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Published in:
Journal of Nursing Education and Practice

DOI:
https://doi.org/10.5430/jnep.v12n11p9

Publication date:
2022

Document Version
Publisher's PDF, also known as Version of record

ORIGINAL RESEARCH

Understanding genetics in nursing care – A qualitative interview study

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Received: April 4, 2022 **Accepted:** June 19, 2022 **Online Published:** June 28, 2022
DOI: 10.5430/jnep.v12n11p9 **URL:** https://doi.org/10.5430/jnep.v12n11p9

ABSTRACT

Objective: The aim of the present study was to investigate the use of genetics/genomics (G/G) knowledge and competencies in a Danish nursing context.
Methods: Using a qualitative approach, thirteen Danish nurses representing different parts of the Danish health care system were interviewed about their experiences with G/G in daily practice. One focus group interview was conducted face to face, and nine individual semi-structured interviews were conducted partly face to face, partly online due to Covid-19 restrictions. Data were analyzed through systematic text condensation using the NVIVO13 tool (QSR International).
Results: We identified five themes: 1) The nature of genetics; 2) Knowledge about genetics; 3) The roles of the nurse; 4) Nurses' engagement with patients and relatives; 5) Patient pathways. Ethics was a recurrent theme in all five themes.
Conclusions: The Danish nurses interviewed generally hold a narrow understanding of genetics i.e. defining it as heredity. They are involved in G/G aspects of care, although the extent and nature of this involvement varies considerably between different care settings. Hence, it seems unlikely that all nurses will require the same G/G knowledge and competencies. Nevertheless, the nurses share the belief that they should possess some basic knowledge about G/G to perform adequate nursing care. Their current knowledge about G/G is typically informed by practice and to a very small degree by their formal education. They agree that G/G literacy will be a general requirement in future nursing. Some of the nurses consider personalized medicine to be the golden road to better patient treatment and care. Some request more knowledge about G/G topics and a vocabulary to communicate adequately with doctors, patients and relatives on these issues. The importance of ethics is emphasized throughout the interviews.

Key Words: Genetics, Genomics, Genomic literacy, Nursing care, Competencies, Nursing education, Ethics

1. INTRODUCTION

During the last 20 years and with the completion of the Human Genome Project,[1] our understanding of the genetic basis of health and disease has increased dramatically. The majority of diseases have a genetic component, and the effects of medicine are also heavily influenced by our genes.[2] This development has led to a need for increased understanding of genetics by healthcare providers, including knowledge and competencies with respect to, e.g., family history taking, genetic risk assessment, referral, genetic testing and pharmacogenetics/genomics.[3–5]

Nurses are a large and important group of healthcare

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providers in close contact with patients and their families. There is a general consensus in the literature that a prerequisite for successful implementation of genetics/genomics (G/G) in healthcare is that nurses have sufficient knowledge of G/G and the competencies that are relevant to working with this knowledge.[6,7] Thus, Tluczek et al.[8] states that all nurses have an ethical responsibility to be knowledgeable about advances in G/G and to incorporate it into their work.

As early as 2001, the National Coalition for Health Professional Education in Genetics (NCHPEG) published Recommendations of core competencies in genetics essential for all health-care professionals.[9] In 2008, Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd edition, was published by the American Nurses Association.[10] These documents specified the knowledge and competencies deemed necessary for nurses.

Genetics/genomics knowledge and competencies are regarded as highly relevant for nurses working in many different medical specialties. One example is oncology nursing, where King and Mahon state that all oncology nurses should have basic knowledge of hereditary cancer syndromes and their management and be able to support patients when they seek information and guidance with respect to genetic testing.[11] This is backed by several other studies, including studies describing the importance of genetics knowledge and competencies in oncology nursing as a means of reducing racial and other disparities in cancer care.[12–16] It is also important that oncology nurses have sufficient insight into the many complicated ethical issues in cancer genetics to be able to advocate for patients' needs and rights.[3] Issues regarding individuals' and family members' right to know, or to decide not to know, their genetic status with respect to a genetic syndrome are relevant in a wide spectrum of nursing fields besides oncology.[17]

Knowledge and competencies regarding pharmacogenetics/pharmacogenomics are also highly relevant to nurses.[5,18] Oncology encompasses the largest share of the current precision medicine market.[19] However, the field is evolving in many medical areas. An example is psychiatric nursing, where the bedside nurse plays an important role in the implementation of pharmacogenomics.[7]

A number of studies in the last 10 to 15 years have demonstrated that many nurses lack the G/G knowledge and competencies that the literature cited above has indicated are important or even essential. In a recent integrated review, Wright et al. found that many nurses fail to meet key criteria for G/G competencies.[4] Interestingly, Wright et al. also found that in several of the 12 papers included in their review, a large majority of the nurse respondents considered G/G to be important to nursing practice.

