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Design Research in Neonatal Healthcare in Urban India

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Abstract

This paper attempts at understanding the core issues plaguing neonatal healthcare amongst the urban sector in India, the approach taken to understand these issues and the implications of the approach. It points out the opportunity for design interventions at various junctures. An attempt has been made to go deeper into the practical problems being faced by the various stakeholders - Mother and family (father, mother-in-law, and maternal members), Doctor and support staff (nurses, attendants), Public health officer/NGO and support staff (aanganvadi and community level health workers), and Baby products shopkeepers.

The research takes into account the demographic breakup, socio-economic and cultural environments and emotional needs of the stakeholders. Extensive field visits, qualitative interviews in naturalistic environments, contextual inquiries and innovative analytics post that have led to strong insights that point to interesting design directions. Video, photo and audio documentation was done to rebuild the scenarios during the analysis phase. The entire research was converged and distilled into 2 point of views that suggest a definitive direction in solving the problems in neonatal healthcare with design intervention through product, service and technology intervention.

Keywords: Neonatal healthcare, design research, action research, low birth weight

Introduction

More than 20 million low-birth-weight (LBW) babies are born every year, mostly in developing nations, with around 8 million in India ("Low birth weight", 2004). The LBW babies are not able to regulate their own body temperature and need external means to stay warm, medically known as hypothermia. UNICEF (2004:1) claims that: 'LBW is closely associated with foetal and neonatal mortality and morbidity, inhibited growth and cognitive development, and chronic diseases later in life.' Many of these babies could be saved with an incubator or radiant warmer, but currently available incubators and radiant warmers are expensive and its treatment is not affordable by everyone. Embrace website (2010) states that: 'Traditional incubators cost up to $20,000.'

Research Methodology

The research methodology comprised of field visits, qualitative interviews in naturalistic environments, contextual inquiries and innovative analytics. This led to insights that point to interesting design directions. Initial hypothesis were formed and they were cross verified with the observations and insights from the field visits. Across various demographics the following were carried out:

- 12 parent/family interviews at hospitals, nursing homes and slums
- 8 doctor interviews at hospitals and nursing homes
- 11 hospitals and nursing homes visited (duration of each visit varied from 3 to 10 hours per visit)
- 10 low-birth-weight (LBW) baby cases encountered and analyzed

Ten user case studies were formed from the 10 LBW baby cases encountered across the various demographics.

Stakeholder identification

Stakeholders spread out across the neonatal healthcare eco-system were identified as:

1. Mother and family (father, mother-in-law, maternal members)

2. Doctor and support staff (nurses, attendants)

3. Public health officer, NGOs and support staff (aanganvadi and community workers)

4. Baby products shopkeepers

Demographic breakup

Contextual inquiries with stakeholders were done across the following demographics based on income levels:

1. High end (those who can afford the best private hospitals medical facilities)

2. Middle end (those who can afford middle range private hospitals and medical facilities)

3. Low end (those who can afford only government hospitals and medical facilities)

Initial hypothesis

The hypothesis formed from pilot visits revolve around the following points:

- Financial impact (government and the private medical sector, stores selling new born baby's products, strain on parents/family)
- Notions of warming and medical equipment used for LBW baby amongst doctors and parents
- Reasons for early and normal discharge of LBW baby for doctors and parents. Issues surrounding weight gain of the baby
- Degree of instructions being followed by parents post the discharge of LBW baby
- Mother's confidence and resources to handle LBW baby at home post discharge

Considering the various hypotheses, the observations and insights revolving around doctors and parents across the various demographics were plotted in tables.

Field visits

Field visits were carried out at hospitals, nursing homes, slums, homes, chawls, aanganvaadis and government offices to develop an understanding of the scenario beyond the obvious and visible. A questionnaire was formed after re-iterations and was covered in the form of having conversations with the stakeholders. Video, audio and photographic documentation of the field visits was done.

