

YOUNG CHILDREN AFFECTED BY HIV & AIDS: A CASE STUDY OF THEIR PERCEPTIONS OF THEIR QUALITY OF LIFE

Angela A. James

University of KwaZulu-Natal, Durban, South Africa

E-mail: jamesa1@ukzn.ac.za

Abstract

In South Africa currently many young children have challenges in social, educational, emotional and biological aspects. Many young children live in a context where there is a high prevalence of HIV positive adults and children, high poverty and unemployment. This research is an exploration of the children's perceptions of their quality of life and their ideas of what it should be. A qualitative, case study research design was used. The sample consisted of seven children who attended a Drop In-Centre, which is a community place where an adult mother figure cares for the two to five year old children during the day and the six to fifteen year old children, before and after school. A questionnaire was administered to capture the children's biographic data and semi-structured interviews provided data on their understanding of their quality of life. The findings indicate that the children have access to school and are acutely aware of their particular context and situations. Also, their overall perceptions of their quality of life at the Drop In-centre are positive but mostly negative for their home life. Children require both material and non-material needs in their homes. The children would experience extensive problems on all fronts, especially for those that live in child-headed homes, if the centres were not there to provide some of their basic needs.

Key words: children's understanding, quality of life, orphans, HIV and AIDS.

Introduction

Early Childhood Development (ECD) is a broad term that includes reference to the policies and practices that focus on the development of children from birth to nine years of age. According to the White Paper 5, the Education and Training Policy document (2001, p. 9), "early childhood development is an umbrella term that applies to the processes by which children from birth to at least nine years grow and thrive, physically, mentally, emotionally, spiritually, morally and socially." The development of young children is viewed in a holistic manner in that all the human facets are considered, but, for children from deprived contexts this development could be compromised.

In many developed and developing countries the provision of basic needs to children is recognized as a right for all children. The World Declaration on the Survival, Protection and Development of Children, agreed to by many nations at the World Summit of Children in 1990, focused on the rights of children "to give every child a better future" (United Nations Committee on Education, 1990, p. 1). The early years for children are critical for their development later on in life. According to the White Paper 5 policy document, quality education in South Africa, and "educational efficiency would improve as children would acquire the basic concepts, skills and attitudes required

for successful learning and development” (2001, p. 8). Essentially, all the above-mentioned policies were concerned with an integrated approach to the cognitive, social, emotional and psycho-social development of children (Education White Paper, 2001).

All South Africans, especially children’s rights are recognized in the constitution. All South Africans are constitutionally “afforded certain basic socio-economic rights such as the rights to have access to health care services; social security; sufficient food and water; adequate housing and a safe environment” (Statistics, South Africa, 2010, p. 1). Children are further protected by these rights in that “additional protection afforded to children includes the right to basic nutrition, shelter, basic health care services, social services and protection from abuse and neglect” (Statistics, South Africa, 2010, p. 1). Approximately three-quarters of children in South Africa fall into the African race group and a quarter live in the KwaZulu-Natal province (Statistics, South Africa, 2010), the province in which this research was conducted. The context of many African children in South Africa is further illustrated:

An estimated 3, 6 million South African children are either maternal, paternal or double orphans. In addition to this biological parents play a limited role in raising their children. Less than a third (32%) of South African children live with both their biological parents and a quarter of children do not live with either of their biological parents (Statistics, South Africa, 2010, p. 3).

This creates a situation where many children are expected to live on their own in child-headed homes or supported by community members or organizations.

Currently, many government or community-based facilities in South Africa cater for children who are orphaned or vulnerable. In this research the children attend a community-based non-governmental organization (NGO), the Community outreach Centre, which operates as a Drop In-Centre. The local meaning of Drop In-Centres describes it as a place that the children attend where they receive support with provisions of food, clothing and health care needs. According to the *housemother*, “the Drop In-Centre provides the children with basic needs, most importantly food because most of the children are from child-headed homes and they do not have anyone to look after them.” In these households, only the elder brother or sister takes care of the siblings. Even though child-headed households “make up a very small proportion of all households in South Africa (0,6%), their proportion has remained virtually unchanged during the past 8 years, possibly indicating that more needs to be done to create safety nets for them” (Statistics South Africa, 2010, p. 3). It is therefore possible that many of these children experience living conditions that only a social worker or a community volunteer is aware of, not the general public. Since minimal research had been conducted on the conditions that the children experience, this was the gap in the scientific literature that required attention. The research questions that drove this research were:

1. What are the children’s perceptions of their present quality of life and how could these be changed?
2. Why do the children have these particular perceptions?

