CASE STUDY

Managing an adolescent with Type 1 Diabetes and socioeconomic deprivation in a remote primary care setting — Ethical challenges

SHYAMSUNDAR J RAITHATHA, APEXA RAITHATHA, SANJANA BRAHMAWAR MOHAN, PAVITRA MOHAN

Abstract

This case study discusses the ethical challenges encountered by a primary care team in managing a 17-year-old girl with Type 1 diabetes in a socio-economically deprived tribal area. The case highlights critical issues such as justice in access to essential medicines, ethical dilemmas arising from complex family dynamics, and systemic failures within the public health system. By examining these challenges, this case study underscores the importance of addressing broader social determinants of health to ensure just and effective healthcare delivery in rural and tribal settings.

Keywords: *adolescent, type 1 diabetes, tribal, ethics, primary care*

Introduction

Primary healthcare is the essential foundation of healthcare delivery, especially in rural and underserved regions, where it serves as the crucial initial point of contact for individuals, families, and communities [1, 2]. It facilitates access to essential medical services and promotes overall health and well-being. However, in most underserved communities, primary healthcare often becomes the only accessible point of contact due to various barriers, including resource constraints, geographical isolation, and socio-economic challenges.

Managing chronic conditions such as Type 1 diabetes in such settings presents significant ethical dilemmas and challenges. These include ensuring justice in resource allocation, addressing complex family dynamics, overcoming systemic failures, and adhering to the principles of beneficence and non-maleficence. Unfortunately, primary care physicians are typically not trained to navigate these complex ethical issues during their medical education. Moreover, there is a lack of role models and practical guidance for young medical professionals in handling such situations.

The ethical issues of concern to tertiary care medicine such as genetics, organ donation, euthanasia, etc [3] may not be a high priority in a primary care practice where one needs to deal with dilemmas around basic healthcare access and equity. While there is some published literature available on ethical dilemmas encountered by primary care teams, there is a lack of narratives from their real life experiences [4-6].

We are a group of primary care physicians working across two remote and rural communities in South Rajasthan and South Gujarat. In our daily practice, we frequently encounter significant ethical dilemmas. We believe that narratives describing these dilemmas, along with the subsequent decision-making processes, can provide valuable learning resources for students and primary care professionals as well as policy makers, and advance the discipline of medical ethics.

Here, we present the case of an adolescent tribal girl with Type 1 diabetes mellitus who sought care at our remote, rural primary care clinic (Purna Clinic). Purna Clinic is situated in a tribal district of South Gujarat (the Dangs) in the hamlet of Morzira, near the Gujarat-Maharashtra border. The Dangs district, with a population of 270,000, is predominantly tribal (95%). The clinic serves the tribal populations from both states and offers a range of services including family medicine and physiotherapy consultations, laboratory services, pharmacy, day care (oxygen, nebulisation, IV fluids, minor procedures), and community-based rehabilitation services. The tribal community served by the clinic faces several adverse health determinants such as high malnutrition rates, high prevalence of smokeless tobacco and alcohol use, seasonal migration, low educational levels, and limited employment opportunities.

Case description

Laxmi (name changed), a 17-year-old girl from a small village near our clinic, was referred to us by our field worker due to Type 1 diabetes mellitus. She presented with classical

Authors: **Shyamsundar J Raithatha** (corresponding author — ss007.office@gmail.com https://orcid.org/0000-0002-5617-5737), Purna clinic, TIDE trust, Ahwa Chinchli Road, Morzira, Ahwa, Dang, Gujarat 394710, INDIA; **Apexa Raithatha** (apexa.raithatha@gmail.com, https://orcid.org/0000-0003-2763-1139), Purna clinic, TIDE trust, Ahwa Chinchli road, Morzira, Ahwa, Dang, Gujarat 394710, INDIA; **Sanjana Brahmawar Mohan** (sanjana@bhs.org.in), Basic Healthcare Services, VBRI, Badgaon, Udaipur, Rajasthan 313001, INDIA; **Pavitra Mohan** (pavitra@bhs.org.in), Basic Healthcare Services, VBRI, Badgaon, Udaipur, Rajasthan 313001, INDIA

To cite: Raithatha SJ, Raithatha A, Mohan SB, Mohan P. Managing an adolescent with Type 1 Diabetes and socioeconomic deprivation in a remote primary care setting — Ethical challenges. *Indian J Med Ethics.* Published online first on October 30, 2024. DOI: 10.20529/IJME.2024.070

Manuscript Editor: Olinda Timms

Peer Reviewer: Vijayaprasad Gopichandran

symptoms of polyuria, polydipsia, and polyphagia, alongside significant weight loss and progressive vision impairment. On examination, Laxmi was severely undernourished, with a body mass index (BMI) of 10.2 kg/m² (height: 135 cm, weight: 18.6 kg), bilateral cataracts, and a distended abdomen.

