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Genetic counselling resources in non-english languages: A scoping review

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ABSTRACT

Objective: Genetic counselling is essential for individuals seeking genetic or genomic testing. Whereas innovative strategies for GC delivery are being explored to meet the growing demand on the clinical genetics workforce, it is essential to consider the unique needs of culturally and linguistically diverse populations.
Methods: We conducted a scoping review to examine the extent, range, and gaps in the body of non-English, patient-facing educational resources available for Limited English Proficient (LEP) patients accessing clinical genetics and genomics services.
Results: The literature search returned 246 unique resources, most available in several languages. Forty-six languages were represented, with Spanish, Russian, and French being the most common. Resources were in various formats and were of varying quality.
Conclusions: There is a lack of high-quality supplementary genetics education material available in languages other than English, which limits the quality-of-care that LEP families may receive compared to their English-speaking counterparts. Of equal concern is the difficulty in finding existing resources and in determining their quality.
Innovation: This research highlights the important need for genetics education material that is of good quality in languages other than English and the challenges associated with identifying this material. A central, curated repository, perhaps sponsored by a genetic counselling organization, would be of great benefit to help genetic counsellors meet the needs of their culturally and linguistically diverse patients.

1. Introduction

Genetic counselling (GC) is recommended for individuals considering genetic or genomic testing (GT) to ensure that the risks, benefits, and implications of testing are understood [1]. GC is defined as "the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease." [2]. GT is expanding rapidly but there is a significant shortage of genetic counsellors. To meet the growing demand, innovative strategies for GC delivery are being explored [3-5].

In developing these strategies, it is important to consider the unique needs of culturally and linguistically diverse (CALD) populations so that all families receive services of comparable quality. Communication barriers are broadly accepted as a major contributor to healthcare disparities experienced by CALD populations in many English-speaking countries [6-8]. The identification of language as a major barrier to healthcare access for populations with Limited English proficiency (LEP), paired with the increasing complexity of genomic information, may lead to disparities in the quality of care these individuals receive when accessing clinical genetics services [9]. The paucity of minority genetic counsellors compounds this issue. Initiatives have been established to enhance minority representation in the genetic counselling population in order to better serve these communities [10-13]. Further, informed consent cannot be guaranteed without comprehension of genomic testing, which raises ethical concerns [14,15].

Healthcare interpreters are available in many major medical centers and are an important resource for bridging the communication divide between providers and patients. Translator training to address genomic sequencing specifically has been implemented [16]. However, issues regarding accuracy of translating technical genetics terms and the different dynamic introduced by an additional person present have been identified as limitations of this approach [17-20]. Providing good quality, patient-facing materials in languages other than English is a valuable opportunity to improve CALD patients' experiences, however the availability and quality of such resources have not been well documented.

A scoping review was conducted to develop an introductory understanding of the extent, range, and gaps in the body of non-English, patient-facing clinical genetics/−omics educational resources. Based on our clinical and research experience, we hypothesized that relevant resources would have wide-ranging utility, sources, and quality. Given this

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hypothesis, the scoping review methodology was advantageous because of its ability to address broad research questions that pertain to potentially heterogenous bodies of literature [21,22].

2. Materials and methods

The search strategy was developed with an experienced health science librarian. The search was limited to publications/literature in English. A systematic search of seven bibliographic databases (Medline (via Ovid); Embase (via Ovid); Cochrane Central Register of Controlled Trials (CENTRAL, via Ovid); CINAHL (via EBSCOHost); PsycINFO (via EBSCOHost); Communication and Mass Media (via EBSCOHost); and PAIS Index (via ProQuest) and grey literature (i.e., reports or documents produced outside of academic publishing that are not accessible via bibliographic databases) was performed. Grey literature was identified using the Canadian Agency for Drugs and Technologies in Health Grey Matters approach [23], as well as reference mining, CoCites citation-based searching [24], and targeted searches on additional relevant websites. Websites for rare disease organizations, public health education organizations, and genetics professional societies were surveyed for patient materials available in non-English languages. Where websites contained a repository page for the organization's publications or patient materials, searches were conducted by comprehensively examining all available materials and selecting those that aligned with inclusion criteria. For websites that did not contain such repositories, searches were conducted using terms such as “fact sheet”, “handout”, “brochure”, “language”, “multilingual”, “translation”, etc. In order to maximize the pool of grey sources, for resources identified from a different organization than the original source, the original developer was identified and their website was subsequently searched.

