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Editorial/Uvodnik

Genomics-informed nursing: The future of nursing

Genomsko podprta zdravstvena nega: prihodnost zdravstvene nege

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Nursing and nursing education are about to be revolutionised by the emerging field of genomics-informed nursing. Every individual has their own personal genetic make-up that determines their health and wellbeing. In recognition of the importance of this fact and the opportunities it presents, it is essential for healthcare educators, students and healthcare professionals to enhance their genomic literacy, i.e., the ability to obtain, process, understand, and use genomic information in health-related decision-making (Hurle et al., 2013; Whitley, Tueller, & Weber, 2020).

To improve nurses' ability to integrate genomics into daily nursing practice, it is essential to raise their genomic literacy (Calzone et al., 2018a). To successfully meet this challenge, nurses all around the world must achieve a high level of genomic literacy. Nursing curricula need to be developed to meet these educational needs at the undergraduate and postgraduate levels. Whilst core genomic competencies for nurses are clearly defined, difficulties have been reported regarding the integration of these competencies into existing nursing curricula. To ensure successful integration of genomic competencies into nursing curricula, it has been suggested that instead of developing specific genomic modules, genomic competencies should be embedded into existing elements of nursing curricula so as to facilitate learning (Skirton et al., 2012). Therefore, to meet the demands of future nursing education, it is paramount to develop strategies for incorporating genomic competencies into nursing curricula. This can be achieved through collaboration with multiple stakeholders, including highly involved management, and within a realistic timeframe (Calzone et al., 2018b).

Genomics is a fundamental component of precision medicine and has already established itself in research and medicine worldwide. This, however, is not the case in nursing, especially in Europe (Calzone et al., 2018b). The goal of the '1+ Million Genomes' initiative, launched by the European Commission, is to maximise the potential benefits and actions required in the field of genomics. The initiative aims to accelerate the development of precision medicine, various targeted therapies, and other interventions. Such developments can provide people with earlier diagnosis and treatment and, equally important, adequate information on preventive measures. Genomics can have a tangible impact on the accessibility, inclusiveness, and effectiveness of health systems across the European Union (European Commission, 2022). In addition to European initiatives, the International Council of Nurses has encouraged nurses to enhance their knowledge of new practices, including genetics and genomics, as well as of ethical considerations related to this emerging field within nursing (International Council of Nurses, 2021).

Genomics-informed nursing is a complex field that encompasses all areas of health care, e.g., diabetes mellitus, cardiac diseases, cerebrovascular diseases, oncology, neurology, paediatrics, pharmacology, and pain management. It is therefore extremely relevant to all nurses, regardless of their field of practice (Wright, Zhao, Birks, & Mills, 2019). In addition, genomic competency applied in offering counselling and support to patients and their families will become a growing component of the nursing profession due to an increased interest in direct-to-consumer genetic

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testing and lower prices of genetic testing in health care (Rayes et al., 2019; Martins, Murry, Telford, & Moriarty, 2022). An example of the power of genomics was evident during the global COVID-19 pandemic. The vast number of reported cases revealed several health inequalities, but genomics enabled the development of vaccines and treatments (Denny & Collins, 2021).

Nurses are in a unique position to provide patients and their significant others with information and counselling on sensitive issues related to genomics. It is therefore clear that every nurse should be familiar with the basics of genomics and aware of the ethical issues involved. Patients need to make their own decisions; however, to arrive at an evidence-based informed decision, they often need support in understanding and finding relevant perspectives and options. This is particularly important given the amount of genetic information made available to people through media, the health industry (e.g., direct-to-consumer genetic testing) and healthcare services. Patients have the right to hold their own views, make their own informed decisions and take action based on their personal values. Patient privacy must be respected at every stage of the decision-making process, and in case of an intervention involved, obtaining informed consent is mandatory. However, according to Appelbaum (2017), there are a number of challenges that accompany the process of obtaining informed consent:

– a large amount of information that needs to be communicated;
– individuals faced with decisions about genomics need to understand, in addition to the standard information which accompanies obtaining any clinical or research consent, also:
– the nature of their situation;
– the reason the test is being recommended;
– the likely benefits and risks, such as possible discrimination; and how to deal with secondary findings — a particularly difficult issue, as researchers and clinicians will not know the likely findings or their potential implications at the time the decision is being made.

Ethical competency in a sensitive field of genomics-informed nursing requires a comprehensive understanding of ethical sensitivity and knowledge, skills in ethical reflection, and, most importantly, competence in ethical decision-making, actions, and behaviours (Lechasseur, Caux, Dollé, & Legault, 2018).

How can genomics-informed nursing reshape future nursing?

