

# The impact of diarrhoea in infants on the quality of life of low-income households

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## Abstract

**Background:** This article reports on a study that explored the impact of diarrhoea in babies on the quality of life of low-income households. Diarrhoeal diseases continue to be an important cause of illness and death worldwide. One major cause of infantile diarrhoea is the rotavirus, an airborne virus to which almost all children in both the developing and developed world will be exposed to at least once. The study, as well as the clinical trials and cost studies, was commissioned by GlaxoSmithKline to assist in the decision-making processes regarding whether and how to implement a newly developed vaccine against rotavirus through national immunisation programmes. The objective of the study was to obtain a comprehensive understanding of the impact of severe diarrhoea in babies on the quality of life of a selected group of low-income households.

**Methods:** The study was qualitative, explorative and descriptive in nature. A recently developed quality of life (QoL) assessment instrument, based on a comprehensive list of fundamental needs developed by development expert Manfred Max-Neef, was used to assess the impact of diarrhoea in babies on households. The QoL instrument includes 125 open questions related to basic necessities and activities, localisation, relationships and consciousness of household members. In addition, group and individual interviews were held. Twenty-nine households with children younger than two years of age who had experienced diarrhoea in the previous two months were selected. By means of a number of medical questions related to the duration of the diarrhoea and related symptoms, babies with severe diarrhoea were purposively sampled. After analysis of the data, these babies were classified as follows: 20 had severe diarrhoea, six had moderate diarrhoea and three were diagnosed as having had mild diarrhoea. Two babies were previously admitted to the hospital. Of the 29 households surveyed, 22 households were interviewed using the QoL assessment instrument, and seven households were interviewed by means of group and individual interviews. Ethical approval for the research was obtained from the ethics committee of the Faculty of Theology at the University of Pretoria.

**Results:** Poor housing conditions exacerbated the effect of diarrhoea in infants on the primary caregiver as well as the other household members. Household members complained about the sound of the babies crying and almost half of the mothers reported that they felt stressed or ashamed about the quality of air in their dwellings. One mother said that the smell was so bad that she could not eat her food because it caused her to vomit. The lack of basic necessities, for example the shortage of water in a number of households, intensified the struggle to cope with the diarrhoea. It was found that the burden of care fell mainly on the mothers of the babies with diarrhoea. The pressure experienced by some mothers seems to be related to the way they experience their identity. Mothers indicated that they felt responsible for tasks in and around the household, including the duty of caring for their children. This places a physical and emotional burden on the primary caregiver. Diarrhoea was the cause of tension and conflict in a number of households, not only because of inflated financial costs related to efforts to cope with the illness, but also because of differing views among household members regarding the most suitable treatment – Western or traditional medicine. Mothers identified different causes of the diarrhoea, including teething, heat, wrong food and ‘the problem of the fontanelle’. It became evident that some mothers believed that a sunken fontanelle was the cause of diarrhoea, and this was believed to be best treated by traditional healing methods.

**Conclusion:** A vaccine against rotavirus diarrhoea could benefit the households in this research by:

- Reducing the emotional burden of care on the mother;
- Reducing the physical burden of care on the mother, and
- Reducing the financial burden that childhood diarrhoea imposes on households.

Note of caution: The findings show how rotavirus vaccines could be an adjunct to the primary prevention approach for diarrhoea diseases in children. A vaccine will not substitute for all the other important requirements for a respectable quality of life, such as love, care, education, healthy nutrition, a regular safe water supply, and good sanitation. It is also important to interpret the findings in conjunction with other rotavirus vaccine clinical trials and cost-benefit studies.