Related Work

The literature presents an understanding of the concept of child in the context of vulnerability. Since the research focuses on a child rights perspective with a focus on the positive side of child well-being (OECD, 2009, p. 25) approach to issues confronting children, the concept of quality of life is explored according to the the meaning and approach adopted.

The concept of child used in this article is a person who is under 18 years of age (Meintjies, Hall, Marera & Boulle, 2009, p. 40). Different types of vulnerable children are present in the community, therefore these meanings are explored. Paternal is linked to the death or of no knowledge of the father, maternal to the death or no knowledge of the mother and orphan includes both meanings (UNAIDS, 2006). Vulnerability would also include children who do not have a stable home environment due to the inability of parents to provide for this or the absence of parent figures (UNAIDS, 2006). This meaning is extended to include sociological aspects by Richter, Manegold & Pather (2004) in that these children are affected by the “ensuing deterioration of services, the weakening of social institutions

and face high levels of stress” (p. 3). They further state that many care-givers of the children are too ill to continue to look after them and the children live with very old and frail caregivers (Richter *et al.*, 2004). In this article the concept of orphans and vulnerable children (OVC) as those that live in child-headed homes, where the older sibling looks after them. Orphans and vulnerable children is a serious problem in KwaZulu-Natal, a province in South Africa. According to Statistics South Africa (2010, p. 8) just “under a fifth (19, 5%) of all children in South Africa, are orphaned. Approximately 30% of all orphans can be found in KwaZulu-Natal.” Moreover many of these children have to fend for themselves in the child-headed homes. The household size of “child headed households can range from 45% with 1 child to 0.7% with more than 9 children in the household” (Statistics South Africa, 2010, p. 8). The older sibling takes on the duties of a parent, where possible. The children in these settings are exposed to a number of socio-economic challenges, which impact on their access to education, food and shelter.

Quality of life is a “complex and multidimensional phenomenon which needs to be viewed holistically.” (Kironji, 2007, p. 16). This phenomenon has a historical trajectory in its origin and meaning. It can be traced back to 1964, the United States President Lyndon Johnson stated, “the great society is concerned not with how much but with how good, - not with the quantity of goods but with the quality of their lives” (Noll, 2004, p. 3). Moller (2006) defines quality of life as how well the citizen’s of a country live. Quality of life may be defined as the set of non-monetary attributes of individuals, shapes their opportunities and life chances, and has intrinsic value under different cultures and contexts (OE,CD, 2011, p. 5). In the light of the context of this research the meaning that Lane (1996) aspires where quality of life is not a state but a process with both subjective and objective elements with the active role of personal experience is adopted. Two subjective based elements, “(1) a sense of well-being and (2) personal development, learning growth... The objective element is conceived as quality of conditions representing opportunities for exploitation by the person living a life” (Lane, 1996, p. 259). This takes a more sociological approach where subjective and objective measures (mixed) criteria, which are linked to the living conditions of a person. This approach is different from the economically, statistically driven approach which focuses on income and expenses.

Living conditions is a broad term that encompasses different aspects that constitute the living or lifestyle of an individual. According to Kironji (2007, p. 325), “low levels of education and employment status among household heads strongly influence household quality of life” and the living conditions of individuals. Hence, the focus is on the way people live to meet basic needs. Since in this research it is children’s needs that are the focus, these needs cannot be equated to the needs of adults and are specific to their particular situation (Witt, 2001). Addressing needs is a fundamental component in understanding living conditions (Najemy, 2010). Children in ideal contexts would be such that they have parents and live in a resourced home where they are comfortable and whose basic needs, e.g. shelter, food, security and protection not in need of any basics.

Six dimensions of child well-being or quality of life are identified “to cover the major aspects of children’s lives: material well-being, housing and the environment, education, health, risk behaviours, and quality of school life” (Organization for Economic Cooperation and Development, 2009, p. 28). Children’s ideal living conditions meet material and non-material needs. The material needs are: livelihood, food security and availability of adequate shelter. It also includes health, which is concerned with increased or average nutritional status, providing attention to children when they are sick, to be immunized and to have access to health services. Education, is also included in this categorization - access to education, they should not skip school except for when they have legitimate reasons, and they should be exposed to many vocational opportunities after schooling (OECD, 2009). The non-material needs include protection, welfare and emotional health, in that adequate adult supervision, where social interaction, enough affection and encouragement, and respect are shown (OECD, 2009).

