REVIEWS

A systematic review of nurses' knowledge of genetics

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Abstract

Background: Given the current emphasis on genetics as a relatively new topic in the field of mainstream healthcare, it is interesting to note that authors suggested that genetics should be included in nursing curricula almost fifty years ago. Genetics has been important to the role of nurses in specific specialities for some years. However, some studies reported that the current training with respect to genetics for nurses did not enable them to acquire the necessary skills for their work. The aims and objectives of this review were to examine the available evidence on genetics knowledge of nurses.

Methods: We conducted a systematic review. A search of British Nursing Index, CINAHL, Embase and Medline databases was undertaken for papers published in English between January 2001- September 2011. Six studies satisfied the inclusion criteria.

Resukts: In three of the six studies included, the authors analysed the nurses' perceived knowledge in genetics while in only two studies the authors measured actual knowledge. However, both perceived and actual knowledge of genetics was poor. The amount of genetics education delivered to nurses in these studies was low overall.

Conclusions: However, while genetic content is lacking on educational programs the findings confirm that nurses are open to genetics education and that this should be in a form that enables them to apply genetic principles to their everyday healthcare experience. In particular, integration between science and practice is required to enable nurses to fully utilise genetics for the benefit of patients. It is clear that further educational initiatives are required to equip nurses to practice safely and effectively in the post-genomic era.

Key words

Systematic review, Genetic, Nurses, Knowledge and education

1 Introduction

Genetics has been important to the role of nurses in specific specialities, such as maternal and child health [1] or the haemoglobinopathies [2] for some years. In addition, specialist genetic nurses currently work in many countries, including the United Kingdom (UK) [3], Japan [4] and the United States [5]. However, as there is increasing evidence that genetics will change the practice of medicine and mainstream health-care [6, 7], all nurses must understand genomic information and the concurrent skills and attitudes to enable them to incorporate these changes for patient benefit [8, 9]. In fact, genetic and genomic competencies are integral to the practice of all registered nurses [10, 11], especially given the current focus on personalised medicine which incorporates use of genomic information into diagnosis and management of common

diseases [6]. For example pharmacogenomic information based on normal genetic variants can indicate the most appropriate drug and dosage for an individual [12]. These types of developments in genomics are undoubtedly of relevance to routine nursing care.

Given the current emphasis on genetics as a relatively new topic in the field of mainstream healthcare [13, 14], it is interesting to note that authors Brantl & Esslinger [15] suggested that genetics should be included in nursing curricula almost fifty years ago. Despite this recommendation, medical genetics was not introduced into basic or advanced nursing education [16, 17] until after the turn of the century and it appears that genetics content in nursing curricula is still lacking. Indeed, in a recent international survey by Kirk et al [17] based on the opinions of nursing leaders from ten countries (Brazil, Israel, Italy, Japan, Netherlands, Oman, Pakistan South Africa, United Kingdom (UK) and United States (US)), nursing competences in genetics had been developed in three countries (Italy, UK, US). Although genetics was reported to 'have a presence' in the nursing curriculum in Israel, Netherlands, Pakistan, South Africa and the US, it was suggested that it would still take a number of years to ensure that genetics was appropriately accommodated into the nursing curriculum, estimated as 1-3 years in Pakistan, 1-2 years in Oman and 1-5 years in South Africa. The authors concluded while professionals working in genetic healthcare were active in promoting the integration of genetics into mainstream nursing care, greater engagement by senior nursing leaders and educators was required to ensure this became a reality.

Despite the slow progress reported by Kirk et al [17], there is an increasing acknowledgement in many countries of the need to enhance the genetic education of health professionals [18-21]. However, Burton [22] concluded that the current training with respect to genetics for nurses did not enable them to acquire the necessary skills, even though they may work in settings where they are likely to require those skills [23]. This is not confined to undergraduate programmes; in a study also conducted in the UK, Metcalfe [24] reported a similar lack of content related to genetics in postgraduate nursing education.

In the light of concerns about the genetics/genomics education of nurses and their subsequent fitness to practice, a question arises as to whether nurses have adequate knowledge of genetics or genomics. Some previous studies [25, 26] and reviews have included knowledge as one component of the overall genetic competence of nurses. However, as there appears to be concern about the genetic literacy of nurses, we conducted a systematic review of studies where the particular focus was nurses' knowledge of genetics in order to specifically investigate this issue.