## Introduction

Diarrhoeal diseases continue to be an important cause of illness and death worldwide. Annually, it causes an estimated 2.7 billion cases and 1.9 million deaths in developing countries,<sup>1</sup> and it is one of the major causes of childhood mortality.<sup>2</sup> In South Africa, diarrhoeal disease was found to be in the top three causes of death in babies younger than one year.<sup>3</sup>

One major cause of infantile diarrhoea is the rotavirus, an airborne virus to which almost all children in both the developing and developed world will be exposed to at least once. Globally, the virus accounts for 25 million clinic visits, 2 million hospitalisations and 352 000 to 592 000 deaths in children under five each year.<sup>4</sup> An effective vaccine against rotavirus could prevent illness and death caused by this virus. South Africa has been in the forefront of this vaccine development, with several phases of clinical trials being conducted in the Madibeng District of the North West Province. A number of principles guide the development of the vaccine in South Africa. These are the principles of safety, effectiveness, respect, dignity and relevance in health research, as stipulated by the Research Ethics Guidelines of the South African National Department of Health. Thus, it must be ensured that a vaccine is not only safe and effective, but also that it addresses the broader health and development needs of the country and that it is relevant to the individuals participating in the research and to their communities.<sup>5</sup> Therefore, it is imperative to gain a broad understanding of not only the health, but also the social-economic and emotional, impact of diarrhoea in babies.

The objective of this study was to obtain a comprehensive understanding of the impact of severe diarrhoea in babies on the quality of life of a selected group of low-income households. This information, together with clinical trials and cost studies, can assist in decision-making processes relating to whether and how to implement the vaccine, for instance whether or not to add it to national immunisation programmes. The study was commissioned by GlaxoSmithKline, a company that is in the process of developing a vaccine against rotavirus.

## Method

The study was qualitative, explorative and descriptive in nature. A recently developed quality of life (QoL) assessment instrument, based on a comprehensive list of fundamental needs and developed by development expert Manfred Max-Neef, was used to assess the impact of diarrhoea in babies on households.<sup>6</sup> The QoL instrument helps to generate relevant questions to measure the impact of any positive or negative satisfier (products, solutions, illnesses, etc) on the quality of households. This was the first time the instrument was used to measure the impact of diarrhoea on households. A total of 125 questions were formulated, probing the possible impact diarrhoea could have on the basic necessities, activities, localisation, relationships and consciousness of household members. In addition, more conventional group and individual interviews were also held. The results from the QoL instrument proved to be more comprehensive than the outcome of the conventional group and individual interviews. For the QoL instrument questions, a total of 29 households were selected with children younger than two years of age who had experienced diarrhoea in the previous two months. By means of a number of medical questions related to the duration of the diarrhoea and related symptoms, babies with severe diarrhoea were purposively sampled. After analysis of the data, these babies were classified as

follows: 20 had severe diarrhoea, six had moderate diarrhoea and three were diagnosed as having had mild diarrhoea. Two babies had been admitted to hospital. Of all 29 households surveyed, 22 households were interviewed using the QoL assessment instrument, and seven households were interviewed by means of group and individual interviews.

The methodology applied in this study can be used to generate research questions to test various factors that may influence quality of life, such as other diseases and social problems. It can be applied in any social context. In this case it was used in a typical South African township, with its mixture of formal and informal housing, a high unemployment rate and poverty.

Ethical approval for the research was obtained from the ethics committee of the Faculty of Theology at the University of Pretoria.

## Results

The most important findings of this study include the following:

### **Poor housing conditions, smell and sound**

Many of the households surveyed stayed with large families in small shacks, often with only one or two rooms, no water or flush toilet on the stand, and some shacks without windows. There is no other place to change the nappies than in the sleeping or living room that is also used by other household members. Some household members complained to the primary caretaker about the sound of the baby crying. The bad smell was another problem. Almost half of the mothers reported that they felt stressed or ashamed about the quality of air in their dwellings. One mother said that the smell was so bad that she could not eat her food because it caused her to vomit.