Nursing education occupies a key position in developing the means and opportunities to integrate genomics-informed nursing into nursing curricula and thus enable its transition into nursing practice. Genomics-informed nursing will not only reform healthcare services based on precision medicine and precision nursing, but also create new career opportunities. Prevention of non-communicable diseases will remain one of the most important global challenges in health care (Denny & Collins, 2021). Therefore, nursing educators and clinical decision-makers should focus on preventive healthcare measures, with particular attention to individuals at risk for genomic conditions (Laaksonen, Airikkala, & Halkoaho, 2022). By focusing on preventive care, at-risk individuals will have earlier access to health services, while nursing professionals will be able to use their expertise in educating patients and the general population while incorporating digital and technological innovations into precision nursing (Harrington, 2021).

Demand for nurses' knowledge and skills is increasing in many emerging areas of nursing, including genomics-informed nursing. However, creating consensus and providing quality content in genomics-informed nursing is only possible through international collaboration.

Slovenian translation/Prevod v slovenščino

Genomsko podprta zdravstvena nega bo vnesla velike spremembe tako na področje zdravstvene nege kot tudi izobraževanja. Dobro počutje in zdravje vsakega posameznika določa njegova osebna genetska zasnova. Da bi razumeli njen pomen in se zavedali priložnosti, ki jih njeno poznavanje prinaša, je potrebno izboljšati genomsko pismenost zdravstvenih pedagogov, študentov in zdravstvenih delavcev v smislu sposobnosti pridobivanja, obdelave, razumevanja in uporabe genomskih informacij pri sprejemanju odločitev, povezanih z zdravjem (Hurle et al., 2013; Whitley, Tueller, & Weber, 2020).

Za vključevanje genomike v vsakodnevno prakso zdravstvene nege je ključnega pomena izboljšati in povečati genomsko pismenost medicinskih sester (Calzone et al., 2018a). To pomeni, da morajo medicinske sestre po vsem svetu doseči visoko raven genomske pismenosti. Potrebno je razviti učne načrte zdravstvene nege, ki bodo zadostili tem izobraževalnim potrebam na dodiplomski in podiplomski ravni. Čeprav so temeljne kompetence medicinskih sester s področja genomike jasno definirane, se pri njihovem vključevanju v obstoječe učne načrte zdravstvene nege pogosto pojavljajo težave. Da bi zagotovili uspešno vključitev kompetenc s področja genomike v učne načrte zdravstvene nege, se namesto oblikovanja posebnih modulov genomike predlaga njihova vkjučitev v obstoječe elemente učnih načrtov zdravstvene nege, saj lahko to olajša učni proces (Skirton et al., 2012). Za zadostitev potreb prihodnjega izobraževanja na področju zdravstvene nege je razvoj strategij za vključevanje kompetenc s področja genomike v učne načrte zdravstvene nege ključnega pomena. Uresniči se lahko skozi tesno sodelovanje z različnimi deležniki (vključno

z vodstvom zdravstvenih ustanov) in v realnem časovnem okviru (Calzone et al., 2018b).

Kot temeljno področje precizne medicine je genomika priznana v medicini in raziskovalni dejavnosti po vsem svetu. Vendar pa to ne velja za zdravstveno nego, zlasti ne v Evropi (Calzone et al., 2018b). Namen pobude Evropske komisije, imenovane 1+ milijon genomov, je karseda povečati potencialne koristi genomike in uvesti potrebne ukrepe na tem področju. Njen cilj je pospešiti razvoj precizne medicine, različnih ciljno usmerjenih terapij in drugih posegov. S pomočjo teh razvojnih ukrepov se lahko ljudem zagotovi zgodnejše diagnosticiranje in zdravljenje, prav tako pa tudi ustrezne informacije o preventivnih ukrepih. Genomika lahko pomembno vpliva na dostopnost, inkluzivnost in učinkovitost sistemov zdravstvenega varstva v Evropski uniji (European Commission, 2022). Poleg evropskih pobud je Mednarodni svet medicinskih sester medicinske sestre spodbudil tudi k poglabljanju znanja o novih praksah, vključno tistih s področij genetike in genomike, ter o etičnih vidikih, povezanih z novim in razvijajočim se področjem zdravstvene nege (International Council of Nurses, 2021).

