

## **Genetics knowledge of advanced midwifery learners: Educators' perceptions**

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### **Abstract**

Healthcare professionals require adequate knowledge of genetics to be able to assess, diagnose, manage and prevent in good time genetic-related diseases. Healthcare professionals empowered in this field are able to differentiate at an early stage between genetic and genomic components of diseases. Advanced midwifery learners are trained to provide specialist holistic care that includes genetics upon course completion. Their genetic knowledge is crucial for them to provide genetic services in clinical- and in primary health care (PHC) settings. This study explores perceptions of advanced midwifery educators regarding genetics knowledge of their learners. A qualitative, explorative and descriptive design was employed. A total of 19 participants took part in this study. Data were collected through focus group discussions, individual face-to-face and telephone interviews. Thematic analysis was used for data analysis. Genetic knowledge emerged as a major theme under which genetic concepts, genetic history taking, common genetic disorders, genetic counselling, identification and management of genetic disorders were identified as sub-themes. At present, genetics education is addressed at the discretion of the individual advanced midwifery educators during training. This random kind of teaching is attributed to the lack of a curriculum framework that standardises genetics education at nursing education institutions (NEIs) in South Africa. The importance of genetics education is underrated in advanced midwifery courses, contributing to learners lacking adequate knowledge of genetics. Advanced midwifery learners need a sufficient knowledge of genetics to provide holistic care in clinical and PHC settings upon course completion.

**Keywords:** Advanced midwifery education, genetics, genomics.

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### **Introduction**

Adequate knowledge of genetics is essential to empower healthcare professionals with skills and competence in differentiating between hereditary genetic components of diseases (Canadian Nurses Association, 2005). Healthcare professionals empowered in this field are better able to assess, diagnose and prevent genetic diseases before they occur. Early recognition leads to improvement in the provision of relevant interventions. Genetics has profound implications for the health of society and its influence prevails throughout the

human lifespan, commencing before pregnancy through to old age (Burke & Kirk, 2005; Lashley, 2007). Adequate education of healthcare professionals (including nurses and advanced midwives) in appropriate knowledge of genetics is important to enhance genetics skills and competencies. These professionals are responsible for provision of healthcare in clinical and in PHC settings.

Sufficient knowledge of genetics is required because it helps healthcare professionals, including advanced midwifery learners to adequately assess which clients could benefit from interventions (Lashley, 2007). Calzone et al. (2013) state that application of genetic knowledge and technology in clinical settings has moved into non-speciality healthcare provision. This makes knowledge of genetics an integral component of every healthcare professional's work including the work of advanced midwifery learners upon course completion. Applying the knowledge of genetics in clinical and in PHC settings is crucial for health promotion.

Genetics education in nursing and midwifery remains a global challenge because of lack of accommodation of sufficient genetics content in nursing and midwifery education (Maradiegue, Edwards, Seibert, Macri & Sitzler, 2005; Vural Tonatur, Kurban & Taşpınar, 2009; Thompson & Brooks, 2010; Williams, Prows, Conley, Eggert, Kirk & Nichols, 2011; Godino & Skirton, 2012). Although genetics education is beginning to be recognised among nursing faculties, Collins and Stiles (2011) argue that there are few studies to confirm that genetics content has reached learners. Calzone, Cashion, Feetham, Jenkins et al. (2010) point out that current academic nursing education does not adequately prepare nurses in genetics and its content is not standard in registered nurses' programmes. Benjamin, Anionwu, Kristoffersson, ten Kate et al. (2009) state that genetics teaching is left to individual teachers in some nursing schools in the United Kingdom. This accidental teaching of genetics does not provide required knowledge, skills and competencies among learners.

