by reading and reflecting on materials of the study and ensuring the research credibility, fittingness, auditability and confirmability had been achieved ([Taylor et al., 2006](#); [Tobin & Begley, 2004](#)). Credibility addresses an issue of "fit" between respondents' view and the researcher interpretation ([Tobin & Begley, 2004](#)). Credibility in this study was achieved through member checking and prolonged engagement with the respondents through multiple semi-structured interviews. Fittingness or transferability refers to the extent to which the findings fit with other contexts outside the study setting or the ability for generalizability ([Taylor et al., 2006](#); [Tobin & Begley, 2004](#)). Fittingness or transferability in this study was achieved through the fact that similar findings had been found from other studies and judgment of different findings is shown in the discussion chapter. Auditability or dependability refers to the effort that shows the research process is logical and consistent ([Taylor et al., 2006](#); [Tobin & Begley, 2004](#)). In this study, auditability can be found in documentation of data, methods, decisions and the end product that is consistent with the process. Confirmability is achieved if the credibility, fittingness and auditability can be demonstrated in the study ([Taylor et al., 2006](#)).

Trustworthiness may also be maintained by being reflexive with the study. Being reflexive means being aware of the researcher's own biases and pre-conceptions and taking steps to avoid influencing the results ([Munhall, 2007](#)). This includes making the biases explicit, not asking leading questions, and checking out with the participants that the records of interviews accurately reflect their opinions and

viewpoints (Munhall, 2007). The researchers maintained the trustworthiness through member checking as the participants were asked to check and validate the results they provided during interviews. The participants were approached with a written summary of the interview, to be read and they were asked to add notes of clarification or addition. All of those written documents were returned and were signed by the participants to show their agreement with the content of the interview.

### Ethical Considerations

Ethical approval was gained from the ethics committee at Flinders University. In this study, participation was voluntary and required an informed consent before any interview took place. An information sheet about the study, the purpose, procedures, confidentiality for participants, benefits of research to participants, related to risks and participants' rights were provided together with the informed consent. In terms of storing data, the researcher maintained the anonymity of participants by masking their names in the data (used pseudonyms). Permission for audio recording was requested prior to interviews.

### FINDINGS

The majority of the participants were female and have graduated from a Nursing Diploma program, which is a three-year nursing education program at a vocational level equivalent. There was only one male participant who has already retired but was still needed by Centre 1 due to shortage of nursing staff (Robert, 2014). He was also the only one who had graduated from SPK level (Sekolah Pendidikan keperawatan), the High School Certificate in Health Care (three-year nursing education post completing Primary School). Centre 1 only has three nurses whereas the other three centres have seven nurses.

All of the female participants have worked in the centres for one to four years whereas the male participant has the longest experience (34 years). In addition, all of the participants had experience working either in hospitals or clinics before they worked in the centre. Generally, the main responsibilities of the participants were those of an area manager providing nursing health care through home/school visiting or a centre-based service. Other responsibilities included school health checks; the eradication of Tuberculosis, eye health, child immunization, Integrated Management of Childhood Illnesses (IMCI) and health monitoring.

### Nurses' perception of their roles in early identification and intervention

The perception of nurses' roles in early identification and intervention of developmental delay has been analysed based on the nurses' experience and beliefs about child development. The majority of the participants regarded their roles in child development as based on parental requests. Therefore, if the parents did not express a concern about their child's development, the participants perceived their roles as a focus on curative management. Even if the parents did not raise a concern about their child's development but the child was suspected with delays or having a possible developmental disability, the participants described their roles as provision only in terms of nursing care rather than a child developmental assessment. These include providing motivation and reassurance, providing parent education and information and feeding support. The participants also illustrated their

roles as being alert to discussing a possible developmental delay when they were managing the presenting/primary issue of the children.

#### a. Parents' expression of need

Five participants mentioned that their roles were influenced by the parents' expression of their child's needs. Most of the participants illustrate that parents seek community health nurses due to an illness rather than developmental problems.