One potential reason for the apparent extensive lack of G/G knowledge and competencies among nurses could be insufficient teaching in nursing schools. Donnelly et al. assessed nurse faculty members' knowledge of and confidence in teaching G/G to nursing students.[20] Although all nurse faculty members in the study found it to be very or somewhat important that nurses receive education in the genetics of common diseases, more than half said that they lacked confidence in teaching G/G. Furthermore, there were significant knowledge gaps with regard to basic genetic knowledge among faculty.

Taking a global perspective, Calzone et al. found that there were genomic literacy deficits in both nursing practice and nursing education in many countries, with only one country out of 19 surveyed having a G/G knowledge and skill requirement for practicing nurses.[21]

Recently, the belief that G/G competencies are essential for all registered nurses, regardless of practice setting and medical specialty, has been called into question by Newcomb et al.[22] They used a 38-item questionnaire based on the formulated essential competencies[10] to investigate the current use of G/G nursing competencies in acute care hospitals. The aim of the study was both to describe the use of these competencies and to determine whether clinical nurses perceived them as relevant. Newcomb et al. found that most of the competencies described as essential by the American Nurses Association were never or very seldom performed by the nurses. For example, 59% of the respondents reported that they never obtained a three-generation family history. On the basis of their results, Newcomb et al. argue that there is an urgent need to reevaluate the use, applicability and relevance of G/G competencies for nurses. In a comment to Newcomb et al.'s study, Malone argues that it is neither effective nor productive to mandate competencies in G/G without considering the relevance and value in the specific practice setting.[23]

The findings of Newcomb et al. strongly suggest that there is a need to investigate in more detail how, when and where nurses working in different clinical settings actually utilize – or should be utilizing – G/G knowledge and competencies.

Aim

The aim of the present study was to investigate the use of genetics/genomics knowledge and competencies in a Danish nursing context. In our empirical research, i.e. in our interviews, we used genetics as a broad term covering both genetics and genomics. The term genetics is therefore used

consistently in our description of the methodology of this research. In Denmark, there are at present no official standards, recommendations, or guidelines regarding the teaching and learning objectives of genetics and genomics in nursing education that indicate which G/G competencies graduated nurses should possess. In a study of the teaching of genetics in Danish nursing schools,[24] a large variation between schools with regard to both the number of lessons offered and the G/G curriculum was found. G/G subjects of specific relevance to nursing and healthcare, such as pharmacogenetics/genomics and cancer genetics, were absent from the curriculum in many schools.

To achieve our aim, we conducted in-depth, semi-structured interviews with nurses working in different clinical care settings in Denmark to investigate a) their understanding of the concept of genetics, b) to what extent and how they encountered genetics in their daily work, c) when and how they used genetic knowledge and competencies in their care, and d) whether they believed that they have sufficient knowledge and competencies with regard to G/G to be able to perform their work. To capture these dimensions of individual experience, meaning and personal evaluation, we applied a qualitative methodological approach.

2. METHODS

2.1 Study design

A qualitative, explorative and open-ended analytical approach inspired by the phenomenological and hermeneutical tradition informed the elaboration and systematic re-evaluation of the interview guide and interview process.[25] Focus group and individual semi-structured interviews were chosen to capture the experiential dimensions of genetics in the daily work of nurses. During the process of interviewing and through all phases of analysis, the authors provided important critical feedback to each other to secure methodological rigor and procedural transparency and to eliminate possible misunderstandings and narrow interpretations.

2.2 Sample and settings

Relevant departments representing different parts of the Danish health care system (home care, public hospital etc.) were identified in cooperation with genetic specialists from a clinical genetics department. Departments of psychiatry, oncology, neurology, heart disease and the home care sector were contacted by email, detailing the study's aim and process and requesting their aid in recruiting participants. Hence purposeful sampling was conducted initially, as each department selected one or more eligible nurses who then approached the researchers for enrollment. Later, cascade sampling was used, with some of the enrolled participants assisting the authors in identifying other departments or sectors considered relevant for the inquiry.