The systematic search was completed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) framework [25-27].The protocol was registered and the search continued until March 2021. Sources were screened for eligibility by two independent reviewers (RB and PB); and were selected for inclusion if both reviewers agreed on the fulfillment of all inclusion criteria. Sources were initially evaluated by title and abstract screening, then the full text record for sources deemed relevant was retrieved and read in full. Inconsistencies were discussed until a consensus was reached.

Sources were included if they described any non-English educational resource focused on genetics, genomics or genetic counselling targeted to families accessing clinical genetics services. Sources needed to provide a sample, or otherwise detailed explanation, of the resource to be included. The format and type of sources considered was purposefully left broad to identify as many resources as possible. No publication date, language, or country-of-origin restrictions were applied. Sources were excluded if the resource was meant for individuals who are deaf or use sign language as their primary means of communication. Given that our research questions specifically aimed to locate materials that could be used to supplement patient education, sources were excluded if the resource was intended only as a research tool or outcome measure (i.e., a patient reported outcome measure or questionnaire). Sources were excluded if they were identified for use explicitly by service providers rather than for joint patient-provider or patient-focused use, were abstract-only publications, or required purchase.

Resources were judged on a variety of quality indicators: data were collected regarding whether the resource had been translated by an expert, whether it had undergone peer-review, or was otherwise checked for content by an expert, and if it had been pilot tested with members from the target population. These indicators of quality were chosen to align with what is generally recognized as best practice for translating patient materials [28]. A detailed report of the scoping review methods can be found in Appendix A.

3. Results

A total of 252 of 10,908 initial sources [29-280] met inclusion criteria, of which 246 were unique resources (Appendix B, Fig. 1). A total of 46 different languages were represented; most resources were available in more than one language. The most highly represented languages were Spanish (n = 116), Russian (n = 102), and French (n = 99). Formats included booklet/toolkits (n = 187), leaflet/brochures (n = 42), digital counselling/education platforms (n = 5), and online lexicon/glossaries (n = 4). Resources had a range of indications for use, including general GC and GT (n = 28), general genetics (n = 19), prenatal (n = 14), cancer GC and GT (n = 9), assisted reproduction (n = 4), and pharmacogenetics (n = 1). The remaining 171 were condition-specific resources, the most common being chromosomal microdeletions (n = 54), microduplications (n = 31), and single gene disorders (n = 48). A total of 183 resources were generated from the UK (Unique Charity n = 168 and Eurogen Test n = 15).

Of the 246 unique resources, 213 were confirmed to be translated by experts; 237 confirmed that the resource was peer-reviewed by experts in the field; 7 outlined a process by which the resource was pilot tested with the relevant target population (i.e., community members, patients of the clinic). Only five of the resources [101,131,138,183,197] were confirmed to meet all 3 of these criteria. Two hundred and thirty-seven resources were publicly available for use, the remaining were only described and/or presented in their accompanying publication. Ten resources were retrieved from a systematic search of scientific databases, the remainder (n = 236) were found from grey sources such as public genetics education websites, clinical genetics agencies, or professional society websites.

4. Discussion

4.1. Quantity and quality of resources

The results of this scoping review indicate there is a lack of high-quality genetic and genomic education materials available in non-English languages. Furthermore, most resources were retrieved from various grey sources online which is a time-consuming task that most service providers do not have the capacity to replicate. Patients and families not receiving GC in their preferred language are more likely to experience negative outcomes, such as limited or inappropriate use of GC and GT, inaccurate understanding of risk, and disempowerment or disengagement compared with English-speaking counterparts [14,15,17-19,281].

