Maternal Awareness and Perception in Successful Implementation of Neonatal Screening Program

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Abstract

Context: New-born Screening (NBS) is gaining the momentum from medical fraternities, but the grass root implementation is yet a far reality. Mothers, the immediate caretakers of their new-borns, play a pivotal role in healthcare decisions of their neonates which directly relies on their knowledge and perspectives on health literacy.

Aims: To understand the role of maternal awareness and perception in implementation of NBS for inborn errors of metabolism (IEM).

Methods: This qualitative study design adopted purposive sampling to recruit thirty-five postnatal mothers on third day post-delivery from general wards of tertiary care hospital. Mothers were interviewed using semi-structured questionnaire.

Results: Lack of awareness, strategic outreach programs, government initiatives in mothers and associated economic issues posed a major challenge in the implementation of nation-wide NBS program. Post intervention of health literacy on NBS and IEM, most mothers were eager to both participate and advocate NBS at par with goals of the action component for comprehensive NBS module designing. Counselling services for NBS, when offered antenatal and postnatal period, created an acceptance rate that was dependent on the affiliation of the competent authority involved in the counselling and information dissemination process and the setting in which the counselling intervention was administered.

Conclusions: While there exists a considerable knowledge deficit on disorders of new-born and the importance of early screening, the affiliation of the counsellor influenced mother's perception. This emphasizes the radical need for antenatal counselling, outreach programmes by healthcare professionals to ensure success of NBS; the goal of limiting neonatal morbidities arising from IEM, a reality.

Keywords: *Congenital disorders; metabolic disorders; mothers' perceptions; neonatal screening; sustainable developmental goal 3*

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Introduction

The fourth Millennium Development Goal emphasizes the international commitment to measurably reduce neonatal and child mortality. The neonatal period, the first golden 28 days after birth, represents the most crucial and vulnerable period which determines survival

and healthy development of the new-born [1]. Inborn errors of metabolism (IEM), comprising of a heterogeneous cluster of over 500 disorders, originates from defective and dysfunctional intermediary metabolic pathway. IEMs contribute a significant share to the global infant morbidity and mortality rates. Though individually considered rare, cumulative incidence of IEM spectrum disorders is hugely underestimated, with an estimated prevalence of all-cause IEM to be 50.9 in 1,00,000 live births, case fatality rate of 33% or higher, accounting for 0.4% (23529 deaths/ year) of all child deaths worldwide [2]. Approximately 0.9-6% of all Sudden Infant Deaths (SID) cases involve IEM. Literature identifies at least 43 IEM associated with SID, 26 of which can already present during the neonatal period, with at least 32 treatable disorders and 26 are currently detectable by state of art laboratory diagnostics [3].

Often, adverse and fatal clinical consequences of congenital metabolic disorders are preventable if diagnosed and intervened early. Timely intervention offers reversal and/or halting progression of potentially life-threatening complications [4]. With no recent published data on accurate prevalence of IEM in India, the incidence is estimated based on different small-scale funded projects as one in 1000 live births [5]. Despite constant recommendations and regular publications since 1980s from the Paediatricians, Geneticists, and Diagnosticians, new-born screening(NBS) practice is not yet a standard of care in the Indian Context [4-9]. There is huge need to understand and address the cause for the delay in the implementation of NBS as a public health program. Success strategies of NBS for congenital metabolic disorders in global context including some of the developing countries inkled the need for the equal involvement of the immediate beneficiaries of the program. The knowledge on the role of perceptions and awareness on NBS for metabolic disorders can bring clarity to existing reluctance to the screening from parents and may assist in developing outreach programs/ strategies to help promote NBS.

Parents, the immediate beneficiaries of the NBS program, are the primary caretakers, and make decisions on seeking health care services for their new-born. The study aims to gain insights on the major challenges in successful implementation of NBS program for IEM as national health program and address those in having an established screening module.