Genomsko podprta zdravstvena nega je kompleksna celota, ki zajema vsa področja zdravstva, npr. zdravljenje sladkorne bolezeni, bolezni srca in cerebrovaskularnih bolezni, onkologijo, nevrologijo, pediatrijo, farmakologijo, lajšanje bolečin. Zato je to področje osrednjega pomena za vse medicinske sestre ne glede na njihovo področje specializacije (Wright, Zhao, Birks, & Mills, 2019). Zaradi povečanega zanimanja za genetsko testiranje neposredno pri uporabniku in nižjih cen genetskega testiranja v zdravstvu bodo kompetence s področja genomike postale vse bolj pomemben del poklica medicinske sestre v kontekstu podpore pacientov in njihovih družin ter usmerjanja posameznikov (Rayes et al., 2019; Martins, Murry, Telford, & Moriarty, 2022). Med pandemijo covid-19 je pomen genomike prišel še posebej do izraza. Čeprav je ogromno število odkritih primerov razkrilo različne neenakosti na področju zdravja, je genomika omogočila razvoj cepiv in zdravil (Denny & Collins, 2021).

Medicinske sestre imajo edinstveno nalogo obveščanja in usmerjanja pacientov in njihovih bližnjih v zvezi z občutljivimi vprašanji, povezanimi z genomiko. To pomeni, da mora vsaka medicinska sestra poznati osnove genomike in se zavedati etičnih vprašanj, povezanih s tem področjem. Pacienti se morajo odločati sami, vendar pa za informirano odločitev, podprto z dokazi, pogosto potrebujejo podporo pri razumevanju določenih vidikov in iskanju možnosti. To je še posebej pomembno glede na količino genetskih informacij, ki so ljudem na voljo prek medijev, zdravstvene industrije (npr. genetsko testiranje neposredno pri naročniku) in zdravstvenih storitev. Pomembno je, da imajo pacienti pravico do zavzemanja lastnih stališč, da se lahko odločajo na podlagi lastnih informacij in ukrepajo na podlagi osebnih vrednot. Zasebnost pacientov je potrebno spoštovati v vseh fazah postopka odločanja, pri čemer je v primeru kakršnegakoli posega obvezno pridobiti informirano soglasje pacienta. Vendar pa je po mnenju Appelbauma (2017) postopek pridobivanja informiranega soglasja povezan s številnimi izzivi:

- velika količina informacij, ki jih je potrebno posredovati;
- poleg posredovanja standardnih informacij, ki spremljajo pridobivanje vsakršnega soglasja v klinični ali raziskovalni praksi, morajo biti pri sprejemanju odločitev, povezanih z genomiko, posamezniki seznanjeni še z:
- naravo svojega stanja;
- razlogi za priporočljivost testa;
- verjetnimi koristmi in tveganji (npr. možno diskriminacijo) ter načinom ravnanja s sekundarnimi ugotovitvami, kar je še posebej zahtevna tema, saj raziskovalci in zdravniki v danem trenutku še ne poznajo niti verjetnih ugotovitev niti njihovih morebitnih posledic.

Etična kompetenca na občutljivem področju genomsko informirane zdravstvene nege zahteva celovito razumevanje etične občutljivosti, poznavanje in sposobnost etične refleksije, predvsem pa sposobnost etičnega odločanja, delovanja in vedenja (Lechasseur, Caux, Dollé, & Legault, 2018).

Na kakšen način lahko genomsko podprta zdravstvena nega preoblikuje področje zdravstvene nege?

Izobraževanje v zdravstveni negi ima ključno vlogo pri razvijanju sredstev in možnosti za vključitev genomsko informirane zdravstvene nege v učne načrte zdravstvene nege in s tem za omogočanje njenega prehoda v zdravstveno prakso. Genomsko podprta zdravstvena nega bo ustvarila nove poklicne priložnosti, hkrati pa bo reformirala zdravstvene storitve, ki temeljijo na precizni medicini in precizni zdravstveni negi. Preprečevanje nenalezljivih bolezni bo ostal eden najpomembnejših globalnih izzivov na področju zdravstvenega varstva (Denny & Collins, 2021). Zato bi morali izobraževalci v zdravstveni negi in klinični odločevalci poudarjati in se osredotočati na preventivne zdravstvene ukrepe, zlasti pri ljudeh s tveganjem za genomske bolezni (Laaksonen, Airikkala, & Halkoaho, 2022). Poudarek na preventivnem zdravstvenem varstvu bo ogroženim omogočil zgodnejši dostop do zdravstvenih storitev, strokovnjakom zdravstvene nege pa možnost uporabe svojega strokovnega znanja pri izobraževanju ljudi in bolnikov, obenem pa tudi uporabo digitalnih in tehnoloških inovacij v precizni zdravstveni negi (Harrington, 2021).

Zahteve po znanju in veščinah medicinskih sester na številnih novih področjih zdravstvene nege, vključno z genomsko podprto zdravstveno nego, so vse bolj izrazite. Vendar pa oblikovanje konsenza in kakovostnih vsebin na področju genomsko informirane zdravstvene nege zahteva mednarodno sodelovanje.

Conflict of interest/Nasprotje interesov

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