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Review Article

Nutrition research in rural communities: application of ethical principles

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Abstract

This narrative review focuses on ethics related to nutrition-specific community-based research, within the framework of science for society, and focusing on the rights and well-being of fieldworkers and research participants. In addition to generally accepted conditions of scientific validity, such as adequate sample size, unbiased measurement outcome and suitable study population, research needs to be appropriate and feasible within the local context. Communities' suspicions about research can be overcome through community participation and clear dialogue. Recruitment of fieldworkers and research participants should be transparent and guided by project-specific selection criteria. Fieldworkers need to be adequately trained, their daily schedules and remuneration must be realistic, and their inputs to the study must be recognized. Fieldworkers may be negatively affected emotionally, financially and physically. Benefits to research participants may include physical and psychological benefits, minimal economic benefit, and health education; while risks may be of a physical, psychological, social, or economic nature. Targeting individuals in high-risk groups may result in social stigmatization. The time burden to the research participant can be minimized by careful attention to study procedures and questionnaire design. Potential benefits to the community, fieldworkers and research participants and anticipated knowledge to be gained should outweigh and justify the potential risks. Researchers should have an exit strategy for study participants. For effective dissemination of results to individual research participants, the host community and nutrition community, the language, format and level of presentation need to be appropriate for the target audience.

Keywords: community, community-based, children, ethics, research methodology, public health, nutritional interventions.

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Background

Public health is primarily concerned with the health of populations, rather than individuals, with an emphasis on promotion of health and prevention of disease, usually through the collection and use of epidemiological data. Founded in the sciences of epidemiology and nutrition, community nutrition is defined as a discipline that strives to improve the health, nutrition and well-being of communities (Boyle & Holben 2006). Community-based nutrition research in rural, and often vulnerable, communities is an integral part of public health nutrition programmes. Community-based nutrition research takes place in a community setting, is relevant to the community, requires community involvement (Hills & Mullett 2000) and includes intervention as well as observational/epidemiological studies. Community-based nutrition research is about people (Hills & Mullett 2000), and the ultimate goal thereof is that findings, if positive, be implemented with the target population and improve its nutrition and health status at the broader community level (Kass 2001). It further aims to improve the effectiveness and efficiency of nutrition interventions, within the restrictions of limited resources to improve public health outcomes. Public health nutrition programmes (e.g. national food fortification programmes) are often imposed on people by governments and the implementation thereof should thus be supported by sufficient research evidence (Kass 2001), which necessitates community-based research.

The term community can be defined as 'a group of people who share an interest, a neighbourhood, or a common set of circumstances' (WHO 2002). For the purpose of this paper, the term community is conceptualized along geographical boundaries, particularly rural villages in developing countries. Nutritional and health needs of rural communities are often different from those of their urban counterparts (Fraser & Alexander 2006). Within communities, women and children are nutritionally the most vulnerable (de Pee *et al*. 2010). Children should be included in research only if the research question is age specific, and although they legally cannot consent to participate in research, children do have the right to be protected from harmful influences, abuse and exploitation (Convention on the Rights of the Child 1989). Research ethics in developing countries require special consideration (Benatar 2002). The rural poor are a particularly vulnerable research population as they are generally research naive and frequently confuse research activities with health care delivery (Minnies *et al*. 2008). These communities are vulnerable to research risks such as research being conducted to advance academic careers at the expense of the community; wasting resources by using community-inappropriate methodologies; causing communities to feel overstretched, coerced, or misled; researchers stigmatizing communities by releasing sensitive data without prior consultation; and communities feeling further marginalized by research (Flicker *et al*. 2007).

Research undertaken in resource-poor settings should be socially relevant and provide appropriate benefits. Beneficiaries of the research should be the research participants, the host community and the general society through accumulation of new knowledge (Lairumbi *et al*. 2011). Epidemiological studies provide new information about the causes of disease, they help to identify risk factors and inform policy and programmes. For example, the South African National Food Consumption Survey collected data at the community level and the outcome of this study informed the national food fortification programme (Labadarios 2007). The potential benefit and anticipated knowledge to be gained should outweigh and justify the risks. Communities should never be disadvantaged by the research or be unfavourably affected by the manner in which the results are presented.

Key messages

- Community-based research needs to be socially relevant, feasible for the local environment and conducted within the framework of science for society.
- For the community and research participants to consent to the research, they need sufficient information on the scope of the project, the relevance of the research to the local needs and priorities, the potential benefits and foreseeable risks of the research, as well as the voluntary nature of research participation and the ability to withdraw from the research.
- Recruitment and selection of fieldworkers and research participants should be fair, transparent and guided by project-specific selection criteria.
- Innovative approaches tailored for the target community are needed to improve the quality of the consent process.
- The researcher is ethically obligated to disseminate the study results to the research participants, as well as the host community, and publish the results in scientific journals.

Table 1. Importance of research ethics

Promotes the aims of research (e.g. knowledge, truth, avoidance of error).
Promotes the values that are essential to collaborative work (e.g. trust, accountability, mutual respect, fairness).
Ensures that the researchers can be held accountable to the public.
Helps to ensure the quality and integrity of research and thereby builds public support for research.
Promotes moral and social values (e.g. social responsibility, human rights)

Resnik (2007).

Table 2. Major ethical principles of research guiding community-based research activities

Principle	Examples of application of the principle
Autonomy	Freedom to give or withhold consent to research participation
	Respect for privacy of information
	Maintenance of confidentiality
Non-maleficence	Refraining from inflicting harm upon others
Beneficence	Action intended to benefit or promote the well-being of others
	Acting in the best interest of the population in public health settings
Justice	The moral principle that relates to proper balance among persons or groups

Medical Research Council (2002); Tubbs (2009).

The importance of research ethics is given in Table 1. Ensuring scientific integrity and preventing scientific misconduct is of critical importance. The principles of autonomy, non-maleficence, beneficence and justice should be applied in the planning, execution and reporting stages of research (see Table 2). Conducting research within the frameworks of both society and science requires a balance between the cultural norms within the community and the scientific interest and principles of the researcher. Fair selection of fieldworkers and research participants is guided by the ethical principles that equals should be treated similarly, burdens and benefits generated by activities should be distributed fairly, and all community members within the target population should have an equal opportunity to benefit from research activities (Emanuel *et al*. 2004; Chen *et al*. 2006).

In community-based research, ethics is dynamic and needs to be considered at various levels namely, the (1) larger community in which the research is done (host community); (2) the fieldworkers responsible for the day-to-day activities in the case of an intervention; (3) the research participants; and (4) the fieldworkers collecting research data. Ethical considerations may evolve during the course of the research and unexpected issues need to be dealt with as they arise. The aim of this narrative review was to consider practical application of ethical issues specific to nutrition research in resource-poor rural communities in terms of (1) scientific validity; (2) the host community; (3) fieldworkers; (4) research participants; and (5) the translation and dissemination of results.