Methods

Qualitative study was undertaken in a tertiary care hospital ensuring participants' representability from the southern coastal and Malnad belt of the Karnataka. Postnatal mothers on third day post- delivery were recruited from general wards based on convenience and purposive sampling. Participants' eligibility was identified by the LL when he attended neonates for routine check-up. Ward Nurse introduced interviewer to the 70 mothers aged between 20 and 34 years. PS read the participant informed consent for the interested mothers and interviewed (in either English or Kannada) using semi-structured interview.

Literature evidence driven conceptual framework with key domains that can cover most of parental attitude and health behaviour were constructed which were incorporated into interview guide and administered after being validated by experts and piloted on participants.

High dropout of 50% can be attributed to the vulnerable phase (day 3 post-delivery) during which the interview was conducted. At a time considered prime from achieving maternal and neonatal stability and a period physically and emotionally sensitive for a new mother, an interview or awareness outreach on NBS was an unnecessary marketing strategy rather than an essential standard of care.

Participants were assessed on their baseline awareness and knowledge about new-born and antenatal screening and their demographic features in the first five minutes. This was followed by briefing on screening methodology & IEM disorders (approximately five minutes). Post-intervention, participants were interviewed for their attitude and perception (approximately 15-20 minutes). Reflective transcript completed immediately after each interview were reviewed by the participants themselves.

Analysis

Interviews were conducted until informational saturation was obtained in every domain. All audio recorded interviews were transcribed verbatim, Kannada verbatim were translated into English for the ease of analysis. Couple of transcribed verbatim were coded separately by each of the authors and compared

for the uniformity. The data were coded using both deductive (conceptual framework) and inductive approach (constant-comparative based approach), thus enabling the generation and further exploration of both anticipated and emergent themes. Demographic data and participants responses (anticipated and emergent themes) were presented using descriptive statistics.

Post qualitative data analysis, the challenges and the benefits (themes generated) were addressed in a comprehensive counselling module and administered to four thousand mothers both during antenatal (gestational age of 32 weeks and more) and post-natal period (third day) PS, briefed the information pertaining to NBS & IEM and the potential health benefits to these mothers along with a team of nurses and a neonatologist.

Findings

Though 35 mothers consented for the study, informational saturation was obtained at sample size of 15. However, the interviews were not ceased, continuation for all the consenting participants was carried out to ensure the appropriateness and adequate recruitment based on heterogeneity like different demographic features. presented in Table 1 . Table 2 presents the four major themes generated.

As presented in Figure 1, the status of maternal awareness on NBS prior intervention was indeed poor and below the expected benchmark. The primary challenge in implementation of NBS, descriptive statistics of the key responses of interview, most of which are emergent themes, are represented in Figure1. Figure 2 represents the theme; participants' keenness to support and advocate NBS, post-intervention.

Post qualitative data analysis, of four thousand pregnant mothers who were counselled during antenatal and post-natal period, 3510(87.75%) mothers consented to new-born screening. All consented were counselled by PS and a team of two nurses during their antenatal period followed by a reemphasizing health literacy administered by neonatologists during the routine postnatal check-up. 0.26% of consented and 12.25% (490) non-consented missed one of the counselling sessions, with the post –natal neonatologist's advocacy session being the major session to be missed which could be attributed to the complications and vulnerabilities of the post-natal phase.

Table 1: Participant characteristics

Participant characteristics		**Sample size (n=35)**	**Frequency**
Age Mean age = 28.64 years (SD 4.006)	20-29 years	21	60%
	30-31 years	14	40%
Education	middle school	3	8.6%
	high School	8	22.8%
	PUC	8	22.8%
	graduate and above	11	31.4%
	Nursing GNM and BSc	5	14.3%
Occupation	house-wife	28	80%
	working	7	20%
Socioeconomic status	BPL	9	25.7%
	Lower	6	17.14%
	Middle	20	57.14%