The focus group interview was conducted face to face in February 2020. The results of the focus group interview further qualified the elaboration of a semi-structured, explorative and qualitative interview guide which was subsequently used for the individual interviews. Nine individual interviews were conducted between May 2020 and February 2021, partly as face-to-face interviews, partly as online video interviews due to Covid-19 restrictions (see Table 1).

Table 1. Participants in focus group and individual interviews

# Participants	Departments represented	Years since education	Experience from other departments	Specialist vs. generalist
13	9	Between 3 and 30 years. Mean 17.5 years in nursing.	5 participants only had experience from their current department. 8 participants had experience from more than one department.	3 participants had genetics specialist function, 2 of these had a genetic counselor education. 10 participants had no special function concerning genetics.

All interviews were recorded and manually transcribed verbatim. Two authors checked the transcriptions manually and independently to identify possible misreadings. NVIVO13 (QSR International) was used to aid systematic text condensation and coding. A hermeneutic sensitivity to contextuality and a critical examination of author prejudice[26] were practiced at all levels of data analysis from transcription to text condensation, coding, thematization, re-contextualization and discussion. Methodological inconsistencies were solved pragmatically through dialogue and consensus involving all authors.

2.3 Ethical issues

Informed consent was obtained from all participants according to the principles of the Declaration of Helsinki.[27] The study complied with the Ethical Guidelines for Nursing Research in the Nordic countries,[28] and the Danish Code of Conduct for Research Integrity.[29] According to Danish law, ethical committee approval of this study was not necessary, and the project was internally lodged at VIA University

College Research Center for Health and Welfare Technology.

3. RESULTS

The analysis of the transcribed interviews resulted in five themes: 1) The nature of genetics; 2) Knowledge about genetics; 3) The roles of the nurse; 4) Nurses' engagement with patients and relatives; 5) Patient pathways. Furthermore, ethics was found permeating all the other themes (see Table 2).

Table 2. Identified themes

Permeating theme	**Ethics**				
Themes	The nature of genetics	Knowledge about genetics	The roles of the nurse	Nurses' engagement with patients and relatives	Patient pathways

3.1 The nature of genetics

There was common agreement among the participants that the term genetics is associated with heredity. Some respondents, especially those who were involved with genetic issues on a daily basis, also used terms such as genetic predisposition and preimplantation genetic screening when describing their understanding of the concept of genetics. It is noteworthy that several nurses stressed that the term 'genetics' is not part of their professional vocabulary. Although some of their patients were referred to genetic counseling, the word genetics was seldom used and several nurses described a sense of unfamiliarity with the term:

Of course, genetics, it's like... I know [...] some of our patients go through genetic assessment, but it is not a term we normally use, I would say.

Despite the fact that the term genetics was rarely used in daily practice, it became clear during the interviews that a majority of respondents were in fact engaged with some aspects of genetics in their daily practice and contact with patients and relatives, as described below.

Interestingly, when asked about the future of genetics in health care, most respondents replied that they believed that genetics will gain importance in future health care and nursing. In particular, the nurses working within psychiatry and neurology were highly aware of the potential of genetics/genomics and expressed high hopes regarding future treatment possibilities within the realm of personal or precision medicine. Regarding the use of medicine in psychiatric care, one nurse said:

Being able to determine who can benefit from what ... and who is predisposed to experience side effects ... that would be absolutely marvelous.

3.2 Knowledge about genetics

There was general agreement among the interviewees that nurses should possess some knowledge about genetics. For example, to be able to facilitate communication about G/G subjects between doctors, patients and relatives; to advise patients about possibilities with regard to, e.g., genetic testing, and to help patients and relatives understand and process test results.

A few of the nurses interviewed had specialist functions relating to genetic diseases in their daily work. These nurses had either completed further education or peer training in genetics in the department. These nurses generally felt well equipped and knowledgeable in their G/G-related work.

The majority of the nurses interviewed stated that they had received no further education concerning G/G since their graduate education, and had no specialist function in relation to G/G in their daily work. Among these nurses, the perceived level of knowledge varied considerably. Some of the nurses interviewed argued that they had the knowledge needed in their daily work with regard to genetics. They also felt that the knowledge they had, matched the patients' expectations. Other nurses expressed a need for more knowledge about G/G topics and a vocabulary for such issues, making it possible to communicate adequately with doctors, patients and relatives. As one of the nurses interviewed said:

We need a language!

