

Case: Implementing a Programme to Reduce Mortality of Infants in Gaza

Part 1: You are working as a programme manager for an NGO providing medical aid in Gaza. Gaza undergoes periods of intense conflict and has severe resource limitations; as a result many health services are underdeveloped. One of these is maternal and child health, which your organisation has built up a strong focus in. You have funds to spend on a new programme and after performing a needs assessment, have identified there is a gap in neonatal healthcare provision. Currently 3.7% of deliveries are high risk (3,600 affected babies) with an infant mortality rate of 20-22 per 1,000 live births, requiring specialist care.

You plan a programme that develops training for healthcare professionals to provide neonatal life-support to improve the care of neonates. However, not all the training is properly applied by the local healthcare professionals as they work under conflict settings and there is a culture of working in emergency mode that persists in non-crisis conditions. Outcomes of poor resuscitation can result in neurological disabilities, some of which can be severe, in addition to mortality. These individuals do not have favourable prospects with very high unemployment rates and limited services available to them. In addition, the cost of supporting those with disabilities is very expensive for the family and places a burden on the health care system. If implemented, the programme reduces mortality from 20 to 6:1000 neonates, but results in 5:1000 suffering disabilities. Given these details, should the programme be implemented?

Ethical Issues:

- Utilitarian considerations regarding the number of deaths/disabilities
- Comparing disability with mortality
- Challenges raised by quality of life considerations and impact of morbidity
- Cost in terms of time and resources spent for the family and the burden this places on the local health system
- Cost of suffering and stigmatisation for affected individuals

Part 2: A bigger organisation is very keen for the programme to be implemented and in order to do so, is committed to providing the funds to support the disabled individuals, and at the same time, implementing quality control measures to improve the effectiveness of life support. However, as a result of their support, they require that, twice a year, pictures and videos of the neonates or disabled individuals will be taken and used in their campaigning activities to raise money for supporting the programme. Do you decide to accept the bigger organisation's support?

Ethical Issues:

- Autonomy of family members to decide if children will be photographed versus possibility that this practice is coercive, extortion, exploitative
- Compromising respect for dignity and the stigmatising effects of disability, for the person and the family
- Whether campaigns are local or international and level of anonymity given to individuals
- Outcome considerations for the greater good by saving more lives (utilitarian effect) – this is contrary to the usual Western medicine approach of deontology

- Result of refusal to accept conditions of bigger organisation – who is best placed to make the decision? You / your organisation / the local population? Should they be consulted first?

Learning Outcomes:

1. To identify and consider ethical issues both on the surface and at a deeper level
2. Explore how to decide whether a programme is implemented and ethical / moral justifications
3. Help humanitarian workers to consider the procedures for making decisions +/- public consultation / analysis of the needs and wants of the local population
4. Develop a greater understanding and knowledge of how to apply utilitarian reasoning in ethical decision-making
5. Develop a greater consideration of (commercially) coercive/exploitative practices

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Description of how the Training should be run:

The facilitator will outline the learning outcomes of the session and present the first part of the case study to the group of humanitarian workers, before splitting the trainees into small groups of 4-5 individuals. Each group will separately discuss the ethical issues of the case for 10 minutes. The facilitator may decide to allocate half the groups to argue 'for' implementing the programme, whilst the other half of the groups argue 'against'. After 10 minutes, the two groups will be brought together for a further 10 minutes to discuss the ethical issues that arose and decide whether the programme in the case should be implemented. Alternatively, flip charts and pens could be provided to groups to separately outline main points for consideration in the decision-making process; then compare in feedback.

Following this, the facilitator will introduce part two of the case for each group to discuss for 10 minutes. The groups will then be brought together for the final 10 minutes to discuss the ethical considerations that arose, and if they would accept the support of the bigger organisation. They could also discuss how (if at all) it changed their decision, and why.

Instructions to the Trainees:

This is a case that could arise in the course of your humanitarian work. You will form small groups to discuss the ethical issues that you perceive to arise in the case, the factors to be taken into consideration and how the decision would be made. You will have 10 minutes to discuss the case in your groups before coming to a decision to share with the rest of the trainees and providing an ethical argument for this decision. (+/- you have been provided with a flip-chart and pens to record your main points for discussion.)

