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CHAMPS Case Study

Reducing Stigma and Enhancing Support for Neural Tube Defect Patients at Hiwot Fana Comprehensive Specialized Hospital through the SALT Project, Harar, Ethiopia

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Summary

Neural tube defects (NTDs), such as spina bifida and anencephaly, are serious birth defects that cause significant morbidity, disability, and mortality in Eastern Ethiopia. These defects result in severe neurological impairments and often require extensive medical care, including surgery and lifelong follow-up. Many children with NTDs face limited access to specialized care, leading to poor outcomes and increased mortality rates. The SALT/NTD project aimed to address the burden of NTDs, in addition to its main research objectives, through a comprehensive approach that included taking part in the collaboration with Reach Another Foundation and Hiwot Fana Comprehensive Specialized Hospital to establish a Center of Excellence for Spina Bifida and Hydrocephalus. Additionally, our staff were trained to provide specialized care, link families to the hospital for specialized treatment, support families with limited resources through the project, and facilitate the stay at the 'Gaddissa' house for those travelling from distant areas.

The SALT/NTD project significantly improved the lives of children with noticeable improvement in patient outcomes, with increased survival rates and better quality of life. Patient satisfaction increased, and the Center of Excellence became a beacon of hope for those affected. The project also fostered community engagement and stigma reduction.

The SALT/NTD project demonstrates the power of data-driven strategies through timely data analyses to inform health practice, facilitate capacity building, build strong partnerships and community engagement to address the burden of NTDs.

Background and context

Neural tube defects (NTDs) include a group of serious birth defects characterized by incomplete closure of the neural tube between 21 and 28 days following conception (1). While NTDs like anencephaly, craniorachischisis, and iniencephaly are often fatal, infants born with spina bifida and encephalocele can survive with extensive medical and surgical interventions. NTDs result in high mortality rates, significant morbidity and disability, and substantial psychological and economic burdens (2). The burden of NTDs is particularly severe in low- and middle-income countries like Ethiopia, where access to specialized care is limited.

The impact of NTDs extends beyond the affected individuals. Due to the ongoing care required, families face significant emotional and financial strain. Additionally, NTDs substantially burden healthcare systems, straining resources and diverting attention from other healthcare priorities.
The prevalence of NTDs in Ethiopia is alarmingly high, with rates estimated at 107.5 per 10,000 births (3). Of all the hospitals involved in the Ethiopia study by Berhane and Belachew, Hiwot Fana Comprehensive Specialized Hospital (HFCSH) had the highest overall incidence at 119.4 per 10,000 births (3), far exceeding the global prevalence of 9-22 per 10,000 live births (4).

In the first two years of the Child Health and Mortality Prevention Surveillance (CHAMPS) study in Eastern Ethiopia, neural tube defects (NTDs) were identified as the second most prevalent underlying cause of death among the entire cohort of stillbirths (5) CHAMPS estimated the adjusted mortality rate attributed to NTDs in this region to be 100.4 per 10,000 live births (6). In response to these alarming findings, the "Spina bifida and Anencephaly in Ethiopia, foLate for prevenTion" (SALT) project was initiated. This project is the first to investigate the population-based burden of NTDs in Eastern Ethiopia, utilizing the Kersa, Haramaya, and Harar Health and Demographic Surveillance Systems (HDSS) .

Key activities performed in addition to the research project include:

1. Collaborating with HFCSH and Reach Another Foundation (RAF) in the establishment of a Center of Excellence for Spina Bifida and Hydrocephalus at HFCSH
2. Training SALT study nurses to provide care for children with NTDs;
3. Creating a welcoming environment for patients;
4. Availing the 'Gaddissa' house for short-term stay for families who need to wait for surgery; and
5. Providing financial assistance to very low-income families who struggle to bring their children for treatment due to lack of funds.

Intervention

The SALT/NTD project was a comprehensive initiative designed to address the significant burden of neural tube defects (NTDs) in Eastern Ethiopia.

