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Towards a Thalassemia Free Society: A Study of Service Delivery Challenges for Premarital Screening in Punjab

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Thalassemia is one of the common genetic disorders. Nearly 7.9 million children are born with genetic birth defects worldwide, out of which 94% are in middle-income countries. Pakistan bears 5-8% carrier rate prevalence of beta-thalassemia. Premarital screening is considered one of the effective ways of preventing thalassemia and reducing its prevalence. The present study explores the challenges and barriers to service delivery of premarital screening programs in Punjab. The qualitative methods are used for carrying out this study. The study positions itself within epistemological grounds of interpretive approach. Thirteen health care providers from teaching hospitals of Lahore are selected through purposive sampling. Data is collected using in-depth interviews and thematic analysis is carried out to analyze the results. The findings of the study identify the barriers that include lack of infrastructure (technical support and human resource), economic barriers, public-related barriers (awareness, responsibility, cultural beliefs and family setup), provider-related barriers i.e. knowledge and skill, ambiguity about the professional roles, time constraints and difficulty discussing health anxiety and consanguinity. Moreover, potential burdens in the form of ethical implications and legal concerns are also identified. The study recommends improvements and steps to be taken to address the challenges for the implementation of a failure free policy.

Introduction

Thalassemia is one of the primary causes of birth defects and this hereditary disorder is widespread. Every year, almost 7.9 million children are born with a disability, of which 94% are in the middle-income countries (Christianson et al., 2006). Absconded births due to thalassemia increase the burden of the disease, which is hard to bear for the low-income and developing countries (Riaz et al., 2022). Pakistan is a low-income country with a population of approximately 2 million (National Institute of Population Sciences, 2019) with a wide range of health conditions. While consanguineous marriages are permissible in Islam, Pakistan being a Muslim country widely practices consanguinity. This may lead to an increased prevalence of genetic disorders (Ben-Omran et al., 2020). The carrier rate of beta thalassemia is 5-8% in Pakistan (Ansari et al., 2012). Premarital carrier-screening program for thalassemia is not extensively practised but antenatal screening is offered in various parts of the country. Abortion is the only option, in case fetal anomalies are detected, but it is not permitted by law in Pakistan. However, according to Ahaddour (2022) religious scholars allow termination of pregnancy only in case of serious fetal anomalies or genetic disorders in the fetus and if it is carried out before 120 days (i.e. 17 weeks). Termination of pregnancy, therefore, is a difficult decision for the couples involving various ethical and psychosocial issues (Phaophan et al., 2021; Jafri et al., 2015). Moreover, the treatment option for the most patients of thalassemia major is expensive and an extra burden on families and the healthcare system.

Premarital screening for prospective couples and the youth planning marriage is a viable option to help reduce the disease burden by preventing risk marriages and thus defective births. However, there are some challenges associated with this kind of prevention programs. Arguably, raising awareness and advocacy can help overcome the barriers to the implementation of premarital screening practices. Premarital screening has been in policy debate in Punjab, and the Provincial Ministry of Health and spokespersons have talked about presenting a bill and implementing a policy for premarital carrier screening of thalassemia. However, there are certain barriers and challenges that are anticipated by the health care providers after the implementation of premarital screening of thalassemia. The present study identifies the challenges by examining the views of the health care providers about premarital screening policy and attempts to suggest a framework for the execution of a failure-free policy.

The challenges for genetic services in Pakistan are not significantly different from those of other developing countries. According to Riaz et al. (2019), the reason for the failure to introduce genomics or genetic services into public health is that the majority of births are home births, the network of genetic health services is not established and high rate of consanguineous marriages. In addition, there is a lack of genetic information among the public and health care providers, lack of funding and training for genetic health services, inequalities, cultural and religious factors and priority given to other health issues such as infectious and non-communicable diseases.

The challenges for health screening policies for either genetic disorders, newborn screening or screening for sexually transmitted diseases are more or less similar in the social settings of Asian countries including Pakistan. The major challenges regarding neonatal screening in Pakistan tend to be similar to those identified for premarital screening. Socioeconomic and cultural constraints and deficiencies in the community health systems are also important hurdles for screening programs. In addition, lack of human resource and qualified professionals and lack of awareness among the public are the major obstacles to the implementation of screening policy in healthcare system (Mumtaz et al., 2019).