Aims and objectives

The aim of this systematic review was to establish the current evidence base regarding nurses' knowledge of genetics.

The objectives of the review were to:

- Identify studies in which genetics knowledge was tested;
- Compare evidence on nurses' actual and perceived knowledge.

2 Methods

2.1 Ethics

This was a systematic review, ethical approval was not required.

2.2 Design

A systematic review of literature was conducted to identify and analyse the current evidence [27] on the genetics knowledge of nurses. As reported by Greenhalgh [28], we conducted the review by setting clear objectives, determining appropriate inclusion criteria for the pertinent studies, and using a logical search strategy that is replicable by others.

2.3 Search strategy

A search of the published peer-reviewed literature on education for nurses in genetics was conducted in September 2011.

2.4 Keywords

The search terms were: "DNA or genet* or genome* or genogram* or pedigree*" and "genetic nurs* or health visitor* or midwi* or nurs* or nurse midwi*" and "attitude* or belief* or comprehend* or educat* or knowledge of learn* perception* or preconce* or prejudic* or teach* or train* or understand*". In some countries, 'nurse' and 'midwife' or 'nurse' and 'health visitor' may be used interchangeably, we therefore used those terms as key words to ensure we captured all potential studies.

2.5 Database

The databases using in this research were:

- British Nursing Index
- Cumulative Index of Nursing and Allied Health Literature (CINAHL)
- Embase
- Medline

We also searched the contents of specific journals such as the International Journal of Nursing Practice and the references lists of relevant papers.

2.6 Date

Papers that were published from January 2001 to September 2011 were eligible for inclusion.

2.7 Selection: inclusion and exclusion criteria

The criteria for inclusion in this review were papers reporting the following:

- Primary research
- Studies on nurses alone or where the data on nurses could be extracted from the overall data
- Studies about knowledge and/or learning of genetics or genomics.

We excluded studies about:

- Health professionals other than nurses
- Papers focused on the content of curricula
- Research on pre-registration nurses or the views of nurse teachers

2.8 Validity assessment and search outcome

The search of four databases initially produced 132 potential papers. In addition, ancestral searching of the reference lists for relevant papers was used to identify any further papers of interest, resulting in five further papers. Of the total, 63 were duplicates, leaving 74 for examination. Following review of the title and abstract, 31 papers were assessed as potentially relevant. These papers were read in detail by both authors. Forty-three papers were excluded because they did not correspond to the "inclusion criteria". The six remaining papers were included in the review. The process of identifying the final papers is presented in Figure 1.

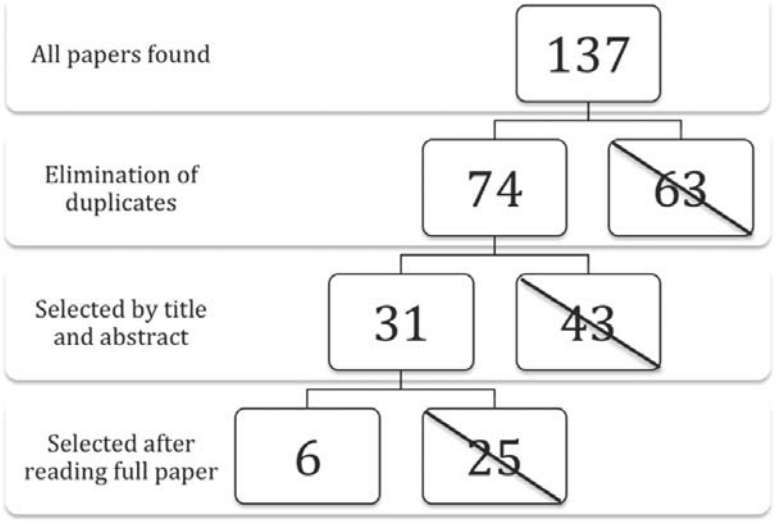

Figure 1. Flowchart of the paper selection process

2.9 Quality appraisal

Both authors assessed the six papers included in the review using the scale for quantitative studies developed by Kmet et al. [29]. Using the guidance in the paper, we assigned a score of between 0 and 2 for each of ten aspects of each paper. The score ranged from 55% to 90%. Table 1 includes the quality scores for each study.

2.10 Data abstraction – Summary of studies included in the review

See the Table 1 for relevant data from all the six studies, including the aims, sample, results, and quality issues. As it was not possible to undertake a meta-analysis of the data, we conducted a narrative analysis of the findings using the analytical methods described by Dixon-Woods et al [30]. Both authors read the papers multiple times, identified key themes and grouped data under those themes.