Key components of the intervention included:

1. Through collaboration with Reach Another Foundation (RAF) and Hiwot Fana Comprehensive Specialized Hospital (HFCSH), establishment of a Center of Excellence (COE) for Spina Bifida and Hydrocephalus (SBH), providing specialized care and improving patient outcomes.
2. To improve the quality of care, we requested a separate room for evaluating children within the hospital. Initially, children were seen alongside adult patients, which led to long waiting times. Once we secured a separate room, we renovated it to create a child-friendly environment that would reduce stress and anxiety for patients and their families (Figure 1 and figure 2).
3. A multi-disciplinary team (MDT) clinic was part of the COE, where children could be evaluated by various specialists based on their specific needs. The team included neurosurgeons, pediatricians, pediatric surgeons, orthopedic surgeons, urologists, psychiatrists, anesthesia specialists, radiologists, physiotherapists, and clean intermittent catheterization (CIC) nurses.
4. As part of the evidence-based aftercare plan, funded by Reach Another Foundation, we conduct bi-monthly health education sessions for patients and their caregivers at the hospital. These sessions cover the causes, treatment, and importance of long-term follow-up for NTDs, challenging the common misconception that NTDs are a curse on the family, particularly the mother. We invite parents who bring their children for follow up to the OPD, parents whose children are admitted at Neonatal Intensive Care Unit (NICU) and neurosurgery ward for surgery or post-surgery to be part of the health education sessions. We also involve parents of children admitted to other pediatric wards for other conditions including those who visit the Nutritional rehabilitation Unit (NRU). By involving all parents (of NTD and non-NTD patients), we aim to create a network of community advocates who can spread awareness and encourage others to seek care for NTDs. In essence, by educating those seeking care at the hospital, we are building a network for reaching as many parts of the wider community as possible.

Additional components of the intervention include offering additional services, such as:

1. Following up patients through phone and availing a dedicated phone line for the parents to call, in case of need of assistance.
2. Providing financial assistance to families in need.
3. Establishing the 'Gaddissa' House, a place for families to stay while their children undergo treatment or to wait for test results. We collaborated with the East Hararghe Regional Health Bureau to secure a room near the hospital to accommodate families needing a place to stay during follow-up appointments.

By combining these strategies, the SALT/NTD project significantly improved the health and overall lives of individuals affected by NTDs in Eastern Ethiopia.

Figure 1. Our first separate room for outpatient follow-up, which has now become the 'CIC and Counseling room.'

Figure 2. The new multidisciplinary team (MDT) room

Impact of interventions

The SALT/NTD project has gone beyond basic research to ensure that children born with NTDs receive the best possible care. Our dedicated staff, in collaboration with Reach Another Foundation (RAF) and Hiwot Fana Comprehensive Specialized Hospital (HFCSH), have played a crucial role in achieving this goal.

1. Through health education sessions, we have seen five NTD cases and their families **linked to care.**
2. Additionally, two **community champion mothers** have emerged, breaking the silence surrounding NTDs and advocating for the best possible care for their children. These mothers are actively working to educate their communities and link families to HFCSH, ensuring that no child with NTD is left untreated.
3. About 15 patients/families have benefitted from the Gadissa home.
4. Thirteen (13) families have been financially assisted.
5. The intervention has also had a **positive impact on health-seeking behavior**. Families are more likely to seek medical attention for their children, leading to earlier diagnosis and treatment.
6. Furthermore, **fathers are becoming increasingly involved** in the care of their children, demonstrating a shift in societal attitudes and responsibilities.

Lesson learned

The SALT/NTD project has provided valuable insights into the challenges and opportunities for addressing the burden of NTDs in Eastern Ethiopia.

1. Strong partnerships are critical in addressing NTD-related health issues.
2. Continuous capacity building, through training healthcare providers on the specific care needs of children with NTDs, is essential to ensuring high-quality care and improving patient outcomes.
3. An additional crucial lesson learned is the importance of community awareness creation and health education initiatives that effectively engage families and involve fathers in the care of their children. Such an approach is essential to fostering strong family-centered care, improving community health literacy, and ultimately enhancing access to and utilization of quality healthcare services.

Recommendations

1. The project's success in improving access to care, enhancing treatment outcomes, and raising awareness about NTDs positions it as a model for addressing this public health challenge in other regions.
2. Further efforts are needed to reach underserved populations. Community-based approaches, including community health extension workers and advocating for home and primary health care, can help bridge the gap between healthcare providers and vulnerable communities.

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