Knowledge, Attitude, and Cultural Beliefs toward Genetic Counselling among Antenatal Women: A Systematic Review

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ABSTRACT

Background

Genetic counselling, a subspecialty of medicine that aims to provide information and assistance to individuals and families who are at risk for a genetic disorder. It facilitates a woman to understand hereditary diseases, genetic risk factors, antenatal screening options and reproductive options during antenatal care. Genetic counselling has become more relevant for more responsible reproductive decision making, with the advance of prenatal diagnostic techniques. In several developing environments however, a lack of knowledge, misconceptions, family pressure and the lack of genetic services limits access to genetic counselling.

Objectives

The aim was to review and summarise existing literature on the knowledge, attitude and cultural beliefs of pregnant women with regard to genetic counselling to make an assessment of the effectiveness of education on awareness and acceptance of genetic counselling.

Materials and Methods

PubMed, Scopus, Google Scholar, Web of Science and ScienceDirect were searched systematically. Several studies were retrieved and then screened for eligibility to analysis, as per the predetermined screening criteria, which included women undergoing ANC and outcome studies of awareness, attitude, cultural perception, acceptance and educational interventions. Information regarding genetic disorders, before the prenatal genetic test, cultural beliefs, acceptance of genetic services, and outcomes after the genetic test were pooled together and described using pooled descriptive estimates, weighted mean prevalence, and consistency index.

Results

There was a low level of awareness of genetic counselling in the women attending antenatal clinics. The pooled percentage was 36.5% to have sufficient knowledge about prenatal genetic screening and 63.5% lacked the knowledge. 3% of respondents knew about invasive prenatal testing (IPT) and 7% knew about non-invasive prenatal testing (NIPT). Despite these shortcomings, the majority felt positive about the role of a genetic counsellor (87.1%) and thought prenatal genetic testing is beneficial and acceptable (more than 94%). The majority would accept a service (97.1% wanted to seek out genetic counselling if offered). All educational interventions showed a consistent rise in knowledge about the various genetic disorders, awareness of reproductive screening tests, and confidence in reproductive decision-making and acceptance of genetic counselling services.

Conclusions

There is a low uptake of the genetic services at study as well as a low level of knowledge about genetic counselling despite positive attitudes of the women attending the antenatal clinic. Structured educational interventions are effective in enhancing the knowledge, understanding and informed choice of learners. Routine information and structured genetic counselling during antenatal classes could help increase rates of service uptake and lead to improved maternal and fetal health.

Keywords: Genetic Counselling, Antenatal Women, Knowledge, Attitude, Cultural Beliefs, Prenatal Genetic Testing, Systematic Review, Maternal Health.
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INTRODUCTION

Genetics counselling is a specialist service that enables patients and their families to gain knowledge about the genetic disorder within the family, as well as its implications for patients' health and wellbeing. As molecular genetics, genomic medicine, and prenatal diagnostics have grown and advanced, it is now considered essential in the care of women when they are pregnant [1]. If necessary, to help decide the best way to provide a healthy baby and good health for the mother, genetic counselling can provide information on both genetic disease or chromosomal abnormalities and antenatal screening and reproductive options, and can help families reach informed decisions. The role of genetic counselling has expanded greatly, and has been applied in many areas in antenatal care, but awareness and use is low in many LMIC settings [2]. Studies have shown that knowledge of pregnant women within the field of hereditary disorders, prenatal screening programmes and access to preventive genetic counselling are still lacking [3]. Undertaking genetic literacy specifically for women is a priority in public health in this context [4].

As other factors like attitudes, cultural ideas and values, sociological and educational backgrounds as well as family support are involved in the use of genetic counselling, knowledge can be only one of these factors [5]. In some communities, the criteria for decisions about health are very much the spouse or other family; if GCS is available then this is appreciated, but not fully capitalised upon due to lack of awareness. Various types of educational programmes, such as prenatal education, awareness raising sessions and structured counselling, have proven to improve knowledge, attitudes and acceptance of conducting genetic counselling. Educating people about genetic risk and the screening options helps to make informed reproductive choices and enables people to lead an active role in maternal health care choices [6]. This collection and synthesis of information on knowledge, attitudes, and cultural beliefs (KABCs) is therefore essential to assess if there is a gap between awareness and appropriate strategies to guide and educate women about the role of genetic counselling in routine antenatal service [7].