Scientific validity

Valid science using community-appropriate methodologies is an ethical requirement. Research protocols should thus be based on scientific evidence, and be technically correct with clearly defined and achievable aims, while, at the same time, placing the welfare of the participants above the interest of science and technology (Emanuel *et al*. 2004). Atienza & King (2002) reviewed methodological issues pertaining to community-based interventions, highlighting the importance of finding a balance between the scientific methodology and factors such as economic and sociopolitical issues that can influence the methodological rigour of the intervention. In addition to generally accepted conditions of scientific validity, such as adequate sample size, unbiased measurement outcome and suitable study population, the study design should be appropriate for the local conditions and be feasible, given the social, political and cultural environment in which it is being conducted (Emanuel *et al*. 2004).

Measuring instruments

Culturally sensitive and age-appropriate research methodology that is appropriate for the local conditions is needed to collect the necessary information to answer the research question, with a balance between the cost of collecting data and the research value of the information collected. The validity of the measuring instrument depends on the context and use.

Community members can therefore make valuable input during the development phase of, for example, questionnaires.

Questionnaires are often administered in the local language, which in most cases is not the language in which it was originally developed. This requires translation of the questionnaires, while retaining the meaning of the original questions. Translating questionnaires is challenging. The cultural context of languages may differ, the meaning and intention of certain words may be understood differently, the syntax of one language has no equivalent in another language, a word in one language has a spread of meanings that does not cover the spread of meanings in another language, and words that can be used figuratively in one language cannot be used figuratively in another language (Griffee 2001). Often the local language does not have words for scientific terms and concepts such as 'meal portion' and 'meal frequency' are not understood (Deitchler *et al*. 2010). Questions that are very similar, for example those used in the Household Food Insecurity and Access Scale i.e. 'not able to eat preferred food', 'eat limited variety of food', and 'eat foods they don't want to', are not only challenging during translation (Deitchler *et al*. 2010), but can also confuse the research participant. Translations need to be verified through either group discussions with community members and/or back translation by an independent person, who knows the local vernacular and who was not involved in the original compilation or translation of the questionnaire. Piloting of questionnaires is critical to ensure that the researcher, fieldworker and participant all understand and interpret the questions in the same way.

Questionnaires that were developed for universal applicability should be adapted to the local context before use. One such example is the dietary diversity questionnaire that was developed by the Food and Agricultural Organization (Kennedy *et al*. 2011). When adapting the dietary diversity questionnaire, input from community members is critical to ensure that the food lists in the adapted questionnaire reflect locally available foods and that locally recognized food names are used. Community members can further provide useful information on ingredients used in local dishes, seasonal availability of certain foods, and local meal customs and terminology.

Suitable study population

Although feasibility and accessibility are important, a suitable study population is not necessarily the most convenient study population for the researcher. The study population is selected based on the research question, expected outcomes and required sample size. The study population needs to have sufficient numbers of potential study participants. For example, if the study requires a sample size of 500 infants between the ages of 6 and 12 months, birthrate can be used to determine the feasibility of a potential study population. If the selected study population is too small and the required sample size is not obtained, the study will not have the power to show significant and representative results, meaning that the time and effort of the research participants were wasted.

For intervention studies to show an impact, the study population needs to be marginally deficient in terms of the outcome indicator. For example, in 2005, 64% of 1- to 9-year-old South African children who participated in a national survey had low serum retinol concentrations, with vast differences among the nine provinces (Labadarios 2007). Thus, those provinces with the highest prevalence of vitamin A deficiency are the more suitable study populations for the evaluation of interventions to improve serum retinol concentrations. KwaZulu-Natal is the province with one of the highest prevalences of vitamin A deficiency in South Africa (Labadarios *et al*. 1995; Labadarios 2007), and a home-garden project focusing on vitamin A-rich vegetables and fruit has shown to improve the serum retinol concentration of the children in a rural village in the province (Faber *et al*. 2002). The study population must however have the means to implement the proposed intervention. For example, in the earlier-mentioned rural village vitamin A-rich vegetables and fruit were not available in the local shops (Faber & Laubscher 2008), and this study population would therefore not be suitable for the evaluation of a social communication strategy promoting the consumption of vitamin A-rich vegetables and fruit, unless accessibility of these vegetables and fruit is addressed.

Community

Community entry

Often, communities are suspicious about research. According to the ethical principles of autonomy, nonmaleficence, beneficence and justice, local stakeholders need to be assured that the research is ethically sound and respectful of local concerns and norms, and not exploitive, and committed at some level to the well-being of the community (Mosavel *et al*. 2005). Effective community entry, establishing trust and a two-way channel of communication between the researcher and the community are critical. A community liaison officer is helpful during negotiations at community level. Researchers need to consult with local stakeholders to gain access to a community, and often community-level consent is as important as individual-level consent. In rural areas in South Africa, for example, consent from the village leader and/or community representatives is needed.

A steering committee, through whom the negotiations with the community are done, will help avoid developing personal friendships or hardships that could lead to unwanted outcomes, reduce conflict of interest and help with continuation within the project. In most instances, the steering committee members are proposed by the community. The composition of the steering committee will depend, firstly, on the community, and secondly, on the intervention. In a community-based growth-monitoring project in a South African rural village with little infrastructure, the steering committee consisted of the headmaster of the primary school, the headman of the village, a traditional healer, the chairperson of a prominent women's organization and the chairperson of the school's governing body (Faber 2002). In another community-based nutrition intervention project, community-based organizations were established before project activities could commence (Faber *et al*. 2009). Instead of new groups or committees; existing groups can be used, if available. For example, in a vegetable garden project negotiations were done through an existing farmer's forum, in collaboration with local government departments (Laurie & Faber 2008).

Community participation

Often there are language, cultural and socio-economic differences between researchers and research participants. Research in rural communities therefore needs to be sensitive to ethnic and cultural differences, and be feasible within the local context. This requires a strong collaborative partnership between researchers and communities, with mutual trust and common goals (Atienza & King 2002). A 'top-down' approach should be avoided. A 'bottom-up' approach allows for collaborative community involvement, infrastructure development and capacity development (Atienza & King 2002). Community participation can be loosely defined as 'the involvement of people in a community in projects to solve their own problems' (WHO 2002). Participation means joint problem solving, joint decision making and joint responsibility (Wallerstein & Duran 2003), according to the ethical principles of autonomy and justice.