*"Basically, we work based on what parents express, for example, if the parents express the child has cough, so we focus on respiratory assessment"* (Clara, centre 1)

*"If the parents of the child did not express about their child's development, we not really concern with that"* (Susanne, Centre 3)

This appeared to be the case even if the child had previously been diagnosed with a developmental disability.

*"If the parents express that, we give intervention as much as we can do, otherwise refer"* (Ruth, Centre 4)

*"Parent of children with Down syndrome, they only come for treatment of cough or cold"* (Anne, Centre 2)

#### b. A focus on curative management

Eight out of the eleven participants frequently described the focus of their roles as curative, often through assessing and monitoring the child's physical growth and nutritional status. One participant perceived curative management as what the centre was for. When they were asked about developmental assessment, they looked unsure, and explained again that they were only focused on monitoring child's growth and nutrition status.

*"Usually we only monitor their growth development, check their nutrition status..."* (Clara, Centre 1)

*"Regarding the child growth and development, we more focused on the child nutrition"* (Anne, Centre 2)

In addition, they argued that the focus should be on curative management because this was part of the centre's program and the government program, believing this to be the more important aspect.

*"Because the main child program in the centre is nutrition and immunization, maybe there is child development monitoring here, but I usually do not do that (laugh)"* (Ruth, Centre 4)

*"The most government concern is about malnutrition, they not really concern with child developmental problem, centre will be considered negative if there any malnutrition case in our area, therefore we also focus on child nutrition"* (Gayle, Centre 4)

#### c. Provision of nursing care

All participants illustrated aspects of their nursing care experience when they meet children suspected of having a developmental delay or disability in the centres. The most frequent nursing care term they mentioned was "referral" with NVivo calculating a word frequency of "refer" or "referral" of 60 times. Referral was shown as a significant aspect as all participants mentioned this.

*"Developmental problems are referred to the specialist"* (Barbara, Centre 1)

*"Refer to Tangerang Selatan hospital, because we only have general practices here, we don't have paediatricians"* (Fiona, Centre 4)

They also explained other aspects of nursing care that they were able to provide, which included: conducting assessments through family interviews (2 participants); collaboration with community health workers, doctors, physiotherapists and nutritionists (3 participants), feeding support (3 participants), providing motivation and reassurance (6 participants), providing parental education (5 participants) and information (4 participants). The following quotes from the participants illustrate these aspects of nursing care.

*"Collaboration with physiotherapy in the centre"* (Susanne, Centre 3)

*"We provide motivation because typically the family has low confident, isolate, the child does not go to school. The point is motivation, to make them socialise with society"* (Michelle, Centre 2)

*"One day there was a child with language delay, I taught the mother to stimulate the child by keep talking and asking questions more frequent"* (Clara, Centre 1)

#### d. Being alert to discuss a possible developmental delay

Seven participants described that when they meet the parents, they are alert to a developmental delay while they manage the main issue as raised by the parents. This may be even if the parent does not raise any concern with the child's development. If the child had not presented with an illness, the developmental delay may have been missed.

*"I have an experience with a child with Down syndrome. Firstly, she comes because of having cough and cold, and because I knew from the child appearance, I validated with the mum, what developmental achievement the child has and how the child feeding"* (Kelly, Centre 2)

*"Children with developmental problems mostly come with comorbid illnesses such as cough, cold, fever, diarrhoea, malnutrition, they frequently come, thus we can analyse why their weight is not increasing, is there any contact with TB? is there any seizures? We investigating by asking the parents"* (Robert, Centre 1)

## DISCUSSION

Participants identified four aspects that they perceive as nursing roles in the early identification and intervention of developmental delays and disabilities. These include fulfilling parents' expression of needs, being alert to discuss a possible developmental delay, providing nursing care for children with developmental disabilities and curative health management. The description of their roles reflects the current practice of Indonesian nurses in the Community Health Centres (CHCs). This practice differs from community health nurses' practice in other countries who describe their roles to include conducting child developmental screenings ([Caley et al., 2006](#); [Fraser et al., 2016](#)), monitoring early signs of Autism ([Barbaro et al., 2011](#); [Pinto-Martin et al., 2005](#)) and supporting parental roles including enhancing mother-child interactions ([Armstrong et al., 1999](#); [Barnes et al., 2003](#); [Fraser et al., 2016](#)) (which are the core of early intervention programs for children with disabilities ([Guralnick, 2005](#))).

