SYSTEMATIC REVIEW | Genetics inMedicine

Genetics/genomics education for nongenetic health professionals: a systematic literature review

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Purpose: The completion of the Human Genome Project has enhanced avenues for disease prevention, diagnosis, and management. Owing to the shortage of genetic professionals, genetics/genomics training has been provided to nongenetic health professionals for years to establish their genomic competencies. We conducted a systematic literature review to summarize and evaluate the existing genetics/genomics education programs for nongenetic health professionals.

Methods: Five electronic databases were searched from January 1990 to June 2016.

Results: Forty-four studies met our inclusion criteria. There was a growing publication trend. Program participants were mainly physicians and nurses. The curricula, which were most commonly provided face to face, included basic genetics; applied genetics/genomics; ethical, legal, and social implications of genetics/genomics; and/or genomic competencies/recommendations in particular professional fields. Only one-third of the curricula were theory-based. The majority of studies adopted a pre-/post-test design and lacked follow-up data collection. Nearly all studies reported participants' improvements in one or more of the following areas: knowledge, attitudes, skills, intention, self-efficacy, comfort level, and practice. However, most studies did not report participants' age, ethnicity, years of clinical practice, data validity, and data reliability.

Conclusion: Many genetics/genomics education programs for nongenetic health professionals exist. Nevertheless, enhancement in methodological quality is needed to strengthen education initiatives.

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Key Words: genetics; genomics; genomics education; health professionals

The completion of the Human Genome Project has opened many avenues for the prevention, diagnosis, and management of various diseases.[1,2] As a result, the demand for genetic services has increased tremendously. Because of the shortage of genetic professionals, nongenetic health professionals are called upon to take family histories, conduct family-history assessments, interpret results of genetic tests, provide genetics/genomics education to patients, and make appropriate referrals for genetic evaluations.[3–5] However, these nongenetic health professionals have not been able to keep up with the advancements in genomics. The lag has been attributed partly to their lack of genomic competencies, skills, and confidence in integrating genomic information and technologies into patient education, management, counseling, and referral.[5,6]

One key approach to addressing the gap between the high demand for genetic services and the limited genetic/genomic competency of nongenetic health professionals is to provide training and education. Ideally, genetics/genomics education should be introduced at medical, dental, allied health, and public health schools and continued throughout individuals' professional development.[7] However, adding new courses such as genomics to the existing rigid school curricula may be difficult.[8] Moreover, genomics is a rapidly changing field; current genomic information and technologies may differ from what nongenetics health professionals learned in school. Therefore, it is necessary to provide continuing training in genetics/genomics for practicing nongenetic health professionals.

Continuing training in genetics/genomics has been developed and disseminated to nongenetic health professionals for many years since the completion of the Human Genome Project. Nevertheless, the following questions are still unanswered. (i) how many such programs have been offered?; (ii) who were the participants?; (iii) what were the characteristics of the programs?; (iv) what was the methodological quality of the published studies?; and (v) were these programs effective in building up participants' genomic competencies? To answer these questions, we conducted a systematic literature review to examine the existing genetics/genomics education programs for nongenetics health professionals. Specifically, we sought to assess the characteristics, study designs, and program evaluations of the programs. A systematic literature review method was selected because it could identify the evidence-based genetics/genomics educational programs via a thorough systematic approach and thereby guide the future development of similar training to build a competent health workforce in genomics.[9]

