



THE ROLE OF PRIMARY CARE IN PROVIDING GENETICS SERVICES TO UNDERSERVED POPULATIONS: A SYSTEMATIC REVIEW

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PRESENTATION OVERVIEW

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STUDY SITUATION & BACKGROUND

- The field of medical genetics has become increasingly complex due to humankind's ever-expanding knowledge of the subject.
- While much progress has been made in improving access to and knowledge of genetic services, serious gaps exist in the delivery of genetic services to medically underserved populations.
- These gaps are created by disparities in the distribution of the medical genetic workforce.
- To bridge these gaps, improving the integration of genetic services with primary care has been singled out as a priority.

The background is a dark teal gradient. In the corners, there are decorative white line-art elements resembling circuit boards or neural networks, with lines connecting to small circles.

RESEARCH QUESTION

What is the role of primary care providers (PCPs) in the provision of genetic services to underserved populations?

RESEARCH QUESTION (CONT.)

Dimensions/sub-questions of the main research question include:

1. What are the comfort level and perceived level of competency for PCPs when it comes to delivering genetic services?
2. How are genetic services being delivered today?
3. What types of barriers (systems-level or otherwise) exist between PCPs and the provision of genetic services?
4. What support resources and integration strategies exist to facilitate the adoption of genetic services in the primary care setting?

STUDY DESIGN & METHODS

- A systematic review was conducted to answer the research question and its four dimensions.
- Using Ovid MEDLINE, the search strategies for the review focused on three broad topics:
 - medical genetics/geneticists and patient-centered care
 - interface of genetics, underserved/vulnerable populations, and primary care/patient-centered care
 - barriers for PCPs and available primary care support and integration strategies

STUDY DESIGN & METHODS (CONT.)

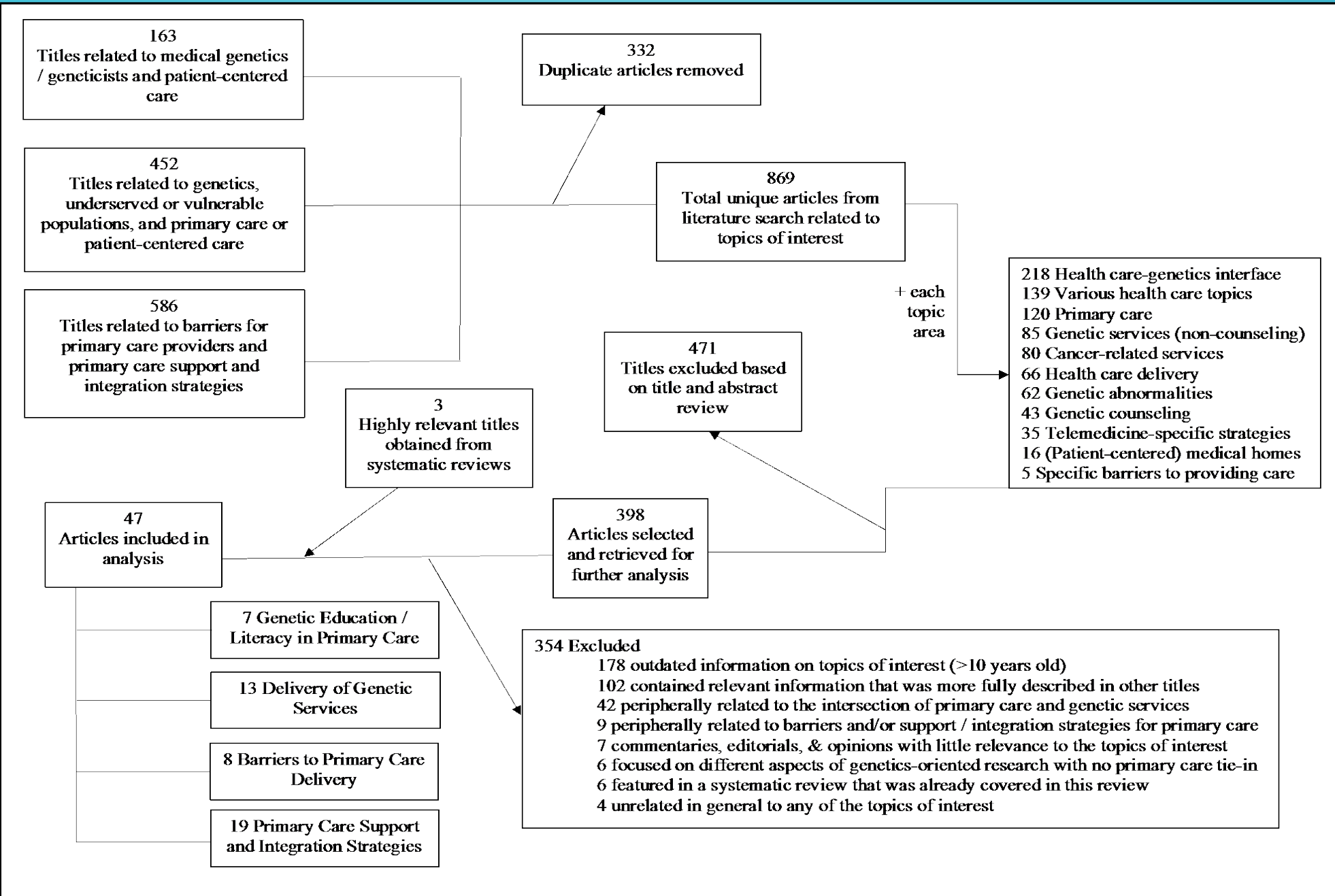
- References from the Ovid MEDLINE searches were extracted and exported to an EndNote library for further analysis.
- References in the library were excluded if they met one or more of seven exclusion criteria or if they were already included in systematic reviews.