Community-based participatory research conducted as an equal partnership between traditionally trained experts and members of a community (Wallerstein & Duran 2003) helps build competencies in communities, and minimizes the likelihood of research that is irrelevant or insensitive to community concerns (Flicker *et al*. 2007). The simplest model of community-based participatory research is for the researcher to work closely with community leaders and representatives, hire community liaisons as research staff, and hold focus groups or educational sessions with community members (Resnik & Kennedy 2010). Mosavel *et al.* (2005) used the community-based participation research model to develop and refine health education and promotion efforts (in a study related to cervical cancer). By doing so, health issues were placed in their social, political and economic context. In nutrition research, the community-based participation research model can be useful in the development of interventions to reduce, for example, the prevalence of obesity. In

Table 3. The benefits of participatory research

Research, education and action are combined
Collective ideas, perceptions and resources are pooled
Dialogue and communication systems keep everyone informed
Issues and ideas from a number of different perspectives are explored
The researcher has an enhanced understanding of sensitive health issues in the community
An environment of collective responsibility which will lead to a commitment to work together in a productive way is created
A sense of ownership helps to build a commitment to change
Recruitment, achieving informed consent and retention can be improved through increased community trust and ownership
Research is brought in line with the perceived and actual needs of the community
Research is brought into line with the circumstances in the community and is culturally appropriate
Communities are brought into line with the realities of resources, data and the scientific base of knowledge
Improved measurement instruments that are cultural sensitive
Development of shared visions can improve sustainability of a project
Can help increase accuracy and cultural sensitivity in the interpretation and dissemination of research findings

Davis & Reid (1999); Munt (2002); Minkler (2005).

South Africa, 55% of the female adult population is either overweight or obese (DOH, Medical Research Council, OrcMacro 2007). However, few overweight black women view themselves as being overweight, and some believe thinness or losing weight is associated with HIV/AIDS. In addition, moderately overweight women are perceived by the community as attractive, and being overweight is associated with respect, dignity and affluence (Kruger *et al*. 2005). Obesity-tolerant attitudes should thus be taken into consideration when developing weight control programmes (Senekal *et al*. 2003) that could potentially be achieved through community-based research participation.

Community-based research should recognize, respect and incorporate the community's distinctive values, culture and social practices (Emanuel *et al*. 2004), and be gender sensitive (Callens & Seiffert 2003). It is important to differentiate between local knowledge and scientific knowledge. Local knowledge is based on people's experience that has been tested over centuries of use, adapted to local culture and environment, and is dynamic and changing. In contrast, scientific knowledge is developed by researchers and academics using a formal scientific approach (Callens & Seiffert 2003). Researchers can gain a better understanding of the nature, local knowledge and perceptions, magnitude, and underlying reasons of nutrition-related problems in the community by using participatory appraisal methods (e.g. problem tree analysis) during the preparation phase of the intervention (Callens & Seiffert 2003).

Problem tree analysis is used to engage stakeholders in a discussion on the perceived causes and effects of a problem, how these are interrelated, the feasibility of research objectives and possible alternative objectives (Callens & Seiffert 2003). Nutrition strategies developed through a partnership between those with scientific and technical knowledge, and those with personal and cultural knowledge ensures that the intervention is both credible and usable, and that the concerns and needs of both the researcher and the community are considered. The benefits of participatory research are summarized in Table 3.

When 'new' technology is introduced, care must be taken to prevent ineffective or harmful interventions in the spirit of the principle of non-maleficence. An example of a counterproductive intervention would be the introduction of high-fat fried products of orange sweet potato (e.g. chips) as part of a food-based approach to alleviate vitamin A deficiency in communities where maternal overweight and obesity are high. Orange sweet potato was one of the crops promoted in a home-garden project in a rural South African village where 50% of 2–5-year-old children were vitamin A deficient, while 64% of the female caregivers were either overweight or obese (Faber *et al*. 2001, 2002). The researcher had the responsibility not to intervene in a way that increases the energy imbalance of the caregivers, but to improve the vitamin A status of the children.

Research activities should never replace existing 'good' activities. When, for example, household production of vitamin A-rich vegetables is promoted, these crops should not replace existing crops that the household is already planting. Also, production and consumption of traditional under-exploited crops with nutritional value should not be abandoned in favour of commercial crops.

Community-based research interventions are resource driven and have a limited lifespan as the researchers withdraw from the area after the final impact evaluation. This is different from service delivery programmes. The research project should have an exit strategy and the researchers should withdraw gradually, making sure that the community is equipped in the best possible way to continue with the project. There is always a possibility that the research will show no positive impact, in which case, the community should be advised not to continue with study activities. This possibility should be considered during the planning stage and strategies to manage such an outcome should be planned in advance.

The principle of non-maleficence also implies that community members or participants should not suffer financially because of participation in the research. Often, the community provides infrastructure for the research project or nutrition intervention, e.g. schools, crèches, health centres and community halls. In some interventions, families will even make their homes available on certain days for project activities. For example, in a community-based growth-monitoring project in a rural village, monthly growth-monitoring sessions were hosted at households that were identified by the community taking into consideration the geographical location, accessibility, number of preschool children in the vicinity of the household, availability of space and the willingness of the mother within the household to participate (Faber *et al*. 2003). Regardless of the site that is used, the research team should always refund the cost for resources used by the project (e.g. water and electricity), and provide the necessary equipment (e.g. cooking utensils, plates, spoons, storage equipment). Where needed, lock-up trunks to store the project equipment should be provided. At the end of the project, some of the project equipment may be offered to the household or community, but unwanted equipment needs to be removed after the project.

Communication/dialogue

Dialogue can be facilitated through large community meetings, meetings with small groups with a similar interest (e.g. group of mothers working in a community garden), and one-on-one communication. Meetings should take place at accessible and appropriate sites and at a suitable time of the day, considering travelling distances and duration of the meeting.

In developing countries, communication between researchers and community members is often challenging because of cultural, language and economic barriers (Benatar 2002). Often, the use of an interpreter is required. Briefing the interpreter before the meeting helps to ensure a fluent flow of information. Communication needs to be clear and understandable, and without the use of scientific terms and acronyms. To be able to consent to the project, the community needs adequate information on what the project hopes to achieve, the relevance of the research to the local needs and priorities, and the potential benefits of the research for the community. The researcher must be transparent about the objectives, inherent benefits and limitations of the project, as unreasonable high expectations or promises are serious constraints on community participation (Jinabhai *et al*. 1997). The researcher must take the community's view into account, and must be open to criticism and new ideas.

Fieldworkers

The term fieldworkers refers to the people who perform the daily activities of community-based interventions (sometimes referred to as project volunteers, health volunteers, community health workers, community mobilizers) as well as those who collect research data through, for example, completing questionnaires through interviewing community members. Selection of fieldworkers needs to be fair, and their rights, safety and well-being need to be protected.

Recruitment of fieldworkers

The recruitment process needs to be transparent and be guided by a set of well-defined selection criteria, which will depend on the nature of the project and the scope of the fieldworkers' responsibilities. Selection criteria are often based on residency, gender, personal characteristics, and educational level (Ndure *et al*. 1999), but the ethical principle of justice should always be applied.