Although genetics forms part of nursing curricula in South Africa, genetics teaching in undergraduate nursing programmes is varied, depends on facilities and staff availability (Policy Guidelines, 2001). The consequence of this kind of teaching arrangement is that undergraduate learners are currently offered genetics education by chance in NEIs. The curriculum framework for genetics education in undergraduate courses has remained a recommendation according to the Policy Guidelines of 2001. Genetics is further entailed in post-basic diploma in nursing science courses offered at various accredited NEIs in South Africa. Advanced midwifery course is also a post-basic nursing course which upon training completion, learners are referred to as advanced midwives as they will have obtained a post-basic diploma in midwifery and neonatal nursing science. During training, post-basic nurses including advanced midwifery learners do not receive genetic education in South Africa (Policy Guideline, 2001). These

learners exit the course with limited genetics knowledge. One-day and distance genetic courses including yearly in-service genetics programmes are available to all nursing staff including educators of advanced midwifery course (Policy Guideline, 2001). Evidence to confirm attendance of these courses by advanced midwifery educators is lacking.

Christianson, Howson and Modell (2006) state that higher prevalence rates of birth disorders are found in the poorest countries and a strategy such as basic medical genetic service knowledge among nurses and advanced midwives, could enhance skills in prevention of genetic disorders. It is also recommended that healthcare professionals, including advanced midwifery learners require genetics training for recognition of causes of disease through appropriate assessment (Christianson et al. 2006). Advanced midwifery learners require such education to attain knowledge, skills and competencies to be able to measure and recognise genetic conditions in clinical and in PHC settings.

Calzone et al. (2010) are of the view that limited genetics competence leads to the inability to take advantage of genetic discoveries to improve health. During training, advanced midwifery learners are placed in clinical settings to practice various skills including those related to genetics. Educators accompany the learners in those clinical settings to teach all kinds of skills in order to correlate theory and practice. Because of current lack of a curriculum framework to standardise genetics education in the course, educators of this course provide slapdash genetics information during theory and clinical learning. In certain instances, educators of this course often rely on someone perceived to be better informed in genetics to offer genetics classes. This unsystematic kind of teaching results in the provision of inadequate information with regard to genetic concepts and principles. Opportunities to provide adequate genetics education are lost, as important genetics information could be inappropriately addressed through current unplanned genetics education. Prospects for health promotion, prevention of diseases and acquiring of new roles of nurses and advanced midwives that could come about with adequate genetics education are missed (Little & Lewis, 2005).

Nursing schools continue to ignore the call for inclusion of adequate genetics into the curricula even though recommendations were made decades ago that this is a major important field for every health discipline (Turnpenny & Ellard, 2007; Tomatir, Sorkun, Demirhan & Akdag, 2006). Lea, Williams, Cooksey, Flanagan et al. (2006) are of the view that much needs to be done to ensure that nurses acquire appropriate knowledge of genetics. It is projected that in South Africa, acceptable accommodation of genetics in nursing curricula could be realised by the year 2017 (Godino & Skirton, 2012). It is anticipated that NEIs in South Africa could embrace sufficient genetics in nursing curricula in the next three years.

The lack of a curriculum framework that standardises genetics education for NEIs in South Africa is a challenge. Learners continue to exit teaching programmes with limited genetics knowledge, skills and competencies needed in clinical and PHC settings. The consequence of this limitation is the resultant unskilled and incompetent learners with regard to knowledge of genetics. The writing of this article was prompted by perceptions of advanced midwifery educators that their learners lack knowledge of genetics.

## **Methodology**

### *Research settings*

The study took place in NEIs, which included five nursing colleges and three universities of three provinces in South Africa. The three provinces are Gauteng, North West and Kwa-Zulu Natal.

### *Research design*

A qualitative exploratory and descriptive research design was used to obtain perceptions of educators regarding knowledge of genetics among learners during training in advanced midwifery.

### *Sample*

A total of 19 participants were involved in this study. All participants were educators of advanced midwifery course and were qualified in the diploma in post-basic midwifery and neonatal nursing science. The sample included females only and various race groups were represented (Black, White, Indian and Coloured). The ages of participants ranged between 43 and 62 years. The participants had taught an advanced midwifery course for more than two years and were all purposefully selected and volunteered to participate.

### *Ethical considerations*

Participants were informed that permission to conduct the research was obtained from the Ethics Committee of the Faculty of Health Sciences at the University of Pretoria (Ref: S38/2013). Information regarding further ethical clearances from provincial departments of health for access to nursing colleges was provided to participants. All participants were informed of obtained permission from heads of nursing schools. Informed consent was obtained from each participant. A consent form and the information leaflet containing the necessary information about the research was given to all participants. Participants were assured of confidentiality and were informed that participation was voluntary.