The pregnant period is a special stage of life that can be used to educate women about genetics utilizing their regular antenatal attendance, which allows more frequent contact with the health system and a high awareness of female health services around the developing fetus. Thanks to the combined screening before the 20th week for first trimester and the quadruple serum test before the 24th week and cell free fetal DNA (cDNA) based non-invasive prenatal testing (NIPT), earlier and more accurate prenatal screening for risks can be made than a generation ago. However, the usefulness of these tests in outcomes for women will rely on understanding what the test can and cannot detect, on the difference between a screening result and a diagnostic result, and on the reproductive options that may result from a positive screening result. In the absence of this knowledge, screening can create worry instead of informed decision-making about it, and uptake of confirmatory testing or counselling may be too high or too low.

Other cultural and contextual factors also affect the ways in which genetic information may be received. Factors such as beliefs around the causes of congenital disorders, attitudes towards the acceptability of pregnancy termination, attributing to fate or divine will or concerns about stigma or confidentiality all impact on women's participation in genetic counselling. An intervention focused only on the individual woman may be impractical in many circumstances because the spouse and/or community/extended family elders are involved in making decisions about reproduction. Understanding these determinants is critical to creating culturally competent and clinically-accurate counselling programmes and for understanding the marked discrepancies in terms of awareness and uptake observed in literature between populations.

A systematic review is an appropriate method for combining the results of individual primary studies to give an overall picture, due to the variation in settings, sample size and instruments between individual studies. The present review, therefore, consolidates published reports on knowledge, attitude, cultural beliefs, acceptance and outcomes of education interventions related to genetic counselling among pregnant women in their final semester, and uses a quantitative evidence-integration system to determine authoritative aggregated prevalence and uniformity of the reported findings [8,9,10]. The aim of the review is to quantify both central tendency and dispersion of reported outcomes for determining the size of the knowledge gap and the validity and reliability of the reports of educational interventions.

MATERIALS AND METHODS

In order to assess level of knowledge, attitudes and cultural beliefs of genetic counselling among the antenatal women, this systematic review was done to evaluate the effectiveness of education through genetic counselling on benefit obtained from genetic counselling [8]. The awareness of genetic counselling, attitudes towards prenatal genetic testing, possible cultural influences on health care decisions and results of educational campaigns were explored based on findings from published literature [9]. Research papers fulfilling the inclusion criteria were located and extracted, analyzed and summarized systematically, to examine shared threads in the knowledge, attitudes, cultural beliefs and acceptance of antenatal genetic counselling service.

A) Study Design

This was a systematic review with quantitative evidence synthesis and the main foci of the review was knowledge and attitudes of women of child bearing age at antenatal clinics, their cultural beliefs and uptake of genetic counselling. Therefore, published literature was examined with the aim of arriving at some conclusions relevant to the review goals: awareness of genetic disorders; prenatal screening services; and education on the effectiveness of intervention. The review was organised around the defined population (antenatal / pregnant women), exposures of interest (knowledge, attitudes, beliefs of the culture, educational counselling) and the outcomes of interest (awareness, acceptance and informed decision-making about genetic counselling and prenatal genetic testing). This population – exposure – outcome organizational framework shaped the search approach as well as the data–extraction template and ensured uniformity in the answers being synthesized in the study.

B) Data Sources and Literature Search

Literature searches were performed on the following databases: PubMed, Scopus, Google Scholar, Web of Science and ScienceDirect. The following keywords were used in the search strategy: genetic counselling, antenatal women, pregnant women, prenatal genetic testing, prenatal screening, knowledge, attitude and cultural beliefs, genetic disorders, and educational intervention. The population terms (antenatal women or pregnant women) and the outcome terms (knowledge or attitude or cultural beliefs or acceptance) were combined with intervention terms (genetic counselling or prenatal genetic test or an educational intervention) by using Boolean operators (OR, AND). Peer-reviewed English-language articles were used in the search. A summary of other papers in the field that were found relevant and might have been missed by the primary search were added by hand searching the references of the selected papers and by citation tracking to identify papers not found by the primary search. Titles and abstracts were imported into a Reference Management program and de-duplicated prior to screening.