Cont... **Table 1: Participant characteristics**

Parity	1	24	68.57%
	2	10	28.57%
	3	1	2.85%
Consanguinity	1st degree	1	2.85%

Table 2: List of themes generated

Themes	Codes
Lack of awareness	Knowledge on IEM
	Knowledge on NBS
Lack of outreach programs	Choice of suitable time for counselling/advocacy campaigns/outreach programs
	Counsellors affiliation for the knowledge dissemination
Lack of government/nation-wide initiative	Subsidized cost
	Mandating /Health policy
	Advocacy campaigns
Financial burden	Associated economic dimension
	Affordability

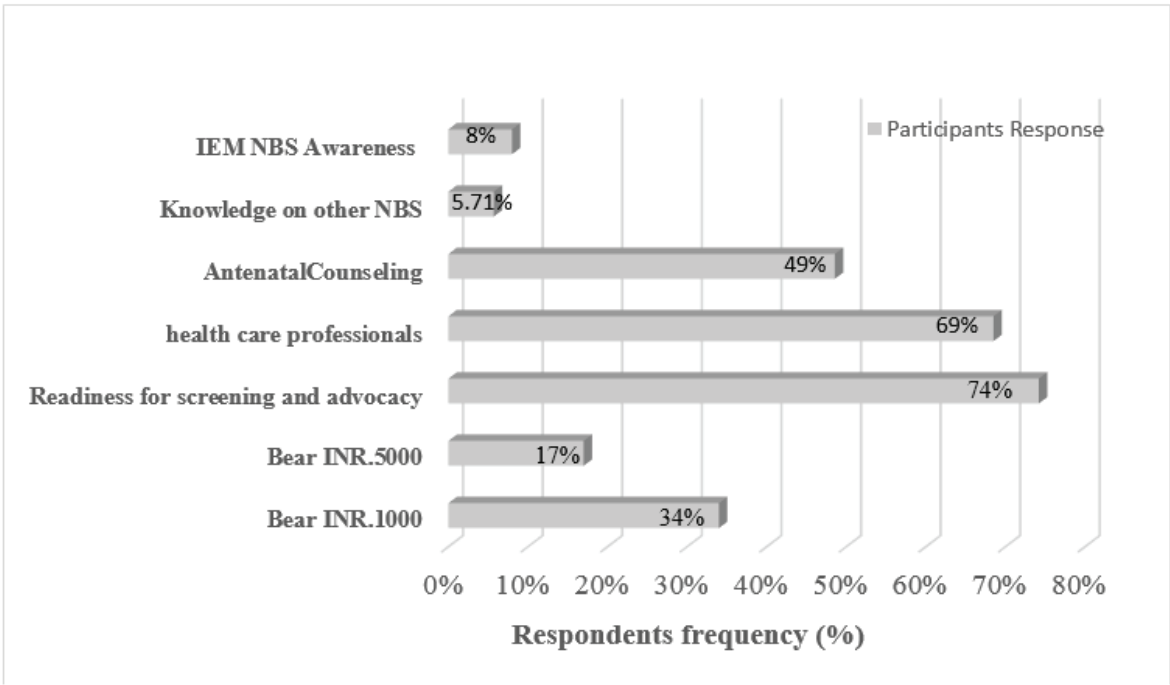

Fig. 1 Key Responses with percentage of respondents

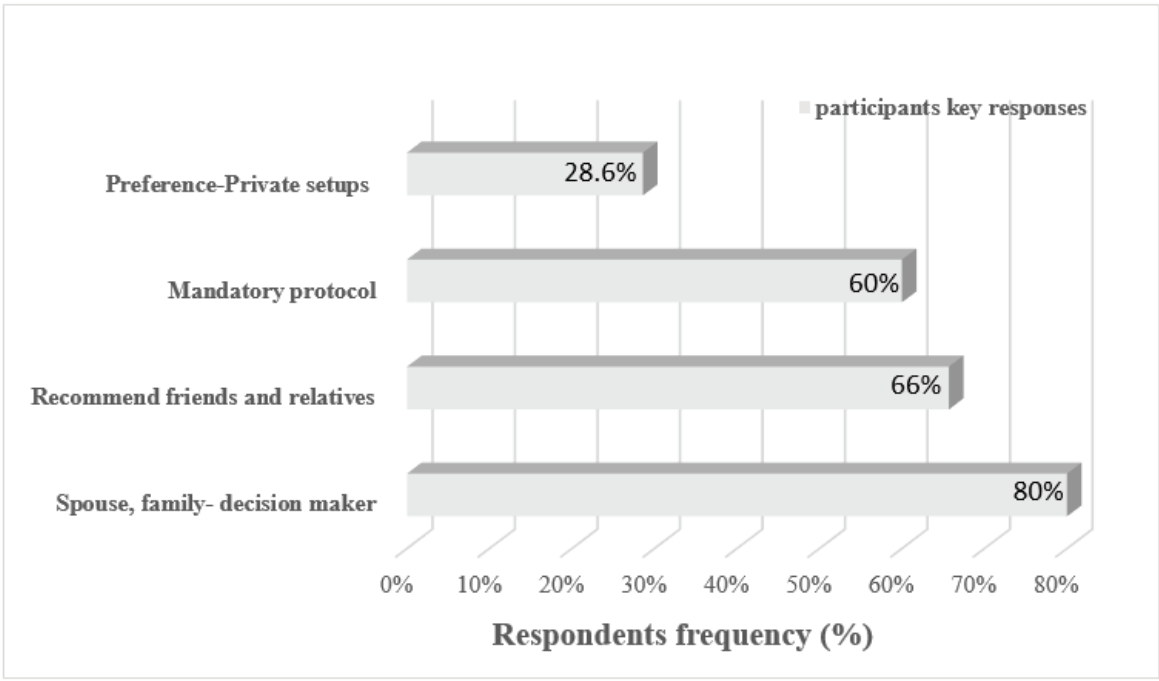

Fig.2 Key Responses with percentage of respondents for the theme; Eagerness to participate in NBS (n=26, f=74%)

Discussion

Although apparently rare, IEM can affect neonatal development and in severe cases can result in neonatal mortality[4].NBS deals with NBS for potentially fatal metabolic and genetic conditions referred to as inborn errors of metabolism and adversely affects neonatal development. Hence early detection can significantly reduce morbidity, mortality, and associated disabilities. The rationale behind screening remains debatable, particularly for disorders with no treatment options and where treatment is predominantly symptomatic, invasive and aims to retard disease progression rather than prevent or cure it. However, it should be appreciated and emphasized that purpose of screening encompasses prevention, amelioration of disease, facilitation of improved quality of life and addressing preventable morbidities rather than the mere detection of a biochemical/genetic disorder [10].