### *Measures of trustworthiness*

Trustworthiness of the data was ensured by the following measures: truth value (prolonged engagement and verification of findings by participants); applicability (purposive sampling and use of co-coder); dependability (consistency and rich description); neutrality (triangulation, audit and reflexivity) and authenticity (fairness, faithfulness and use of verbatim quotes) (Botma, Greeff, Mulaudzi & Wright, 2010).

### *Data collection*

Various qualitative methods were used for data collection namely: focus group discussions and face-to-face- and telephone interviews. The initial data collection method was focussed on group discussions. However, because NEIs in South Africa are widely separated, it was impossible to bring educators from one NEI to another for focus group discussions. The researcher collected the data at each participant's workplace with the exception of telephone interviews. The same type of interview schedule was used for data collection. All focus group discussions and individual interviews were conducted in English, as participants were conversant in it. Three focus group discussions and three face-to-face interviews were conducted in various NEIs. Offices in those NEIs that took part in the study were used for data collection. The telephone interviews were performed in one college and one university. Telephone interviews were performed during office hours at the time when participants were at their workplace, without interfering with their duties. Each telephone interview was written down by the researcher.

### *Data analysis*

Thematic analysis according to six stages of Braun and Clarke (2006) was employed to analyse data. Familiarisation with data as the first stage commenced soon after the first data were collected and continued throughout collection and analysis of data. The data transcription, listening to audiotapes and reading and re-reading of data enhanced the familiarisation stage (Braun & Clarke, 2006). Stage two, which is the generation of initial codes, began as preliminary codes were initiated from data sets. This stage was heightened through transcription of data from audiotapes by the researcher. Margins were made available on each transcript to enable the writing of initial codes. Similar pieces of information from data were highlighted manually as codes (Braun & Clarke, 2006). Searching for themes constituted stage three, where created codes were sorted and collated into themes. Related codes were harmonised to create main themes and sub-themes from data sets (Braun & Clarke, 2006). Reviewing of themes was the fourth stage of thematic analysis, where created themes were reviewed against data sets to verify if those themes adequately captured meanings from

codes to ensure that themes emerged from data sets (Braun & Clarke, 2006). Themes were then defined and named which was the fifth stage of thematic analysis, where the meaning of a theme was determined to ensure that sub-themes were encompassed within the main theme (Braun & Clarke, 2006). The sixth stage was to produce the report, at which point the findings were written based on data sets (Braun & Clarke, 2006).

## **Results**

Six stages of thematic analysis were used to analyse data and genetics knowledge emerged as a theme from data sets. Listening several times to audiotapes, transcribing and numerous reading of data sets provided opportunity for initial familiarisation of the researcher with data. Meanings and patterns were identified and highlighted, especially repeated words (Braun & Clarke, 2006). Initial codes were generated as similar and frequent pieces of information from data sets were coded. Specific patterns of information that seemed to belong together were highlighted to further create codes (Braun & Clarke, 2006). The created codes were sorted and collated to form a principal theme (Braun & Clarke, 2006). Comparable codes were combined to produce a specific theme called “genetic knowledge” under which genetic concepts, genetic history taking, common genetic disorders, genetic counselling, identification and management of genetic disorders were identified sub-themes. The theme and sub-themes were used to describe genetic knowledge of advanced midwifery learners as perceptions of participants.

Participants reported that various genetics concepts were addressed at the convenience of educators during advanced midwifery training. Those concepts that educators selected for teaching were, however, inadequately and superficially addressed. Participants expressed their perceptions as follows: “Some genetics concepts that we know are addressed but very superficially and only in class. I do not do more genetics in advanced midwifery because these were done in basic midwifery training.”

Regarding genetic family history taking, participants mentioned that their learners only took the first-generation history. Taking only the first-generation history was based on the fact that there is a lack of a framework to guide the generation the family history should be taken at. The views of participants were expressed as follows: “Advanced midwifery learners often take the first-generation family history because it is the most important one. Our training currently only ends with first-generation history taking.”