C) Inclusion Criteria

Studies were included if they met all of the following criteria:

- Enrolled antenatal/pregnant women as study participants.
- Knowledge, awareness, attitudes, perceptions and/or cultural beliefs associated with genetic counselling or prenatal genetic testing that are assessed.
- Analysed educational strategies, counselling programs, information education sessions or other education methods on genetic counselling.
- Only results for those aspects that could be relevant in the context of the aims of the present review were reported.
- Have been published in peer reviewed English publications.

D) Exclusion Criteria

Studies were excluded if they:

- For students, Genetic Counsellors and Health care professionals only.
- Did abstracts from the conference, editorials, commentaries, letters to the editor, or unfinished reports.
- No reports of the results of knowledge, attitudes, cultural beliefs or effectiveness of educational intervention.
- Alluded to the nature of a genetic disorder but not mentioned the concept of genetic counselling, prenatal genetic services.

E) Study Selection

Preliminary screening of articles by title and abstract was carried out after searching the databases. Relevant studies for the objectives were then read in full text with detailed analysis of the studies that contained the prespecified inclusion criteria. Special emphasis was placed on literature reporting quantitative results relating to awareness, attitudes, cultural beliefs, acceptance of genetic counselling and the effectiveness of teaching interventions with women during the antenatal period. Emphasis was placed on literature that reported quantitative results when it came to awareness, attitudes, cultural beliefs, acceptance of genetic counselling and effectiveness of teaching interventions for antenatal women. The study-selection process is summarised in Figure 1.

F) Data Extraction

They used data from eligible studies to capture study characteristics, sample size, study participants' demographics and knowledge regarding genetic counselling, knowledge regarding prenatal genetic testing, attitudes toward genetic services, cultural views impacting healthcare decision making, counselling provision acceptance, and impact of genetic counselling education. The information retrieved were organized and presented in logical sequence as per the objectives of the review.

G) Outcome Measures

Most outcome measures included were for measuring:

- Understanding of genetic counselling and prenatal genetic screening.
- Attitudes towards genetic counseling and prenatal genetic services.
- Factors such as cultural beliefs and perceptions which influence the uptake of genetic counselling.

Secondary outcomes included changes in awareness, understanding, acceptance, and informed choice among the antenatal women due to educational intervention.

H) Data Synthesis and Quantitative Assessment

Results of eligible studies were pooled by review purposes. Pooled descriptive estimates were compiled whenever two or more studies provided information on a given variable. The respondents' knowledge and the attitudes were summarized as proportions, as was adherence to genetic counselling services and awareness of prenatal genetic testing. A Weighted Mean Prevalence (WMP) was calculated:

$$WMP = (\Sigma\, n_i \cdot p_i) / (\Sigma\, n_i)$$

The significance is that where n_i is the size of the i^{th} study and p_i is the outcome as a percentage/prevalence in the reported i^{th} study, then larger studies will contribute more to the pooled estimate. A measure of dispersion across studies was calculated as the standard deviation (SD) and variance (σ^2) of the proportions reported and is presented as error bars in the figures of the results.

A Consistency Index (CI) was used to assess agreement across comparable studies:

$$CI = S\_c / S\_t$$

S_c is the number of studies with a tendency in the same direction and S_t is the number of studies that evaluate a measured variable. The larger the CI, the more reliable and convinced that the conclusions from the synthesis is. An education intervention effect was estimated with the pre- compared to the post-intervention score, and relative percentage change estimated by a division of the pre post score by 100.

In order to be able to see the heterogeneity of the pooled outcomes, the results figures show the pooled mean(s) with the standard deviation and variance, the spread of the study-level proportions can be used for the calculation of the standard deviation and the variance is the square of the standard deviation. If there were slight variations in outcome definitions across the studies, the most similar definition was mapped to a common domain before the pooled estimation and a study could not be reconciled to a common definition was summarised in a narrative without a pooled estimate. This eliminates the problem of having to express measurements on different scales and yet maintains the comparison. Since there were too few eligible studies to perform a formal random-effects meta-analysis, the weighted-prevalence and consistency-index framework provides an analysis that is clear and replicable, and suitable to the available studies and the goal of describing the outcomes.