After consolidating health prevention program, service delivery is a critical step where the healthcare system and health professionals face numerous challenges. Potential burdens on the healthcare system make them vulnerable to failures that impede the operation of certain health services. Provider barriers include lack of time, lack of genetic knowledge, the cost for startup and training programs, inadequate funding, limited resources for counselling and testing protocols, lack of access to referral facilities, the burden of treatment and unstable patient-provider relationships (Boothe et al., 2021; Cohen et al., 2016; DeMarco et al., 2012).

Thalassemia is a prevalent genetic disease in Pakistan that poses management challenges for both the families and health care providers. Diagnosis and treatment involves tiring and costly procedures that are difficult for the patients with poor economic conditions to follow. These are the burdens for the country, which is already facing other health issues and their management. In this scenario, premarital screening is necessary to reduce the burden of disease. Although premarital screening has its drawbacks and detriments, it is an effective way for the prevention of hereditary diseases, birth defects and even divorce (Alhosain, 2018). Various studies conducted in Saudi Arabia, Germany, Egypt and Pakistan insist on the importance of premarital screening for the genetic disorders. This indicates a reported positive attitude towards premarital genetic testing to assess disease risk. The present study identifies the challenges and barriers to premarital screening through the views of health care providers who are the key stakeholders in its implementation. This research suggests the formulation of an uninterrupted and robust policy framework to ensure mandatory premarital screening of thalassemia in Punjab.

This study embarks on thalassemia, which is one of the major genetic disorders. The prevention of this prevalent disease through premarital screening is an emerging public health debate in Pakistan. The premarital screening law has been implemented in several countries, such as Iran, Saudi Arabia and Turkey. In Pakistan, this law is under consideration among the decision makers. If premarital screening is made mandatory, there shall be divergent challenges to health care providers for service delivery. This study investigates those potential challenges. There exists a vast body of literature on knowledge, attitude, perceptions and effectiveness of premarital screening of thalassemia in those countries where premarital screening is practiced. However, the scholarly literature about the challenges to stakeholders of screening service delivery lacks in Pakistan. This study identifies the potential challenges that shall emerge to the health care providers, so that the barrier-free premarital screening program could be legislated and regulated.

Literature Review

The literature adequately explains the general barriers that cause hurdles in the healthcare system delivery, particularly in the developing countries. For example, Riaz et al. (2019) in a study examined the challenges related to genetic services in the healthcare system. These challenges comprise a high rate of home births, lack of preconception carrier screening in clinical settings, shortage of genetic specialists, lack of rehabilitation services for genetically disabled individuals, consanguineous marriages, lack of infrastructure in the arenas of genetics, socio-cultural and religious barriers. Although his study is an extensive work on challenges and suggestions, it has not focused much on the prospects of key stakeholders related with policy implementation on healthcare provision and the challenges faced by them.

Uneke et al. (2010) in a study from Nigeria included policy makers, health professionals, in-charges of the health system, the project managers under the health ministry and consultant staff for public health issues and identified the challenges faced by the public health policy. This study documents some challenges of public health policies identified by the stakeholders. These challenges are explained at individual and organizational levels as well the gaps in the use of evidence for health policy and system reforms. Lack of interest in research, poor funding, inadequate facilities and incentives are some of the constraints that the health reforms face. Similarly, the organizational barriers are the poor capacity to collaborate, poor funding, inadequate manpower, political interference, non-participation of health personnel in policy-making and inconsistency in policy making process. The non-use of evidence gaps are insufficient communication between policy makers and researchers, poor networking, lack of database, and lack of experts. The findings of this study are similar to the objectives of the present study, particularly in the developing countries. Arguably, the challenges identified are almost similar in all the developing countries and the study helps support the idea behind the present study.

Baars et al. (2005) investigated the ‘knowledge’ related to genetics required for practice among the passing-out medical students in Netherlands. They noted that for the indicators of “essential knowledge” in the questions designed by the study designers, among the clinical geneticists and non-genetic health care providers, only 0%, 26% and 3% of the participants passed respectively. These results established that there should be changes in the courses and genetic knowledge should be a part of the medical studies. This study strengthens the idea of “lack of genetic knowledge” among the health care providers as a barrier to the provision of premarital screening. The current study also explored the challenges and prospects from the standpoint of health care providers. Several other studies have already identified the factor, “lack of genetic knowledge” as one of the barriers that may cause obstruction in the process of premarital screening. Therefore, the findings from Baars and colleagues appear to be closely linked to the current study.

