RES MILITARIS
REVUE EUROPEENNE D ETUDES EUROPEAN JOURNAL OF MILITARY STUDIES
Social Science Journal

Understanding Social Dimensions on the Knowledge, Awareness, and Attitude toward Hemoglobinopathies and Premarital Screening among People in India

By

Mr. Bala Ganesh Pichamuthu
Research Scholar, School of Public Health, SRMIST, Chennai

Dr. Kantha Deivi Arunachalam
Dean, Center for Environmental and Nuclear Research, SRMIST Mobile Number - 9962211166
Email: kanthad.arunachalam@gmail.com

Dr. Kalpana B
Associate Professor, School of Public Health, SRM Institute of Science and Technology, Kattankulathur, Tamil Nadu

Dr. Kantha Deivi Arunachalam
Dean, Center for Environmental and Nuclear Research, SRMIST Mobile Number - 9962211166
Email: kanthad.arunachalam@gmail.com

Abstract

Background

Genetic blood disorders/hemoglobinopathies are a common group of inherited diseases responsible for major physical and mental disabilities. Creating consciousness and teaching the public about the disorder might be cost-powerful withinside the lengthy run, decreasing the frequency of the condition in the society, & making contributions to enhance patients' quality of life. It is crucial to apprehend diverse groups' attention to various hemoglobinopathies and premarital screening and its acceptability to keep away from in addition disparities in fitness care. This systematic review aimed to assess knowledge, attitudes, and perception (KAP) towards different hemoglobinopathies and premarital screening among students, parents, and the general population.

Method

In this review, databases (MEDLINE, PubMed, and Cochrane Central Register of Controlled Trials on the Wiley platform) had been looked for the relevant articles published in English from 2017 onwards. All steps like screening, preference of research articles, assessment, and records were extracted one after the other through researchers.

Results

Out of 553 articles searched, 20 articles had been observed appropriate for inclusion in the final review. Nevertheless, identical trend were found in a maximum of the one-of-a-kind populations in the knowledge of thalassemia/sickle cell anemia and premarital screening programs, regardless of country of origin.Age, education, gender, family income, and positive family records have been key elements that anticipated the population's KAP. The assessment revealed the gaps in knowledge of the public and the necessity of primary care physicians to increase the awareness of genetic diseases in the society and emphasize the potential

importance and benefits of premarital screening, which can address the misconceptions and especially help parents to decide who intend to have a child.

Conclusion

Health education programs will play a pivotal role in disseminating hemoglobinopathies-associated information and make a contribution to developing effective intervention strategies to increase awareness and knowledge to lessen the detected blemish and veto pertaining to hereditary disorders and premarital screening applications in ethnic minority groups.

Keywords: knowledge, attitude, hemoglobinopathies, premarital screening

Introduction

Hemoglobinopathies are a collection of recessively inherited genetic disorders affecting the hemoglobin element of blood. They are developed as a result of a genetic change (mutation) withinside the hemoglobin.The condition develops when a child inherits from one's parent by the genetic transmission of two copies of the non-working gene instructions inside each cell.(1) With about seven percent of the global populace tend to be carriers, hemoglobinopathies all-too-common monogenic illnesses and one among the important health problems worldwide. Thalassemia is the most common genetic disease global approximately 4.83%, particularly β Thalassemia, followed by 1.92% of sickle cell anemia.(2)

Although records about the appropriate global distribution and frequency of inherited hemoglobin problems remain limited, there's a growing burden on international health resources withinside the future. It has been expected that there's an excessive frequency of birth with hemoglobin problems in low- or middle-income countries, specifically in families with a deep-rooted social trend of consanguinity. (3)

Educating the general population and employing various testing modalities will be a widespread method to diminish its incidence in resource-restricted settings. A knowledge, attitude, and practices (KAP) survey may additionally assist measure people’s reponse to a idea or a problem, their views and their ability or mannerism to deal with [4]. For example, investigating students, parents, and common people's understanding of, stories with, and attitudes towards hemoglobinopathies and early intervention using premarital screening might also additionally pick out misconceptions that could make contributions to bad outcomes.