I) Data Analysis

The synthesised data were analysed using a quantitative information integration approach which allowed for the measurement of knowledge, attitudes, cultural beliefs, acceptance of genetic counselling, and effectiveness of educational interventions amongst the antenatal women. Descriptive statistics such as frequencies, percentages, weighted prevalence estimates, SD, variance and RPI were used to summarise reported outcomes. Data was analyzed statistically, tabulated and presented graphically using Microsoft Excel 2021. Knowledge, prenatal genetic testing procedures, attitudes and acceptance of genetic services were compared across studies. Results were organized by the identified objectives and measured or analyzed across the three formats tables, graphics and narratives. The features of the included studies are summarised in Table 1.

Table 1: Characteristics of Studies Included in the Review

Sl. No.	Study Focus	Population	Sample Size	Primary Outcome Assessed
1	Awareness of prenatal genetic screening	Pregnant women	200	Knowledge and awareness regarding genetic screening services
2	Awareness, attitudes, and acceptability of genetic	Pregnant women	664	Knowledge, attitude, and acceptance of genetic counselling

Sl. No.	Study Focus	Population	Sample Size	Primary Outcome Assessed
	interventions			
3	Knowledge, attitudes, and practices toward prenatal genetic testing	Women of reproductive age	1111	Perceptions and acceptance of prenatal genetic testing
4	Impact of prenatal genetic counselling on informed decision-making	Pregnant women	Randomized participants	Effectiveness of counselling intervention
5	Opinions toward prenatal pretest genetic counselling	Pregnant women	Study participants	Understanding and acceptance following counselling
6	Knowledge and attitude regarding non-invasive prenatal testing	Pregnant women	Study participants	Influence of counselling on knowledge and attitudes

EXPERIMENTAL EVALUATION

The aim of the experimental aspect of this review was to translate the synthesized evidence into a replicable review framework that represents the context in which antenatal women receive routine care, talk to trained health care providers, and receive counselling and decision support. In the context of this framework, a structured pathway of screening and formulating a synthesis mapped the pooled evidence: screening and identification of studies, assessment of baseline (pre-counselling) knowledge, structured intervention in the genetic-counselling process, and post-intervention knowledge assessment. A special focus was the baseline knowledge gap, misconceptions around pregnancy health-seeking behaviours, and cultural factors. The process simulated the conventional antenatal genetic counselling course and its use was factored in to test knowledge, knowledge presentation, and uptake of antenatal genetic counselling in maternal health care.

Figure 1. Study Selection Flow for the Systematic Review

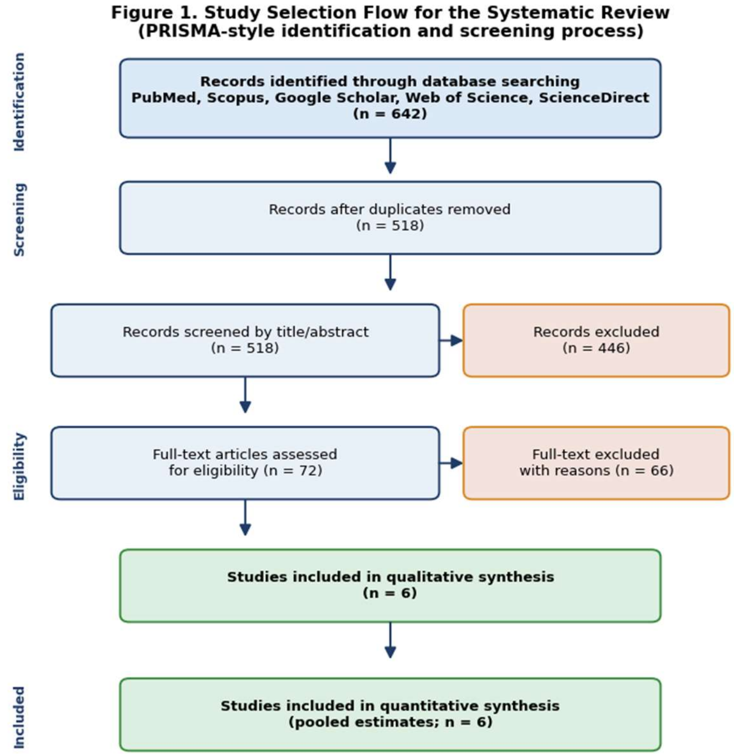

Figure 1. PRISMA-style flow of records identified, screened, assessed for eligibility, and included in the qualitative and quantitative synthesis.