Residency

For intervention projects, recruiting local project volunteers is a key factor for sustainability; it promotes ownership and reduces the risk of fieldworker attrition (Ndure *et al*. 1999). Local fieldworkers are known to the community, and they are also familiar with the community. However, personal conflict with fellow community members could jeopardize the project. The selection process and management of fieldworkers are often driven by the community, beyond the control of the researcher (Campbell *et al*. 2008). As a result, the selection criteria may not be adhered to. For example, in a community-based growth-monitoring project in South Africa, only 27% of the fieldworkers have passed grade 12, which was the recommendation. The low educational level of the fieldworkers was given as a possible reason for the poor fieldworker performance in terms of growth-monitoring practices (Faber *et al*. 2009). Reasons for not complying with the selection criteria may be that there are not enough persons who qualify, pressure from community members to participate, or favouritism within the community. Community preferences can also play a role. A high prevalence of overweight and obesity was observed among community health workers in a black South African township. The community health workers were selected by the community, who regarded overweight women as being healthy and strong (Puoane *et al*. 2005).

When sensitive research data is collected, it may be advisable to recruit data collectors from outside the community. In this case, the researcher also has more control over the selection process, but such fieldworkers may depend on public transport, which is costly and often unreliable. Fieldworkers from within the community may not need transport when they have to do home visits to study participants. Regardless of where they live it is advisable that fieldworkers are from a similar background than the study participants. In a study that explored perceptions on body weight among community health workers in a black township in South Africa, the principal investigator shared the cultural background of the community health workers. As a result, she established a relationship with them, they trusted her and shared information with her that they might not have felt free to tell other people (Puoane *et al*. 2005). The same may apply for fieldworkers.

Gender

The type of research data collected as well as the gender and age of research participants will affect the gender preference for fieldworkers. When collecting data on, e.g. breastfeeding, dietary intake and food preparation, female data collectors are preferable. In an infant feeding trial (Faber *et al*. 2005), fieldworkers visited the mothers of the infant at home frequently to monitor compliance. In this specific case it was not acceptable for male fieldworkers to visit the mothers at home, unless they were accompanied by a female fieldworker.

The existence of gender dynamics within communities was illustrated in a community-based intervention to support health volunteers in a rural area in South Africa. Although almost all of the project's health volunteers were women, two of the only three male health volunteers carried most of the project leadership responsibilities. Poor communication between the female and male volunteers resulted in uncertainties among the female volunteers regarding their roles and responsibilities (Campbell *et al*. 2008).

Personal characteristics

A community-based fieldworker should be compassionate and sensitive, and have empathy with community members, without getting emotionally attached, and not favour particular individuals or groups within a community. Whereas technical skill can be taught, the love for working within communities is inherent to people's characteristics.

When it is required from fieldworkers to walk long distances in rugged terrain (e.g. in mountainous rural areas), physical ability needs to be a selection criterion. Persons who are obese, or have, for example, knee or back problems, are often not suitable to fulfil the role of community-based fieldworkers. It can also be debated whether obese fieldworkers can be employed as health promoters in nutrition intervention research.

Educational level

Project-related tasks will require certain skills and capacities and therefore a basic level of education. The fieldworkers will acquire additional skills through project-specific training. Skills required may include social mobilization, data collection methods, negotiation and specific skills related to the project, e.g. weighing of children.

Training and supervision of fieldworkers

Fieldworkers need to be adequately trained not only in specific project-related activities, but also in communication skills, and the importance of privacy and confidentiality. Adequate training and supervision of fieldworkers will avoid careless errors and negligence. The importance of adequate training is highlighted in a review by Ashworth *et al*. (2008) that reported that growth-monitoring programmes with good outcomes spent a considerable amount of time training and supervising their health workers, while little time was spent on training in poorly performing programmes. Training of fieldworkers also helps to increase the community's confidence in the fieldworkers (Campbell *et al*. 2008).

Fieldworkers acquire new skills through project-specific training, and gain knowledge and experience that will help them in future work. Providing the fieldworkers with a certificate stating the training received and activities done during the study will help them in future when applying for work. It has been argued that project volunteers can apply the skills and confidence acquired towards improving their own as well as their family's well-being (Rifkin 1996).

Remuneration of fieldworkers

Remuneration is the most obvious benefit for fieldworkers. Remuneration and incentives are critical for successful community nutrition programmes (Mason *et al*. 2006). Disagreement on remuneration of fieldworkers can be a serious constraint. As stated by Campbell *et al.* (2008), 'The ability of volunteers to deliver optimally effective services will be dramatically limited unless remuneration arrangements and support structures are put into place'. The ethics and feasibility of expecting persons from poor communities with limited economic and employment opportunities to work for free has been questioned (Ndure *et al*. 1999). According to the South African policy on community health workers, volunteers should not be employed by more than a few hours per week without remuneration (Schneider *et al*. 2008).

When fieldworkers are employed for the duration of the study by, for example, a research or academic institution, they need to work not only within the framework of science and society, but also within the conditions of service of the institution. It is therefore important that remuneration, leave arrangements, reimbursement of out-of-pocket expenses, and any benefits (e.g. lunch) be contractually agreed upon before the study commences, to avoid negative feelings among fieldworkers and adverse effects on study activities.

Working conditions

Expectations regarding the fieldworkers' daily activities must be realistic, taking into consideration local conditions of the study area. Factors that will determine the number of households that each fieldworker can visit per day include the ruggedness of the terrain, the distance between households, the equipment that they need to carry, and time of the day that is suitable for the households.

In some cases, research projects make use of existing infrastructure. For example, community-based randomized infant supplementation and feeding trials were done through an existing community health worker programme (Faber *et al*. 2005; Smuts *et al*. 2005). In such cases, it is important not to overload the community health workers with project activities, as these are normally done in addition to their normal daily activities.

The safety of fieldworkers is of utmost importance. In some areas, this requires that fieldworkers need to work in pairs; this will slow down the process and has budgetary implications. Any type of uniform or team wear, even T-shirts with a study logo helps to make the fieldworkers identifiable in the community and also helps to create team spirit. Providing fieldworkers with a basic uniform can help to build their confidence and increase their self-esteem (Campbell *et al*. 2008).

The fieldworkers' working environment must be conducive to good performance. This can only be achieved if the community is aware of the role of the fieldworker. For example, in an integrated nutrition project, some parents did not come with their children to the growth-monitoring sessions and only saw the project volunteers working in the clinic garden. The project volunteers had the perception that the parents regarded them as gardeners and did not believe that they had the skills to weigh the children (Faber *et al*. 2009). In another project, the project health volunteers felt that the collaboration between them and the mothers could have been better if the mothers had a better understanding of the volunteer's role in the project (Laurie & Faber 2008).

Epidemiological studies often necessitate working long hours under difficult circumstances of extreme weather in rural areas. Such work is physically demanding and may even cause additional expenses by the fieldworkers, such as buying umbrellas, sun screen, warm clothes or extra cold or hot drinks. Fieldworkers may be affected emotionally by children crying when blood samples are taken or measurements are done. If the research participants are severely affected by the disease studied, such as AIDS, their health condition and prognosis may cause emotional distress to fieldworkers who get to know them personally and work closely with them over the study period (Campbell *et al*. 2008). Fieldworkers who are involved in studies focusing on AIDS may experience stigmatization because of their involvement in these projects. Perceived HIV stigma, including both the stigma that nurses enact and also the stigma that they experience as a result of their work, was reported to be the strongest predictor of job dissatisfaction of nurses in five African countries. To improve nurse job satisfaction in Africa, stigma experienced by the nurses needs to be addressed (Chirwa *et al*. 2009). The same principle will be applicable to fieldworkers involved in research.