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MATERIALS AND METHODS

Literature search

We adopted Garrard's[9] matrix method to conduct our literature review. Guided by a systematic literature review specialist affiliated with Texas A&M University, we searched five electronic databases—MEDLINE, EMBASE, Global Health, CAB Abstracts and CINAHL—for articles relevant to genomics education for nongenetic health professionals. Search terms included "genetics," "genetic testing," "genomics," "genetic predisposition to disease," "genetics education," "family history," "continuing education," "professional education," "professional development," "professional role," "staff development," "professional competence," "continuing nursing education," "continuing medical education," "training," "evaluation," "impact," "allied health personnel," "health personnel," "nursing," "nurse," "clinician," "doctor," "physician," "health occupation students," "health professional," and "health care professional." The search period was from 1 January 1990 to 28 June 2016. We selected the year 1990 as the start of the search period because the Human Genome Project began that year, thereby shifting the paradigm from traditional *genetics* education focusing on single gene disorders to *genomics* education, which addresses complex genomics diseases such as cancer and diabetes, and generating newer, more advanced genetics/genomics techniques.

Article selection

Figure 1 illustrates the article search and selection procedure. Using a reference management program—RefWorks (Refwork Co, Bethesda, MD)—two of the authors (D.T. and L.S.C.) examined and discussed titles and abstracts to initially screen articles. For studies selected through the initial screening, full-text articles were obtained for further evaluation. We selected the studies that met the following inclusion criteria: (i) were published in an English-language peer-review journal; (ii) were original studies; (iii) reported on genetics/genomics education programs that are delivered directly to nongenetic health professionals; (iv) presented the evaluation findings of genetics/genomics education programs; and (v) reported outcomes related to participants' practice with patients (e.g., taking family health histories and providing genetic risk assessments). If multiple articles were published from the same genetics/genomics education program, then we included only the study that reported the most comprehensive evaluation findings. We excluded articles if (i) they were not written in English; (ii) only abstracts were published; (iii) the studies were theoretical or perspective (e.g., proposing suggestions for developing genomic education curricula and/or presentation of those curricula); (iv) all participants were students; (v) participants did not receive genetics/genomics education training; (vi) participants were asked to review guidelines or a website; (vii) the educational programs focused on one specific type of disease or genetic testing/screening; or (viii) the studies did not report the evaluation findings of the proposed genetics/genomics education programs.

Thirty-nine studies met our inclusion criteria. Next, the references cited in the 39 articles and any studies that cited these articles were examined using Scopus and Web of Science to identify other articles eligible for inclusion in this review. We also used Google Scholar to identify additional articles that might have been published but had not been indexed in the five electronic databases we searched. Using these two methods, five additional articles were identified. Accordingly, 44 articles became the final sample for this systematic literature review.[6,10–52]

Data extraction and synthesis

Data from the 44 articles were extracted and entered into a matrix table (**Supplementary Table S1** online) independently by the two authors (D.T. and L.S.C.). As shown in **Supplementary Table S1** online, the matrix table included the characteristics of the genetics/genomics programs (e.g., study time and location, participants' information, and program components) and an evaluation of the programs (e.g., program evaluation methods, data analysis, and main findings). Of note, the content of curricula was classified as basic genetics/genomics (e.g., concepts related to Mendelian disorders, genetic inheritance patterns, and chromosomal abnormalities), applied genetics/genomics (e.g., pedigree analysis and genetic risk assessment), ethical, legal, and social implications (ELSI) of genetics/genomics (e.g., ethical, financial, or social issues associated with genetic testing), and genomic competencies or recommendations in a particular professional field (e.g., genomic competencies recommended by the National Coalition for Health Professional Education in Genetics). The program evaluation methods were categorized as follows: one-shot case study/descriptive cross-sectional design (i.e., evaluating the educational outcomes of a group at one point in time), pre-/post-test, quasiexperimental, or experimental (randomized controlled trial) designs.[53] Classifications of data analysis methods were characterized as descriptive statistics, inferential statistics without controlling for covariates (e.g., ANOVA and chi-square), and inferential statistics controlling for covariates (e.g., linear regression and ANCOVA).