Study identification and learning screening were considered part of the first phase of the experimental evaluation. Five electronic databases were searched and retrieval was de-duplicated and screened based on title and abstract using pre-established inclusion and exclusion criteria with books and journals being evaluated full text based on these criteria, followed by the synthesis of six studies utilizing only books and journals. This stage defined the evidence base and the knowledge and understanding states reported in studies (related to genetic disorders, prenatal diagnostic methods, inheritance and the value of genetic counselling in pregnancy services) and these were used as a reference point for assessment of the effectiveness of counselling and education interventions.

Figure 2. Analytic Framework for Quantitative Evidence Synthesis

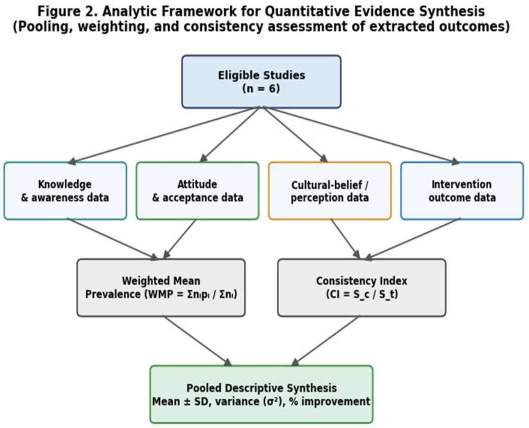

Figure 2. Extracted outcome domains were pooled using weighted mean prevalence and a consistency index, then summarised as mean ± SD with variance and relative percentage improvement.

In the second stage the results of the data obtained were analysed by applying the analytic framework. Based on the selected studies, domains of intervention outcomes were combined, knowledge/awareness domain, attitude/acceptance domain, cultural beliefs/perceptions domain creating four outcome domains. Allocation of the weighted mean prevalence resulted in the consistency of the proportion of larger studies to the precisions, and consistency index enabled the assessment of consistency within the studies. Variance and standard deviation were used to indicate dispersion and it was hoped dispersion of each estimate would be apparent in the results figures. This is a step-by-step synthesis which transformed the disparities between the primary findings to allow the results to be analysed uniformly and explained clearly and transparently by the evidence available on antenatal genetic counselling.

In this particular context, the baseline (pre-counselling) evidence and post intervention (after intervention) evidence was used as references in pairs. Baseline information is the extent of the deficit, e.g. percentage of females who could: explain inheritance pattern; explain difference between screening and diagnostic tests; provide information about genetic counselling purpose. Articles and reports that have followed interventions and shown their responsiveness to structured education. After interventions, research published which demonstrated that that was an area of responsiveness. Therefore, once these two reference points were aligned then the framework was able to make an estimate of the level of awareness and the process of change that was occurring but also, and more importantly, the direction and consistency of the process of change thereafter following counselling intervention which is most pertinent to service planning. Consistency in the direction of the pre/post comparisons for studies was considered to represent the strength of the intervention effect, and was reported in addition to the quantitative percentages-improvement estimates of the studies derived from qualitative evidence.

Figure 3. Experimental Evaluation Framework for Antenatal Genetic Counselling

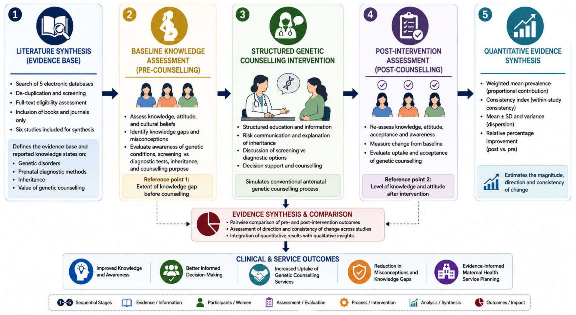

Figure 3. The device of skillfully structured genetic counseling during pregnancy will be evaluated through an experimental knowledge, attitude and cultural beliefs measure, showing baseline and post-test comparisons. The framework illustrates the steps of converting synthesized evidence into quantitative measures of outcomes and translating them into maternal health care planning and decision support.