Several of the nurses interviewed said that most or all of the knowledge they had with respect to G/G topics was gained through work experience. They had obtained their knowledge through collaboration with more experienced nurses and physicians, but also from workshops they attended as nurses, rather than through formal education, i.e. nursing school.

A nurse from one care setting, who had no experience in other working areas, and who did not find that G/G was specifically mentioned in her own, expressed a very limited knowledge of G/G and did not find such knowledge relevant for her work. In contrast, another nurse from the same care setting who had experience from several other departments found G/G aspects to be very relevant to her work. She described how she profited substantially from her broad

experience when considering G/G in her nursing tasks:

. . . If I had only been in this setting, then I wouldn't have been very well prepared for this [genetics], I think.

Some of the nurses believed G/G topics will become more important in future nursing and expressed a wish to be adequately prepared through further education. Despite the fact that some participants expressed a lack of knowledge about G/G issues, there was nevertheless broad agreement among the participants that their education had prepared them well for handling ethical issues relating to the field.

3.3 The roles of the nurse

The interviews showed considerable variation in how much contact nurses have with G/G aspects of care. Some nurses explained that G/G is generally perceived as the physician's field of expertise. Nurses are not typically invited into this domain, unless they have received specialized training:

It is the physicians' domain ... we have not been invited, but maybe we should [be].

Nevertheless, the interviews demonstrate that Danish nurses do perform several roles related to genetics. Notably, they are taking family histories, communicating with patients and relatives about genetic diseases, genetic tests and treatment options, referring patients, translating doctors' messages into language that is meaningful to patients, giving advice and emotional support to patients with genetic disease and their relatives, and generally functioning as patient advocates, just to mention the most prominent roles. A psychiatric nurse observed:

One of the first things you ask [...] is whether there is psychiatric illness in the family.

Nurses are, as one nurse formulated it, "the ethicists". Another stressed that nurses should always be on the patient's side, defending the patient's right to autonomy. In general, the nurses described how 'being there' for the patients and listening to their worries with respect to, e.g. genetic tests, giving advice and emotional support, encouraging hope and generally being the patient's advocates were important aspects of their nursing care.

However, some nurses commented that working within a non-directional paradigm of genetics, emphasizing respect for autonomy, voluntary choice and non-coercion, sometimes seemed to conflict with the principle of benevolence that stresses the importance of professional responsibility and care for vulnerable patients. Some respondents underlined that one of the most important roles of the nurse is often to refer patients and relatives to specialists with extensive knowledge in the field. To do so, however, nurses need to have sufficient insight to know and act on the limitations of their own knowledge and competencies.

3.4 Nurses' engagement with patients and relatives

Some participants described the special issues at stake in their relationship with patients and relatives when genetic diseases are involved, since a genetic diagnosis can carry predictive information for related family members. The nurses have to be able to communicate and provide information and support to family members seeking advice and information about hereditary matters and possible treatment options. They emphasized that relatives are often very active in seeking advice and searching for alternative treatment options. The matters discussed are, however, often of an existential and ethical nature. The notions of guilt and shame were mentioned several times during the interviews. More than one nurse described that some patients feel guilt at having passed on a genetic disease to their children. These feelings have to be properly and respectfully addressed. Another participant described how a genetic diagnosis could actually provide parents with a sense of relief. In her experience, it could help the parents overcome feelings of guilt and shame, if they were brought to understand and acknowledge that they had no role in causing the disease through particular acts of behavior (or omissions of behavior) or interactions with the child, before birth or during childhood:

So this woman, she just sat there, all the pieces in the puzzle falling into place. All this guilt she had felt [. . .] for maybe being too hard on her daughter [...] It was not what triggered the girl's oddity! It was a serious, chronic disease, and it was actually something running in the family.

Thus, the nurses seem to play important roles in facilitating understanding, hence identifying and correcting prejudice and false beliefs about the nature of a given disease through their communication with patients and relatives.

3.5 Patient pathways

Several nurses from both hospital and home care settings emphasized that it is very difficult to ensure a smooth and secure transition of patients from the hospital setting to home care if there is a lack of knowledge about genetics among the home care nurses. The general attitude among the practicing nurses seemed to be that genetic illness and issues relating to genetics are properly handled at the hospital and do not concern the home care setting, which is more focused on the patients' functioning and wellbeing in everyday life. However, as some respondents pointed out, patients' safety and quality of care can be negatively affected if the home care nurse at 'the receiving end' is not informed about the consequences of a genetic diagnosis for the patient's daily

life. The quality of care would clearly improve if more cooperation and sharing of knowledge took place between the various sectors of the healthcare system:

... if we receive someone with that sort of disease [Huntington's chorea], then there is very little knowledge about it, you see, and that will of course have an impact on the treatment of the patient, because we have to sort things out along the way [. . .] I believe that the quality of our treatment would improve considerably, if we worked much more closely together on this.