Current scenario deduced from findings

High end private hospitals charge anywhere between INR 5,000 to INR 25,000 per day to keep the baby in a Neonatal Intensive Care Unit (NICU) which has incubators and radiant warmers. Middle end nursing homes charge anywhere between INR 1000 to INR 4000 per day to keep the baby in an incubator/radiant warmer (there is no NICU). Though government hospitals charge just a minimal fee of around INR 550 once for entry into NICU, they are extremely crunched on resources and sometimes they place 3 to 4 babies in a radiant warmer where only 1 is to be kept. The duration of keeping the LBW baby also decreases to a few hours per baby. There are many premature babies that never make it to the hospital. Desperate methods to take care of these vulnerable babies include placing them under 100 watt bulbs, wrapping hot water bottles around their bodies, using hair dryers and placing them near ovens. Doctors across demographics say that these solutions are unsafe and cause many infants to die. If given simple and proper medical treatment, many would not only survive, but grow and thrive.

Key findings and Insights

The key findings and insights derived from the field visits were categorized according to initial hypothesis.

1. Financial Impact and Resources Available

Figures in this section are approximate and have been deduced from field visits to hospitals and clinics. Actual rate cards and hospital record books were checked, re-confirmation was done by calling the hospital, head neonatologists were interviewed and opinion of the nurses and medical staff was taken on site. Shopkeepers/pharmacists were interviewed for the cost price of the medicines and artifacts:

- Number of LBW babies admitted to the NICU of the district government hospital in Bangalore, per month: 600 (minimum)
- Number of radiant warmers available in the district government hospital: 16
- Number of incubators available in the district government hospital: None

- Number of LBW babies admitted in the NICUs of all high end private hospitals in Bangalore, per month: 60
- Number of radiant warmers available per private hospital: 10
- Number of incubators available per private hospital: 3

Financial impact: Government hospitals versus Private hospitals/clinics

Topic	*Government Hospital*	*Private Hospital/Clinic*
Admission charges	INR 550	INR 1000 to 15000
Per day NICU charge	None	INR 1000 to 20000
OPD/Regular checkup	INR 10 for three visits	INR 200 to 1000 per visit
Bribe	INR 2000 to INR 3000	No instance registered
Medicines cost per day	Around INR 500	INR 1000 to 5000
Cost of Mother's room per day	None	INR 1000 to INR 15000

Table 1

Following table compares the cost of new born products being sold by low end stores which includes the street vendors outside government hospitals and the high end branded stores like 'Mommy&Me', 'JustBorn' and others.

Cost of new born products by high end and low end stores

Product name	*Low end shop*	*High end shop*
Baby sleeping bag	INR 70 to 120	INR 600 to 1000
Baby wrap	INR 70 to 110	INR 300 to 1000
Diapers	INR 40 (pack of 5)	Not sold
Baby vest	INR 5	INR 100
2 socks + cap + sweater pack	INR 40	INR 400
Baby powder + soap + oil pack	INR 30	INR 300 to 500

Table 5

This difference in financial affordability plays a major role in decision making criterion for many parents, as will be highlighted further ahead. The sheer number of LBW babies admitted in the NICU of a government hospital and the mismatch with the amount of facilities available there, point towards a major issue in dealing with the health of the babies visiting the government hospitals. More than the absolute numbers, an attempt has been made to highlight the disparity between the private and government health sectors in terms of neonatal healthcare. It points towards opportunity in design intervention in terms of a service model involving a medical product that can be rented to parents on low cost to keep the LBW baby warm till it waits for its turn to be incubated.

2. Notions of Warming

Problem identified: The neonatologists have fixed medical notions about the warming environment required for the LBW baby, but their actions inconsistent with the pre-cautions they state. Following is the compiled list of insights derived from the contextual inquiries and environmental study at government and private hospitals at Bangalore. It is in the form of question and answers to get a better idea of the context.