Concerning common genetic disorders, findings showed that various familial genetic disorders were selected and discussed with learners in class. Participants mentioned that these conditions were, however, partially discussed, as most

disorders were already addressed during basic midwifery training. Indication for selecting specific genetic disorders was once again the lack of a curriculum framework. The following quote bears evidence: “Down’s syndrome was done in basic midwifery training but it is briefly discussed in class with advanced midwifery learners. Edward syndrome and cystic fibrosis are also briefly discussed. The most common disorders are superficially discussed.”

With regard to genetic counselling, participants indicated that advanced midwifery learners lack knowledge and skills to provide genetic counselling. The lack of a standardised curriculum framework to guide genetics education was blamed. Participants expressed their views as follows: “Advanced midwifery learners are unable to provide a better genetic counselling.”

On identification of genetic disorders, it was revealed in the findings that learners have knowledge, skill and competence to identify genetic disorders. Identification of women at risk for genetic disorders is one skill that learners have. The views of participants were expressed as follows: “Learners refer pregnant women with history of genetic disorders to the specialist for chromosomal analysis.”

With regard to management of genetic disorders, it was revealed that learners lacked knowledge and skills to manage genetic disorders. Management of genetic disorders is a speciality area for specific healthcare professionals. The views of participants were expressed as follows: “Genetics is a speciality area. Genetic nurse must come back because she is better empowered in addressing genetics problems. Genetics is the field for that nurse and not the field for our learners.”

## **Discussion**

The limited knowledge of genetics among learners was the main finding. The basis for this lack is that genetics concepts were superficially addressed during advanced midwifery training. The consequence of the shallow teaching of genetics concepts resulted in unskilled advanced midwifery learners. The jumbled teaching of genetics concepts defy a call made in the study of Conley, Biesecker, Gonsalves, Merkle et al. (2013) that it is required of nurses to have the acceptable knowledge of essential scientific genetics concepts to be able to provide appropriate genomic healthcare.

With regard to genetic history taking, it is noted that learners only obtain the first-generation history during interactions with pregnant women. Obtaining this kind of history means that valuable information about the family is missed and family assessment is incompetently explored. Attaining a three-generation history assists in identifying conditions that could be inherited and require

follow-up, so that risk assessment is performed with a three-generation history (Lashley, 2007). Taking sufficient family history in clinical and PHC settings assists in the determination of individuals who could be referred early for genetic tests. Satisfactory history taking of three generations and constructing a pedigree for a particular family sensitises learners of advanced midwifery for early genetics tests required to avert unfortunate implications (Lashley, 2007). Advanced midwifery learners lacked the knowledge for obtaining a three-generation history.

Although most (89%) participants indicated that learners had knowledge of common genetic disorders, the information should be examined with caution as mode of inheritance of these disorders were not sufficiently addressed during training. There is a disconnect between the perceived knowledge of common genetic disorders that are often addressed in class and the translation of the same knowledge in clinical and PHC settings. The situation of selecting certain common disorders was worsened by the lack of a curriculum framework to guide on teaching content with regard to genetic disorders. For healthcare practitioners to sufficiently contribute to holistic healthcare, educational preparation needs to embrace adequate genetic content (Kirk, 1999). This might improve knowledge of most familial genetic disorders so that an existing genetic knowledge gap in advanced midwifery learners is addressed.

Findings showed that learners have knowledge of genetic risk factors that contribute to genetic disorders. According to Christianson and Modell (2004) “*genetic risk factors are common gene variants that cause problems relatively rarely*”. Queißer-Luft and Spranger, (2006) state that a parent or parents with genetic disorders, those practising consanguinity and women of advanced maternal age are among genetic risk factors. Participants mentioned that selected risk factors for genetic disorders were addressed in class. Advanced maternal age is the concept most addressed among other risk factors for birth defects (Christianson, et al. 2006). In this study, participants also related mostly to advanced maternal age as the greatest risk factor for genetic disorder. Nevertheless, a full picture of genetic risk factors received narrow attention during advanced midwifery training. Breast cancer is a risk factor for genetic disorder especially if it “*occurred in one’s mother, sisters and aunts*”, which would signify high risk for breast cancer (Lashley, 2007). This disease can be one of the hereditary cancers present in blood relatives (Lashley, 2007). Advanced midwifery programmes have to improve regarding adequate inclusion of genetic risk factors to ensure that learners acquire sufficient knowledge.