Another issue was raised concerning patient safety, quality of treatment, and care and equality in health. This issue relates to the fact that knowledge about genetics in a specific hospital department often depends on the specialist knowledge of single staff members, primarily physicians. As one nurse stressed, it often comes down to personal professional interest whether there is genetic expertise present in individual departments. Hence, it appears to be somewhat arbitrary whether attention to genetics is in fact informing diagnostics, treatment and care.

Some nurses expressed hope that future developments in G/G can lead to smoother and better patient pathways and engender trust in the healthcare system. As mentioned above, the developments within personal medicine in particular were considered by some of the respondents to be the golden road to improved treatment outcomes, more patient-centered care, and better relationships between nurses and patients:

... it would be fantastic if we could gain that trust much faster. I mean . . . if our patients could come to trust the professionals, if we didn't miss our target each time ... As it is, they become discouraged, the treatments never seem to be coming to an end . . . they spend so much time testing medicine that doesn't help them.

4. Discussion

The competencies and knowledge of nurses with respect to genetics/genomics (G/G) have been the subject of numerous studies. The majority of these studies have used surveys to collect data. In a recent integrative review of nurses' competencies in genetics by Wright et al. 10 of the 12 studies included were cross-sectional surveys.[4]

In our study, we conducted semi-structured interviews with thirteen Danish nurses working in different settings in the Danish health care system in order to gain deeper insight into nurses' thoughts, competencies and knowledge in relation to genetics. We asked the nurses what the word genetics meant to them, in which situations they encountered genetics in their daily work, and whether they felt they had sufficient knowledge about genetics. We believe this method has given us valuable access to new and multifaceted information about these nurses' subjective experiences related to genetics.

The importance of genetics in the daily practice of the nurses seemed to vary considerably. Some of the nurses interviewed performed a variety of roles in relation to genetics, such as taking family histories and communicating with patients and relatives about genetic tests. Others stated that they did not use or encounter the word genetics in their daily work, or that the concept was unfamiliar to them. Thus, to some of the nurses interviewed, genetics was not experienced as a part of their nursing practice. Instead, it was regarded as the physicians' field of expertise. One of our main findings was, however, that even though the concept of genetics was not explicitly used in their daily language, genetics was nevertheless in most cases relevant to their nursing practice. This insight emerged during the interviews but, for the most part, was not initially acknowledged by the nurses themselves.

For the majority of the nurses interviewed, the first association that came to mind when asked about the meaning of genetics was heredity. For many of them genetics seemed to be almost equivalent to heredity. This is an interesting finding, since it indicates that for these nurses, the fact that genes, including disease genes, are inherited from parents to their offspring, encapsulate what genetics is about. The emphasis seems to lie on where a person's genes, or rather, alleles, are coming from, rather than on the significance of these genes in the patient's body with respect to health, risk of developing diseases and reactions to medication. This rather narrow understanding could be a hindrance for the integration and use of genetic knowledge and technologies by nurses in health care. For example, in pharmacogenetics/genomics, a genetic subject generally considered especially important to nurses,[7, 18, 19] the focus is typically on how specific alleles in a patient's genome can affect the response to treatment, rather than on the inheritance of these alleles.

During our interviews, we found large variations in the answers given to the question about the role of genetics in the daily work of the interviewees. This is perhaps not surprising since the thirteen nurses worked in very different clinical settings. But it suggests that perhaps not all nurses need the same competencies and knowledge about G/G. It might also indicate that only a few nurses require extensive insight into genetics to perform their daily work. This assertion seems to be supported by Newcomb et al's inquiry,[22] where a majority of nurses answering a questionnaire said that they never or only very rarely performed many of the competencies deemed essential for all nurses by the American Nurses Association.[10]

Nevertheless, a tendency emerging from our analysis was that nurses who had experience working in several different departments seemed to find genetic knowledge more relevant and important for the nursing profession than those who had no prior experience from other fields of nursing care. It appears that nurses who have little work experience in other areas of nursing care may not be capable of adequately identifying and assessing the present and future need for genetics-related knowledge and competencies.