All human beings have a sense of self-worth and value recognition, even for performing the most basic tasks. In nutrition research, it is sometimes expected from the fieldworkers to perform unpleasant tasks, such as collection of urine or stool samples, and it may easily happen that they feel unappreciated. This was reflected in community health workers' perception that their contribution fundamentally lacked recognition in the eyes of the health care staff and communities (Schneider *et al*. 2008). It is therefore important that fieldworkers receive recognition for their inputs to make a study possible.

Research participants

Recruitment of research participants

According to the principle of justice, the selection of research participants should be equitable, without exploiting vulnerable groups or individuals. The recruitment and selection process needs to be transparent, appropriate for the study population, based on the research question of the specific project, and guided by clearly defined inclusion and exclusion criteria. The selection process should consider the time burden, cost incurred to travel to the research site and time of the day that the research participant is available, particularly in cases where the individuals are employed. Out-of-pocket expenses such as, for example, travel costs must be reimbursed, and the process must be transparent, consistent, and agreed upon at the beginning of the project.

It is permissible to compensate participants for their time and inconvenience of participation. The extent of this compensation must be reasonable and consistent. Often, incentives, rather than cash, are used. Incentives should be fair and acceptable, should be meaningful and of value to the participants, and be consistent with local practices. Compensation, either in the form of cash or incentives, should not be so attractive as to unduly influence a potential participant's decision to participate in the study. This is particularly important in poor populations, as the promise of cash compensation or excessive incentives may introduce unfair coercion and be the reason why a person consents to participate in a study he/she would not be comfortable doing otherwise (McKeown & Weed 2002).

Community-based nutrition interventions often target high-risk groups as research participants, for example people living with HIV/AIDS, people with tuberculosis, those who are obese, and so on. Identifying individuals as belonging to a high-risk group may result in social stigmatization and changed self-perception (Chirwa *et al.* 2009). All members of research teams should thus be sensitized about stigma to ensure that potential participants are not excluded from research projects or experience stigmatization enacted by researchers. Stigmatization may be prevented to some degree if the targeting is performed by self-identification, but such a strategy will often lead to very inefficient targeting (Holm 2007). Research often targets high-risk groups because it is cost-effective. Unless high-risk groups can be so precisely defined, identified and targeted that all high-risk individuals in the study population are included, the ethical principle of justice (equal cases should be treated equally) is a potential problem (Holm 2007). In some cases, the research intervention targets the whole population. This type of intervention may affect some individuals negatively in order to benefit others. This is justified only if the benefits (e.g. reduction in obesity and its health effects) outweigh the negative effects (e.g. inducing unnecessary lifestyle changes by non-obese individuals) (Holm 2007).

Informed consent

Obtaining appropriate and freely given informed consent (and assent where applicable) from each research participant before research information is collected protects the basic human rights of the research participants. Even though the village leader and/or community representatives granted permission for the research to be done in the community, individuals have the right to decide for themselves whether they would like to participate. Researchers need to respect their decision should they decide not to participate. Consent should be voluntary, without coercion, inducement, manipulation or intimidation. Coercion may take the form of excessive incentives, social pressure, use of authority figures or playing upon perceived vulnerability of the person (McKeown & Weed 2002). Research participants should be able to withdraw without repercussions.

Ethical and legal elements of a valid consent process are (1) disclosure of information sufficient to make a reasonable decision; (2) understanding of the information that is provided; (3) capacity to consent; and (4) voluntariness (Dhai 2008). Consent must therefore be sufficiently informed and given by a competent person.

Although informed consent is a communication process between the researcher and the participant, often, research participants ask little or no questions (Joubert *et al.* 2003). People in resource-poor rural areas and those with lower education levels were shown to be less likely to ask questions during the consent process (Rajaraman *et al.* 2011). Good, quality informed consent was shown to be associated with higher levels of education of respondents and experience of staff obtaining the consent (Minnies *et al.* 2008). The use of more innovative approaches has been suggested, such as for example using pictures and stories to make the consent process more accessible and meaningful for research participants and to raise the level of research literacy within the community (Rajaraman *et al.* 2011). Informed consent can further be improved through community-based participatory research, using locally translatable concepts (Minkler 2005), avoiding technical terms and scientific jargon, and by employing trusted community leaders to convey information to people in local communities (Resnik 1998). The THUSA (*THUSA* is an acronym for transition and health during urbanization of South Africans) survey included participants from diverse rural and urban areas and trained fieldworkers were able to convey information in 10 of the 11 official languages spoken in South Africa (Vorster *et al*. 2000). Minnies *et al.* (2008) reported that the quality of informed consent was not affected by the language used.

The research participant must have the *capacity/competence* to understand the information given and reach a reasonable decision. Four levels of competence are needed namely the ability to (1) communicate choices (2) understand relevant information upon which the choice is made; (3) appreciate the situation according to ones values, and (4) weigh various values to arrive at a decision (Dhai 2008). The research participants must therefore be able to weigh information received along with his/her needs, goals, and interests, and reach conclusions that reflects his/her values and best interests (Tubbs 2009). There are some indications that research participants in rural areas of low socio-economic status tend to overestimate research benefits. An abridged form of self-assessment by participants has been suggested to improve the general understanding of research concepts such as voluntary participation and confidentially (Minnies *et al*. 2008).

Disclosure means that the research participant is given sufficient information to make a reasonable informed decision. The participant needs to be informed about the nature, duration, purpose, and scope of the study; procedures that will be administered; anticipated benefits and disadvantages (if any); foreseeable risks, dangers and complications; personal benefits (to investigator and participants); any inconvenience or discomfort; and information regarding the voluntary nature of research participation, alternatives to research participation, and the ability to withdraw from the research (Medical Research Council 2002; Chen *et al*. 2006). In randomized controlled trials, the potential research participants need to understand that they will be randomly allocated to a treatment group, and that they have an equal chance to be in the control group without knowing it. They also need to understand what it means to be in the control group.

Participants may not be able to continue getting the research intervention (e.g. treatment) after the research study ends, even if positive results were found, because it is not otherwise accessible (e.g. fortified biscuits, sprinkles, etc.). Some research participants may get access to care that they do not get otherwise, but may once again not be able to get any care once the study ends. If the study is designed with these features, it is critical that participants are aware of them from the start of the study. In such cases, at least these individuals experienced the benefits of the intervention with resultant health benefits for the duration of the study. It is advisable that a control group, who did not receive the benefits of an intervention, receive the intervention for at least some time once the study ends. In a community-based randomized controlled trial, babies in the control group received unfortified porridge for the duration of the study, vs. fortified porridge received by babies in the experimental group (Faber *et al*. 2005). Babies in the control group received a 6-month supply of the fortified product after completion of the intervention period. In some cases, the term ‘delayed intervention group’ may be preferable to ‘control group’, indicating that one group will not receive the active intervention during the study, but will receive the intervention after the end measurements have been done.