Ascertaining the views of the community at large and parents, about NBS, forms a critical milestone in the success of NBS programs. Although several factors influence parental views about NBS, parents have been found to be generally supportive when made aware of the facility and positive attitudes are not necessarily dependent on detailed knowledge of individual disorders constituting the screening panel. Many new mothers are not even aware of the provision of NBS. The lack of information about parental attitudes in relation to NBS has been identified as an area demanding significant and sensitive deliberation. The perspectives of the "mothers" on NBS, their potential concerns and hindrances, aide the development of effective awareness campaigns and modules on NBS thus presenting NBS as an option which rational parents might like to consider.

NBS maybe seen as a potential intrusion at a vulnerable time and if not adequately counselled priorly, seems to be an insignificant burden and remains greatly unrecognized area in the field of diagnostics and healthcare. During the post-natal period, mothers receive a plethora of information on diverse aspects of neonatal care and remain anxious on getting the essentials right for their new-born [11]. The UK National Screening Committee necessitates providing evidence-based information on consequences of screening to potential participants that assist them in making an informed choice, but it could be argued that if parents

were truly and appropriately informed then choosing to have their baby screened would be automatic [10]. Studies have emphasized that the time, the way, and the clarity at which screening information is provided was a critical determinant in shaping a mother's view on the necessity of NBS.