Moreover, the KAP survey outcomes may assist us todiscover gaps in people's knowledge andcapabilities important for participation in effective premarital screening programs. Therefore, the objective of this article was to evaluate recent available cross-sectional data for evidence of the knowledge, attitude, and awareness among people towards different hemoglobinopathies and premarital screening.

Materials and Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines.

Search Strategy

Databases like MEDLINE, PubMed, and Cochrane Central Register of Controlled Trials on the Wiley platform were used for literature search. The search terms used were a combination

of (i) thalassemia OR sickle cell AND (ii) knowledge AND (iii) student OR parent OR people. Boolean operators such as 'AND' and 'OR' were used in combination during the search.

The review consists of primary research that is aimed especially to analyze the overall population /parents /students' knowledge, awareness, attitudes and perceptions or provide data on participants' motives towards intentions, interest, or real comprehension of premarital testing for prevention and control of hemoglobinopathies. In addition, the research explores the knowledge gaps and perceptions concerning thalassemia/sickle cell anemia and the factors related to refusal of genetic testing or genetic counseling. Furthermore, research that explored the consequences of an academic intervention on the self-care behaviors of the patients had been presently embraced, those services frequently move side-by-side, and we desired to peer if there had been vital attitudes affecting uptake. Finally, we included both qualitative and quantitative research performed globally and published in a peer-reviewed journal from the year 2017 onwards in English language.

A manual search of references of included studies and relevant papers was also carried out. Studies were considered eligible for inclusion if: (i) involved participants above the age of 12years, (ii) assessed the knowledge priorto and post health education program intervention (iii) were cross-sectional studies that could provide meaningful insight into the attitude of people towards SCD or Thalassemia(iv) English studies. There was no restriction on sex, study population, ethnicity, and qualification.

Studies were excluded if: (i) inappropriate design, including case reports, case series, letters, reviews, animal studies, comments, and book chapters, (ii) irrelevant studies, (iii) overlapped data or data that cannot be extracted, and (iv) studies with no available full-texts or studies with abstract only. The primary outcome was to explore participant's knowledge, awareness, and attitudestoward genetic disorders like thalassemia/SCD and premarital screening (PMS)

We additionally scanned reference lists of included research for any extra articles. The articles received from the databases have been compiled with the use of the EndNote referenceUmanager. Two unbiased reviewers performed the title and summary screening, full-textual content screening, and fine assessment. Disagreements have been resolved with the aid of using discussion and consensus.

The characteristics of the included study are described in Table 1.

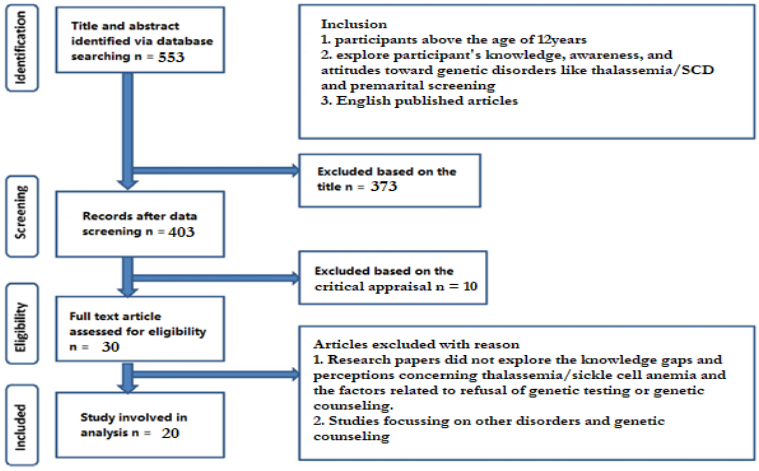

Fig 1: *PRISMA flow chart showing identification & selection process of articles included.*

Quality Assessment of Selected Studies

Research articlesmeeting the inclusion criteria were thoroughly studied, all necessary data were collected, and assessed for risk of bias.