In addition, among the participants who described not having any particular knowledge about genetics, some said that they also did not need such knowledge in their daily practice. Interestingly, nurses in the same care setting, who had gained genetic knowledge from previous professional experience in other fields of nursing, found such knowledge to be useful and important in their professional activity. Given such disparities, nurses' subjective assessments of the need for greater knowledge do not necessarily reflect what might be beneficial for the nurse and for health care in general. This clearly raises important ethical issues about how and to what extent one can ensure equal access to care and quality treatment for all patients, if there are considerable disparities in work experience and knowledge about genetics among care personnel.

However, it is indeed possible that not all nurses need extensive genetic knowledge to perform their daily work satisfactorily. If this is the case, it might be misleading to promote a set of genetics/genomics competencies and knowledge that all nurses should possess. A more targeted approach may be to distinguish between different nursing settings and promote the competencies that are relevant in each setting.

On the other hand, if genetic testing becomes routinely used on a broader scale in future health care, then basic insight into genetics will undoubtedly become more widely required. This is supported by most of the nurses we interviewed, who agreed that genetics will become increasingly important. The nurses working in psychiatry, oncology and neurology in particular promoted this view. The importance of being able to give meaning to tests, and provide support to patients and relatives facing ethical dilemmas and legal and financial issues, is stressed by several respondents in our interviews. Supporting the autonomy and integrity of each individual, and abstaining from persuading or exerting undue pressure on the patient to make a particular choice regarding genetic testing, for example, are furthermore described by several respondents as important aspects of care in G/G contexts.

Our findings suggest that the traditional divisions of labor between nurses and physicians, and internalized assumptions about medical expertise in the area of genetics, may prevent some nurses from becoming involved in the use of G/G knowledge. The problem with such a conception is that important nursing perspectives might not be considered when planning individual therapeutic and care schedules. Furthermore, there is a risk that the general nurse will not come to possess the necessary vocabulary or insight to contribute in an adequate manner to the important social debate about ethical dilemmas arising in medical practice, and for negotiating the role of genetics in future health care. This is a problem, since professional nursing perspectives could enrich the public discourse on ensuring high quality care and equality in a future personalized and data-driven healthcare system.

Several studies have shown that there are deficiencies in nurses' knowledge about genetics.[4, 20, 21] As discussed in the literature, one potential reason for these deficiencies may be the insufficient teaching of genetics and genomics in nursing schools.[20, 24, 30] It is interesting to observe that the nurses in our study said that most or all of their knowledge about genetics was gained through experience, i.e. obtained during their working life. In most cases any genetics education they received at nursing school appeared neither relevant nor significant to their actual practice and what was required of them today.

Based on our findings, we suggest that nursing students should receive more practice-oriented education about G/G during their graduate education. Since it is highly unrealistic to expect that all students can obtain practical experience with G/G in a clinical environment, it is essential that they are at least presented with situational knowledge and 'thick descriptions' from practice as a part of their theoretical training. A case-based format is well suited to promote reflection on nursing care in this area. Rich case studies about the role and meaning of genetics in clinical settings could, for example, help students become more attentive to the ethical and social dimensions and complexities of genetics and genomics in practice - and create greater awareness about their own professional roles, responsibilities, competencies and challenges.

Danish nursing education has an increasing focus on theme-based learning, and it is only natural to consider how G/G knowledge could be incorporated into such an approach. Traditionally, genetics has often been perceived as a natural science subject in Danish nursing education. Our findings indicate that G/G aspects are clearly relevant and meaningful for nursing students in various human and social sciences as well, for example, in relation to public health matters and clinical leadership. Notably, the relevance of ethics to genetics, genomics and personalized medicine was emphasized by

all respondents in our interviews, and thus, we suggest that ethics should play a major role in the teaching of G/G.

If we wish to prepare nursing professionals for a more personalized future health care system in which G/G will play a critical role, it is important to consider more than basic education. The graduated nurses will also need further education to keep up with the developments within G/G. This was underlined by several of our respondents. In line with the findings of Pestka et al., it may be beneficial to make at least some aspects of this further education specific to each area of nursing specialization.[31]

In recent years, there has been an increasing focus in Denmark on updating the theoretical and practical education of physicians in the area of personalized medicine. In our view, it is a matter of urgency to ensure that similar educational considerations extend to other health professionals such as nurses.