Given that most resources were developed in Western, predominantly English-speaking countries, we expected the language breakdown of identified resources to follow the distribution of minority languages spoken in these regions; that is, Spanish, French, Mandarin, Cantonese, Punjabi, Urdu, and Arabic [282-285]. Therefore, there is an indication that only some CALD populations are being served by currently available non-English materials: our results indicate Speakers of Punjabi, Urdu and Arabic are far less likely to find materials in their languages compared to regional official language minorities such as Spanish or French.

A small minority of resources were confirmed to meet all three of our quality criteria. It may be difficult for professionals seeking resources to be confident in their quality and relevance without explicit confirmation, especially when the professional is unfamiliar with the language. Translated materials should consider both linguistic and cultural accuracy so that the message of the text remains clear, which is particularly important in the complex and sensitive GC context [286-288]. Linguistic accuracy captures the semantic meaning of words and is achieved by working with expert translators and having experts in the subject matter check the translation and/or back translation for meaning [28]. Cultural accuracy refers to the connotation words may carry and can be optimized by having culturally competent translators, and by pilot testing with individuals from the target community [28]. From an ethical perspective, appropriate translation of material used for assisting with obtaining informed consent from individuals seeking GT is a unique consideration given that values and perspectives of privacy, risk, and disease etiology differ amongst cultures [289].

4.2. Indication and availability for use

The majority of resources were focused on specific genetic conditions, mostly created by a single UK-based charity. This UK-bias (74% of total

included resources) also raises concerns about generalizability of resources across healthcare systems. General information about genetics, GT, and GC accounted for another significant proportion of resources. According to the most recent National Society of Genetic Counsellors (NSGC) Professional Status Survey, cancer genetics and prenatal genetics were the most frequently cited areas of practice for NSGC members in 2022 [290]. However, cancer- and prenatal-specific resources accounted for very few resources in our review, which may indicate a paucity of material for these patients. Opportunities to engage with material outside of the GC session may be particularly beneficial for LEP families, especially following results disclosure [9,19,287]. As such, the distribution of result-specific resources during or following results disclosure sessions is of value to enhance the quality of care offered to CALD families by providing another opportunity to engage with this novel, complex, and potentially emotionally charged material [19].

Most resources exist as printable booklets or toolkits. However, there is evidence that text-limited, visual and auditory-focused material is more useful for some CALD individuals [17,139,286,291-293]. Providing such materials through interactive web-based platforms may be particularly effective, given the increased opportunity for wider dissemination, content personalization, addition of auditory and visual aids, and inclusion of culturally sensitive features [17,183,291]. The results of this review indicate such resources are clearly underrepresented, and few of these are publicly available.

Providing information that is accessible and individually tailored is an important factor in patient-centered education, a tenet valued highly by genetic counsellors [3,286]. Our group recently developed (along with patient partners) a customizable genomic results e-booklet that helps families to understand their genomic testing results that has been translated into French, Simplified Chinese, Punjabi and Arabic [294]. The paucity of resources identified through this review points to a crucial unmet need. Genetics professionals should prioritize the development of high-quality translated material for use in conjunction with GC services. Furthermore, a central, curated repository of validated genomic education materials, perhaps sponsored by a genetic counselling organization, would help genetic counsellors meet the needs of their underserved, CALD patients. Groups addressing this need should consider evidence-based frameworks for the development of culturally sensitive genomic education resources, as developed by Uebergang and colleagues (2021), to optimize utility and accuracy of the material [286].