Quality appraisal of the included studies was done based on the criteria mentioned below, questions [5]:

Q1. Was the populace properly defined?
Q2. Was the study objective clearly mentioned?
Q3. Was the participant selection done based onan unbiased and random manner?
Q4. Were the inclusion and exclusion criteria in reality defined?
Q5. Whether the survey unbiased?
Q6. Sample size calculation and power analysis are explained in detail?
Q7. Were there anydropouts or no responses counted?
Q8. Was the survey pilot tested or reviewed beforeits use?

Results

Search results

After an electronic database search, 553 studies were identified; among them, 403 were selected after duplicate removal using the Endnote reference manager.30 articles were assessed for qualitative analysis. Finally, 20 articles were included for the analysis.

Data items

The following items were extracted from each included study: methods – study design, setting, and country; participants – selection criteria, gender/ age, number analyzed; population characteristics; outcomes outlined based on the knowledge, awareness, and attitude.

General characteristics of the study

All original research studies published in 2017-2022 were included, among which 20 articles met the inclusion criteria.

All the included studies were conducted in different places suchas Bangladesh, Indonesia, Thailand, Malaysia, Cambodia, Oman, Iran, India, Saudi Arabia, and Nigeria.Most of the study samples were selected based on the survey data obtained, which assessed knowledge, awareness, attitudes, and perceptions, or provided evidence on participants' reasons for or against interest, intentions, or actual uptake of premarital screening process for prevention and control of hemoglobinopathies. Some studies focused on exploring the knowledge gaps and perceptions regarding thalassemia/sickle cell anemia and the factors are related to the refusal of gene tests or genetic counseling. In contrast, others explored the impact of an educational intervention on the behaviors of the patients in their self-care to see if there were important attitudes affecting uptake.

The general characteristics of all studies are illustrated in **Table 1**.

Quantitative assessment

Knowledge -

The segment on knowledge comprises of a well structurally designed questions on the etiology, clinical manifestations, and treatment of thalassemia/sickle cell anemia. The knowledge section comprised 10-12 relevant questions, which were marked as 1 for the "Yes" response or 0 for the "No/I don't know" response in order to arrive at a total knowledge score.

Attitude and perception -

Measures of attitudes/beliefs/perceptions in the view of gene tests or genetic counseling were used. For example, some studies were based on attitude scores, while others reported the statement agreement percentage.

Domain 1 - Students

Knowledge -

Eight studies assessed the knowledge and attitude of students towards hemoglobinopathies and the purpose of premarital screening.

Most studies indicated sound knowledge among students in science discipline about the cause, carriers, consanguinity, detection, treatment of thalassemia/sickle cell anemia, and PMS programs. However, this considerable variability in knowledge levels among students of different disciplineswas due to variation in theirsources of information like school subjects, family, friends, media, newspaper reports, health care services,and a known family history of the hereditary disease (11.9% of the student population with family history).In addition, the research confirmed that the knowledge score was no longernotably significant across sociodemographic data, while the knowledge scores varied extensively by the academic discipline.

Attitude and perceptions -

All the studies reported the attitude mainly related to students' perception and inclination toward hereditary blood disorders and PMS program awareness. Overall, a better percentage of the students who heard of thalassemia/sickle cell anemia showed nice attitudes and desired premarital screening to prevent hemoglobinopathies. The majority of the students agreed that consanguinity ought to boom the threat of hereditary diseases. Since half of the study members had been females (56.8%), they agreed that carrying out the screening tests is vital (P = 0.016) and had been in choice of making the tests mandatory prior to marriage (P = 0.002) in comparison to male students. Females had been additionally much more likely to aid the introduction of legal guidelines and guidelines to forestall weddings at times of positive test results (P = 0.010). Likewise, 90% thought that their academic organization has to train them to unfold consciousness about thalassemia/sickle cell anemia withinside the community.