3 Results

Figure 1 provides detail of the flow studies included in the analysis.

3.1 Study characteristics

Of the six papers included, all were based on quantitative studies using a cross-sectional survey design. Three studies were conducted in the US, one in the UK, one in Turkey and one in Singapore. In two studies the type of nurse was not indicated, in one practice nurses were studied [31] in one only hospital nurses were recruited [32], while in two studies [33, 34] they were specified as nurses undertaking an advanced practice educational programme.

3.2 Quantitative data synthesis

We present the results of the data synthesis under three main themes: nurses' actual knowledge, nurses' perceived knowledge and genetic education.

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Table 1. Summary of papers included in the review

Authors and reference	Title	Aim(s)	Method	Sample	Analysis	Main results or findings	Kmet et al score (27) and quality issues
Bankhead et al, 2001	New developments in genetics-knowledge, attitudes and information needs of practice nurses.	To measure the activity, confidence and knowledge around genetics in primary care nurses.	A cross-sectional survey.	909 practice nurses from England and Scotland were invited to participate. 600 nurses responded (66.0%).	Free text responses were coded and a score for each answer produced. Descriptive statistics were used to analyze the result.	96.0% of practice nurses reported that they collected family history. Nurses were significant confident dealing with patient concerns about familiar breast cancer than colorectal cancer. The majority of nurses overestimated the risk of cancer to the patients in both the breast and colorectal cancer scenarios.	Score= 16/20=80%
Bottorff et al, 2005	The Educational Needs and Professional Roles of Canadian Physicians and Nurses regarding Genetic Testing and Adult Onset Hereditary Disease.	To investigate the knowledge, professional involvement and confidence of Canadian nurses and physicians in providing genetic services for adult onset hereditary disease.	A cross-sectional survey.	1,425 physicians and 1,425 nurses from Canada were invited to participate. 543 and 975 respectively responded (50%; 79%).	Descriptive statistics were used to analyze the result.	48% of physicians and 31% of nurses lacked formal education in genetics. However, 43% of physicians and 14% of nurses responded correctly to all five items assessing genetics knowledge and 34% and 35%, respectively, responded correctly to four items. Their levels of confidence that they could perform tasks, such as counseling about predictive genetic test.	Score= 18/20=90%
Maradiegue et al, 2005	Knowledge, Perceptions, and Attitudes of Advanced Practice Nursing Students Regarding Medical Genetics.	To describe the current medical genetic knowledge and perceptions of graduate advanced practice nursing students.	A cross-sectional survey.	A convenience sample of 46 graduate-level advanced practice nursing students from two universities located in the north eastern United States who had received and responded (100%).	The survey used consisted of 109 multiple-choice questions. Descriptive statistics were used to analyze the result.	The majority of respondents reported some or high knowledge of topic such as trisomy 21, mitosis, meiosis, sickle cell disease and colon cancer. A majority reported none or minimal knowledge of haemachromatosis, DNA translation, phenylketonuria and trisomy 18. A majority were not comfortable during a pedigree or speaking with a family diagnosed with a genetic condition.	Score= 15/20=75% The questionnaire assessed nurses' perceptions of their knowledge rather than their actual knowledge.

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Table 1. (continued)

Authors and reference	Title	Aim(s)	Method	Sample	Analysis	Main results or findings	Kmet et al score (27) and quality issues
Pestka et al, 2010	Education outcomes related to including genomics activities in nursing practice in Singapore.	To describe the impact of a genomic educational intervention.	A descriptive cross-sectional survey.	85 nurses working for Singapore Health Services participated in a nursing genomics seminar in 2008. All were invited to participate, 76 nurses responded (89.3%).	Descriptive statistics were used to analyze the result.	Nurses identified a case from previous practice and reported the assessment and intervention strategy in that case. Of a possible total of ten, nurses reported a mean of 7.2 assessments or interventions in relation to pregnancy, 6.5 in cancer cases and 4.9 in cases of hypertension. The most frequently used intervention item was discussing family history risk factors.	Score=11/20=55% The authors relied upon nurses' ability to accurately recall a case and assess their own performance with regard to genetic assessment and intervention in that case.
Spruill et al, 2009	Knowledge, Beliefs and Practices of African-American Nurses Regarding Genetics/Genomics	To explore the knowledge, beliefs, practice, and interest of African-American nurses in genetics.	A descriptive, naturalistic design.	A convenience sample of 77 African-American nurses completed the survey.	Descriptive statistics were used to analyze the result.	56% described their knowledge of genetic nursing as fair or poor, 43% as good. 60% reported that they had never had a course in genetic nursing. 86% responded that they knew how and 85% had completed a family health history.	Score=15/20=75%
Tomatir et al, 2006	Nurses' Professed Knowledge of Genetics and Genetic Counseling.	To describe nurses' current approaches to and knowledge about human genetics and genetic education in Denizli, Turkey.	A descriptive cross-sectional survey.	106 nurses who worked full time in one of the 26 health clinics in one province were invited to participate. 86 nurses responded (81.1%). In Turkey	Descriptive and inferential statistics were performed using the statistical package for social sciences (SPSS).	Most of participants reported having insufficient knowledge about basic genetics, the ethics of human genetics, and genetics counseling. Only seven nurses knew about some of the genetics counseling centers in Turkey and only ten nurses knew about the genetic counseling center in Denizli.	Score=17/20=85%