STUDY DESIGN & METHODS (CONT.)

- Articles included in the review were assigned to one of four categories for analysis:
 - Genetic Education / Literacy in Primary Care
 - Delivery of Genetic Services
 - Barriers to Primary Care Delivery
 - Primary Care Support and Integration Strategies

SEARCH TERMS FOR THE REVIEW

- patient-centered care
- delivery of health care
- primary health care
- child health services
- medical homes
- primary health care
- underserved populations
- vulnerable populations
- rural populations
- genetic risk assessment
- geneticist
- genetics
 - population
 - medical
 - general
- genetic diseases
 - inborn diagnosis
 - prenatal diagnosis
- genetic counseling
- patient anxiety
- access to geneticists
- insufficient time
- access to counseling services
- primary health care
- barriers to health care
 - infrastructural
 - financial
 - legal
 - professional
- frustration with genetic testing industry
- Telegenetics
- Telemedicine
- ECHO model / project ECHO
- learning communities
- rural populations
- disease management model
- patient satisfaction.



163
Titles related to medical genetics / geneticists and patient-centered care

452
Titles related to genetics, underserved or vulnerable populations, and primary care or patient-centered care

586
Titles related to barriers for primary care providers and primary care support and integration strategies

332
Duplicate articles removed

869
Total unique articles from literature search related to topics of interest

+ each topic area

- 218 Health care-genetics interface
- 139 Various health care topics
- 120 Primary care
- 85 Genetic services (non-counseling)
- 80 Cancer-related services
- 66 Health care delivery
- 62 Genetic abnormalities
- 43 Genetic counseling
- 35 Telemedicine-specific strategies
- 16 (Patient-centered) medical homes
- 5 Specific barriers to providing care

471
Titles excluded based on title and abstract review

3
Highly relevant titles obtained from systematic reviews

47
Articles included in analysis

398
Articles selected and retrieved for further analysis

7 Genetic Education / Literacy in Primary Care

13 Delivery of Genetic Services

8 Barriers to Primary Care Delivery

19 Primary Care Support and Integration Strategies

354 Excluded

- 178 outdated information on topics of interest (>10 years old)
- 102 contained relevant information that was more fully described in other titles
- 42 peripherally related to the intersection of primary care and genetic services
- 9 peripherally related to barriers and/or support / integration strategies for primary care
- 7 commentaries, editorials, & opinions with little relevance to the topics of interest
- 6 focused on different aspects of genetics-oriented research with no primary care tie-in
- 6 featured in a systematic review that was already covered in this review
- 4 unrelated in general to any of the topics of interest