A large body of literature attempts to recognize the barriers of delivery of genetic services. Lack of referral to genetic services by the health care providers is one of the major obstacles determined in literature. Delikurt et al. (2015), by reviewing nine relevant studies, maintain that there are further barriers attached to the lack of referral of patients to genetic services. These barriers are either patient or provider related. Patients-related barriers are lack of awareness about personal risks, lack of medical knowledge and family history and lack of knowledge about genetic services. Health care providers related limitations include lack of training, lack of genetic education, inadequate workforce and lack of referral coordination. These findings are consistent with the key objectives of the current study and strengthen the approach used by the researchers. This literature review provides evidence of existing barriers from the perspective of not only policy makers but also the health care providers. It will help to establish failure-free policy criteria so that the stakeholders can hold themselves responsible for the concerned challenges.

In a study, investigating expected barriers of screening policy for colorectal cancer, Aljumah and Aljebreen (2017) held that screening policies for colorectal cancer need multidisciplinary involvement that include funding, skills, education programs, logistic measures and resources. Similarly, the screening policies for thalassemia will also require the aforementioned resources. While the policy implementation involves various disciplines, there are chances of facing barriers and having opportunities. Some of the barriers against colorectal cancer screening policy in Saudi Arabia are lack of political interest, focus on treatment approaches, overlooking prevention and control strategies, competing health problems and limited advocacy skills. Furthermore, Cohen et al. (2016) in a study related to advantages, limitations and barriers to genetic counselling models explored that travel distance, wait time, and logistical issues such as billing and arranging for genetic testing are the major limitations of genetic counselling in the clinical practice. Other researchers stated these limitations in the same vein and are in line with the present study. Extensive studies for the screening policies of other diseases are present in the literature, while thalassemia with reference to premarital screening still needs scholarly attention in terms of policymaking and service delivery. Findings by Aljumah and Aljebreen (2017) contribute to the current study for exploring the prospects and challenges of premarital screening of thalassemia in Punjab.

Methodology

The qualitative research model and epistemological position

The process of conducting a study builds on philosophical foundations of a research paradigm that determines the subsequent steps in research planning, data collection and its analysis. The research design clearly orients research questions, objectives and strategies to gather data (Denzin & Lincoln, 2018). For the present study, the interpretive approach is employed that advocates the use of qualitative research methods. The researchers aimed to understand the barriers in premarital screening service delivery through the perspective of the health care providers, who are directly involved in providing premarital screening services. Their views, in form of qualitative data, were gathered to understand the potential challenges for the healthcare system.

Site selection

Lahore is the selected site for the present research. It is the provincial capital of the Punjab province. There are eleven teaching hospitals in Lahore, with four major hospitals, including Jinnah Hospital, Sir Ganga Ram Hospital, Services Hospital and Mayo Hospital. Among these hospitals, Sir Ganga Ram Hospital was selected as the site of conducting this study since Punjab Thalassemia Prevention Program is being operated at this hospital. Two private hospitals, Mid City Hospital and Hameed Latif Hospital, were also selected because they either have genetic departments or have more than one geneticist. Public hospitals do not have genetics departments, which is of central interest to the researchers in the present study. Some of the geneticists are therefore approached in the private hospitals.

Sample size and recruitment of the participants

Thirteen health care providers from the selected hospitals were contacted for conducting the interviews. Interviews were conducted with the permission of the administrative staff of each department. A permission letter for the collection of data from the head of every department was obtained and presented to the participants prior to an interview. The interviews lasted for 40 to 45 minutes and the health care providers shared detailed information about the challenges of service delivery. They expressed interest in the research topic and keenly discussed the barriers and gave suggestions for the execution of a failure free policy.

Tools for data collection

The methods for collecting data included in-depth face-to-face interviews. The interview guide was designed for the health care providers in relation to service delivery that included semi-structured open-ended questions. The first part of the interview guide included the questions about the demographics of the study participants. Later, the issues related to common challenges and barriers to premarital screening were discussed. Furthermore, other specific questions on lack of awareness, willingness of policy makers and public, religious barriers, and lack of infrastructure were discussed.