Limitations

There are a number of limitations to this study. We have tried to accomplish density in our data collection by incorporating perspectives from a wide range of care settings. However, we cannot rule out that the purposeful sampling and cascade sampling methods employed in the recruitment of respondents might have resulted in a skewed perspective. If we had interviewed other nurses, we might have encountered other experiences and perspectives. Nevertheless, our study offers a unique insight into Danish nurses' everyday experiences and thoughts about genetics. Due to Covid-19 restrictions during most of our interview period, most of the interviews were performed online. This restriction does not appear to have affected the interview quality in any discernible way.

5. Conclusion

The Danish nurses interviewed generally hold a narrow understanding of genetics i.e. defining it as heredity. Our interview findings support the notion that nurses are indeed involved in genetics/genomics aspects of care, though the extent of the involvement and the tasks performed vary considerably between different care settings. Thus, it seems unlikely that nurses in general need expert knowledge. Still, there was general agreement that nurses should possess basic knowledge about G/G in order to provide adequate nursing care. Their current knowledge about G/G is typically informed by practice and to a very small degree by their formal education. They agree that G/G literacy will be a general requirement in future nursing. Some of the nurses consider personalized medicine to be the golden road to better patient treatment and care. Other nurses request more knowledge about G/G topics and a vocabulary to communicate adequately with doctors, patients and relatives on these issues. The importance of ethics is emphasized throughout the interviews. This calls for further research into how to develop practice-based education and didactics in the area of genetics and personalized medicine in nursing education, to support the future adaptation and optimization of patient care.

Acknowledgements

We would like to thank dr. Judith Bishop for her excellent assistance in revising this article. Also, we thank all departments in their assistance in recruiting interviewees, and we are grateful to all the nurses offering their time, thoughts and insight when participating in interviews.

Conflicts of Interest Disclosure

The author declares that there is no conflict of interest.

References

[1] Heilig R, Eckenberg R, Petit J, et al. International Human Genome Sequencing Consortium. Nature. 2004; 431: 931-945. https://doi.org/10.1038/nature03001

[2] Jackson M, Marks L, May GHW, et al. The genetic basis of disease. Essays Biochem. 2018; 62(5): 643-723. https://doi.org/10.1042/EBC20170053

[3] Curr Beamer L. Ethics and Genetics: Examining a Crossroads in Nursing Through a Case Study. Clin J Oncol Nurs. 2017; 21(6): 730-737. https://doi.org/10.1188/17.CJON.730-737

[4] Wright H, Zhao L, Birks M, et al. Nurses' competence in genetics: An integrative review. Nurs Health Sci. 2018; 20(2): 142-153. https://doi.org/10.1111/nhs.12401

[5] Youssef E, Buck J, Wright DJ. Understanding pharmacogenomic testing and its role in medicine prescribing. Nurs Stand. 2020; 35(7): 55-60. https://doi.org/10.7748/ns.2020.e11543

[6] Davies K, Dwyer AA. Genetic Competencies for Effective Pediatric Endocrine Nursing Practice. J Pediatr Nurs. 2019; 48: 127-128. https://doi.org/10.1016/j.pedn.2019.06.006

[7] White MM, Walker DK, Howington LL, et al. Pharmacogenomics and Psychiatric Nursing. Issues Ment Health Nurs. 2019; 40(2): 194-198. https://doi.org/10.1080/01612840.2018.1513615

[8] Tluczek A, Twal ME, Beamer LC, et al. How American Nurses Association Code of Ethics informs genetic/genomic nursing. Nurs Ethics. 2019; 26(5): 1505-1517. https://doi.org/10.1177/0969733018767248

[9] Jenkins J, Blitzer M, Boehm K, et al. Recommendations of core competencies in genetics essential for all health professionals. Genet Med. 2001; 3(2): 155159. https://doi.org/10.1097/00125817-200103000-00011

[10] Consensus Panel on Genetic Nursing Competencies. Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines,

and Outcome Indicators (2nd ed.). American Nurses Association, Silver Spring, Maryland, 2008.

[11] King E, Mahon S. Genetic Testing: Challenges and Changes in Testing for Hereditary Cancer Syndromes. Clin J Oncol Nurs. 2017; 21(5): 589-598. https://doi.org/10.1188/17.CJON.589-598

[12] Allen D. Genetic Testing: How Genetics and Genomics Can Affect Healthcare Disparities. Clin J Oncol Nurs. 2018; 22(1): 116-118. https://doi.org/10.1188/18.CJON.116-118

[13] Cummings S, Dobrea L, Bodurtha JN, et al. Fundamentals of Genetics and Genomics in Oncology Nursing Practice and Navigation. J Oncol Navig Surviv. 2019; 10(10): 388-397.