4.3. Limitations

Although every attempt was made to confirm quality criteria within the resource, or otherwise from the source it was retrieved, it is possible some of the resources do meet some or all of the quality criteria without specifically indicating such. As broad terms were used for bibliographic database searches and a thorough survey of relevant grey sources was conducted, some available resources may have been overlooked (particularly those developed at the gene or syndrome level. In order to properly assess the sources, we required that a sample or otherwise detailed explanation of the resource was included in the accompanying publication. This inclusion criteria resulted in a significant portion of identified sources being excluded from further analysis (see Fig. 1 in Appendix C). Given our search was limited to English publications/materials, we may not have captured resources published in other languages. Furthermore, since we did not review the linguistic or cultural suitability of the materials, it is difficult to assess the true "quality" of included citations.

4.4. Innovation

This research highlights the current need for high quality genetics education materials in languages other than English. Given that language barriers have been identified as a major contributor to health disparities facing LEP individuals, we believe that the development, validation, and distribution of non-English resources that have been expertly translated and co-developed or pilot tested with the target population is of paramount importance. An accessible central, curated repository of these materials would be of great benefit to help genetic counsellors meet the needs of their culturally and linguistically diverse patients.

4.5. Conclusion

There is a lack of high-quality supplementary genetics and genomics education materials available in languages other than English. This likely limits the quality-of-care CALD families may receive compared to their English-speaking counterparts. Of equal concern is the difficulty in finding existing resources and determining their quality.

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CRediT authorship contribution statement

Rhea Beauchesne: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing. **Patricia Birch:** Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing – review & editing, Supervision. **Alison M. Elliott:** Conceptualization, Methodology, Writing – review & editing, Supervision, Funding acquisition.

Declaration of Competing Interest

We declare that none of the authors has any competing interests in the completion and submission of this research.

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Appendix A. Scoping review protocol

The protocol for this review was developed in accordance with the methodological framework for scoping reviews originally published by Arksey & O'Malley (2006) with enhancements by Colquhoun and colleagues (2014) and the PRISMA Extension for Scoping Reviews [25-27].

As indicated, the following seven bibliographic databases were searched to identify published scientific literature: Medline (via Ovid); Embase (via Ovid); Cochrane Central Register of Controlled Trials (CENTRAL, via Ovid); CINAHL (via EBSCOHost); PsycINFO (via EBSCOHost); Communication and Mass Media (via EBSCOHost); and PAIS Index (via ProQuest). The search strategy was developed with an experienced health sciences librarian. See Appendix B for the search strategy used in Medline (via Ovid), which was translated for the other bibliographic databases. An alert was set up for each search so that relevant articles could be identified up to publication of this review.

Duplicates were removed except for cases where multiple sources described different stages of production (i.e., development, validation) of the same resource, or described the same resource developed in different languages.

Sources were screened for eligibility by two independent reviewers (RB and PB); sources were only selected for inclusion if both reviewers agreed on the fulfillment of all inclusion criteria. Sources were initially evaluated by title and abstract screening, then the full text record for sources deemed relevant were retrieved and read in full. Inconsistencies were discussed until a consensus was reached.

The first author (RB) completed the data charting process independently. Descriptive data was gathered from the included sources regarding the origin, quality, and type of patient education material. For the origin, data were collected regarding the creator of the resource and the location from which it was retrieved. For quality, data were collected regarding whether the resource had been translated by an expert, whether it had undergone peer-review, or was otherwise checked for content by an expert, and if it had been pilot tested with members from the target population. These indicators of quality were chosen to align with what is generally recognized as best practice for translating patient materials [28]. Furthermore, resources were identified according to the format of distribution (i.e, leaflet, brochure, video, etc.) and indication for use (i.e, general GC/GT, general genetics, prenatal, condition-specific).