Before actual interviews, several pilot interviews were conducted to check the functionality of the tool. These interviews were conducted with health care providers based in Lahore city of Punjab province. Pilot interviews were recorded to estimate the duration of an interviews and understand other issues to improve the interview guide. The interviews were conducted in the local language, i.e. Urdu, and were audio recorded. The recorded interviews were immediately transferred to the laptop to keep the data safe in case of any technical problems.

Data analysis

After completing the fieldwork, the researchers transcribed the interviews and translated them from Urdu to English. After a rigorous coding process, key themes and sub-themes emerged for data analysis and interpretation. Identifiers of the participants such as their name and designation were changed for confidentiality and codes were assigned for their further use in analysis. In the written article, only the names of the specialized departments are used to which the participants belonged in order to ensure their anonymity. The study findings, after the analysis of data, were written and the important quotes related to the themes were used in the write up.

Findings

This study examines the challenges of premarital screening for thalassemia in both clinical and preventative settings of service delivery. The researchers interviewed health care providers in both areas to obtain an overview of the service delivery challenges for thalassemia premarital screening in prevention and treatment. These challenges are illustrated in terms of screening services and health care delivery. As research progresses, it is noted that the two settings in the healthcare system face different kinds of challenges. Some of the challenges in preventive settings may become facilitators in diagnostic and clinical settings. In addition, this study examines the professional views of the health care providers regarding potential burden of mandatory premarital screening in the current healthcare system.

Finally, the study suggests recommendations for accessibility policy on premarital screening of thalassemia. The themes uncovered in this study are discussed with reference to other diseases in similar healthcare settings. This helped examine the reliability of results associated with premarital screening for thalassemia in Punjab. The findings of the study, in form of themes that emerged from the analysis of data, are discussed in detail.

Lack of infrastructure and human resource

The present research found that lack of infrastructure for screening services was one of the main barriers to service delivery. The participants from both the prevention and diagnostic areas believed that the lack of infrastructure poses challenges to the introduction of premarital screening in Punjab and impedes the process of implementing screening policies. Moreover, transport and screening equipment is also needed because people do not show interest in such services until it is provided at their doorstep. One of the participants from the thalassemia prevention program explained:

> We need support for screening services. Tools, equipment, screening kits and buildings (labs and offices) are needed. The government will have to allocate a separate budget for screening services. We need transport for long distance travelling to provide the service at door step for people. Otherwise, it will not be possible for us to provide the service.

In addition, existing infrastructure will have to be modified according to the policy requirements. Human resource barriers associated with technical staff are another issue in providing premarital screening. While discussing barriers to domestic violence screening, Kirk and Bezzant (2020) found that lack of training and a limited number of technical and experienced staff are the barriers to providing screening services. Similarly, the participants in the present study opined that a mandatory premarital screening policy would require new recruitments. They believed that a shortage of qualified staff would challenge the performance of new screening services. One of the participants claimed:

> Oh yes! We will definitely need new hiring of skilled staff either doctors and technical staff or genetic and psychological counsellors.

While the burden on health care providers regarding their regular duties is already a challenge, the study participants stated that hiring new staff for the respective needs of premarital screening program will share their burden. They considered that this will lead towards equal dissemination of duties and responsibilities among the health professionals working for the screening program.

Economic barriers

The present study found that the government budget allocated for health is mostly limited. Even if funded interventions are formulated with adequate resource allocation, the allocated funds may not be released in a timely manner. The funds are usually transferred to other national emergencies, such as disasters, pandemics and wars during the implementation and execution phase. One of the participants from the thalassemia prevention administration explained the phenomenon:

> The health budget is spent on other issues; little amount is left for thalassemia screening. When funds are allocated, the timely release of the funds is an issue and the staff does not get their salaries. We cannot buy the screening kits, ultimately we have to stop working. Sometimes funds are transferred towards other national disasters, such as floods and earthquakes and the reserved amount for screening is consumed.

The above discussion shows how the lack of budget or untimely allocation of financial coverage for healthcare interventions is a major challenge in service delivery. The adequate financial allocation for new healthcare projects is needed for the failure free execution of the premarital screening program for thalassemia. Moreover, the budget needed for new prevention programs should be assessed beforehand, so that economic constraints may not interfere the efficiency of the program.

