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Midwifery Education in Practice

The first competency based framework in genetics/genomics specifically for midwifery education and practice

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ABSTRACT

This paper details a competency framework to help address the need for structured guidance around genetic and genomic education and training for midwives.

A one-day expert panel consensus meeting was convened to review and revise a previously published joint framework for nurses, midwives and health visitors. Fifteen midwives from practice, management, education and policy and three genetic counsellors (two with midwifery backgrounds) attended. An in-depth knowledge of genetics/genomics was not a requirement. Personal narratives covering a range of experiences across the pre- and post-natal periods were used to stimulate discussion and debate. Identified themes were mapped to the original framework to identify gaps and differences. Inclusion of additional themes into the new framework was voted upon.

All original competencies were found to be valid but required amendment in order to focus specifically on the role of the midwife and the needs of the mother, child and wider family. Revisions have resulted in a framework that is more directive and which addresses the time-critical nature of information-giving, decision-making, testing and referral that are crucial components of midwifery practice. Learning outcomes and practice indicators offer educators and trainers a means of developing student/staff knowledge and skills over time and with increasing experience.

1. Introduction

Genetics has become an integral component of the entire maternal and family health care pathway from pre-conception through to the post-partum period. For many pregnant women the genetic component of their childbearing experience may be limited to the advice given regarding folic acid supplementation, diet and lifestyle; taking of family history information during the booking appointment; and information provision and consent for 'routine' antenatal and newborn screening tests. These interventions may not even be perceived as being related to genetics. For other women, more obvious risk factors such as a positive or high-risk screening result, knowledge of an inherited condition in the family or the identification of an unexpected condition during the anomaly scan or at birth, may extend their experience of genetic healthcare. This can include diagnostic testing of the fetus, referral to specialist services, and decision-making around continuation of pregnancy, care planning or termination of pregnancy. While midwives need to utilise their core skills in communication, compassion and ethical care in these situations (Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser, 2012), they also require core knowledge of genetic concepts that can be drawn on and applied to each specific case.

The complexity of midwifery practice continues to increase as our understanding of genetics and genomics (the inter-relationships of genes and the environment, and the associated ethical, legal and social issues) expands. Scientific findings are translated alongside technological developments, into advances in the clinic. For example newborn bloodspot screening (NBS) is used around the world to detect inborn errors of metabolism and other inherited disorders. Advancements in technology now make comprehensive screening for 50 + conditions possible. In the United Kingdom (UK), midwives are involved in consenting for and taking of samples, and sometimes in the return of results. Therrell et al. (2015) describe the global variation in provision (ranging from countries with full population screening mandated to

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those with no or minimal screening) and the complexity of delivering NBS in many regions. Even within Europe the picture is very mixed and is dynamic. In Great Britain for example, four conditions were added to the NBS panel over recent years bringing the total number of conditions currently screened for to nine. Another example of a significant advancements in maternity care, is non-invasive prenatal testing (NIPT) for Down syndrome (trisomy 21/T21) and other common aneuploidies using cell free fetal DNA (cffDNA). Already available within the private sector, evaluation of this technique within the National Health Service, as an alternative to the current options of the combined or quadruple tests, has been recommended (UK National Screening Committee, 2016) and is ongoing.

Midwives will be required to manage such developments in current practices, incorporating the increase in information that needs to be provided to women and their families to support informed decision-making around screening and testing. This professional responsibility is emphasised in the UK policy document *Compassion in Practice* (Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser, 2012). However, a recent study by John (2017) examining 100 first consultations with midwives (n = 16) found that not all women were fully informed about Down syndrome and screening.

Whilst not currently utilised routinely in the newborn period, exome and whole genome sequencing (WGS) is becoming increasingly accessible in a clinical context to confirm clinical diagnoses and identify at-risk individuals. Recognising that such use can inform clinical management and decision making, Borghesi et al. (2017), offer a rationale for the use of whole exome sequencing (WES) in the critically ill newborn infant. Howard et al. (2015) discuss the issues and challenges of using this technology within NBS programmes. Their recommendation, endorsed by a number of international organisations, is that a targeted approach to the identification of "preventable or treatable conditions, for which treatment has to start in the newborn period or in early childhood" remains (Howard et al., 2015 p.1598). As WGS and other similar advances intersect more frequently with the midwifery role, midwives will need to incorporate them successfully into practice. Ideally, fundamental core knowledge and skills in genetics/genomics should be in place as part of competency attainment during pre-registration education, becoming embedded once in practice and thus provide a foundation to build upon when new clinical situations such as WGS arise.