Several studies reported multiple statistical methods, and we chose to include the most rigorous type used for analyzing the evaluation data. Theoretic constructs adopted mainly from the social cognitive theory[54] and the theory of planned behavior[55] were utilized to organize the key evaluation findings in terms of knowledge, attitudes, skills, intention, self-efficacy, comfort level, practice behavior, and program assessment. We reported only the findings that were statistically significant, except in descriptive studies, for which we described the results in percentages. The interrater reliability score (Gwet's AC1) was 0.93, indicating very good agreement between the two coders.[56]

Methodological quality score

We developed a methodological quality score (MQS) to evaluate the methodological quality of the included studies, with possible scores ranging from 4 to 23. Specifically, after

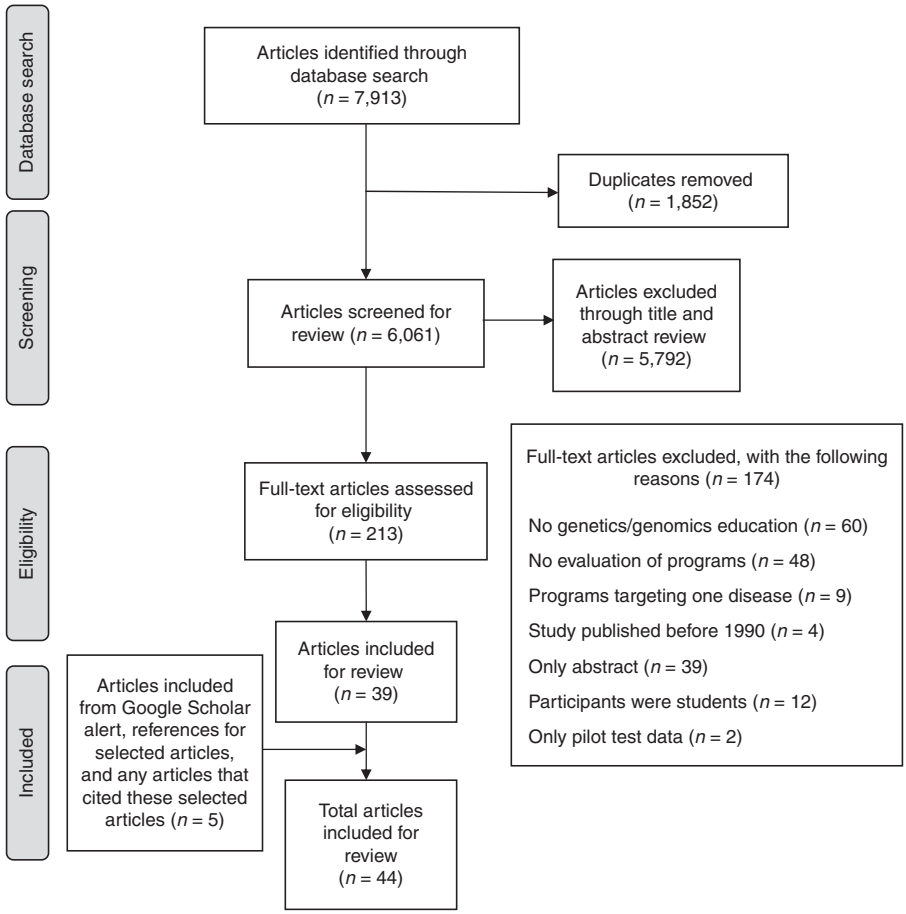

Figure 1 Article search and selection procedure.

careful review of all the included studies, the MQS was first developed by adapting the evaluation criteria from previous literature.[53,57,58] The research team later discussed and revised the MQS, which was utilized to assess the sample size, availability of participants' demographic information (i.e., ages, races/ethnicities, and years of practice), program characteristics, the use of a theoretical framework, content of curricula, data validity and reliability, program evaluation design, and data analysis. A higher MQS represented better methodological quality of the study. **Table 1** details the MQS criteria and summarizes findings from the studies we reviewed.