- What the neonatologists say? (Government and Private Hospitals)
  - 36 to 37 degree Celsius temperature range is crucial for LBW baby. It needs to be kept warm with precision.
- What does the neonatologist do? (Government and Private Hospitals)
  - Usually the nurses are delegated the responsibility of giving instructions. Parents don't get precise instructions on keeping the baby warm. They are told things like, 'use multiple layers of cloth', 'hand touch to measure temperature'. It leaves scope for confusion and ambiguity.
- Parents understanding of the matter. (Government and Private Hospitals)
  - There is loss of information while conveying it to the parents and they end up with ambiguous notions of keeping the child warm.
- Hypothesis on why doctors behave differently then what they say? (Government Hospitals)
  - Doctor's do care for the patients. It's just that they have become despondent and emotionally overwhelmed by the sheer numbers, and the infrastructural difficulties.

3. Early Discharge

Problem identified: When an LBW baby weighing less than around 2 kg is discharged by an NICU then it is said to be an early discharge. It can be dangerous because the baby weighing less than 2 kg is still critically LBW and needs to be kept under medical observation. The doctor's reasons for giving an early discharge and the parents' responses to it on the hospital premises have been compared and contrasted across the demographics. Post that the comparative study of doctor and parent's responses to a normal discharge have also been presented. Categorization into low, medium and high has been done according to the fees/money charged by the hospital/clinic/nursing home and the associated medical costs borne by the parents.

Low = Low end hospitals/nursing homes (government sector)

Medium = Medium end hospitals/nursing homes (private sector)

High = High end hospitals/nursing homes (private sector)

Comparing reasons for Early Discharge: Doctor versus Parents responses

Response by	*Low*	*Medium*	*High*
Doctor	- Distance from home - Lack of support structure		
		- Financial problems - Baby will get well faster at home	
	- Lack of awareness - Lack of resources		
Parent	- Distance from home		
		- Financial crunch - Baby will get well faster at home - Elderly experience at home is enough	
	- Lack of awareness		

Table 2

Comparing reasons for Normal Discharge: Doctor versus Parents responses

Response by	*Low*	*Medium*	*High*
Doctor	- Breast feeding started - Lack of support structure - No infection/illness		
		- Satisfactory weight gain (1.4 to 2 kg)	
	- Palleda feed is on		- Mother is confident
Parent	- Doctor advised		
		- No infection/illness	
	- Lack of awareness		- Mother is confident - Satisfactory weight gain

Table 3

4. Degree of Instructions Being Followed by Parents

This section compares and contrasts between the degree of instructions being followed by parents at low end government hospitals and at high end private hospitals.

- Who usually visits a government hospital? How do they react to doctors instructions?
  - Low income group people (monthly income of less than INR 10,000) who are mostly semi-literate (can partially read, but not write) visit. They have no access to alternate channels of information apart from visiting a hospital. For them to reach a government hospital having an NICU is a big task. On an average, the baby is kept for a period ranging from a few hours to 3 days in the NICU. The doctors word is 'GODs' word for the parents. They follow it blindly. Doctors use simple means to communicate the instructions (example: writing 'pampers diaper' on a chit of paper, which the parent goes and gives to the pharmacist). The doctors focus on only 1 or 2 important instructions and promote them strongly. Example: Mothers are promoted to breast feed the baby every 2-3 hours. They are recommended to buy the INR 100-200 baby bag to keep the baby warm; the baby bag which is available with the street vendors and shopkeepers around the hospitals has become an aspiration. Kangaroo Mother Care (KMC) is promoted.
- Who usually visits private hospital/nursing homes/clinics? How do they react to doctors instructions?
  - Middle and high income group parents (monthly income of around INR 15,000 and above) visit. They have access to alternate channels of information regarding healthcare and are well educated. On an average the baby is kept for 15 to 20 days in an NICU. Breast feeding by mother is encouraged and the parents are given instructions on how to handle the baby a few days prior to the baby's discharge. There is a training session for mothers for a few days prior to discharge to help train them on how to handle the baby when back at home. The parents are sometimes overindulging and don't consider the doctor's instructions as the final word. They want to take multiple opinions and do some research themselves. Many times the parents force for early discharge.