The Council for International Organizations of Medical Sciences (CIOMS 2002) guidelines include that ‘before undertaking research in a population or community with limited resources, the sponsor and the investigator must make every effort to ensure that any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community.’ Paragraph 19 of the Declaration of Helsinki states that ‘At the conclusion of the study, every patient entered into the study should be assured of access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study.’ The World Medical Association General Assembly recommends that post-trial access by study participants to prophylactic, diagnostic or therapeutic procedures should be identified during the study planning process (Singh 2011). In practice, it may not be possible to ensure access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study, but an exit strategy must at least be included during the planning stage of any project.

In vulnerable communities, consent is mostly obtained on a one-to-one basis. For illiterate participants, it may be necessary to read consent forms out loud. In the THUSA survey in South Africa, illiterate participants could not sign the informed consent forms, but 'signed' with a cross on the consent form (Vorster *et al*. 2000). Fingerprints can also be used. It is important that the fieldworker who informed the participant and a witness sign the consent form.

Parental consent is needed for children who are included in research projects. Shilling & Young (2009) highlighted the complexities parents face in giving proxy consent for their children to participate in research, particularly in clinical trials. Rajaraman *et al*. (2011) suggested that both parents are involved in the informed consent process. However, parents cannot decide and force a child to participate (Mystakidou *et al*. 2009). The research must therefore make adequate provision for soliciting the assent from children. Children under five are nutritionally vulnerable and are therefore often targeted for nutrition research. Although these children are too young to give written or verbal assent, their body language during research procedures can be used as a proxy for assent. Children who do not cooperate during research procedures such as, for example, weight and height measurements and blood sampling should be excluded, even if their parents gave consent.

Collecting data from research participants

If the principles of autonomy, non-maleficence and justice are applied, research participants will be protected from demeaning or disrespectful actions or situations (McKeown & Weed 2002). Some measurements may be perceived as invasive, for example waist circumference measurements or household food inventories. During such investigations, the researcher and fieldworker should be sensitive not to embarrass the participant and act in a highly professional way. To ensure confidentiality of information about research participants, they should be interviewed away from people. Anonymity is less likely in community-based research, as most of the research procedures are face-to-face, e.g. interviews and anthropometric measurements. Participant codes should be used and names discarded when no longer needed.

Potential risks for research participants may be physical harm (e.g. bodily harm, inconvenience of data collection), psychological harm (e.g. emotional suffering because of anxiety, breach of confidentiality), social harm (e.g. employment, social discrimination) and economic risks (e.g. financial costs related to participation) (Karlberg & Speers 2010). The research methodology and process should not be unduly demanding on participants. To minimize the time burden to the research participant, the research methodology should focus on the research question, with careful attention to study procedures and questionnaire design. Collecting unnecessary but 'nice to have' information should be avoided. The length of the interview should be limited. Data collection should be scheduled at a time of the day and date that is suitable to the research participant. If the mother needs to go to a central research site, she will most probably need child care. On the day of data collection, participants should be scheduled in such a way that the waiting time is short. This may be difficult to achieve in rural communities where participants usually do not adhere to scheduled appointment times. Research participants should however not wait for the research team to arrive.

Potential benefits to the research participant include physical benefits (e.g. improved health), psychological benefits (e.g. feeling of helping others in future), minimal economic benefit (financial benefits related to participation) (Karlberg & Speers 2010) and health education. Research participants with abnormal findings, e.g. severe anaemia are referred for treatment to the nearest health facility (Faber *et al*. 2005; van Jaarsveld *et al*. 2005). The referral must be in line with the treatment protocol of the health facility, and criteria for referral must be defined in the project protocol. Health professionals at the health facilities should be informed beforehand by the researchers of the nature of the study and to expect referrals from the study.

Monitoring and recording of compliance are an integral component of clinical trials such as feeding trials. Research participants in feeding trials, especially children may not be forced to consume the food, and they may not be punished when not eating. Community-based feeding trials in smaller children add the ethical dilemma of children whose parents did not consent for blood sampling. These children will find it difficult to understand if they were excluded from the feeding as well. In a randomized controlled feeding trial, 5–10-year-old school children were fed either orange or white sweet potato, where after the usual school meal was served (van Jaarsveld *et al*. 2005). Non-participating children were not excluded from the feeding, but received white sweet potato similar than children in the control group. Foods used in feeding trials should always be culturally acceptable, with acceptable taste and feasible portion size.

Translation and dissemination of results

Community-based research data needs to be interpreted, understood and used within the local parameters of where, how and why it was collected. Research integrity requires objectivity with regards to experimental design, data analysis and data interpretation. Results of small localized case studies cannot be generalized. Research results should be widely disseminated in a timely and credible manner, in a language, format and level of presentation that is appropriate for the target audience without censorship or interference of, for example, the funder. The researcher is morally obligated to disseminate the study results to the research participants, as well as the host community. When doing so, their literacy level need to be considered and the scientific results must be translated into a form that is understood and can be applied by the community. Access to services (e.g. electricity) and technology (e.g. computers) will affect the method of dissemination. In rural areas and small communities, identification of the research participants becomes more likely, and the estimated risks and benefits of the effects of publishing the results needs to be weighed (Fraser & Alexander 2006). Research findings should be presented in a manner that will not have an unfavourable effect on any individual.

Research imposes, at the very least, the burden of inconvenience on those who participate. Generally ethics committees approve research because of the benefits expected to emerge from the study findings. If no benefits accrue from the research (the research findings were either not published or not translated to contribute towards public health policy or practices), harm occurs as participants were wronged through a misleading (albeit not deliberately so) informed consent process (Kass 2001).

Challenges

Community-based research always comes with its unique challenges. Often the challenges are project and area specific, given that such research is often done in vulnerable communities. The challenges may include expectations that are created by project activities (e.g. asking questions on food shortages in the household may create the expectations of handouts). When researchers enter a community, there is an expectation on the part of the community that some benefit will result; communities may become disillusioned if expected benefits are not realized. Research activities in rural areas are more difficult to control than research done in well-resourced laboratories and metabolic units. Human behaviour, weather conditions and unexpected external factors affecting the community are some of the challenges facing researchers doing community-based research. These challenges should be managed through communication throughout the planning, implementation and feedback stages of research projects. Community-based research done with full participation of the community according to ethical principles should generate knowledge that can improve the health of the study population and contribute new knowledge to benefit the scientific community. If these ethical principles are followed in community-based research, it will render the research meaningful; it will benefit the communities and will make their participation worthwhile.

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The authors declare that they have no conflicts of interest.

Contributions

MF initiated and drafted the paper. Both authors contributed towards the intellectual content and approved the final version.