Confidentiality of screening results: an ethical challenge

While considering ethical implications, the participants discussed that confidentiality is an integral part of health service delivery. While test results are to be kept confidential at the request of screened individuals, it is difficult to maintain confidentiality in a set-up where family members are involved. They discussed the difficulty of maintaining secrecy in a hostile environment. A study participant articulated:

> I know the importance of keeping the results confidential but the family members are always curious about the status of the screened individual. They pressurize us to disclose the results.

This shows that how the health care providers see the challenges of maintaining confidentiality as the major barrier to service delivery. There is a need of formulating clear rules for maintaining the confidentiality of the results of thalassemia screening so that it may not interfere the workability of the program and the chances of stigma and fear of health anxiety may also be reduced.

Psycho-social concerns and post result arrangements

The diseases are often associated with stigma. The present study found how people tend to fear stigma after getting positive results. For premarital screening, people fear positive results and may face mental health issues such as anxiety, depression and poor self-image. The study found that how social difficulties are associated with positive results of premarital screening of thalassemia e.g. finding a suitable partner after the positive carrier status is one of the major difficulties that usually results in negative mental health outcomes. One of the participants explained:

> In thalassemia where marriage is involved, being discriminated on the basis of health status is a big issue in our society. People with positive carrier status may become mentally disturbed and face anxiety. So, we have to refer them to psychological care services.

In this backdrop, the study points out that patients with positive test results require special services from psychologists. Therefore, in the premarital screening program, special hiring of the psychologists becomes a necessity of the program.

Legal implications

The study participants explained how the legal implications are likely to emerge against the premarital screening of thalassemia in Punjab. However, the health care providers stated that they do not have to do much about the legal implications if written rules and regulations are already in place. There are other bodies such as the law and the judiciary responsible to enforce the law. The participants in the current study agreed that the legal concerns were not a service delivery issue, and that in case of a mandatory screening program there would be a clear plan for implementation. However, the health care providers were found to be plagued by their lack of legal knowledge and fear of legal action for violating premarital screening laws. A physician said:

> We are not concerned about the legal implications, but yes, the health care providers do not have much legal knowledge about the implications of violating premarital screening law and that might be a concern.

While devising the new laws, the legislatures with the collaboration of legal and judicial bodies, develop the rules and regulations, and also decide penalties in case of violations. Violation of any law automatically results in penalization, once the law is enforced. The study found that legal concerns in terms of violation of premarital screening will primarily be a challenge for the public, and not the health care providers. However, if the law is implemented, the study participants opined that the health care providers will be required to have detailed legal knowledge about the rules and the penalties of the law. They considered that the legal collaboration will be a viable means for the service delivery providers.

Public related barriers

In the policy-making process and its implementation, the ultimate beneficiary of public policy or public health promotion programs i.e. the consumer or public is one of the most important stakeholders. While policy implementation faces various service delivery challenges, public-related barriers also create impediments and contribute towards crippling the entire process of service delivery.

In this study, the health care providers discussed the public-related barriers that impede the process of service delivery. These barriers include lack of awareness, lack of responsibility, cultural beliefs, common family setup, stigma and societal discrimination, economic barriers, and women's lack of autonomy. A participant from the prevention domain shared her views:

> There are various issues that cause hindrance in the service delivery; a major among them is lack of awareness and responsibility. Secondly, we are sometimes stuck due to financial constraints that people have. Cultural beliefs that are strongly embedded in our society also play a detrimental role when it comes to screening and especially premarital screening.

The other major public related barriers identified by the study are the conservative cultural beliefs and lack of responsibility. The study participants shared how the challenges related to patients or the public are difficult to manage. The awareness campaigns in this regard can help to overcome the challenges related to the public, so that the premarital screening program may not face failure due to non-utilization of the prevention services.

Provider related barriers

Health care providers, such as doctors, nurses and other health care professionals, play an important role in the delivery of healthcare services. However, many studies have shown that there are a variety of challenges associated with health care providers. Various factors are identified that act as barriers to the provision of screening services. In addition, a health care professional's view of the screening program can help provide relevant information about the difficulties they face while being part of the system.