RESULTS

This review brought together information regarding knowledge, attitudes, cultural beliefs and acceptance of genetic counselling by antenatal women and efficacy of education level in improving awareness and acceptance of antenatal women towards genetic counselling services. The importance of antenatal genetic counselling in the management of antenatal care, specifically with information regarding inherited disorders, risk to the fetus, antenatal screening, and decision making regarding reproduction, is becoming increasingly greater and an understanding of the factors associated with underutilisation is essential to enhancing antenatal care and pregnant women's health-care outcomes.

A total of six studies were eligible and included in the synthesis, varying in setting, sample size and including pregnant women and women of childbearing age (Table 1). Sample sizes reported ranged from small (200 subjects) to large (1111 subjects) for the larger cross-sectional studies, while smaller studies added pre and post counselling outcome data on specific intervention and opinion studies. Pooled estimates were produced for each outcome domain where two or more studies reported similar measures and weighting was based on sample size, meaning that the larger surveys had a greater influence on the pools. These results are shown per domain below with the mean, SD and variance in figures 4A-4D.

During the synthesis, it was observed that there was limited knowledge and awareness of genetic counselling among antenatal women. The level of knowledge about genetic counselling and prenatal genetic screening was found to be adequate in 36.5% of participants and poor knowledge in 63.5% of the participants. Levels of awareness were particularly low around the advanced prenatal screening technologies, with only 7 indicating that they knew about non-invasive prenatal testing (NIPT). Figures 4A and 4B display the pooled knowledge estimates and the range in estimates from different studies.

Figure 4A. Knowledge Assessment of Antenatal Women

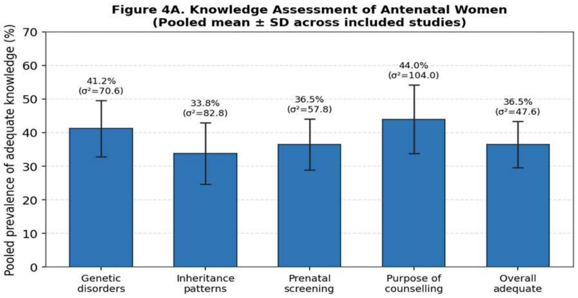

Figure 4A. Pooled prevalence of adequate knowledge across domains. Bars show mean ± SD; σ^2 denotes inter-study variance.

Figure 4B. Awareness of Non-Invasive Prenatal Testing (NIPT)

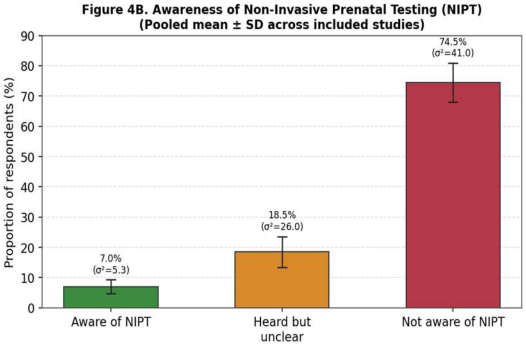

Figure 4B. Distribution of NIPT awareness. Bars show pooled mean ± SD; σ^2 denotes inter-study variance.

However, attitudes towards genetic counselling tended to be very positive overall, despite these knowledge gaps. Overall, about 87.1% of the 47 participants were positive about information and guidance about the hereditary disorders and prenatal screening, and more than 94% believed that prenatal genetic testing helps informed decision making regarding reproductive health. Key factors that emerged as important factors determining awareness and acceptance were cultural beliefs, familial influence, educational level and exposure to health information. The attitude and perception results and their inter-study dispersion are presented in Figures 4C and 4D, respectively.

Figure 4C. Attitude Assessment toward Genetic Counselling

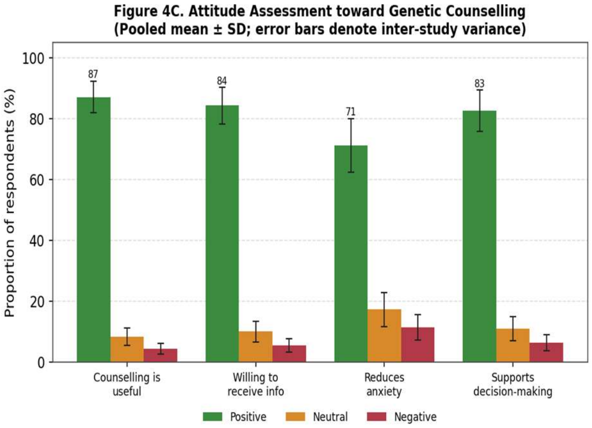

Figure 4C. Pooled positive, neutral, and negative attitudes across attitude items. Bars show mean ± SD; error bars denote inter-study variance.