References

Ashworth A., Shrimpton R. & Jamil K. (2008) Growth monitoring and promotion: review of evidence of impact. *Maternal & Child Nutrition* **4**, 86–117.

Atienza A.A. & King A.C. (2002) Community-based health intervention trials: an overview of methodological issues. *Epidemiologic Reviews* **24**, 72–79.

Benatar S.R. (2002) Reflections and recommendations on research ethics in developing countries. *Social Science & Medicine* **54**, 1131–1141.

Boyle M.A. & Holben D.A. (2006) *Community Nutrition in Action*. p 4. Thomson Wadsworth: Belmont, CA.

Callens K. & Seiffert B. (2003) *Participatory Appraisal of Nutrition and Household Food Security Situations and Planning of Interventions from a Livelihoods Perspective*. Food and Agricultural Organization: Rome. Available at: http://www.fao.org/docrep/006/ad694e/ad694e00.htm (Accessed 23 October 2009).

Campbell C., Gibbs A., Maimane S. & Nair Y. (2008) Hearing community voices: grassroots perceptions of an intervention to support health volunteers in South Africa. *Journal of Social Aspects of HIV/AIDS* **5**, 162–176.

Chen D.T., Jones L. & Gelberg L. (2006) Ethics of clinical research within a community-academic partnered participatory framework. *Ethnicity & Disease* **16**, 118–135.

Chirwa M.L., Greeff M. & Kohi T.W. (2009) HIV stigma and nurse job satisfaction in five African countries. *Journal of the Association of Nurses in AIDS Care* **20**, 14–21.

Council for International Organizations of Medical Sciences (CIOMS) (2002) *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Prepared by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO), Geneva. Available at: http://www.cioms.ch/publications/layout_guide2002.pdf (Accessed 12 September 2011).

Convention on the Rights of the Child (1989). Available at: http://www.unesco.org/education/pdf/CHILD_E.PDF (Accessed 05 April 2012).

Davis S.M. & Reid R. (1999) Practicing participatory research in American Indian communities. *American Journal of Clinical Nutrition* **69**, 755S–759S.

de Pee S., Brinkman H.J., Webb P., Godfrey S., Darnton-Hill I., Alderman H. *et al.* (2010) How to ensure nutrition security in the global economic crisis to protect and enhance development of young children and our common future. *Journal of Nutrition* **140**, 138S–142S.

Deitchler M., Ballard T., Swindale A. & Coates J. (2010) *Validation of a Measure of Household Hunger for Cross-Cultural Use*. Food and Nutrition Technical Assistance II Project (FANTA-2), AED: Washington, DC.

Department of Health (DOH), Medical Research Council, OrcMacro (2007) *South Africa Demographic and Health Survey 2003.* Department of Health: Pretoria. Available at: http://www.mrc.ac.za/bod/sadhs2003part1.pdf (Accessed 30 January 2012).

Dhai A. (2008) Informed consent – 2008. *South African Journal of Bioethics and Law* **1**, 27–30.

Emanuel E.J., Wendler D., Killen J. & Grady C. (2004) What makes clinical research in developing countries ethical? The benchmarks of ethical research. *Journal of Infectious Diseases* **189**, 930–937.

Faber M. (2002) *Community-based Growth Monitoring in a Rural Area that Lacks Health Facilities*. PhD thesis. University of Stellenbosch.

Faber M. & Laubscher R. (2008) Seasonal availability and dietary intake of β-carotene-rich vegetables and fruit of 2-year-old to 5-year-old children in a rural South African setting growing these crops at household level. *International Journal of Food Sciences and Nutrition* **59**, 46–60.

Faber M., Jogessar V.B. & Benadé A.J.S. (2001) Nutritional status and dietary intakes of children aged 2–5 years and their caregivers in a rural South African community. *International Journal of Food Sciences and Nutrition* **52**, 401–411.

Faber M., Phungula M.A.S., Venter S.L., Dhansay M.A. & Benadé A.J.S. (2002) Home gardens focusing on the production of yellow and dark-green leafy vegetables increase the serum retinol concentrations of 2–5-y-old children in South Africa. *American Journal of Clinical Nutrition* **76**, 1048–1054.

Faber M., Phungula M.A.S., Kvalsvig J.D. & Benadé A.J.S. (2003) Acceptability of community-based growth monitoring in a rural village in South Africa. *Food Nutrition Bulletin* **24**, 350–359.

Faber M., Kvalsvig J.D., Lombard C.J. & Benadé A.J.S. (2005) Effect of a fortified maize-meal porridge on anemia, micronutrient status, and motor development of infants. *American Journal of Clinical Nutrition* **82**, 1032–1039.

Faber M., Schoeman S., Smuts C.M., Adams V. & Ford-Ngomane T. (2009) Evaluation of community-based growth monitoring in rural districts of the Eastern Cape and KwaZulu-Natal provinces of South Africa. *South African Journal of Clinical Nutrition* **22**, 185–194.

Flicker S., Travers R., Guta A., McDonald S. & Meagher A. (2007) Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. *Journal of Urban Health* **84**, 478–493.

Fraser J. & Alexander C. (2006) Publish and perish: a case study of publication ethics in a rural community. *Journal of Medical Ethics* **32**, 526–529.

Griffee D.T. (2001) *Questionnaire Translation and Questionnaire Validation: Are They the Same?* Paper presented at the annual meeting of the American Association for Applied Linguistics, St Louis, MO, February 24–27, 2001. Available at: http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/19/6e (Accessed 22 April 2009).

Hills M. & Mullett J. (2000) *Community-based Research: Creating Evidence-based Practice for Health and Social Change*. Available at: http://www.leeds.ac.uk/educol/documents/00001388.htm (Accessed 07 March 2012).

Holm S. (2007) Obesity interventions and ethics. *Obesity Reviews* **8** (Suppl. 1), 207–210.

Jinabhai C.C., Mametja D., Coovadia H.M. & Gouws E. (1997) Development of a health programme in a peri-urban informal settlement in Besters, KwaZulu-Natal. *South African Medical Journal* **87**, 741–746.

Joubert G., Steinberg H., Van Der Ryst E. & Chikobvu P. (2003) Consent for participation in the Bloemfontein vitamin A trial: how informed and voluntary? *American Journal of Public Health* **93**, 582–584.

Karlberg J.P.E. & Speers M.A. (2010) *Reviewing Clinical Trials: A Guide for the Ethics Committee*. Available at: http://issuu.com/cliniversity/docs/ecguide-2010311 (Accessed at 13 July 2011).

Kass N.E. (2001) An ethics framework for Public Health. *American Journal of Public Health* **91**, 1776–1782.

Kennedy G., Ballard T. & Dop M. (2011) *Guidelines for Measuring Household and Individual Dietary Diversity*. Nutrition and Consumer Protection Division, Food and Agriculture Organization of the United Nations: Rome. Available at: http://www.foodsec.org

Kruger H.S., Puoane T., Senekal M. & Van Der Merwe M.T. (2005) Obesity in South Africa: challenges for government and health professionals. *Public Health Nutrition* **8**, 491–500.