Instructions given by Doctor when the baby is discharged from an NICU

Instructions by	*Low*	*Medium*	*High*
Doctor	- Breast feed the baby every 2 to 3 hours - Baby should pass urine around 6 to 8 times a day - Keep baby warm using multiple layers of cotton clothes - Maintain hygiene (clothes, surroundings, diapers) - Check baby for vomiting, breathing rate, lethargy, rashes - Check temperature (thermometer, hand touch)		
		- Regular KMC: Kangaroo Mother Care - Come back for regular check ups - Use room heater to keep child warm	
	- Check baby for bleeding in conjunctiva, vagina, skull and breast enlargement		- Oiling for baby (post 2 to 2.5 kg) - Printed material given (instruction brochures, reports) - 24*7 help line for parents

Table 4

5. Scenario at NICU

This section compares and contrasts the environment and the parents' conditions at a NICU at low end government hospital and high end private hospital.

Government Hospital: Transporting the LBW baby to the NICU is parents' responsibility. Once the baby is admitted, mothers wait in the hospital corridors and breast feed the baby every 2-3 hours while sitting in the corridors. No one is allowed in the NICU premises, not even the mother. There is no added charge per day for the mother to stay back in the hospital. But, the father/other relatives if any usually sleep in the hospital corridor as there is no provision for them to stay in the hospital and they can't afford to go back home and come back to the hospital as they usually live far from the hospital. Average time spent by an LBW baby in NICU: few hours to 3 days. LBW Babies admitted per month: 500 to 600. Ratio of Nurse:Baby = 1:5 and ratio of Doctor:Baby = 1:7.

Private Hospital: Specialized ambulance is used for transporting the LBW baby by the hospital. Mother's go home after delivery and then come a few days prior to the baby's discharge. There is an additional charge of INR 1000 (medium end) to INR 15000 (high end) per day for the mother to stay. Both the parents are allowed in the NICU (they are sanitized and need to wear special hospital clothes). Average time spent by an LBW baby in the NICU: 15 to 20 days. LBW Babies admitted per month: 10 to 15. Ratio of Nurse:Baby = 1:1 and ratio of Doctor:Baby = 1:3.

6. Mother's confidence and resources at home post LBW baby's discharge

This section compares the parents and doctor's perception of mother's confidence and available resources at home post the LBW baby's discharge form the hospital.

Doctor's perceptions: They feel that regardless of financial status, everyone has basic resources to keep baby warm. Mother is trained by the doctors and hospital staff at high end private hospitals from the day the baby is admitted. There are doubt clearing and confidence building sessions for parents at the high end private hospitals. Private hospitals usually have a 24 hour call line dedicated to receive stress calls from the

mothers regarding handling the baby at home. All the hospitals are open for visit 24 hours. Doctors feel that the mother's become stressed after a few weeks due to the pressure of handling the LBW baby at home. At low end government hospitals, doctors feel that due to illiteracy the mother might face issues in implementing instructions and hence develop a lack of confidence.

Parents' perceptions: Parents across demographics believe that the mother is not confident to take care of the LBW baby at home. They feel that there is not much training being given to the mother and have hope that maybe the doctors and hospital staff will train the mother in the last 2 days or 5 to 6 hours prior to discharge. Low income group parents feel they will need to buy many resources to take care of the LBW baby at home.

Analysis

The insights, observations, key findings, photo and video documentation (total of 5 GB) were initially categorized in the form of tables, question and answers under various sections as mentioned above. Two new analytical frameworks specific to this research were then evolved to relate to the empathy of the mothers and doctors. They are 'Stress Mapping' and 'Confidence Mapping'. The spikes in the graphs suggest interesting directions for design intervention. Other analytical tool used was the established 'Point of View' method based on the 'User-Need-Insight' framework. Also, to aid in better understanding of the overall situation, 10 specific user case studies were developed based on the 10 LBW baby cases encountered during field visits.

