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Article abstract

This case study examines a child with a rare genetic condition in Indonesia whose access to care depended on community mobilization in the context of limited institutional support, revealing a tension between the principles of beneficence and justice in resource-constrained health systems. While acts of beneficence are morally commendable, we argue that justice should take priority by motivating equitable, institutional solutions that avoid reliance on ad hoc community goodwill and prevent unequal access to care among patients with comparable needs.

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ÉTUDE DE CAS / CASE STUDY

When Good Intentions Are Not Enough: Ethical Tensions in Rare Disease Care in Indonesia

Ardita Hartanti Pramudani[a,b], Ika Septiana Eryani[c], Agustini Utari[a,d], Tri Indah Winarni[a]

Résumé
Cette étude de cas porte sur un enfant atteint d'une maladie génétique rare en Indonésie, dont l'accès aux soins a dépendu de la mobilisation de la communauté dans un contexte de soutien institutionnel limité, mettant en évidence une tension entre les principes de bienfaisance et de justice au sein des systèmes de santé aux ressources limitées. Si les actes de bienfaisance sont moralement louables, nous soutenons que la justice doit primer en favorisant des solutions institutionnelles équitables qui évitent de dépendre de la bonne volonté ponctuelle de la communauté et préviennent les inégalités d'accès aux soins entre des patients ayant des besoins comparables.

Mots-clés
Indonésie, solidarité, bienfaisance, justice, maladie rare

Abstract
This case study examines a child with a rare genetic condition in Indonesia whose access to care depended on community mobilization in the context of limited institutional support, revealing a tension between the principles of beneficence and justice in resource-constrained health systems. While acts of beneficence are morally commendable, we argue that justice should take priority by motivating equitable, institutional solutions that avoid reliance on ad hoc community goodwill and prevent unequal access to care among patients with comparable needs.

Keywords
Indonesia, solidarity, beneficence, justice, rare disease

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INTRODUCTION

Rare diseases in Indonesia reveal major disparities in healthcare access, ethical guidance, and social support. While international guidelines for comprehensive interdisciplinary care exist (1), their implementation in Indonesia is constrained by limited infrastructure, resources and regulation (2,3). This case study shows how families together with community members navigate these systemic barriers while managing conditions like Silver-Russell Syndrome (SRS), a rare genetic condition requiring long-term specialist care, including growth hormone therapy (4). The example highlights the ethical challenges of relying on community solidarity in terms of financial aid over institutional support, leading to tensions between the principles of beneficence and justice.

CASE

Sarah[1], a two-year-old girl from rural Indonesia, presented with growth delay and developmental concerns that were first identified during a routine child-weighing program conducted by community health workers. With encouragement from the community health workers, her mother sought care through the primary health system, followed by referrals to regional and tertiary hospitals. Sarah was eventually diagnosed clinically with Silver-Russell Syndrome (SRS) (5), which is not adequately covered by insurance in Indonesia (6,7). To enable access to care, the community health workers acted beyond their formal roles by mobilizing community resources and accompanying the family on long-distance referrals, compensating for the family's lack of financial means to access the needed healthcare attention.

Ethical Analysis

This case raises a tension between the ethical principles of beneficence and justice. Beneficence pushes the community to help the patient with a rare genetic disease receive adequate care, support, and resources, despite the limitations within the community. This collective response aligns with the concept of solidarity as a form of beneficence. Prainsack and Buyx (8) conceptualize solidarity across three tiers: interpersonal, group, and contractual/legal/administrative. The actions in this case exemplify Tier 2 solidarity, characterized by organized yet informal community-based mutual aid. Specifically, the community health workers accompanied Sarah and her family to referral hospitals and paid for some medical services, extending support beyond their legally mandated roles and responsibilities.

[1] Pseudonyms were used and identifying details modified to protect confidentiality.

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While this community support aligns with the principle of beneficence, reliance on such support simultaneously raises concerns regarding justice. The actions of the community health workers risk privileging the needs of one individual over those of others in the community who may face equally pressing health and social needs but lack access to comparable assistance. As such, we argue that, although supporting patients with limited financial means is ethically commendable, justice requires that community health workers not compensate for structural deficiencies by selectively leveraging informal community resources, as this may contribute to inequitable access to care and obscure the need for systemic, institutional solutions.