Fulfilling parents' expressions of needs is regarded as a component of the nursing role. When parents show concern with their child's development, the nurses provide support including motivation and reassurance; they offer parental education and further assessment, but were often limited with insufficient guidelines and facilities. Unfortunately, if the parents do not express concerns regarding their child's development, the nurses acknowledge that they do not really address child development care and focus on the program that has been

set up by the manager of the centre. This perception may hamper early detection of developmental delays and intervention, even though they believe that child developmental monitoring is part of their nursing role. In cases where parents have initiated concern for their child's developmental needs, the AAP algorithm for developmental-behavioural surveillance and screenings is put in place to elicit and attend to parents' or care givers' concerns ([Marks et al., 2011](#)). The algorithm suggests primary care professionals should consistently ask parents questions about their child's development using open-ended questions ([Marks et al., 2011](#)). Parents may not disclose information if the clinicians do not ask ([Glascoe, 2005](#)). Moreover, parents from low income status may be unlikely to raise developmental concerns ([Glascoe & Dworkin, 1995](#)). Importantly, parental concerns are indicators of their child's general development including speech and language ([Marks et al., 2011](#)). Reasons why parents may hesitate to raise developmental concerns vary. It may be due to the social myths surrounding motherhood, childhood and medicine ([Williams, 2007](#)). A qualitative study exploring mothers' beliefs around the detection of subtle developmental problems in young children found that mothers were hesitant in seeking advice from others including health professionals due to a mythical notion of a "good" mother, and their perceptions of childhood and medicine ([Williams, 2007](#)). The study concluded that mothers view good child developmental and behaviour as being the result of good motherhood and vice versa, leading to self-blame if the child is having developmental problems.

Participants described their role as one of being ready to discuss a possible delay even when the child has been brought to the centre by the parents because of acute illness. Furthermore, when it is suspected or observed, that the child has delayed development or has developmental disabilities, they will raise concern with either parents or their colleagues (doctors and midwives). The findings are similar to a Randomised Controlled Trial (RCT) study in 2008 which was concerned with signs of developmental delays and mother-infant relationship problems ([Skovgaard et al., 2008](#)). [Skovgaard et al. \(2008\)](#) revealed that community health nurses are regarded as being able to identify young children with mental disorders when they raise concerns of child development problems and mother-child relationship problems during general health surveillance ([Skovgaard et al., 2008](#)). Moreover, the study highlights that even nurses who have no formal training in infant mental health assessment, and rely only on their empirical knowledge about developmental milestones, can relate their concerns to a potential diagnosis of mental disorders. This study emphasizes the importance of being alert and to raise a concern when a developmental problem (e.g. red-flag in developmental milestones) or mother-infant relationship problems (e.g. emotional, behavioural, sleeping and eating disorders) is suspected. Being alert, however, should be followed by careful and close monitoring of the child's development, and recommendation for further assessment and evaluation ([Marks et al., 2011](#)) as well as referral to an early intervention program ([Giordano, 2008](#)) such as through an intensive home visiting program ([Squires et al., 2002](#)) which forms part of a community health nurse's role ([Armstrong et al., 1999](#)) or Child and Family Health Nurses roles ([Fraser et al., 2016](#)).