Notes for Facilitators:

Part 1

This case brings up complex ethical issues that can be primarily approached by applying a utilitarian construct. These issues include quality of life considerations in the gravity of comparing disability with mortality, and in weighing up the number of affected individuals/deaths. Furthermore, there are ethical issues in assessing the cost of the outcomes of the programme in terms of time and resources spent by the family caring for the affected individual, in addition to the burden this places on the health system as a whole. The programme also needs to be placed in context, and trainees should recognise the suffering that disabled individuals may experience in a potential discriminatory society, with limited possibilities and little support adding to their suffering. The following questions and points may help to raise relevant issues for the group to discuss, and some of the positions that may be taken:

Is it better to reduce the number of mortalities if some of those will have increased morbidity instead?

- Taking a utilitarian view that there is reduced mortality, the programme should be implemented. Disabled children will still be alive.
- Considering the welfare of disabled individuals will reduce the utility of choosing to implement the programme.

How do you compare disability with mortality?

- Discussions of a life worth living and the value of life. What is a 'life worth living'? Who decides? Who has the right to decide?
- Placing the discussion in context and what it would mean to be disabled within this society. Should this affect how your decision is made?

What is the value of the life you are saving if it will be disabled, possibly severely disabled?

- Considerations of context and available support
- Cost for individual in society and discrimination
- Cost and time for family
- Cost for health services as supporting individuals with disabilities greatly reduces available resources for other programmes, in a country in which resources are generally scarce already. There is little or no specialist equipment to support severely disabled children.

Encourage trainees to discuss different numbers and if this would impact on benefit/harm considerations, and if that would change the decision, for example:

- Saving 14 lives, but all these individuals will be disabled
 - Individual benefits as it is better than dying: are they 'better off dead' than living with disability?
- Saving 14 lives, but 14 other individuals will be disabled
 - The lives saved will be a benefit, but at a cost to someone else
- Saving 14 lives, but 28 other individuals will be disabled

- The lives saved will benefit at the cost of two other individuals
- There are greater harms than benefits. Is disability a 'harm'? Why?

Explore reasons for and against implementing the programme.

Part 2

This part of the case encourages the trainees to consider issues of autonomy, coercion and exploitation, and respect for dignity. In addition, some trainees may approach the case from a utilitarian construct by applying 'for the greater good' reasoning. The following question and points may help to raise relevant issues for the group to discuss, and some of the positions that may be taken:

Are parents given enough autonomy to decide whether pictures of their children should be taken?

- Or at all? Who are we (the NGO) to decide without public consultation / informed consent documents?
- Has / will any consideration or respect be given to issues of consent?
- Should the benefit of the 'bigger organisation' funding outweigh the potential harm / risk to disabled children? In order to raise funds, the bigger organisation needs to raise awareness of its work – it will simply be a 'return' on their investment. This will also ensure that the money keeps coming in.
- Can it be guaranteed that funding will continue, or is it only for a limited time? Is it crueller to start treatment / care and then stop it, than to not start it at all in the first place? (Healthcare as a strategic / political tool rather than altruistic action)
- What will happen if the funding is refused? Should we apply a deontological approach here? Why / why not?
- Can the funding be spent elsewhere / better within this community's health system?
- Will there be funding for disabled adults as well (i.e. follow-up care)? After all, disabled children will grow into disabled / vulnerable adults. Is the 'bigger organisation' discriminating against one group because of age? They will still need the same level of care as adults.
- Consider the Principlist ethics approach and how this decision would be viewed through each of the four pillars:
 - Autonomy (Parents? Older children? NGO?)
 - Beneficence (actions of the bigger organisation?) } **Rests potentially on the decision**
 - Non-maleficence (actions of the NGO?) } **taken by the NGO re: funding**
 - Justice (distributive justice, loyalty to local population and the need to 'do the best thing' for everyone) – bear in mind charities tend to have specific aims and purposes.
- Does virtue ethics play a part? How best would you achieve the ideal of being the 'virtuous practitioner'? Is that by accepting funding and benefitting the wider population, or refusing and protecting them from potential exploitation / coercion?

- What if the bigger organisation offered cash incentives, paid directly to families to care for their disabled children (instead of providing corporate resources to the NGO)? Would this alter your decision-making strategy / approach?

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