Stress Mapping

Stress and relief (considered as opposites of each other) levels have been plotted on the Y-axis on a 6 point scale. The positive 3 points represent stress and the negative 3 points represent the relief levels. This graph has been made in order to get a better understanding of the empathy and mental scenarios of the two major stakeholders - the Mother and the Doctor. The X-axis is represented by the chronological time line of an LBW baby's post-delivery events. By plotting their stress and relief points across the space of this graph, one gets a better understanding of the situation they would be in when they take crucial decisions pertaining to LBW baby and Mother's health.

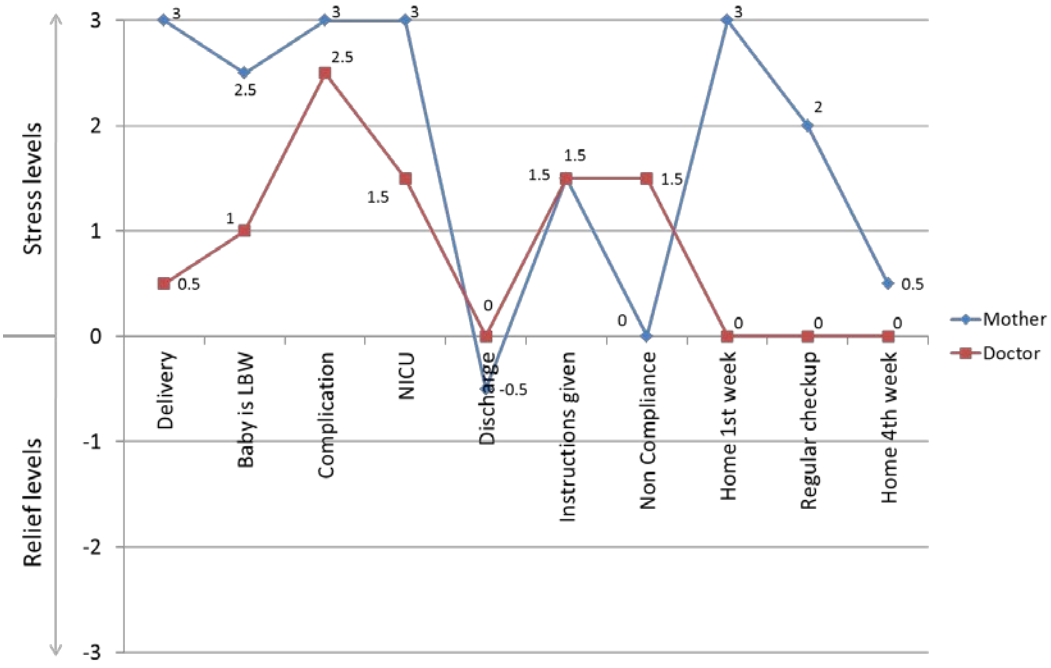

Figure 1 Stress Mapping Graph

Confidence Mapping

Confidence and anxiety (considered as opposites of each other in the given context) levels have been plotted on the Y-axis on a 6 point scale. The positive 3 points represent confidence and the negative 3 points represent the anxiety levels. The X-axis is represented by ante-natal and post-natal phases during an LBW baby's birth. This graph has been made in order to assert the empathy and confidence level of the Mother in handling the various situations during ante-natal and post-natal healthcare. This gives a much broader and clearer understanding of the mindset of the mother when she is taking crucial decisions regarding the health of her LBW baby.