Participants describe various approaches to nursing care based on their experiences in dealing with children with developmental delays or neurodevelopmental disabilities (e.g. Down syndrome, Autism, and Attention Deficit Hyperactivity Disorders). In general, providing



referrals is the most frequent of their roles. This action may reflect the fact that they do not want to lose the child from the centre's service but it also indicates they are unable to conduct developmental assessments, identified as one of their barriers. Therefore, they refer the child to the doctors in the centres in the first instance, then to the Tangerang Public Hospital as the main referral. Participants further explain that referral is instigated by providing a letter of referral to be used at either the Tangerang Public Hospital or other private child developmental clinics. However, referrals may prove ineffective as the nurses rely on parental motivation to initiate the process. According to [King et al. \(2010\)](#) there should be a system of referral-tracking as many families do not follow through with referrals and often do not understand why they are being referred.

Indonesian nurses describe their roles as focusing on curative management and include monitoring child growth and nutritional status. The nurses believe that frequent illness, delays in child growth and malnutrition influence child development. Two studies on child development in developing countries support the argument that poverty, malnutrition and infectious disease are factors that put a child at high risk of having poor cognitive development ([Grantham-Mcgregor et al., 2007](#); [Walker et al., 2007](#)). Poverty leads to inadequate provision of nutritious food to protect brain development during pregnancy and infancy, whereas infectious disease may affect the process of organ development, reducing the child's physical activity and play ([Grantham-Mcgregor et al., 2007](#); [Walker et al., 2007](#)). [Walker et al. \(2007\)](#) argue that stunting as a result of malnutrition; inadequate cognitive stimulation; iron and iodine deficiencies are risks factors that need urgent intervention in developing countries. These two articles support the findings of the current study in the Indonesian context, as most of the participants perceive their roles to focus on curative management through monitoring nutrition status as well as infectious diseases.

It can be concluded that Indonesian nurses' perception of their roles in early identification and intervention of developmental delays may differ from other nurses in particular, those from developed countries. For example, [Walsh and Mitchell \(2013\)](#) explain that Australian general practice nurses' roles include immunisations, child health checks, general child health and development, asthma, feeding, fever and settling or sleeping management. Interestingly, Australian nurses also raise the need for professional development in childhood growth and development ([Walsh & Mitchell, 2013](#)). They describe that child health checks which include areas addressing parental concerns about development, child head circumference and height ([Walsh & Mitchell, 2013](#)) are similar to this study. In addition, nurses in Australia are developing more contemporary services including provision of home visits, individual consultations, drop-in clinics, parental management clinics and Positive Parenting Program (Triple P program) ([Barnes et al., 2003](#)) which cover concepts of an early intervention service ([Guralnick, 2005](#)). According to [Guralnick \(2005\)](#) early intervention aims to improve parent-child interaction; influencing parents to provide home and community experiences that can substantially influence a child's development; ensuring that the home environment contains appropriate toys and materials; engaging with social activity that is stimulating and interactive; and ensuring child health and safety through providing proper nutrition and maintaining a preventive healthcare regime (immunization and well-baby care).

## CONCLUSION

Early identification of developmental delays and disabilities is critical to support the optimal development of children. One of the main aims of an early identification program is to ensure that children in need receive appropriate and timely intervention. Although early identification of developmental delays (DD) and intervention for children with developmental delays and disabilities exist in most developed countries, this may not happen in developing countries, particularly in Indonesia.

In regard to early intervention for children with developmental delays and disability, the nurses perform their role through the provision of nursing care. Nursing care includes providing the motivation and encouragement to support the inclusion of the children with developmental delays and disabilities, a principle of disability delivery service which is similar to delivery in developed countries. In addition, the nurses believe that children with disabilities should not be kept at home or become a source of shame for the parents. Thus, intervention in the form of inclusion and participation is predominant in the perception and beliefs of the nurses, although not enough to support the full inclusion and participation of children with developmental delays or disabilities.

## DECLARATION OF CONFLICTING INTEREST

There is no conflict of interest to be declared.

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## AUTHOR CONTRIBUTION

Concept generation, data collection, writing and editing of the manuscript (M), Concept generation, critically reviewed, writing and revision of the thesis (LC and PJ).

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