Children in different social contexts will undoubtedly have different living conditions. Vulnerable children in all contexts have inadequate care or support because they do not have the family structure or suitable adults to look after their well-being and ensure that they have suitable living conditions. OVC in child-headed homes live in conditions that are on average worse than those in mixed generation households. They are less likely to live in formal dwellings, or to have adequate

sanitation and water on site. This, in some ways could be because they are located outside of cities where better services are available (Statistics South Africa, 2010). These children are faced with a number of problems and these can occur in domains of material problems affecting poverty, food security, education and health, as well as non-material problems related to welfare, protection and emotional health (Richter *et al.*, 2004). There are different reasons for the impact of different factors on the living conditions of these children: decreased access to quality food and nutrition, quality education and healthcare due to lack of money, understanding and action necessary for access.

Research on children's perceptions on the living conditions suggests that these are plagued with methodological aspects. Sommer, Samulesson and Hundeide (2010) state that the 'descriptions of children's perceptions on living conditions do not qualify as child perspectives because they are often anchored on adults perceptions' (p. 22). In exploring children's perceptions their experiences and understanding of their living conditions in their lives is the purpose. It is imperative that the research focuses on the child as a subject in his or her own world and expresses his or her opinion without it being interpreted by adults' experiences and perspectives. Adults should attempt to understand the child's world through the child's eyes or lived experiences without impounding their own preconceived ideas of what the child's perceptions are on his or her particular living conditions (Sommer *et al.*, 2010).

Methodology of Research

The study is framed by an interpretive paradigm. It is an interpretive study, because as researchers, interpreted the data, in a particular context and at a particular time. As interpretive research seeks to understand what the children's perceptions of their quality of life is (living conditions are) and why this is the case. We analysed the interviews to see meaning embedded in these texts (de Vos, Strydom, Fouche & Delpont, 2002).

The research approach is a one of qualitative methods of data collection and analysis. The children's questionnaires on their living conditions, their understanding of good/bad living conditions, and why they have these understandings were analysed qualitatively. While data were collected from more than one child, various sources of data were used to obtain in-depth information about a particular context, a particular case of living conditions (Punch, 2009). The researcher aimed to capture the reality of the participants' lived experiences of, and understandings of a particular situation (Cohen, Manion & Morrison, 2000). While the children came from different homes (households), they all attended the Drop In-centre.

All the school going children under ten years of age who attended the Drop In-centre, seven in total, were selected. The focus of the research was on young children, hence the age limit. The children were given consent forms that were completed by a parent or guardian figure (the housemother at the centre was also given approval from the Outreach centre to sign the consent letters).

Data were collected using two instruments, a questionnaire and a semi-structured interview for children.

Questionnaire

The children's questionnaire was designed to collect biographic information. Questions on the age and gender of the children and discrimination against the children were included. There were also questions about the children's experience of and the changes that could be made at the Drop In-Centre. Since the children are Zulu-speaking and second language English teachers, the questionnaire had to be translated into isiZulu. Children responded in their mother tongue and their responses were translated by an isiZulu speaking translator. The translator was taken through the questionnaire beforehand and was very familiar with the questions in the instrument.

Interview

The questions in the interview explored the children's living conditions, their understanding and experiences of it. The questions were about the actual location of the homes, the types of structures

of their homes, the number of members in the home and the access to electricity, water and sanitation resources. Questions about the way in which children could make changes to their environment to increase their food security were also included.

The questionnaire and interview are fit for the purpose as they were designed with the research questions in mind. All data collected served the purpose of answering the research questions. A limitation of the study may be the fact that little triangulation occurred as the two different instruments produced different data and answered different questions. The fact that children were interviewed individually ensured that they were not influenced by each other.

Data Analysis

The data was analysed, using the six dimensions for well-being or quality of life. The data was read, entered into electronic form and categorized by placing the responses into the categories as stated by the material and non-material needs of learners. The material needs of food security and availability of adequate shelter were considered. The non-material needs considered included, welfare (who they lived with) and emotional health, with regard to social interaction (OECD, 2009).

Results of Research

The findings are reported in two parts: Firstly, children’s responses to the questionnaire and secondly the children’s responses to the interview questions. The questionnaire was divided into four main questions and the results are reported in table 1 below. One part deals with the biographic and discriminatory information about the children and the second part deals with the children’s perception of the Drop In-Centre. The results from the two sections serve to answer research question one and two. Table one presents the results for the questionnaire.

Table 1. Children’s biographic information, discriminatory information and perceptions of the Drop In-centre.