The health care providers discussed the premarital screening program and methods to make it successful, bearing in mind the problems they generally faced. These include time pressure, ambiguity about professional roles, and difficulty in discussing health anxiety and consanguinity. A pediatrician expressed:

> We are already burdened, especially while having out-door patients (OPD). This results in lack of extra time to counsel the patients about premarital screening or thalassemia. It is still not clear that whose responsibility is to counsel, convince and refer the patients. In addition, there is lack of knowledge among health care providers about thalassemia and its prevention that makes it difficult to communicate with the patients.

This shows that the service providers are aware of the professional difficulties that they may face after the implementation of the premarital screening program for thalassemia. Arguably, their awareness about the challenges should help them to overcome several difficulties to ensure effective screening program.

Discussion

The results of this study explore how the current healthcare system in Punjab may face several challenges if premarital screening for thalassemia is implemented. The issues that emerged from the fieldwork are discussed in the literature in the context of other diseases. The previous studies conducted in similar social and medical settings are consistent with the findings of the current research. During the interviews, it was noted that health care providers in Punjab support premarital screening, but they are not satisfied with the current healthcare service delivery system. They identified a range of challenges related to the healthcare system in order to implement the policy of mandatory premarital screening of thalassemia in Punjab.

Predominantly, the barriers in the field of healthcare system are related to infrastructure, human resource, and technical support. Lack of infrastructure often leads to policy and project failure. It is found to be a major challenge in the delivery of healthcare services, especially in developing countries (Pang & Ostergaard, 2014). The current study takes a similar position regarding the lack of infrastructure and screening facilities. It is found that how human resource and technical support for screening services are important factors in the successful implementation of any health prevention program. While discussing the barriers of screening for domestic abuse, academics establish that lack of training and limited number of technical and experienced staff are the barriers to provide screening services (Kirk & Bezzant, 2020; Pantecost, 2021). The results of the present study correspond to these findings of the previous studies to highlight the importance of infrastructure, human resources, and technical support.

This study further reveals the professional challenges that the health care providers are likely to face in the existing healthcare system in case premarital screening program for thalassemia is initiated in Punjab. These findings are in line with the previous studies on lung cancer, colorectal cancer, genetic and neonatal screening programs in various developing countries where inadequate professional knowledge and skill, time constraints and being unclear about the professional role in context of screening services are found to be the major challenges (Abbasi et al., 2017; O'Malley et al., 2004; Mikat-Steven et al., 2015; von dem Knesebeck et al., 2019).

Similarly, the findings of the present study highlight the barriers related to public awareness, responsibility and cultural beliefs. Almost all of the study participants mentioned these challenges as the potential hurdles against thalassemia program in Punjab. Abbasi et al. (2017) identified the major patient related barriers against lung cancer screening. They explained that the barriers include lack of participation in the utilization of screening services due to financial restrictions, health anxiety, and fear of negative results. These barriers prevent people from getting screened and health care providers have to put efforts in convincing the public before starting the screening process.

While discussing the potential burdens of the screening program, ethical implications and legal concerns are also highlighted in the study. Confidentiality of screening results is a major factor discussed in previous studies. While discussing the ethical implications in screening of breast cancer and prenatal genetic testing, Mikat-Steven et al. (2015) stressed that the test results should be kept confidential considering the implications for other family members. While the findings of the present study are consistent with other research conducted on screening, the study participants argued that it is difficult to maintain confidentiality in Pakistani society where there are strong ties among the family members. The practice of keeping the results confidential often deters the screening process and tends to place a burden on the health care providers. Finally, the research moves towards the recommendations that can help improve the health prevention services to address the challenges against premarital screening of thalassemia.

Conclusion

The present study explored the service delivery challenges and barriers for premarital screening for thalassemia in Punjab. The study revealed various challenges for health care providers regarding the screening process and its potential impacts on the healthcare system. The study identifies challenges related to infrastructure, technical support, public and provider barriers, and ethical implications related to confidentiality and legal concerns.

In addition, health care providers recommended improving service delivery in premarital screening for thalassemia. They suggested that awareness-raising campaigns through the use of media and religious education support from clergies and family elders would contribute to the effective implementation of screening policies. In addition, the education and training of qualified staff, interdepartmental cooperation, and the establishment of the department of genetics in hospitals will help reduce the burden of service delivery. Engaging thalassemia families in thalassemia campaigns and facilitating targeted screening is effective in the field of new thalassemia premarital screening programs.

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