Domain 2 - Parents

Knowledge -

Out of 20 studies, two evaluated the knowledge and parental perspective on hereditary disorders and the factors influencing screening programs.In phrases of knowledge, maximum of them knew that Thalassemia is a genetic disorder that may be avoided with suitable remedies and have longer lifestyles expectancies. However, the knowledge rating became substantially better in educated participants with high income level. There have been no substantial variations in knowledge scores in concerning to gender of the participants, high mortality linked with hemoglobinopathies or having a thalassaemic child.

Attitude and perception -

About 9.2% of mothers and fathers refused to screen, believing that the child was now no longer at risk. Whereas rest held them responsible for not taking up the premarital screening tests, and a most participants stated that, they might have averted marriage in the event that they had been well-knowledgeable about the sufferings of thalassemia patients. The fundamental motive for the refusal and exercise of prenatal screening might be the conservative spiritual lifestyle or social stigma.

Domain 3 – General population
Knowledge, attitude, and perception -

Adequate expertise and positive attention to genetic issues and premarital screening checks were influenced with the aid of using the participant's academic level ($P < 0.001$), the sector of study ($P < 0.001$), and family month-to-month income ($P < 0.001$). The belief in gene tests became usually effective and encouraged by the respondent's variations in age ($P < 0.016$), academic level ($P < 0.001$), the field of study ($P < 0.001$), and known positive family records ($P < 0.001$). Participants with their own circle of relatives history of genetic disease had higher scores than the ones without ($p=0.000$). 60.4% had a positive mindset towards PMS, at the same time as 32.8% had an impartial one, and 6.7% had a bad mindset.

Domain 4 – Effect of education intervention
Knowledge, attitude, and perception -

Out of 20 studies, two focussed on knowledge and attitude towards the control and prevention of severe Thalassemia in both control as well as the intervention groups prior to and following health education. Concerning knowledge of people, the difference between both the research groups prior to the intervention were statistically not significant. Nevertheless, both the groups demonstrated a drastically accelerated response in terms of entirety of the objects.

Highly recommended benefits of genetic counselling and gene tests for hereditary disease threat included: to assist make choices on screening, encouraging self-examination, receipt of records for own circle of relatives/being capable of assisting family and children, lessening problems about hemoglobinopathies to reduce uncertainty, to offer a sense of personal control, to assist plan for the future. However, greater variation becomes visible in attitudes towards benefits such as: helping make essential lifestyles choices, offering reassurance, supporting the improvement of genetic disorders, and assisting make decisions about premarital/prenatal screening.

Age group, gender, education, residence, own circle of relatives month-to-month income and positive family records factors are accountable for understanding. The four major contributing elements to mindset have been age group, gender, education, and family month-to-month income.

Qualitative assessment

The risk of bias issummarized in **Table 2**. Out of 20 included studies, six had a high risk of bias, and 14 had a moderate risk.

Discussion

KAP survey statistics and the associated methodologies is the prime model of a high-satisfactory methods to evaluate health care delivery by figuring out breaches in knowledge, cultural beliefs, or behavioral styles which could facilitate the educational procedure of gathering a huge quantity of qualitative and quantitative statistics to assist plan, put in force and evaluate, as well as pose issues or create boundaries to development efforts. (26) "Knowledge" has extra goals to evaluate, "Attitude" is exactly associated with acquired traits of a person, inclusive of affective feeling elements, cognitive, and an inclination to deed (27). However, the high-satisfactory of incorporated research become numerous and diversified in nature, and there had been variation in structure, samples obtained, and results concluded; numerous comparable themes were arrived as a result of data examination from attention groups.

This systematic review showcased that knowledge, attitude, and awareness ofhemoglobinopathies and premarital screening among students, parents, and the generalpeople.The knowledge score of the genetic risk of hemoglobinopathies and the importance of premarital screening differed across the studies that were taken into consideration, from low up until moderate levels, highlighting a critical knowledge gap and societal misperceptions about thalassemia/sickle cell anemia. However, knowledge about hemoglobin issues pertaining to the the genetic background cannot be related to intentions to check people who lack the information about the hereditary nature of thalassemia/sickle cell anemia. May now no longer pursue genetic testing that is applicable to them. In general, study findings imply low degrees of information, with greater than half of the members, having no awareness about the existence of the disease. Besides, though people who had knew about the disease, established insufficient information on the fundamental concepts of genetic issues. In addition, the study members had better misconceptions and emotional burdens. The predominant source of records had been friends & family members (34.4%), observed through college text (30.3%), print media reports (18.5%), and services related to healthcare (16.8%). (13)