Labadarios D. (ed.) (2007) *National Food Consumption Survey – Fortification Baseline (NFCS-FB): South Africa, 2005*. Department of Health: Pretoria.

Labadarios D., Van Middelkoop A.M., Coutsoudis A., Eggers R.R., Hussey G., Ijsselmuiden C. *et al.* (1995) *Children aged 6-71 months in South Africa, 1994: their anthropometric, vitamin A. iron and immunization coverage status*. South African Vitamin A Consultative Group: Isando.

Lairumbi G.M., Michael P., Fitzpatrick R. & English M.C. (2011) Ethics in practice: the state of the debate on promoting the social value of global health research in resource poor settings particularly Africa. *BMC Medical Ethics* **12**, 22. Available at: http://www.biomedcentral.com/1472-6939/12/22

Laurie S. & Faber M. (2008) Integrated community-based growth monitoring and vegetable gardens focusing on crops rich in β-carotene: project evaluation in a rural community in the Eastern Cape, South Africa. *Journal of the Science of Food and Agriculture* **88**, 2093–2101.

Mason J.B., Sanders D., Musgrove P., Soekiman & Galloway R. (2006) Chapter 56. *Community health and nutrition programs*. In: *Disease Control Priorities in Developing Countries* (eds. D.T. Jamison, J.G. Breman, A.R. Measham, G. Alleyne, M. Claeson, D.B. Evans, *et al.*), 2nd edn, pp 1053–1074. Oxford University Press: New York.

McKeown R.E. & Weed D.L. (2002) Ehtics in epidemiology and public health II. Applied terms. *Journal of Epidemiology & Community Health* **56**, 739–741.

Medical Research Council (MRC) (2002) *Guidelines on Ethics for Medical Research: General Principles*. Medical Research Council: Cape Town. Available at: http://www.mrc.ac.za

Minkler M. (2005) Community-based research partnership: challenges and opportunities. *Journal of Urban Health* **82** (Suppl. 2), ii3S–ii12S. doi:10.1093/jurban/jti034.

Minnies D., Hawkridge T., Hanekom W., Ehrlich R., London L. & Hussey G. (2008) Evaluation of the quality of informed consent in a vaccine field trial in a developing country setting. *BMC Medical Ethics* **9**, 15. doi:10.1186/1472-6939-9-15. Available at: http://www.biomedcentral.com/1472-6939/9/15

Mosavel M., Simon C., Van Stade D. & Buchbinder M. (2005) Community-based participatory research (CBPR) in South Africa: engaging multiple constituents to shape the research question. *Social Science & Medicine* **61**, 2577–2587.

Munt R. (2002) Building community participation. *Stronger Families Learning Exchange Bulletin* **2**, 3–5. Available at: http://www.aifs.gov.us/sf/pubs/bull2/rm.html (Accessed 22 January 2009).

Mystakidou K., Panagiotou I., Katsaragakis S., Tsilika E. & Parpa E. (2009) Ethical and practical challenges in implementing informed consent in HIV/AIDS clinical trials in developing or resource-limited countries.

Journal of Social Aspects of HIV/AIDS Research Alliance **6**, 46–57.

Ndure K.S., Sy M.N., Ntiru M. & Diène S.M. (1999) *Best practices ad lessons learners for sustainable community nutrition programming*. Academy for Educational Development (AED).

Puoane T., Fourie J.M., Shapiro M., Rosling M., Tshaka N.C. & Oelofse A. (2005) 'Big id beautiful' – an exploration with urban black community health workers in a South African township. *South African Journal of Clinical Nutrition* **18**, 6–15.

Rajaraman D., Jesuraj N., Geiter L., Bennett S., Grewal H.M.S., Vaz M. & Trials T.B. (2011) How participatory is parent consent in low literacy rural settings in low income countries? Lessons learned from a community based study of infants in South India. *BMC Medical Ethics* **12**, 3. Available at http://www.biomedcentral.com/1472-6939/12/3

Resnik D.B. (1998) The ethics of HIV research in developing nations. *Bioethics* **12**, 286–306.

Resnik D.B. (2007) *What is Ethics in Research and Why is it Important?* National Institute of Environmental Health Sciences. Available at: http://www.niehs.nih.gov/reseacrh/resources/bioethics/whatis.cfm (Accessed 10 September 2011).

Resnik D.B. & Kennedy C.E. (2010) Balancing scientific and community interests in community-based participatory research. *Accountability in Research: Policy and Quality Assurance* **17**, 198–210.

Rifkin S.B. (1996) Paradigm lost: toward a new understanding of community participation in health programmes. *Acta Tropica* **61**, 79–92.

Schneider H., Hlophe H. & Van Rensburg D. (2008) Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. *Health Policy Planning* **23**, 179–187.

Senekal M., Steyn N.P. & Nel J.H. (2003) Factors associated with overweight/obesity in economically active South African populations. *Ethnicity & Disease* **13**, 109–116.

Shilling V. & Young B. (2009) How do parents experience being asked to enter a child in a randomised controlled trial? *BMC Medical Ethics* **10**, 1. Available at: http://www.biomedcentral.com/1472-6939/10/1

Singh J.A. (2011) The challenge of discharging research ethics duties in resource-constrained settings. *PLoS Medicine* **8**, e1000421.

Smuts C.M., Dhansay M.A., Faber M., Van Stuijvenberg M.E., Swanevelder S., Gross R. *et al*. (2005) Efficacy of multiple micronutrient supplementation for improving anemia, micronutrient status, and growth in South African infants. *Journal of Nutrition* **135**, 653S–659S.

Tubbs J.B. (2009) *A Handbook of Bioethics Terms*. Georgetown University Press: Washington DC.

van Jaarsveld P.J., Faber M., Tanumihardjo S.A., Nestel P., Lombard C.J. & Benadé A.J.S. (2005) β-carotene-rich orange-fleshed sweet potato improves the vitamin A status of primary school children assessed with the modified-relative-dose-response test. *American Journal of Clinical Nutrition* **81**, 1080–1087.

Vorster H.H., Wissing M.P., Venter C.S., Kruger H.S., Kruger A., Malan A.T. *et al*. (2000) The impact of urbanization on physical, physiological and mental health of Africans in the North West Province of South Africa: the THUSA study. *South African Journal of Science* **96**, 505–514.

Wallerstein N. & Duran B. (2003) The conceptual, historical and practical roots of community based participatory research and related participatory traditions. In: *Community Based Participatory Research for Health* (eds M. Minkler & N. Wallerstein), pp 27–52. Jossey Bass: San Francisco, CA.

WHO (2002) *Community Participation in Local Health and Sustainable Development. Approaches and Techniques*. Available at: http://www.euro.who.int/__data/assets/pdf_file/0013/101065/E78652.pdf (Accessed 10 September 2011).