Our results emphasize that mothers considered it effective and beneficial if awareness on NBS is created during the prenatal period as it would enable effective transfer of detailed information and provide an opportunity to address the parental doubts and concerns. Quoting a respondent viewpoint, 'No, I don't have any idea and am not sure whether I will do' who on post intervention about the benefits and need of screening, volunteered to screen her baby and was giving inputs for successful NBS program.

Few mothers were totally dependent on their spouse and in-laws to arrive at any decision though they agreed the need for NBS after informational intervention. Many agreed antenatal screening is essential for both the maternal and neonatal well-being, preferred antenatal counselling on NBS or at least an information brochure about the same in local language.

Government initiative, with subsidized screening cost would be a good acceptable start, according to most participants. Assured and convinced with quality of service, mothers were ready to bear upto 1500 INR in lieu of NBS, irrespective of their family income. However, mothers thought government should bear the expenses completely / subsidize the cost and or should make it mandatory.

The findings clearly elicit the need of policy makers to become an integral part of the NBS initiative and ensure realistic, subsidized and cost-effective NBS, particularly relevant and important in the largely disproportionate socioeconomic population distribution settings of our country.

Further, our study revealed that mothers are okay with heel prick and its momentary pain if it could make a significant difference for their baby. In accordance with this, previous studies indicate that though parents might be "sad" for having their new-born undergo heel prick for NBS, it far outweighs the satisfaction of the beneficial difference that NBS could make for their neonate by early diagnosis, intervention and improved quality of their life. It is reasonable to anticipate that the attitudes of parents whose child has been diagnosed through NBS would significantly differ from those screened negative and emphasizes the point that "pain" or "sample storage" were only trivial addressable concerns, if appropriate awareness and clarity about the rationale for NBS is provided. The need for ensuring sound health of their baby thus far outreached any other non-significant concerns.

Findings of study suggests mothers were largely unaware of provision or relevance NBS for IEMs and felt uninformed. Further, mothers opined that awareness on NBS should be provided in the prenatal period in the form of direct awareness through their OBG consultants as well as in the form of pamphlets provided in local languages and community-based outreach programmes. "Pain" or "inconvenience" to the new-born and the family emerged as trivial insignificant concerns if the significant relevance of NBS and its associated procedural concerns are well addressed in advance and there seemed to be an appreciable percentage of mothers opining that the role of government assistance was essential and indispensable in making the success NBS programmes, a reality [12].

Post data analysis of the interview, the challenges and facilitators were addressed in a screening module and its translational outcome/applicability was recorded using observational study design. Four thousand mothers were offered screening services along with counselling. While 3510 mothers, counselled directly/ indirectly by their medical team, consented for the screening, the rest did not consent as they considered it an unnecessary burden or even a mere marketing strategy of the diagnostics arena since they were not initiated and introduced to the concept by their medical team. This observation made it very clear that it is just not the counselling (health literacy) but also the affiliation of the counsellor that influences the perceptions and the health seeking behaviours unlike the theory that says knowledge (improved health literacy) alone improves practice.

Conclusions

Hence, paucity of awareness and outreach programs to mothers in their antenatal period and the lack of

government initiative in offering a realistic screening platform emerged to be the main challenges in the road of NBS implementation and success, in our country. If only these prime concerns of the prospective mothers are effectively addressed with the designing of community based and government aided national NBS awareness modules and subsidies, it could bring about a radical transformation in the implementation and success of NBS as a national program. Further, it could make the two essential child health-based targets of SDG 3, a reality.

Sources of support: VGST/CESEM/Grant No. GRD 308/2014-15, Karnataka.

Grand Challenges Canada [R-ST-POC-1707-07275]

Conflicting Interest : NIL.

Ethical Statement: (IEC 824/2016; CTRI/2017/02/007894)

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