RESULTS

Program characteristics

Study year and location. **Supplementary Table S2** online summarizes the key findings of the 44 included studies. There was a growing trend in publications related to genomics education for nongenetics health professionals during the following time periods: 1990–1994 (n = 0), 1995–1999 (n = 3), 2000–2004 (n = 4), 2005–2009 (n = 12), 2010–2014 (n = 17), and 2015–June 2016 (n = 8). The majority of the studies were conducted in the United States (n = 30), and the remaining studies were conducted in Canada (n = 3), the Netherlands (n = 3), the United Kingdom (n = 2), Australia (n = 1), Lebanon (n = 1), Italy (n = 1), Taiwan (n = 1), Sri Lanka (n = 1), and Singapore (n = 1). One study was conducted using a study population from different countries and included Lebanese and Arab general physicians.[29]

Participants. Participants who attended genetics/genomics training included physicians and residents in various specialties as well as allied health professionals (i.e., nurses, dieticians, pharmacists, social workers, health educators, physician assistants, laboratory technicians, and mental health professionals). The numbers of participants in the studies varied, ranging from 10 to 710. More than half of the studies (n = 27; 61.4%) had fewer than 100 participants. Fifteen studies (34.1%) reported participants' ages and 20 studies mentioned the years of practice (45.5%). Only eight studies (18.2%) reported participants' ethnicity.

Genetics/genomics education curricula: theoretical framework and content. Of the 44 reviewed studies, merely one-third (n = 13; 29.5%) indicated that their genomics education

Table 1 Frequency distributions of methodological criteria among reviewed articles (n = 44)

Methodological criterion	Points	Frequency distribution	
		N	%
Sample size			
0–100	1	27	61.4
101–200	2	10	22.7
201–300	3	4	9.1
More than 300	4	3	6.8
Age			
Not reported	0	29	65.9
Reported	1	15	34.1
Ethnicity			
Not reported	0	36	81.8
Reported	1	8	18.2
Years of practice			
Not reported	0	24	54.5
Reported	1	20	45.5
Program characteristics			
Key elements of program design not reported	0	2	4.5
Key elements of program design reported	1	42	95.5
Theoretical framework			
Not reported	0	31	70.5
Reported	1	13	29.5
Curricula content (i.e., Basic genetics/genomics, applied genetics/genomics, ELSI of genetics/genomics, genetic competencies or recommendations in a particular professional field)			
Only one	1	3	6.8
Two	2	12	27.3
Three	3	21	47.7
All four	4	8	18.2
Data validity testing			
Not reported	0	29	65.9
Reported	1	15	34.1
Data reliability testing			
Not reported	0	33	75.0
Reported	1	11	25.0
Program evaluation design			
One-shot case study/descriptive cross-sectional	1	11	25.0
Pre-/post-design	2	26	59.1
Quasiexperimental	3	2	4.5
Experimental (randomized controlled trial)	4	5	11.4
Program evaluation follow-up			
Not reported	0	29	65.9
Reported	1	15	34.1
Data analysis			
Descriptive statistics/qualitative	1	8	18.2
Inferential statistics without controlling for covariates (ANOVA, chi-square)	2	31	70.5
Inferential statistics controlling for covariates (linear regression, ANCOVA)	3	5	11.4

ANOVA, analysis of variance; ANCOVA, analysis of covariance; ELSI, ethical, legal, and social implications.

curricula were based on a specific theory/model or a theoretical framework.

Additionally, 3 of the 44 studies did not report information regarding their genetics/genomics training curricula. The curricular content of the remaining 41 articles, included (i) basic genetics/genomics, (ii) applied genetics/genomics, (iii) ELSI of genetics/genomics, and (iv) genomic competencies and/or recommendations referred in a particular professional field, which were identified in 72.7%, 95.5%, 56.8%, and 43.2% of reviewed articles, respectively.