3.3 Nurses' actual knowledge

There were two studies in which the knowledge of nurses was assessed using objective measures. Bankhead et al [31] used scenarios, one based on familial breast cancer and the other on colon cancer, to assess general practice nurses' understanding of levels of genetic risk based on the family history. Of 600 respondents, only 19.7% (n=118) were correct in assessing a woman seeking advice about breast cancer had a similar risk to women in the general population, while the remainder overestimated the risk. However, of these, only 40.7% (n=48) correctly stated that the appropriate action would be to reassure the woman that her risk was low. In response to information about a family history of colon cancer, 9.3% (n=56) believed the risk was about the same as population risk and only 28.6% (n=16) of those would have reassured the patient. In two further scenarios based on patients with family history of either myocardial infarction or diabetes, far fewer nurses (6.5% and 4.0% respectively) replied that they would provide reassurance (this would have been inappropriate), potentially indicating that they were more familiar with dealing with patients with common conditions. Strengths of this study include the high response rate (66%) and large sample, although the questions did not require nurses to justify their answers in any way and the limited options for response (e.g. high risk or population risk) could have influenced the numbers of correct responses due to chance.

Bottorff et al. [35] conducted a study to investigate the knowledge, professional involvement and confidence of Canadian nurses and physicians in providing genetic services for adult onset hereditary disease. The authors stated that the opportunity to do this comparison provided information about potential areas for multidisciplinary collaboration in education programs and for arrangement of health care services to support the provision of genetic services. Surveys were sent to 1,425 physicians and 1,425 nurses, with responses from 543 physicians and 975 nurses. As well as investigating knowledge, the authors considered current practice and expected professional role in providing genetic services, confidence in providing genetic services and perceived usefulness of participating in genetics continuing education. The knowledge score was based on responses to five items on autosomal dominant inheritance risk (n=1), familial cancer (n=3) and definition of a mutation (n=1). Two questions were in multiple choice format and three required either a true or false answer. Of the nurses, 35% (n=341) responded correctly to 4 items and only 14% (n=136) had all 5 items correct. There were large differences between the knowledge of nurses and physicians for two items. Sixty-two per cent of physicians (n= 336) correctly identified the 50% inheritance risk to a child of a person with an autosomal dominant condition, compared with 32.3% (n=314) of nurses, while 81.1% (n=440) of physicians knew that testing for a breast cancer gene mutation could not tell a woman that she had breast cancer, compared with 49.9% (n=486) of nurses. One of the weaknesses of this study is the option to reply only true or false to three items, which could have had an impact on those answering correctly by chance. Nurses who had recently undergone continuing education on genetics ($p<0.05$), had medical genetics content in their pre-registration courses ($p<0.01$), had done a course in genetics ($p<0.05$) or had a bachelor's ($p<0.01$) or master's degree ($p<0.01$) were more likely to achieve higher knowledge scores.

3.4 Nurses' perceived knowledge

The evidence from studies in our review indicates that nurses perceive that their knowledge of genetics is generally poor. Maradiegue et al [34] conducted research with a sample of 46 advanced practice nursing students. The survey consisted of multiple-choice questions that examined their awareness and understanding about genetics, with potential responses being 'none', 'minimal', 'some' or 'high'. Fifty-seven per cent of the students (n=26) said they had none' or 'minimal' knowledge of a genogram, while the numbers of those who had 'some' or 'high' knowledge of terms such as meiosis, mitosis or DNA replication were 65% (n=30), 61% (n=28) and 55% (n=25) respectively. Knowledge of actual genetics conditions was even poorer, with a number having no knowledge of diseases such as Klinefelter syndrome (48%, n=22), phenylketonuria (15%, n=7), Tay Sachs disease (24%, n=11) and fragile X (44%, n=22).