[14] King EM, Smith EC. Diversification of Nurse Practitioner Practice: Genetic Cancer Risk Assessment. J Nurs Pract. 2020; 16(6): 447452. https://doi.org/10.1016/j.nurpra.2020.02.022

[15] Lacovara J, Bohnenkamp S. Genetic Testing in Oncology for the Medical-Surgical Nurse. Cancer Care. 2018; 27(2): 117-120.

[16] Yoes MV, Thomas L. Hereditary Cancer Genetic Risk Assessment, Testing, and Counseling: A Nurse Practitioner–Led Program in a Community Setting. J Nurs Pract. 2020; 16(9): 660-665. https://doi.org/10.1016/j.nurpra.2020.07.006

[17] Steck MB. Decision Making: Approaches and Tools to Respond to Ethical Issues in Genetic and Genomic Nursing. Clin J Oncol Nurs. 2018; 22(4): 386-389. https://doi.org/10.1188/18.CJON.386-389

[18] Cheek DJ, Bashore L, Brazeau DA. Pharmacogenomics and Implications for Nursing Practice. J Nurs Scholarship. 2015; 47(6): 496-504. https://doi.org/10.1111/jnu.12168

[19] Dodson C. Pharmacogenomics: Principles and Relevance to Oncology Nursing. Clin J Oncol Nurs. 2017; 21(6): 739-745. https://doi.org/10.1188/17.CJON.739-745

[20] Donnelly MK, Nersesian PV, Foronda C, et al. Nurse Faculty Knowledge of and Confidence in Teaching Genetics/Genomics: Implications for Faculty Development. Nurs Educ. 2017; 42(2): 100-104. https://doi.org/10.1097/NNE.0000000000000297

[21] Calzone KA, Kirk M, Tonkin E, et al. The Global Landscape of Nursing and Genomics: Global Genomic Landscape. J Nur Scholarship. 2018; 50(3): 249-256. https://doi.org/10.1111/jnu.12380

[22] Newcomb P, Behan D, Sleutel M, et al. Are genetics/genomics competencies essential for all clinical nurses? Nursing. 2019; 49(7): 54-60. https://doi.org/10.1097/01.NURSE.0000554278.87676.ad

[23] Malone L. Too soon for genetics/ genomics competencies. Nurs Manage. 2019: 50(4): 8-9. https://doi.org/10.1097/01.NUMA.0000554344.55260.4b

[24] Nissen KK, Mikkelsen TR, Christiansen K. Genetics in the Danish nursing education: A questionnaire study. J Nurs Educ Pract. 2019; 10(1): 75-84. https://doi.org/10.5430/jnep.v10n1p75

[25] Brinkmann S, Tanggaard L. Kvalitative metoder: En grundbog. 2nd ed. Hans Reitzels Forlag. 2015. Available from: http://hansreitzel.dk/Metode-og-videnskabsteori/Kvalitative-metoder/9788741259048

[26] Gadamer HG, Weinsheimer J, Marshall DG. Truth and method. 2nd ed. Continuum. 2004.

[27] World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. JAMA. 2013; 310(20): 2191. https://doi.org/10.1001/jama.2013.281053

[28] Northern Nurses Federation. Ethical Guidelines for Nursing Research in the Nordic Countries. Vard Nord. Utveckl. Forsk. (Nordic Journal of Nursing Research). 2003; 23: 1-19.

[29] Ministry of higher Education and Science. Danish Code of Conduct for Research Integrity. 2014. Available from: https://ufm.dk/en/publications/2014/files-2014-1/the-danish-code-of-conduct-for-research-integrity.pdf

[30] Read CY, Ward LD. Misconceptions About Genomics Among Nursing Faculty and Students. Nurs Educ. 2018; 43(4): 196-200. https://doi.org/10.1097/NNE.0000000000000444

[31] Pestka EL, Meiers SJ, Shah LL, et al. Nurses' perceived benefits, barriers, and educational recommendations for using family pedigrees in clinical practice. J Contin Educ Nurs. 2012; 43(11): 509-517. https://doi.org/10.3928/00220124-20120904-36