Genetics/genomics education programs: delivery methods and incentives. In terms of the delivery methods for genetics/genomics training, one study did not specify the approach. Overall, in-person education was the most common approach, as seen in half of the reviewed studies (n = 23, 52.3%). With respect to incentives, almost half of the studies (n = 21, 47.7%) did not report offering any incentives for their participants. Among the other half, incentives were provided in various forms (e.g., salaries, coupons for coffee, book vouchers, other types of monetary compensation, training certificates, and continuing education units.)

Program evaluation

Program evaluation design. Of the 44 studies, more than half (n = 26; 59.1%) used the pre-/post-test design. Among these, the majority (n = 23) collected post-test data immediately following the education programs. In the other three studies,[15,26,51] however, the post-test data were collected 2–6 months posteducation. Moreover, less than half of the studies we identified (n = 15; 34.1%) collected follow-up data. Although the follow-up durations varied—from 1 to 36 months—the majority took place over the course of more than 6 months. Eleven studies (25.0%) used the one-shot case study/descriptive cross-sectional design. Only a few studies adopted rigorous study designs, such as quasi-experimental designs (n = 2; 4.5%) and randomized controlled trials (n = 5; 11.4%).

Data validity, reliability, and analysis. Only one-third of the reviewed studies (n = 15; 34.1%) reported that they examined data validity. Data reliability was mentioned in even fewer articles (n = 11; 25.0%). Regarding data analysis, the majority of studies (n = 31; 70.5%) utilized inferential statistics without controlling for covariates (e.g., paired t-test, chi-square, McNemar's test, and Wilcoxon signed-rank test). Eight studies (18.2%) simply described the frequencies of the genomics training outcomes. Only five studies (11.4%) utilized a more advanced statistical approach—an inferential statistics approach controlling for covariates—to evaluate the effects of their genetics/genomics education programs.

Main program evaluation outcomes of the genetics/genomics education programs. All studies evaluated training outcomes with respect to participants' changes in one or more

of the following areas: knowledge, attitudes, skills, intention, self-efficacy, comfort level, and practice behavior. More than half of the studies (n = 26, 59.1%) provided participants' assessments of the training programs. The results of each key finding of the genetics/genomics training programs are discussed below.

Knowledge. Of the 30 studies (68.2%) that assessed knowledge as one of the key findings of the training programs, 23 reported that, after training, participants had increased their genomics knowledge in a statistically significant way. For instance, in a study of a university-based residency program utilizing didactic lectures and standardized patients, Macri et al.[18] reported a significant improvement in obstetrics–gynecology residents' knowledge regarding genetic counseling and genetic diagnosis.

Attitudes. Five of the 44 studies (11.4%) measured attitudes as a major outcome of the training programs. Four studies[12,25,27,52] reported positive attitudes toward genetics/genomics in general; in the fifth study,[22] mental health providers exhibited mixed attitudes toward the use of genetic tests in clinical practice. For instance, in a basic genetics training program conducted in community health clinics, Kolb et al.[12] found that, compared with the baseline and post-test data, 121 participating primary health-care providers reported a significantly positive change in attitude toward providing genetic services to their clients.

Skills. Five studies (11.4%) examined whether genomics education programs influenced nongenetic health professionals' skills in genomics practice. Four of those studies[33,37,39,43] reported the statistically significant impact of genetics/genomics training programs on nongenetic health professionals' practice skills; the fifth study[13] published descriptive findings. Roter and colleagues,[39] for example, reported that physician assistants in the intervention group who watched four 2-hour online genetics training modules exhibited significantly higher genetic skills while collecting a detailed family history of cancer than the control group.