A year later, Tomatir et al [32] conducted a survey to describe nurses' current approaches to and knowledge about human genetics and genetic education in Denizli, Turkey. The participants were 86 nurses who worked full time in one of the 26 health clinics in one province (81.1% response rate). The majority of the participants (68.7%, n=59) reported that they had no knowledge of mitosis and meiosis (64.6%, n=31), the ethics of human genetics (77.1%, n=37) or genetic counselling

(72.3%, n=34). Only 28.6% (n=18) stated that they knew about genetic conditions common to the health service setting in which they worked. These results do not differ greatly from those obtained by Spruill et al [36], who conducted a survey to explore the genetics knowledge of African-American nurses in the United States. Of the 77 nurses who participated in that study, 56% described their knowledge of genetics as poor, while 43% described it as good.

In a completely different type of study, Pestka et al [33] aimed to describe the impact of a genomic educational intervention in nursing practice by asking nurses to retrospectively apply their learning to a previous clinical experience. The population for this study was identified as nurses who worked at Singapore Health Services and who had participated in a genomics seminar during October 2008. Pestka et al [33] asked 76 nurses (89.3% response rate) who had attended the nursing genomics course to recall a case from their previous practice and identify genomics interventions they had used in the context of that case. The interventions indicating use of genomics knowledge were classified as discussion of family history and risk (72%, n=55), providing patient education (55%, n=42), discussing legal, ethical, cultural or social support related to genomics (28%, n=21) and facilitation of a genetics referral (28%, n=21). As can be seen from the results, nurses appeared to be more familiar with taking a family history than providing support, but the level to which this study can be regarded as assessing knowledge is uncertain. Nurses may not have had sufficient knowledge of genomics before the study to use the skills described, or they may not have had the ability to identify relevant aspects of genomic healthcare following the course. As an indicator of nurse knowledge, therefore the findings are unhelpful.

3.5 Genetics education

In Bottorff et al's [35] study, nearly half of the nurses and almost a third of the physicians reported receiving no formal education in genetics. Only 7% of the nurses reported completing semester courses in genetics. The authors considered that this may have been due to the average age (46.9 years) of respondents and the lack of formal genetics received by those who graduated from professional programs many years ago. In another paper it was reported that the majority of participants (60%) had never had a course in genetics nursing and 64% of nurses responded that in their nursing curriculum did not include genetics nursing [36]. Of the advanced practice nursing students who completed Maradiegue et al's [34] survey, over 95% had no information on a range of genetic conditions provided during their undergraduate training programs. Of possible ways in which genetics education might be provided, use of case studies and problem based learning was seen as desirable by 89% of the students, reflecting the need for methods that enable students to learn to apply genetic principles to healthcare.

Respondents to the study by Tomatir et al [32] reported that their sources of genetic knowledge were mainly books (n=43), with courses at school and college (n=40) cited as the second most common way in which knowledge was obtained. However, the vast majority reported needing more education on a range of topics from ethical and legal issues (100%), genetic counselling (100%), inheritance patterns (98.9%) and genetic basis of disease (96.4%). It should be noted that education on applied aspects of genetic healthcare appeared to be most lacking most and the authors suggest that nurse educators need to become more familiar with these concepts in order to educate nursing students. These findings are consistent with those Bankhead et al [31]. In that study, 97.5% of practice nurses would have found more genetics education either useful or very useful and only 12% of those studied had actually received genetics education in the previous year.

4 Discussion

This review has been conducted specifically to establish the evidence base for nurses' knowledge in genetics. First of all we differentiated between those studies that measured perceived and actual knowledge of genetics, as authors of some studies claimed to report knowledge but this was based only on nurses' self-assessment of their knowledge (for example, the study Tomatir et al [32]). However, the results of the studies were in fact similar because it is clear that both actual and perceived knowledge of genetics is poor.