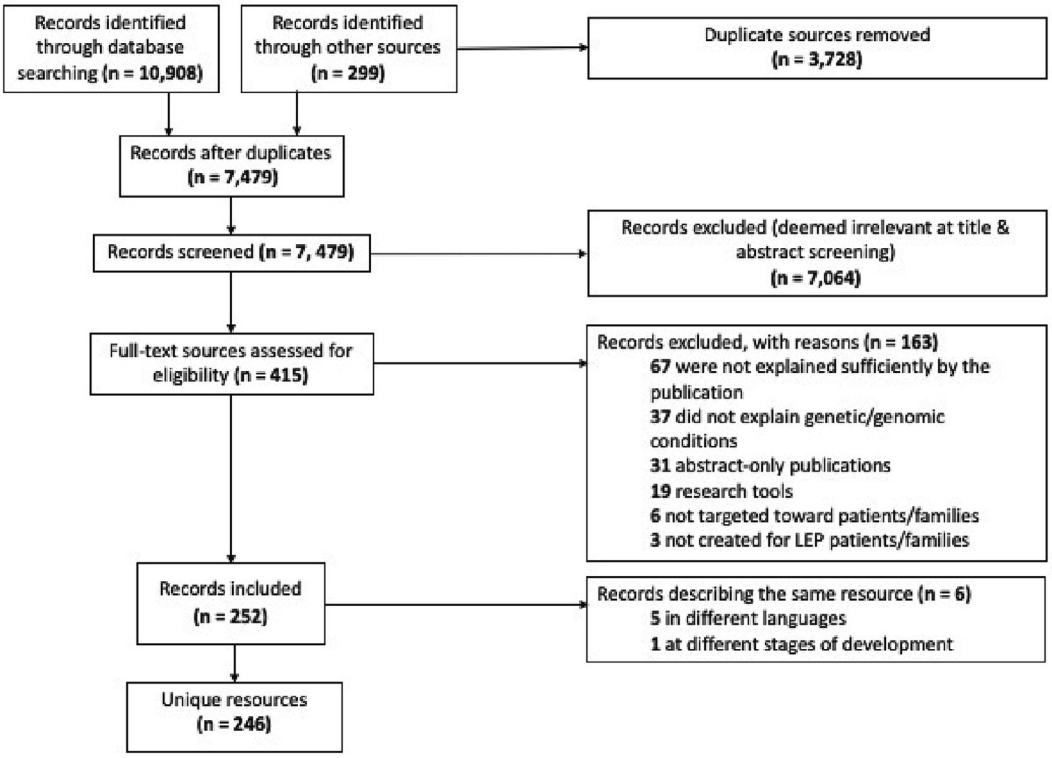
This scoping review protocol was registered prospectively with the Open Science Framework on March 5, 2021 [https://osf.io/tepsu].

Appendix B. Medline (Ovid) search completed on February 23, 2021

#	Query	Results from 23 Feb 2021
1	human genetics/ or genetics, medical/ or genetic counseling/	28,007
2	((genetic* or genomic*) adj3 (counsel* or service*)).kw,ab,kf,tw,ti.	22,252
3	((clinical or medical) adj3 (genetic* or genomic*)).mp.	44,727
4	1 or 2 or 3	70,359
5	Translating/	5288
6	Translations/	5432
7	translat*.mp.	379,169
8	5 or 6 or 7	379,169
9	cultural diversity/ or cultural competency/	16,715
10	((cultural or ethnic) adj3 (adapt* or divers* or competen* or sensitivit*)).mp.	29,213
11	(cross-cultural communication or multicultural* or multi-cultural*).mp.	3914
12	9 or 10 or 11	31,485
13	((medical or service* or healthcare) adj3 interpret*).mp.	2242
14	Communication/ or Communication Barriers/ or Limited English Proficiency/	92,353
15	(barrier* adj3 (communication or language)).mp.	10,103
16	(english adj3 (limited or proficien* or lack or low or abilit*)).mp.	3916
17	14 or 15 or 16	98,337
18	Multilingualism/ or Language/	46,042
19	(multilingual* or bilingual* or language* or polylingual* or polyglot* or trilingual*).kw,ab,kf,tw,ti.	169,874
20	(dual adj2 language*).kw,ab,kf,tw,ti.	219
21	18 or 19 or 20	189,374
22	8 or 12 or 13 or 17 or 21	664,201
23	4 and 22	2992

Appendix C. PRISMA flow diagram of resource selection

Fig. 1PRISMA flow diagram of resource selection.



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