Sarah's case illustrates how community solidarity can alleviate immediate needs while simultaneously revealing persistent ethical challenges within rare genetic disease care in Indonesia. Limited health insurance coverage, fragmented referral systems, and uneven access to specialized services contribute to structural inequities in diagnosis, treatment, and counselling (9), leading communities to intervene where possible, while remaining constrained by the absence of formal support. These conditions raise concerns about justice and fair access to care, as families' ability to obtain appropriate medical support often depends on geographic location, financial capacity (10,11), and may also depend on informal social networks rather than guaranteed health entitlements.

Despite being the fourth most populous country in the world and the most populous in Southeast Asia, with approximately 285 million people (12), Indonesia has not yet issued specific policies addressing rare diseases, resulting in limited formal support compared with neighbouring countries in Southeast Asia such as Philippines, Singapore, Malaysia, Vietnam, and Thailand (1). Without such policies, families face a "genetic odyssey," a long, fragmented diagnostic journey across multiple facilities (13), that eventually leads to difficulties in accessibility.

Through this analysis, we conclude that dependence on community mobilization is unsustainable because it leads to inequitable care distribution. While community health workers actions align with beneficence by preventing immediate harm, justice requires institutional systems that ensure equitable care independent of community capacity. Not all patients have communities capable of mobilizing; those who are socially isolated, marginalized, or have less social capital will receive inferior care. Justice requires institutional systems that provide access to equitable care regardless of a patient's community resources, and equally shared responsibilities according to roles and capacity. As such, community health workers should not pay for healthcare services for patients who do not have the financial means.

DISCUSSION QUESTIONS:

1. To what extent is it ethically acceptable for community solidarity to compensate for gaps in institutional healthcare support without normalizing systemic inequities?
2. How can healthcare institutions integrate community-based support while preserving justice and avoiding the displacement of formal responsibility onto informal actors?

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REFERENCES

1. Shafie AA, Chaiyakunapruk N, Supian A, et al. State of rare disease management in Southeast Asia. Orphanet J Rare Dis. 2016;11:107.
2. Utari A, Faradz SMH, Ediati A, et al. Challenges in the treatment of late-identified untreated congenital adrenal hyperplasia due to CYP11B1 deficiency: Lessons from a developing country. Front Endocrinol. 2022;13:1015973.
3. Sari JI, Pramudani AH, Ediati A, Utari A. Caring for girls with salt-wasting congenital adrenal hyperplasia: A qualitative study from Central Java, Indonesia. J Pediatr Health Care. 2025;40(3):e38-47.
4. Mascarenhas JV, Ayyar VS. Russell Silver syndrome: a perspective on growth and the influence of growth hormone therapy. Indian J Endocrinol Metab. 2012;16(5):840-2.
5. Piekoszewska-Ziętek P, Witt-Porczyk A, Chrzanowska K, Zadurska M, Kowalczyk DO. Silver-Russell syndrome: phenotype features and oral health status. Orphanet Journal of Rare Diseases. 2025;20:370.

6. Ariani Y, Soeharso P, Sjarif DR. Genetics and genomic medicine in Indonesia. Mol Genet Genomic Med. 2017;5(2):103-9.
7. Budiastrawan IPA. Keluarga Tak Mampu, Yahya Terpaksa Enam Bulan Tidak Berobat. detikbali. 18 Jan 2023.
8. Prainsack B, Buyx A. Solidarity in Biomedicine and Beyond. Cambridge: Cambridge University Press; 2017.
9. Susilo D, Wulandari LPL, Sukmayeti E, et al. Can Indonesia achieve universal health coverage? Organisational and financing challenges in implementing the national health insurance system. SSM - Health Systems. 2025;5:100138.
10. Sambodo NP, Van Doorslaer E, Pradhan M, Sparrow R. Does geographic spending variation exacerbate healthcare benefit inequality? A benefit incidence analysis for Indonesia. Health Policy Plan. 2021;36(7):1129-39.
11. Mulyanto J, Kringos DS, Kunst AE. Socioeconomic inequalities in healthcare utilisation in Indonesia: A comprehensive survey-based overview. BMJ Open. 2019;9(7):e026164.
12. World Population Dashboard. Indonesia Population 2025. United Nations Population Fund.
13. Cornish F. Genomics 101: What is the diagnostic odyssey? Genomics England. 15 Jan 2025.