Family background and socioeconomic context

Laxmi lived in a household of seven, including her parents, younger sister, elder brother, his wife, and their child. The family's livelihood depended on monsoon-dependent farming and seasonal migration to neighbouring Maharashtra for agricultural labour. They faced extreme poverty exacerbated by alcohol addiction among her father, elder brother, and mother. Domestic violence was a frequent occurrence, with Laxmi's mother often leaving home due to abuse from her father, who also directed physical and verbal aggression towards Laxmi. Food insecurity was a constant challenge, with rice being the only available food most of the time.

Medical history and initial challenges

Diagnosed with Type 1 diabetes three years earlier, at a government facility located 25 kilometres away, Laxmi was advised administration of daily insulin injections. However, due to the chaotic circumstances at home and the logistical difficulties of traveling to the district hospital, she could not adhere to the treatment regimen. Her Random Blood Sugar levels remained consistently above 500 mg/dL, contributing to the development of bilateral cataracts and other systemic complications. Despite being aware of her deteriorating health, her family perceived her medical care as an economic burden, prioritising immediate survival over her long-term health needs.

Initial referral and response

Recognising the urgency of her condition, our primary care clinic recommended immediate hospitalisation at the nearby government district hospital. There was unwillingness on the part of the family to get her hospitalised. Continuous follow-up by our field team eventually facilitated her referral to the district hospital via an ambulance. Although hospitalised for a brief period, her father discharged her against medical advice, citing mistreatment by hospital staff, and neglected to collect prescribed insulin and medications.

Continued care and barriers

Acknowledging the critical nature of her condition, we arranged for Laxmi's referral to a secondary care hospital located 85 kilometres away. Our organisation covered the costs of transportation and an escort, ensuring she received treatment without any financial burden. At the secondary care facility, she was initiated on an insulin regimen, leading to some improvement in her blood sugar levels. However, after getting discharged from the facility, the inconsistent administration of insulin by her father, who was the sole family member capable of administering it, posed ongoing challenges. Insulin was stored in suboptimal conditions, further compromising its effectiveness.

Deterioration and final efforts

As Laxmi's health continued to deteriorate, we facilitated her admission to another secondary care hospital operated by a charitable trust, also 85 kilometres away. Despite initial resistance from her father, persistent efforts from our healthcare team led to her hospitalisation. Here, her blood sugar levels were better controlled, and plans were made for cataract surgery. Post-discharge, our Community-Based Rehabilitation (CBR) team provided consistent home follow-up. However, by now, following several hospitalisations, the father refused provision of any further care and decided to leave her to her fate. Subsequently, Laxmi herself began refusing treatment, despite multiple interventions by our team to persuade her family otherwise.

We eventually ceased active follow-up on Laxmi's case. The experience left a profound emotional impact on our team, prompting reflection on the ethical dilemmas and limitations inherent in managing complex chronic illnesses in resource-constrained settings.

Discussion

Laxmi's case presented numerous ethical challenges in managing her care, compelling us to navigate complex decisions. Such scenarios are not uncommon in remote tribal locations, each opening a Pandora's box of questions, reflections, and dilemmas. Similar case compilations have been published by organisations working in tribal areas of central India [7].***1. Access to essential life-saving medicine: insulin***

Laxmi's inability to consistently access insulin, despite its availability at a district hospital 25 kilometres away, underscores significant ethical issues related to justice. The principle of justice in healthcare dictates that every patient should have equitable access to necessary treatments regardless of socio-economic status [8]. In Laxmi's case, socio-economic hardships, geographical barriers, and the lack of a supportive healthcare infrastructure exacerbated the inequity. While another girl from a higher socio-economic background managed her diabetes effectively, Laxmi's condition deteriorated due to these barriers. This disparity highlights the failure of the public health system to provide equitable care and support for marginalised populations. Ensuring health equity requires the availability of responsive health services within close proximity to all individuals, irrespective of their ability to pay or their socio-economic background.

2. Ethical issues in family dynamics

Laxmi's family dynamics posed significant ethical challenges, particularly concerning autonomy and family obligations. The hostile environment, with an alcoholic and abusive father, severely compromised Laxmi's autonomy

and well-being. Ethical issues here include parental negligence and the obligation of the family to support a vulnerable member. Despite our efforts to counsel and influence the family, their reluctance to provide consistent care, driven by socio-economic stress and possibly discrimination against Laxmi's gender, hampered her treatment. The family's failure to act in Laxmi's best interest, coupled with her lack of autonomy, raises serious ethical concerns about their duty of care and support [9]. Should healthcare providers intervene legally or socially when a family's neglect jeopardises the patient's health? This situation also calls into question the role of healthcare professionals in advocating for patients whose family dynamics hinder their medical care.