ORIGINAL PLAN VS. REALITY

Original Plan

- ✓ Devise appropriate search strategies
- ✓ Create an EndNote library with relevant sources
- ✓ Create a flowchart summarizing literature review
- ✓ Prepare evidence tables analyzing selected titles

Reality

- ✓ Devise appropriate search strategies
- ✓ Create an EndNote library with relevant sources
- ✓ Create a flowchart summarizing literature review
- ✓ Prepare evidence tables analyzing selected titles

RESULTS

- A total of 47 articles were selected for analysis.
- Of those articles, we identified:
 - 11 cross-sectional studies
 - 9 reviews
 - 3 randomized controlled trials
 - 3 implementation studies
 - 21 other studies and articles

TABLE I. Evidence Table for Genetic Education / Literacy in Primary Care

References, Country	Study / article type	Objective	Data collection or population studied	Selected findings and conclusions
Lopes-Junior et al. [2017], Brazil	Cross-sectional study	To determine the level of genetics-related education, knowledge, and experiences among nurses and physicians who provide primary care in São Paulo	Data were obtained from questionnaires that were completed by 24 physicians and 30 nurses.	Roughly 85% of respondents stated that they received some genetic content during their undergraduate education. Despite this, about 78% indicated that they did not feel prepared to deliver genomics-based health care in primary care. It was concluded that primary care nurses and physicians lack the knowledge to provide genomics-based health care.
Paneque et al. [2016], Portugal, UK, and the Netherlands	Systematic review	To evaluate genetics educational interventions in the context of primary care to determine if there is a common theme to direct guidelines	Following the guidelines from the Centre for Reviews and Dissemination, five relevant electronic databases were searched. The results were coded and categorized.	Current literature is insufficient about how to inform educational interventions in genetics for primary care providers. Educational initiatives should be assessed using changes in practice to determine if they are effective in causing significant changes in practice in genetic risk assessment and appropriate management of patients.

MAJOR THEMES FROM REVIEW: BARRIERS

- PCPs identified the following barriers to providing genetics services:
 - insufficient time to provide services
 - a lack of clinical guidelines
 - a lack of access to appropriate genetics resources
 - a lack of training in genetics

MAJOR THEMES: STRATEGIES FOR INTEGRATION

- **Use telegenetics**: Patients are generally just as satisfied (if not more satisfied) with telegenetics services as they are with face-to-face consultations.
- **Project ECHO** is described as being a practical way to connect PCPs in underserved areas with specialists, such as geneticists.
- **Promote patient-centered medical homes (PCMHs)**: PCMH can enhance access to and quality of care.

MAJOR THEMES: STRATEGIES FOR INTEGRATION

- **Educate PCPs** on the many tools that are available to facilitate gathering information on family history and hereditary risk factors.
- **Patients need to be educated** more on the benefits and harms of genetic testing.

IMPLICATIONS FOR RESEARCH QUESTION

- Due to the population size and distribution of the US, PCPs are now becoming the front line in providing genetic services, especially to medically underserved populations.
- Many of the barriers described earlier can be addressed using support resources and integration strategies like Project ECHO and patient-centered medical homes.

IMPLICATIONS FOR RESEARCH QUESTION (CONT.)

- The results of many of the studies support the idea that the US government should increase funding for telemedicine communication systems in order to improve the quality of care being delivered.
- Since PCPs do not receive adequate training in genetics, a twofold approach involving a restructuring of postgraduate training for primary care specialties and increasing the use of models like ECHO to provide education to practicing providers should be used.

THE NEXT STEP: FOR THE PROJECT

- The information presented in this paper will help to set the stage for future implementation projects.
- The work is almost done for this project; only a few more elements need to be added before it is ready for publication.
- Besides publication in a journal, we anticipate giving oral and poster presentations of the study and its results.

THE NEXT STEP: FOR ME

- Doing this review has greatly expanded my knowledge of the expectations of and obstacles facing PCPs around the world.
- I believe that I now have a good amount of foundational knowledge for future research of the topics covered this summer.
- I anticipate working on another project with Dr. Chou that was originally intended to be worked on this summer but was postponed due to schedule conflicts.
 - It involves the role of medical genetics in the PCMH model.

QUESTIONS?



THANK YOU FOR YOUR ATTENTION!