### **Diarrhoea and poverty**

The lack of basic necessities in a number of the households intensified the struggle of the caregivers to cope with the diarrhoea of their babies. The shortage of water in or near the house is one example. No single household in the survey had a water tap inside the house, and many households had to collect and carry water from taps some distance away. Water is important for several actions related to diarrhoea:

- Clean water is needed for mixing the Oral Rehydration Solution (ORS);
- Enough water is important to wash the baby and surfaces, especially where spilling of body fluids occurs;
- Disposable nappies are unaffordable in the majority of cases and some households cannot even afford cloth nappies. The combination of a shortage of clothes and the lack of water on the stand makes the burden of washing and cleaning much harder than usual. When it rains, for example, clean dry nappies and clothes are quickly used.

In addition, more soap is needed to clean surfaces, reduce the bad smell and wash the baby. It is evident that diarrhoea has a negative impact on the already insufficient budgets of some of the lowest income households. As such, it can push the poorest and most vulnerable families below the threshold where they are still able to cope.

### **The role of the mother: carrying the burden of care**

It was found that the burden of care falls mainly on the mothers of the babies with diarrhoea. Much time and effort were spent on tasks such

as washing nappies, carrying water from sources a distance from the household, cleaning the house to get rid of the smell of the diarrhoea, and attending to the baby with diarrhoea. Mothers complained that they were more tired than before and had less time to relax because of the increased workload caused by the babies' diarrhoea.

The pressure some mothers experienced seems to be related to the way they experience their identity. Mothers indicated that they felt responsible for tasks in and around the household, including the duty of caring for their children. The diarrhoea meant more washing and cleaning of surfaces and fetching of water, in addition to their usual responsibilities, such as cooking for the family and paying attention to the other household members.

### ***Intra-household relationships and the role of different healthcare providers***

The support of other household members differed from family to family. In some cases the mother experienced a lack of support, while in others the father of the child or other family members were an important source of emotional or practical support.

In a number of households, diarrhoea was the cause of tension and conflict within the household because of issues such as the financial costs related to the illness, the smell and the noise of the baby crying. Differing views among household members regarding the most suitable treatment – Western or traditional – was another source of conflict. The different types of healthcare providers that were consulted by the mothers were as follows:

- Clinics and hospitals that provide modern Western medicines;
- A large variety of churches that provide prayer, herbal teas and other rituals; and
- Traditional healers providing traditional treatment.

However, in one case the father did not believe in Western treatment, while the mother did, and in another case the grandparents, living in the same house as the parents, wanted the baby to be treated by a Western doctor instead of a traditional healer, the initial choice of the mother. Both situations led to conflict between the mother and the other household members.

The study was not designed to be a representative sample of households suffering from rota virus diarrhoea in the area. It rather aimed to provide an indication of preferences and beliefs amongst those families interviewed. Table I shows that the majority of the mothers who visited the traditional healer also visited the clinic and/or applied the sugar-salt water solution at home, which they said they had learnt from the clinic's nurses. Other mothers in the same community visited the clinic only and explained that they did not believe in traditional methods. The homes of the respondents with these different views were often within walking distance from one another.

**Table I:** Answers to the question: What treatment do you prefer: traditional or Western?

Cure	Number of respondents
Both	41% (n = 9)
Western treatment/ORS	36.4% (n = 8)
Traditional treatment	9% (n = 2)
No answer	13.6% (n = 3)

As these results show, 41% of the mothers believed that both Western and traditional remedies can cure diarrhoea. Other questions revealed

that traditional treatment is not provided only by traditional healers, but also by some churches. When asked who the mother trusted the most in treating the baby, the church and clinic came out strongest. The church, however, did not play a large role in terms of educating mothers on the prevention and treatment of diarrhoea. When asked where mothers had learnt how to treat the baby (e.g. preparing ORS), the respondents indicated that they had learnt from the clinic, their families and other people in the community. As the majority of the respondents were churchgoers, it should be investigated if churches could not possibly play a larger role as information centres to guide women on where to find quality care for their babies with diarrhoea.

**Table II:** Answers to the question: Who do you trust the most: the Western doctor, the church or the traditional healer?