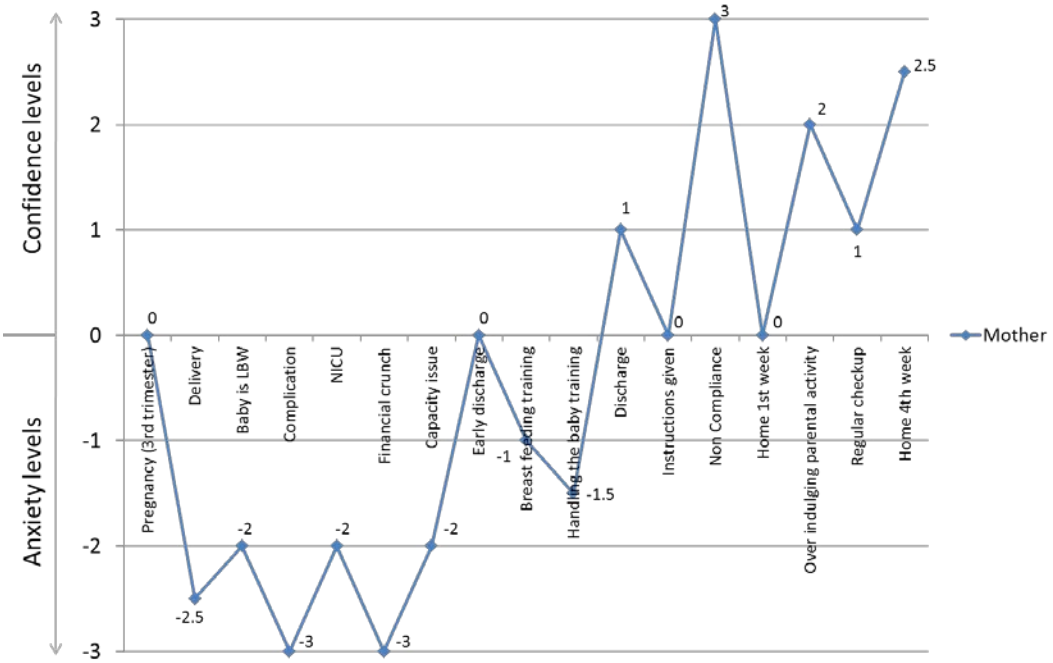

Figure 2 Confidence Mapping Graph

Initial Point of Views

'Point of View' (PoV) hypotheses are based on the 'User-Need-Insight' framework. They give a better understanding of the context specific needs of the 2 major stakeholders – doctors and parents across various demographics. Each POV points to an opportunity for design intervention to improve the situation. The initial iteration is as follows:

- PoV 1
  - User: Well respected and highly proficient doctor at a high-end NICU
  - Need: Feels frustrated and helpless in his ability to address patient non-compliance with instructions and lack of follow-up after discharge
  - Insight: Financial crunch, distance from home, keeping the baby at home are major reasons for non-compliance
  - Design opportunity: A service design approach involving mobile phone based healthcare and tele-medicine to address the issue of follow-up after discharge.
- PoV 2
  - User: Highly educated, well qualified and experienced doctor at high end hospital