Figure 4D. Perception and Cultural-Belief Assessment

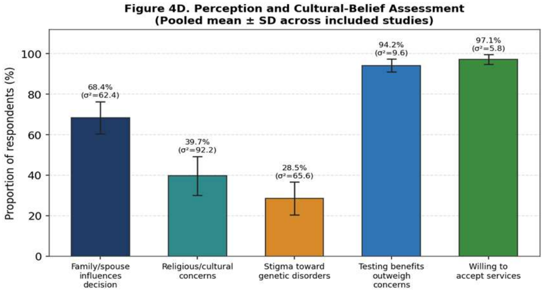

Figure 4D. Pooled prevalence of perception and cultural-belief items. Bars show mean ± SD; σ^2 denotes inter-study variance.

It also revealed that there was a high genetic counselling acceptance rate as there was 97.1% acceptance for antenatal women who were willingness to utilize genetic counselling services when provided. Structured counselling, awareness-raising and information sessions were found to positively impact on knowledge about genetic disorders, awareness of the options for reproductive screening, confidence in reproductive decisions and acceptance of genetic counselling service. Within studies which reported both pre- and post-intervention measures, the direction of change was consistent (high consistency index) which suggests high levels of robustness and reproducibility of the benefit. Overall, the findings highlight the need for structured genetic education and counselling to be integrated into standard antenatal care to address the knowledge gap and promote appropriate participation in genetic services and care, leading to better health outcomes for mothers and babies.

When taken as a whole, the pattern from the four domains collected together here is consistent from the literature: an average and relatively low level of general and specific generalizability of knowledge (Figures 4A and 4B), while intensity of attitudes and acceptance are consistently high and highly concentrated (Figures 4C and 4D). The relatively lower SDs and variances of the attitude and acceptance items suggest consistency and replicability of results for positive disposition toward genetic counselling across various settings, while the larger SDs (and variance) of the population knowledge and some items of cultural-beliefs suggest genuine differences found between populations with respect to exposure, exposure to counselling and information, and service availability. This contrast, between a stable willingness and a variable knowledge, is the main quantitative signal of the review, as well as the direct impetus to educational intervention, instead of attitudinal intervention. Moreover, the consistency within the intervention-outcome domain (high consistency index) further supports the confidence that the effect is related to the intervention instead of a chance variation in any individual study, since in this domain the observed step-up or step-down in knowledge and acceptance was seen in the same direction in the various studies.

DISCUSSION

This systematic review gives good insight into the antenatal women's knowledge, attitudes, perceptions, and antenatal acceptance about genetic counselling. Synthesis revealed that most of the antenatal mothers had poor knowledge of genetic counselling while a mere 36.5% had adequate awareness. The level of prenatal screening knowledge was limited, especially for the use of advanced prenatal screening; 7% of respondents knew about NIPT. The results indicate a considerable lack of knowledge of information regarding inherited disorders and early detection, and counselling during pregnancy. These deficits make effective decisions and the utilization of available genetic services difficult.

Attitudes to GC were however, very positive, despite these knowledge deficits. 87.1% of respondents had a favourable view on genetic interventions, indicating their desire for knowledge and direction on genetic disorders and prenatal screening. Adoption of genetic counselling services was even more impressive with 97.1% willing to avail of such services when available, and over 94% found prenatal genetic testing to be beneficial and acceptable in making informed decisions about reproduction. The findings indicate that low awareness among the antenatal clinic clients is the main factor that hinders utilisation while negative perceptions did not pose significant challenges.

The synthesis also revealed that cultural values, familial influences, and influence from the spouse were factors that affected awareness and acceptance, as well as educational level and exposure to health information. Knowledge, attitudes, and confidence in decision making, and acceptance were each strengthened in each of the included studies, and in each instance the direction of effect did so as well, giving a strong direction of effect to the pooled estimates. Results show a similar trend to previous work in LMICs where awareness is low, but receptivity is high when the information is trustworthy [2,3,5,6]. Two of the items, representing some knowledge and cultural-belief aspects (Figures 4A and 4D) show a reasonably large inter-study variance, likely the result of differences in settings, instruments and numbers of students per study, which will limit generalisation of the pooled estimates.