Intention. Five studies (11.4%) assessed participants' intention to practice genetics/genomics in the future. Four of those studies reported descriptive findings[25,27,29,38], and one study reported a statistically significant increase in participant's intention to incorporate genetics/genomics in their practices.[40] For example, after the 4-hour genetic symposium entitled "Genetics for Primary Care Physicians" at a continuing medical education conference in Lebanon, attendees expressed their willingness to start or refer patients for genetic testing and counseling.[29]

Self-efficacy. Self-efficacy or confidence in practicing genetics/genomics was evaluated by nearly half of the studies (n = 20; 45.5%). Among those studies, most acknowledged that their programs successfully enhanced participants' confidence in applying genetics/genomics in their professional practices in a statistically significant way. Swank et al.,[14] for instance, noticed that nurses who completed the self-instructional genetics training reported significantly higher scores in perceived ability to identify egg donors' genetic risks.

Comfort level. Among the reviewed studies, two (4.5%) evaluated comfort level with clinical genetic skills as an important outcome of the genomics training.[23,26] Altshuler et al.,[23] for example, conducted a yearly "Genetics Objective Structured Clinical Exam" program among three cohorts of pediatric residents. Postprogram interviews revealed that participants felt that the training enhanced their comfort level in performing 5 of the 12 tasks requiring specific genetic skills.

Practice behavior. Fewer than one-third of the studies we assessed (n = 13; 29.5%) examined changes in genomic practice, which were self-reported by participants. Although all of these 13 studies assessing practice behavior reported positive behavior outcomes regarding clinical genetics practice after completion of the training, only 4 articles[15,33,35,40] reported statistically significant findings (the remaining articles presented only descriptive results).

Program assessment. Participants' assessments of genetics/genomics training programs were recognized in more than half of the reviewed studies (n = 26, 59.1%), which stated that the majority of their participants were satisfied with their training programs. For example, Gaff et al.[13] concluded that the majority of oncology nurses participating in the cancer genetics resource training course indicated that the course was very useful and relevant to their work.

MQS

Within the possible range of 4–23 for the MQS, the average MQS of the included studies was 11.4 (SD = 3.0; range: 6–17). As seen in **Table 1**, most studies had fewer than 100 participants (61.4%) and lacked participants' information regarding age (n = 29), ethnicity (n = 36), and years of practice (n = 24). Nearly all studies (95.5%) reported key elements of the program design. Almost half (47.7%) incorporated three types of genetics/genomics content in their programs, but only approximately one-third of curricula were based on theoretical frameworks or specific theories/models. Data validity and reliability were reported in 15 (34.1%) and 11 (25.0%) studies, respectively. More than half of the studies (n = 26; 59.1%) utilized pre-/post-test designs to evaluate the effectiveness of their training programs. Only 15 (34.1%) of the total reviewed studies collected follow-up data. Finally, the majority of the studies (n = 31; 70.5%) performed inferential statistics without controlling for covariates as their data-analysis methods.

DISCUSSION

This systematic literature review synthesizes existing literature on genetics/genomics education programs among nongenetic health professionals. The 44 articles that we examined provided valuable, evidence-based insight into the development, implementation, and evaluation of such programs. Our review yielded several significant findings. Over the period of 1 January 1990 to 28 June 2016, there is an increasing publication trend

with this body of literature in providing genomics training for nongenetic health professionals. Although many types of nongenetic health professionals were the target audience, several specialty groups, such as dentists, physical therapists, and occupational therapists, are also undereducated in this area. Moreover, the majority of the training focused on physicians and nurses. Additional educational programs for other disciplines of nongenetic health professionals are desirable.

Second, the majority of the studies we reviewed focused on the knowledge gained by participants and overall program assessment as the main outcomes of their genetics/genomics education training programs. Although these factors are important, other components are also vital for evaluating the effectiveness of these programs. Health behavioral theories have documented that both knowledge and psychological factors are essential for promoting behavioral changes.[59] Assessment of psychological variables associated with behavioral changes, such as attitudes, intention, and self-efficacy, is needed for future research. Furthermore, fewer than one-third of the studies measured practice behavior, yet this construct is key in assessing whether trainees actually implement in clinical practice what they learn from the programs. Future studies should evaluate participants' behavioral changes after training sessions.