3. Addressing emotional distress

Laxmi was under immense emotional distress due to her chronic illness, family hostility, poverty, and hunger. This distress led her to tobacco use and severe emotional reactions, which were overwhelming for us to address. The ethical challenge here revolves around providing adequate mental health support and addressing the broader determinants of her distress. Inadequate mental health resources in rural settings exacerbated her suffering, highlighting a critical area of need in the healthcare system. Professional mental health support could have played a crucial role in alleviating her distress and improving her overall well-being, yet it was unavailable in her setting.

4. Moral and ethical distress of practitioners

As primary care physicians in resource-limited settings, we face dilemmas about our role in addressing broader social determinants of health. Dr Yogesh Jain's concept of being a "doctor 2.5" reflects this extended responsibility [10]. Witnessing extreme suffering, feeling helpless due to unachieved better outcomes, and lacking support for addressing socio-economic factors contribute to significant ethical and professional distress. Moreover, determining the boundaries of our care for Laxmi involved weighing the principles of beneficence and non-maleficence. While we aimed to provide the best possible care within our primary care centre, her condition necessitated long-term management at a secondary or tertiary facility. Socio-economic barriers impeded ongoing specialised care, leading us to manage her primarily through teleconsultations and home glucose monitoring. Ensuring no harm (non-maleficence) while attempting to provide beneficial care (beneficence) was a constant ethical balancing act.

5. Public health system failure

Laxmi's case starkly illustrates the failure of the public health system to support marginalised populations effectively. The system's inability to provide accessible, equitable healthcare for a vulnerable patient like Laxmi represents a critical lapse. Ideally, Laxmi should have been diagnosed through a robust school health programme and provided with consistent, accessible treatment from the nearest primary care centre. A responsive follow-up system, involving reminders and home visits, would address barriers to obtaining insulin. Community health volunteers would ensure continuous monitoring and support, delivering insulin as needed. Village women's groups could assist the family in overcoming domestic issues and link them to necessary entitlements. In such a system, Laxmi would have received timely, effective care, completed her schooling, and enjoyed a quality of life comparable to more privileged peers.

Conclusion

Laxmi's case report highlights the ethical dilemmas and challenges faced by a primary care team in providing care amidst significant barriers to healthcare access. The attempt to address multiple vulnerabilities with limited resources not only presents these dilemmas but also leads to emotional burnout for healthcare providers. Managing such situations is not typically taught in medical colleges and requires learning from real-life experiences. We welcome feedback and suggestions from ethicists, primary care practitioners, and lay readers on navigating such complex cases.

References

1. World Health Organization. Primary health care. [cited 2023 Oct 10]. Available from: https://www.who.int/news-room/fact-sheets/detail/primary-health-care
2. PATH. What is "PHC" and why is everyone talking about it? 2019 Aug 12 [cited on 2023 Oct 10]. Available from: https://www.path.org/articles/what-is-primary-health-care/
3. Bowman D, Spicer J, eds. *Primary Care Ethics.* Radcliffe Publishing; 2007. 234 p.
4. Gágyor I, Heßling A, Heim S, Frewer A, Nauck, F, Himmel W, Ethical challenges in primary care: a focus group study with general practitioners, nurses and informal caregivers. *Fam Pract*. 2019 Apr; 36(2):225-230. https://doi.org/10.1093/fampra/cmy060
5. Giannetta N, Villa G, Pennestrì F, Sala R, Mordacci R, Manara DF. Ethical Problems and Moral Distress in Primary Care: A Scoping Review. *Int J Environ Res Public Health.* 2021 Jul 16;18(14):7565. http://dx.doi.org/10.3390/ijerph18147565
6. Papanikitas A, Toon P. Primary care ethics: a body of literature and a community of scholars? *J R Soc Med.* 2011 Mar 1;104(3):94–6. https://doi.org/10.1258/jrsm.2010.100353
7. Jan Swasthya Sahyog Chhattisgarh. Chronicles from Central India: Atlas of Rural Health [cited 2024 Apr 8]. Available from: https://www.jssbilaspur.org/book-announcement-atlas-rural-health/
8. Varkey B. Principles of Clinical Ethics and Their Application to Practice. *Med Princ Pract.* 2020 Jun 4;30(1):17–28. https://doi.org/10.1159/000509119
9. Olejarczyk JP, Young M. Patient rights and ethics. In: StatPearls. Treasure Island (FL): StatPearls Publishing; 2023 [cited 2023 Nov 26]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK538279/
10. Jain Y. I'm Doctor 2.5 (two-point-five). TEDxWalledCity. 2016 [cited 2024 Apr 8]. Available from: https://www.youtube.com/watch?v=6wlWC9JoLZo