The finding that nurses' knowledge is generally poor was confirmed by another study which was not eligible for the review because it combined results from both nurses and midwives. Gharaibeh et al [37] studied nurses' and midwives' knowledge and perceptions of their role in genetic teaching. A self-completion questionnaire covering knowledge, perceptions of the nursing/midwifery role in genetics and responsibility in genetic teaching was developed. Each question was scored out of 5 and each participant received a total score ranging from 25 to 125. Scores of 100 or more were considered "adequately knowledgeable". Findings indicated that the majority (86%) of nurses and midwives scored less than 100, indicating an inadequate level of knowledge. However, only two of the 25 questions were actually testing knowledge, while the remaining questions were investigating subjective opinions and attitudes. The two questions that appear to test knowledge both related to prenatal genetic diagnosis. The authors reported a mean score of 2.88 out of 5 (SD=1.08) in response to the statement "ultrasound is not useful in genetic diagnosis". This indicates that a large proportion of respondents were unaware or unsure that ultrasound can be a very useful tool in an identifying a malformation due to a genetic disorder. In response to the statement "all pregnant women between the ages of 35-40 years need to have amniocentesis" that mean score was 3.76 out of 5 (SD=1.04), indicating agreement with the statement. However, the questions could be interpreted somewhat ambiguously, for example a nurse may know that a woman of over 35 years would be eligible to be offered amniocentesis, but also understand that ethically she should not be forced to have one. The limitations of this study also reinforce the need for well-designed research into nurses' knowledge of genetics.

In the study reported in this review by Bottorff et al. [35] it is clear that nurses' knowledge of genetics was much less satisfactory than that of physicians in the study. This may not be surprising since the analysis indicated that the majority of respondents to the reviews studies had not received formal education in genetics. The situation regarding the delivery of genetics/genomic content into undergraduate and postgraduate nursing curricula does not appear to have markedly changed since the survey conducted by Kirk [38] of educational institutions in the UK. The results of that survey indicated that the majority of nursing pre-registration programs included less 10 hours of genetic content, related mainly to bioscience rather than to issues related to genetic counselling or health related issues. A later study by Metcalfe and Burton concluded that post-registration education was also deficient with respect to genetics content [39]. As the studies included in our review emanate from Canada, Turkey, Singapore, UK and US, this indicates that the challenge to improve the genetic literacy of nurses to support their practice is an ongoing and global one. Indeed, in the international study by Kirk et al (2011) making genetics/genomics a substantive part of the nursing education was cited as a challenge that would not be overcome for a number of years into the future. While that was a study based on the views and experience of key nursing leaders in ten countries, the findings definitely concur with the results of our review of empirical studies.

However, while genetic content is lacking, the findings confirm that nurses are open to genetics education and that this should be in a form that enables them to apply genetic principles to their everyday healthcare experience. This is consistent with the view of Frazier et al [40] who emphasised the need for integration between science and practice to enable nurses to fully utilise genetics for the benefit of patients and with the nursing leaders who responded to Kirk et al [17], who also stressed that the final outcome should be not just enhanced nursing knowledge of genetics, but the ability of nurses to access and utilise that knowledge in their day to day contact with a wide range of patients. This is essential if nurses are to provide personalized genetic and genomic healthcare [41]. Initiatives such as the 'Telling Stories- Understanding Real Life Genetics' project [http://www.tellingstories.nhs.uk/], which is based on genuine cases, may be helpful in this regard. This resource offers educational programme support to students, teachers and practising professionals and is aligned to the UK genetics core competences [42].

5 Conclusion

This review has enabled a synthesis of current evidence regarding nurses' knowledge of genetics internationally. Nurses' knowledge of genetics and genomics is not adequate to enable them to offer appropriate genetic healthcare, for example to ascertain whether a condition may be inherited, to understand and explain simple inheritance patterns and risks to a family, or to refer families to specialist services where appropriate. We strongly recommend that further educational initiatives are

required to equip nurses to practice safely and effectively in the post-genomic era. Furthermore, with the shift to personalised medicine, it is essential that genetics is not seen as a specialised topic. It is therefore important that it is fully integrated into curricula to ensure that it becomes an intrinsic part of nursing care.

6 Limitations

This review has been conducted systematically. However the small number of relevant studies and the lack of research into actual nursing knowledge of genetics means the findings need to be viewed cautiously. Further studies in this area are required to identify genetic and genomic topics essential to nursing practice, determine nurses' knowledge, the level to which they can apply that knowledge and the most effective form of educating nurses to provide appropriate genetic healthcare.

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Conflicting interest

The authors have no conflicts of interest.

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