Third, although near all studies indicated that their training programs successfully increased participants' knowledge, attitudes, skills, intention, self-efficacy, comfort level, and/or practice behavior in genomics practice, a few studies adopted rigorous study designs and evaluation plans. In fact, only 7 of the 44 reviewed articles[6,24,34,37,39,43,45] used a quasi-experimental design or randomized controlled trial/experimental design. The majority of the studies did not collect follow-up data, utilize advanced statistical techniques to control potential confounders, or report data validity and reliability. More rigorous evaluation designs that include measurement of the retention of the main outcomes of the education programs should be considered in the future.

Fourth, along with evaluation components, the characteristics of the genetics/genomics training programs are important, yet theoretical frameworks or theories/models were largely missing among the identified studies. Because theoretical groundwork is crucial in guiding the development and evaluation of programs and/or interventions, the application of theoretical frameworks or theories/models to developing genomics curricula can define both program outcomes and associated mediating factors.[59] Moreover, less than half of the curricular context included genomic competencies and/or recommendations referred in a particular professional field. ELSI concepts were covered in only slightly more than half of the curricula. Nevertheless, genomic competencies defined in a professional field and ELSI knowledge are imperative for ensuring that trainees from genetics/genomics education programs develop adequate knowledge, skills, and awareness of relevant ELSI considerations to adopt genomics into clinical practice. Accordingly, future genetics/genomics education programs should be based on theoretical frameworks or theories/models and should also include ELSI and genomic competencies as recommended in professional fields.

Fifth, the demographic information for participants, such as age, ethnicity, and years of practice, were reported in 34.1%, 18.2%, and 45.5% of the studies identified in this systematic review, respectively. These are modifying factors that might have influenced participants' knowledge, practice behaviors, and associated psychological variables.[59] Absence of such information hinders data interpretation with regard to how demographic information might be related to the effectiveness of the genetics/genomics curricula. For example, literature has linked genetics/genomics knowledge to age, as recently graduated health professionals are better trained in genetics/genomics.[4,60–62] It is unknown whether there would be better practice outcomes following genomics training for younger health professionals than practitioners from an older generation. For these reasons, providing the demographic information for participants in genetics/genomics education programs is necessary for future programs.

Our systematic review exhibited several limitations. First, although we conducted a thorough literature search in major databases and adopted various search strategies to identify articles published in English, we might have missed articles that were not indexed in these databases and/or written in languages other than English. In addition, although our review focused primarily on nongeneticist professionals, a few studies included geneticists and/or genetic counselors as a small portion of their participants. Findings from these original studies could not be separated according to genetic versus nongenetic professional groups. Because we did not want to omit important articles on genetics/genomics education, we retained these studies in this systematic review. Third, we organized the findings from the reviewed articles into categories such as attitudes, knowledge, and self-efficacy based on health behavior theories. Ideally, these constructs should be measured as multiple-item scales; however, most studies measured these constructs by asking only one question. Finally, because the study designs of the included articles varied (i.e., one-shot case study/descriptive cross-sectional, pre-/post-test, quasi-experimental, and experimental designs), there is no gold standard for evaluating this body of literature. The criteria for MQS were self-referenced. Nevertheless, our research team attempted to address this potential bias by carefully assessing the articles included in this systematic review and adapting the evaluation criteria from the previous literature[53,57,58] to develop the MQS measures.

Despite these limitations, this systematic review contributes to the genomics field by summarizing and assessing the characteristics and evaluation findings of genetics/genomics education programs for nongenetic professionals. Our findings suggest that although a number of such programs exist, enhancement in the methodological quality of this body of literature is needed to strengthen education initiatives. The results from our review

may guide the development of similar training programs to build a competent genomics health workforce in the future.

SUPPLEMENTARY MATERIAL

Supplementary material is linked to the online version of the paper at http://www.nature.com/gim

DISCLOSURE

The authors declare no conflict of interest.

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