On the issue of genetic counselling, findings showed that learners lacked knowledge and skill to perform genetic counselling in keeping with Williams, Skirton and Masny’s (2006) study where healthcare practitioners were not well enough prepared to provide genetic services including counselling in clinical



practice. Participants in the current study acknowledged that learning genetic counselling is not well planned; therefore, learners were not equipped with adequate counselling skills.

Regarding identification of genetic disorders it is revealed in the findings that learners have knowledge and skill to identify genetic disorders. The learners often refer pregnant women identified as suspects for genetic predisposition for necessary interventions. According to Lashley (2007) a situation that suggests a genetic problem is a family history of genetic disorders. Women who had experienced repeated spontaneous abortions, stillbirths or infant death of unknown origin or genetic causes (Lashley, 2007). However, participants in the study reported on in this article could not refer to the aforementioned maternal and child health related challenges to be caused by genetics problems. Genetics services are integrated into Maternal, Child and Women's Health services even though genetics influence every level of care delivery (Policy Guidelines, 2001).

On the management of genetic disorders, findings revealed that learners lacked knowledge and skill to manage genetic disorders. Participants considered inclusion of adequate genetics information in the current education to be irrelevant because genetics is a speciality area that is the domain of specific persons. Participants could not regard genetics as part of an advanced midwifery course as they relied on genetic nurses to provide information in class or in clinical practice in the event of a new-born baby born with genetic disorders. The views of participants are consistent with findings from Kirk, Calzone, Arimori and Tonkin (2011), who found that nurses could not consider genetics as applicable to their practice. Participants in the study by Gharaibeh, Oweis, and Hamad (2010) perceived teaching genetics like explaining genetic diagnosis as the role of healthcare professionals other than nurses.

Calzone et al. (2013) point out that limited genomic competency among nurses and nursing faculties results in limited capacity to deliver safe and effective genomic-based care. Faculties in the form of advanced midwifery educators reported the lack of curriculum framework to be the reason for insufficient genetics teaching. The views of participants were that a standardised curriculum framework could guide genetics education. The lack of suitable knowledge and skills in genetics among learners could be attributed to the lack of knowledge among educators of advanced midwifery course. This information is congruent with that from other studies where educators lacked the capacity to satisfactorily implement genetics education (Calzone et al., 2013; Burke & Kirk, 2005).

Genetics education is underrated in advanced midwifery course in South Africa, as the content is superficially addressed during training. Learners in advanced midwifery exit the programme with scanty knowledge of genetic concepts. Further, the understanding of common genetic disorders is lacking while

assessment for genetic risk factors is performed superficially. In addition, provision of genetic counselling is limited while identification and management of genetic disorders in clinical and PHC settings are lacking. Opportunities to promote health, prevent diseases and acquiring of new roles that could come about with suitable genetics education are delayed. Upon course completion, advanced midwifery graduates provide insufficient genetic healthcare in clinical and PHC settings. The genetic knowledge of learners is deficient as perceived by educators of advanced midwifery course who participated in this research study.

### **Limitations**

The vastness of provinces made it difficult for educators to leave their respective areas to attend focus group meetings in other far away settings. The number of educators in most NEIs was also low, making it difficult to have more members in focus group discussions. Gate keepers in a specific NEI declined participation in the current study on behalf of prospective participants, mentioning that these educators were too busy.

### **Conclusion**

Advanced midwifery learners lack suitable genetic knowledge. This lack is attributed to the absent curriculum framework required by participants for them to integrate adequate genetics in advanced midwifery course. Genetics learning outcomes are required and these could be an achievement for learners if attained through advanced midwifery course. It is required of advanced midwifery educators to empower themselves with adequate genetics information to be able to transfer knowledge to their learners. A curriculum framework to standardise genetics education if developed and implemented could assist NEIs in South Africa in appropriately accommodating genetics required to empower learners in advanced midwifery course with genetics knowledge, skills and competence.

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