1.1. The impetus for a genetics/genomics framework for midwifery

In many countries over the last 15 years there have been concerted efforts to drive integration of genetic and genomic healthcare into services. Examples include the UK Government's White Paper *Our Inheritance Our Future* (Department of Health, 2003) and the more recent 100,000 Genomes Project (Siva, 2015), the US' Precision Medicine Initiative (The White House, 2015) and Australia's National Health Genomics Policy Framework (Australian Health Ministers' Advisory Council, 2017). In the UK, the Department of Health commissioned and funded the development through stakeholder consensus, of a combined genetics competency framework for UK nurses, midwives and health visitors (Kirk et al., 2003). Seven statements, each with learning outcomes and practice indicators, articulated what were determined to be the minimum standards of knowledge and skills in genetics required by the profession as a whole. The framework provided the base for work to develop a set of competencies that could be applied across different health professions in Europe (Skirton et al., 2010a). The United States (US) and Japan are the only other countries with genetics/genomics competencies for nursing (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009; Greco et al., 2012; Arimori et al., 2007). There are no competence frameworks specifically for midwifery.

Current midwifery education and training within the UK is based on the pre-registration standards set out by the Nursing and Midwifery Council (NMC, 2009). There is no detailed curriculum and individual higher education institutions decide how to structure training in order that their students meet the requirements for practice at the point of registration. As a result there is no specific guidance on the genomics knowledge, skills or attitudes required for competence by students or the practicing midwife.

Skirton et al. (2012) in their paper on nursing competence discuss the importance of confidence in addition to knowledge and skills and the role it may play in an individual's willingness to use their knowledge and skills. Confidence in undertaking genetic based activities in clinical practice has been shown to be low within the midwifery profession (Metcalfe et al., 2008; Benjamin et al., 2009) although showing some improvement over time (Crane et al., 2012) although the differences may be a result of education, training and/or healthcare systems between countries. Pre-registration education in the UK was also found to be patchy and insubstantial when Kirk and Tonkin (2006) surveyed UK nurse and midwifery educators, using the original competency framework as a benchmark. None of the competencies were being achieved in full in any institution for any midwifery programme and under half of the midwifery programmes that responded (n = 46) assessed any learning in genetics. A subsequent systematic literature review (Skirton et al., 2010b) determined that midwives in the UK and in Japan were not satisfactorily achieving any of their country's prescribed competencies in genetics at that time. The number of empirical studies that have looked at midwifery confidence, competence and education in genetics/genomics is small and there are no data available to determine whether this picture has changed in recent years. Studies of specific aspects of practice might provide some insights but would have limited value considering the actual breadth of competence required. We suggest that whilst there might be pockets of improvement driven by local/individual interest in genomics and developments in maternal/child services, wide scale, consistent improvement across the midwifery profession is unlikely to have occurred in the absence of focused initiatives.

Aware of the significant advances being made across healthcare in relation to genetics and genomics and the anticipated developments in midwifery practice, the authors made a decision to undertake a review of the Kirk et al., 2003 framework. Additionally, it was decided to consider midwifery independently from the whole of nursing practice, thus allowing the development of specific competency statements by the profession, which could be used to help address gaps in education, training and practice.

This paper sets out the approach taken to produce the framework, the outcome and the implications for the profession across the UK and internationally.

2. Methods

2.1. Consensus panel

A stakeholder expert panel consensus meeting, broadly based on the established Nominal Group Technique (Delbecq et al., 1975), was selected for data collection having been applied successfully to similar studies by team members for over a decade (Kirk et al., 2003; Kirk et al., 2014a,b). The method allows for structured interaction within a group through an iterative process of idea generation, feedback, discussion and voting. The conceptual framework for the event and details of the participative thematic analytical approach taken, are set out by Kirk et al., (2014b). In summary, stakeholders with expertise and experience from a range of backgrounds (midwifery practice, management, education and policy, and genetic counselling) were invited to a one day workshop in June 2010. Travel expenses were reimbursed. Participants were identified through the professional networks of team members and colleagues, or selected based on their role within an organisation or professional body including national antenatal/newborn screening programmes, the Nursing and Midwifery Council, Royal College of Midwives and the Royal College of Nurses (midwifery and women's