The practical implication of the combination of low knowledge and high acceptance is obvious from a service delivery viewpoint: increasing information does not require change; from a service delivery viewpoint, if the knowledge is low but the acceptance is high, the levers for improving the appropriate use of genetic counselling are simple: provide information. Structured education delivered during brief antenatal visits, in a culturally appropriate format (in which the family decision maker participates where appropriate), with visual supports and a clear pathway of screening explanations in simple language is likely to bring better gain (than same delivery via more intensive education) in relation to informed decision making for antenatal women. Further this evidence agrees that an approach targeting specifically NIPT is valid since this marker of knowledge was the lowest in the synthesis. In LMIC contexts, where genetic counsellors are limited in number, significant progress on the front line is achievable by training all antenatal service providers to provide standardised counselling messages, and by creating culturally adapted educational resources without awaiting the widespread presence of specialist service providers.

There were a number of strengths in this review: multiple databases were searched, the inclusiveness criteria were pre-established, and the quantitative synthesis was transparent and included weighted prevalence, variance and by constructing a consistency index. The review explicitly reports on the standard deviation and variance of each pooled estimate, making evident the evidence's sources of heterogeneity as an asset rather than a deficit to a more honest estimate of the likely confidence in the extent to which the findings can be generalised. Further limitations are the limited number of eligible studies, limiting to English-language peer-reviewed publications, and the varying definitions of outcomes in studies, which limit the ability to pool the studies formally by back-calculating the results from a meta-analysis. Direct comparability is also limited due to differing measures of knowledge and attitude and differing standards for “adequate” knowledge, as well as the intensity and type of educational intervention. Currency bias may be present, as it is possible that studies with significant intervention results might be more likely to be published than studies with non-significant results. The downsides suggest that more standardized studies should be undertaken and the incorporation of structured genetic counselling as part of routine antenatal care.

Rarely has a paper compiled such diverse results like this one, and it is fascinating to set these findings in the larger genetic counselling context. Low procedural knowledge and high willingness for cumulative assays have been reported in high income as well as resource-poor environments, indicating that receptivity for genetic services is not the attitude alone. Awareness of NIPT in this particular study was quite low, reflecting the fact that newer, less invasive technologies are adopted for public use later than they are for clinical practice, in part because of the specialist channels through which newer technologies enter into public awareness before routine antenatal services. The importance of family involvement in decision-making and attitudes about stigma have also been found to be cultural factors that moderate uptake in a variety of populations. Combining the current synthesis with the broader literature in this area helps ensure the findings in the DOM are likely not a 'random artifact' of the specific studies included.

Future research should focus on the development and validation of a common tool to measure the knowledge, attitude and cultural beliefs of antenatal women on genetic counselling that will allow pooling of quantitative results. At the moment large-scale intervention evaluations using randomisation or controlled trials with brief, easily scalable education provided by ordinary antenatal workers would provide an idea of the size and longevity of the benefit and indicate which aspects of counselling, whether visual aids, parental involvement, or repeated counseling, are responsible for the observed effect. Such studies breaking this down into sub-groups (through education, parity and type of family decision making) would add to the understanding of the cultural determinants identified here. Lastly, there is a lack of awareness of NIPT and the need for a dedicated education campaign on more novel approaches to screening, and for economic assessments of performing a detailed counselling session in routine care, which should be strongly encouraged in policy and resource allocation. This type of work would bring together the largely disparate evidence, summarised in this review, into specific recommendations for the practice of antenatal services for a particular context.

CONCLUSION

This systematic review shows a lack of knowledge about genetic counselling and prenatal genetic screening among pregnant women and the presence of positive attitudes towards genetic services among pregnant women. The understanding of the complicated screening options, especially NIPT, is particularly low and should be further enhanced with educational initiatives. Where genetic information is trustworthy and easily accessible, then women are also keen accepters of genetic counselling and prenatal genetic testing, even during their pregnancy. The educational interventions were found to have a consistent and positive effect on awareness, knowledge, confidence in decision making and acceptance of counsellor services. Incorporating structured genetic knowledge and counselling into normal antenatal service could thus result in better maternal and foetal outcomes of reproduction.

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Conflict of Interest

The authors declare no conflict of interest.

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