  - Need: Doctors need an unambiguous, concise and reassuring way of communicating to mothers that they can take care of the baby at home by following simple instructions
  - Insight: Parents don't have access to much information on the topic, following instructions regularly becomes stressful for them
  - Design opportunity: Communication design involving illustrated and simple instruction sheet in vernacular language on keeping the LBW baby warm at home to be handed out to parents during discharge, e-copy emailed to them and voice message recordings of instructions sent on parents mobile
- PoV 3
  - User: Illiterate, quick to act on advice, poor father
  - Need: Awareness and guidance to get treatment for his LBW baby
  - Insight: In spite of being illiterate and in a financial crunch, he rushed the baby and his family overnight to a 'bigger' hospital on a local doctor's advice
  - Design opportunity: Communication design for an awareness program through information broadcasting portals at local clinics, nursing homes and slums
- PoV 4
  - User: Confident and educated middle class father
  - Need: Financial support/low expense solution and better instructions on how to handle the baby post discharge
  - Insight: Though being educated and having access to alternate sources of information, they still didn't know about radiant warmer/incubator or about keeping the baby at 36-37 degree Celsius (the baby was in NICU for 27 days), they are low on information regarding the issues related to the health of the LBW baby. They believe baby will get well fast at home with mother by its side
  - Design opportunity: Service design approach to develop a rental model for a low cost medical device to keep baby warm at home
- PoV 5
  - User: Inexperienced doctor, pursuing a degree in Master of Pediatrics, handling over-utilized NICU facilities at low end government hospital
  - Need: To avoid cross infections and monitor multiple babies with crunched resources as one radiant warmer is shared between 2 to 3 babies
  - Insight: Body parts of baby touch broken parts of the warmers as the space meant for one baby is being used for 3 babies, only one baby can be monitored at a time
  - Design opportunity: Design for a low cost healthcare product that can act as a transition point to keep babies warm till they await their turn in radiant warmer
- PoV 6
  - User: Overworked staff (experienced nurses and inexperienced doctors) who counsel parents at overcrowded NICU of a low end government hospital

- Need: To give clear and easy to implement instructions to the mother and the family members on child care requirements post discharge
- Insight: The doctors and nurses have to communicate important child care requirements to parents regardless of them being illiterate and speaking various languages. Miscommunication could be high risk for the health of the baby as follow up by parents is rare due to distance and financial constraints
- Design opportunity: Communication design in the form of an illustrated information sheet and an information dissemination portal at the hospital

Outcome of the Research

The entire research was converged and distilled into 2 definitive design directions which point towards a product/technology intervention enveloped within a service design model to solve the problems plaguing neonatal healthcare in urban India.

The demographic and empathy based considerations for the parents, which were evolved from the research have been captured in the table below. This, along with the key insights/findings section and analysis section listed above, forms the basis of the final two design directions on two distinct demographics.

Demographic and empathy based considerations for parents

Topics	*Low income group*	*Middle income group*	*High income group*
Monthly income	Below INR 5,000 Divided into 2 groups: 1. Between INR 3000 to INR 5000 2. Less than INR 3000	Between INR 5,000 to INR 30,000	Greater than INR 30,000 per month
Attitude	- Make do with minimum facilities and resources - Doctor is 'God'	- Confident - Struggle to get more information - Quick to act on advice	Not being considered. Reasons of non-consideration: - They can afford all the facilities available at the high end hospitals, they have alternate sources of information - The high end NICU has got enough warmers/incubators, nurses and doctors - 24*7 support from highly experienced NICU staff
Profession	Construction workers, Daily wage laborers, House maids	Service sector employees, Bank officers, Call center employees, Drivers, House maids	
Aspirations	2 good meals per day, Bed/cot in house, TV, More housing space, Reaching a government hospital for medical treatment People earning less than INR 3000 per month face the issue of getting even a single good meal per day	Family car, Shopping from high end malls, Medical treatment in middle/high end private hospitals	

Table 6

Design direction 1

Focus group: Low income group parents (monthly income less than INR 5,000)

Premises of approach: Preventive, curative and awareness based

Design direction: Strained, malnourished and uneducated families have been struggling to keep the pregnant mother and the new born healthy. Though Government hospitals are the best options for them; in most cases finances and lack of awareness keeps them away from the Neonatal Intensive Care Unit (NICU) ward, prescribed nutritive food and medicines. It points towards a re-look into the matter with a more holistic approach.

Design direction 2

Focus group: Middle income group parents (monthly income INR 5,000 to INR 30,000)

Premises of approach: Curative and awareness based

Design direction: Insecure new mothers, who are confident to take new steps, need a long term affordable solution that takes care of all the basic needs of a low-birth-weight (LBW) baby's health along with well planned, systematic follow up sessions with the doctors to decrease her stress.

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