Low cognizance and comprehension had been additionally emphasized in qualitative studies as barriers to attending tests related to genetic disorder. Participants counseled a want for cognizance and academic ministrations, specially emphasizing the significance of the bloodline records of hemoglobinopathies. (28) Qualitative research diagnosed numerous misconceptions like alienation of mother / father and the child from the society, deterring the sufferers from attending premarital screening programs. (29)

Among students, the knowledge score was satisfactory for those who belonged to science discipline/medical students, were females, had known family history, and had positive parental perception towards disease. Regarding parents, most of them (of about 65% of them) had no idea about the process of prenatal examiantion, which could be related to insufficient information, illiteracy, scarce resources, conservative religious culture, and more importantly these might not be affordable to all. (7)

Multifarious cynical attitudes and conceptions influencing people to undergo these tests had been observed amongst ethnic minority groups, which includes a reluctance to speak about hereditary problems among family, issues about stigma, and worries about the emotional response to the present process of gene tests. (30)

Besides the entire family, few research discovered that especially women with poorknowledge scores had been 0.04 are prone to high degree of refusal to screen (P = 0.002), presuming that their baby became now no longer in danger (46%) or the kid denyed to be screened (38%), or scared of the consequences (8%) and others (8%). (10) Meanwhile, a couple of research on premarital screenings observed that each women and men had favorable attitudes in the direction of it via way of means of imposing the authorities to amend certain modifications by developing legal guidelines and policies to impede marriages in case of positive test results. (13)

The low mean educational attainments displays an extensive meagreness of expertise in the disease. It is important to deal with those misconceptions, as those deficits in expertise can also additionally cause branding and an emotional toll on thalassemia carriers.

So, research by Gharaati et al.,2019 (14), Cheng et al.,2018 (12) has proven the dexterity of health schooling by incorporating community-level prevention and cognizance program. By manner of corroboration, an appreciably better range of individuals abided a blood test in the

intervention group (84.7%) on contrary to that of the 56% people in the control group (p-value < 0.001). Thereby developing a nice impact on the individuals' attitude, knowledge, and self-aid behaviors. Professional groups with skillability in genetics and interpersonal communications are accountable for growing society's cognizance and making plans and improvising in their decision-making, mainly for mothers and fathers who intend to have a child.

Limitations and Strengths

- Interpreting results were limited as few studies were explanatory
- Some studies lack data information
- The questionnaires have not been fully validated.
- Only studies in English were taken into consideration

Despite these limitations, the strength of this study includes: this was the first systematic review in this field. In addition, dimensions of knowledge, attitude, practice, related clinical recommendations, sources of information, and post-intervention results were also discussed. Finally, this study's results can serve as a base for future research works.

Conclusion

The need to prevent thalassemia/sickle cell anemia is essential because of its excessive prevalence, the economic burden imposed on healthcare facilities, problems in providing the most suitable remedy for sufferers because of the weighed down healthcare facilities, and the morbidities/mortalities from untreated patients. An essential element of cognizance has to be the dissociation of prenatal analysis with social stigmatism, that's quite popular even amongst lineages with excellent scholastic as well as socioeconomic backgrounds. The advent of solemn schooling on Thalassemia in faculty and organizing premarital screening camps might also additionally assist in triumph over this stigma. Creating cognizance and instructing the public concerning the sickness may be cost-powerful withinside the lengthy run, lower the prevalence of sickness withinside the community, and enhance the quality of lifestyles of patients with thalassemia/sickle cell anemia

Source of funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of conflict interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Acknowledgment

This research was supported by We thank Dr. Harinipriya and the team for their valuable help in the preparation of the manuscript and for their critical and helpful comments on the drafting.

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