Provider of treatment/healing methods	Number of respondents
Western doctor/clinic	45.5% (10)
Church	32% (7)
Traditional healer	9% (2)
Traditional healer and church	9% (2)
Church and Western doctor/clinic	4.5% (1)

Mothers identified different causes of the diarrhoea, including teething, heat, wrong food and 'the problem of the fontanelle'. Whereas it was not the purpose of this study to look at the relation between cause of illness and type of health care sought, it became evident that, for mothers who believed that the sunken fontanelle was the cause of diarrhoea, this was believed to be best treated by traditional healing methods. Apart from two respondents interviewed with the QoL instrument, the problem of the fontanelle was raised several times in the individual and group interviews. The sunken fontanelle is a folk illness recognised in many societies across the world.<sup>7</sup> In the community where the present research was done, mothers reported that both healthy and sick children were taken to the traditional healer to receive 'fontanelle' treatment; in some instances as a preventative measure, in other cases to treat the symptoms of babies that already had diarrhoea.

### ***Emotional impact***

There are many factors related to diarrhoea that have a negative impact on the mental wellbeing of the mother. These factors include the stress caused by conflicts around appropriate treatment, complaints of household members regarding the smell and sound, and the additional costs of cleaning material. In addition, 87% (n = 20) of the mothers interviewed with the QoL instrument worried about the wellbeing of their babies. Most were concerned about the baby losing appetite, being weak, vomiting and fainting. A total of 22% (n = 5) felt that the baby was less beautiful now that he/she was sick. Three mothers were afraid that the baby could die from the illness.

### ***Conclusion***

Diarrhoeal disease is a major health problem in resource-poor settings and this study has shown that the undesirable effects of diarrhoea are more than a health issue. Diarrhoea has significant adverse effects on the quality of life of poor households. The lack of space and running water increase the negative impact of diarrhoea on the household markedly. The lack of running water is thus not only a problem in terms of hygiene and organisms, but also in terms of quality of life and the experience of illness. While a safe and effective vaccine against rotavirus diarrhoea could prevent illness and save the lives of many

babies, this study has shown that such a vaccine could also improve the quality of life of low-income households, whose specific conditions, such as crowded housing and limited access to water, make them more vulnerable to the impact of diarrhoea. A vaccine against rotavirus diarrhoea could benefit the households in this research by:

- Reducing the emotional burden of care on the mother;
- Reducing the physical burden of care on the mother; and
- Reducing the financial burden that childhood diarrhoea imposes on households.

It therefore could be argued that a vaccine against rotavirus would be in line with the ethical principles of addressing broader health and development needs and benefiting the individuals participating in the clinical trials and their communities.

#### Note of caution and themes for further research

The findings show how rotavirus vaccines could be an adjunct to the primary prevention approach for diarrhoea diseases in children. A vaccine will not substitute for all the other important requirements for a respectable quality of life, such as love, care, education, healthy nutrition, a regular, safe water supply and good sanitation. It is also important to interpret the findings in conjunction with all other rotavirus vaccine research results, such as clinical trials and cost-benefit studies.

The findings regarding health-seeking behaviour indicate that, for a successful implementation strategy for a vaccine against diarrhoea, one would have to take into account the different beliefs around the causes of diarrhoea and the different stakeholders involved, such as family members, churches and traditional healers. More research is needed to investigate the perceptions of all the stakeholders around a vaccine against childhood diarrhoea and what role the different stakeholders could play in the possible introduction thereof.

This study provides a clear indication that further research into this illness and its serious impact on the quality of life of millions of people is required. Most of the respondents were unemployed women. It would be relevant to conduct a similar study among working mothers to find out how childhood diarrhoea affects their daily life. The findings are also context specific. For a comprehensive picture on the benefits of a vaccine in a specific country, research in other settings is required, such as households in the medium to higher income groups and in families of different religious backgrounds, (gender) norms, values, etc.

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