Pseudo-name	Gender	Age (in years)	Do you have friends, how many do you have?	Do you enjoy being at the centre? Why?	Do you think that there is a need for gardens at the centre? Why?
Senzo	M	5	Yes, 7 friends	Yes, food and attention	No
Simo	M	7	Yes, more than 10	Yes, food and play with others	Yes, to get food
Sipho	M	4	Yes, five friends	Yes, food	Yes, to get food
Zama	F	5	Yes, six friends	Yes, food and play with others	Yes, to get healthy food
Zandi	F	4	Yes, four friends	Yes, food and attention	Yes, to get food
Sanele	M	5	Yes, five friends	Yes, food and play with others	Yes, to get food
Zandile	F	5	Yes, three friends	Yes, food and play with others	Yes, to get food

The results show that children in the group comprised both girls and boys, ranging in age from 4 7 years of age. The responses to the question on if the children had friends were answered positively by all the children. This question was asked because it was said by the housemother that ‘the children have a stigma about coming to the Drop In-centre and in some cases are discriminated against by other children who do not attend the centre’. The question about whether the children enjoyed being at the centre was a sensitive one as the children seemed uneasy when they were asked the question. The children were assured that their responses were confidential and it was important that they gave

a true response. All the children stated that they enjoyed being at the centre. All the children gave the access to food as an important factor for their enjoyment. Two children also indicated that their enjoyment was attributed to the attention that they received at the centre, while four children enjoyed playing with their peers at the centre. Six children agreed that there was a need, while one child did not see the need to have food gardens at the centre.

When the children were asked to explain what quality of life (living condition) means, their responses could be placed in three categories: place, environment in which they live (three children); situation around them (one child) and hardships they are facing (three children). Table 2 below depicts the childrens' understanding of their quality of life and their state of living at home.

Table 2. Understanding of what forms part of quality of life and the state of living at home.

Pseudo-name	Understanding of what forms part of quality of life						State of living at home		
	Food	Money	House	Clothes	Car	Care	Not good	No money	No food
Senzo	x	x	x			x	x		
Simo	x	x					x		
Sipho	x	x		x		x	x		x
Zama	x		x	x			x		
Zandi	x	x	x	x		x	x	x	x
Sanele	x	x	x		x		x	x	x
Zandile	x	x	x		x		x		

The aspects that form part of the quality of life for the children are food, money, a house, clothes, a car and care. All the children consider food, six children considered money and five children considered a house to be a part, three children stated care, while a car is the one that only two children stated. The basic needs of food, shelter and care were included in the list but not by all the children. Simo, though only saw food and money, while Zama saw food, a house and clothes as part of the living conditions. All the children stated that their living at home was not good. Two children stated that it was because there was no money and no food, while a third child said it was because of a lack of food.

The children's responses to the interviews expressed their understanding and experiences of their quality of life at home and this provides further data on their living at home. The details of these are indicated in table 3 below:

Table 3. Children's experiences of their quality of life at home.

Pseudo-name	Who do you live with and how many people in the home	I live in a...	We get water from	Do you have electricity?	I do chores at home
Senzo	Grandmother 4	House	tap in the house	Yes, use a paraffin stove and candles	sometimes
Simo	Sibling 2-3	Shack	community tap	Yes, use a paraffin stove and candles	sometimes
Sipho	Aunt 6-9	Shack	community tap	Yes, use a paraffin stove and candles	sometimes

Pseudo-name	Who do you live with and how many people in the home	I live in a...	We get water from	Do you have electricity?	I do chores at home
Zama	Aunt 6-9	Hostel	community tap	Yes, use a paraffin stove and candles	sometimes
Zandi	Sibling 2-3	House	tap in the house	Yes, use a paraffin stove and candles	sometimes
Sanele	Sibling 2-3	Shack	community tap	Yes, use a paraffin stove and candles	always
Zandile	Sibling 2-3	Shack	community tap	Yes, use a paraffin stove and candles	sometimes

The results indicate that one child lives with his grandmother, two with an aunt and four with siblings. The number of family members is more than four for all the family members except one. Zandile lives in a shack with her two siblings, while Zama lives with her aunt in a hostel with over six family members. Only two children lived in a house but these were houses with and just three rooms, which are kitchen, bedroom, lounge/dining room and an outside toilet/bathroom. Access to potable water in a home is rare for many homes. If electricity is fitted in the homes and shacks, then this would be the type that you use coupons to pay for it. Since electricity is expensive, all the children and their members use an alternative source for cooking – a paraffin stove and an alternative source for light – candles. As there are duties cleaning the house/shack and clothes, many children are expected to carry out this duty. Another duty was fetching water from the communal tap for use in the home.

Discussion

The results show that the children have particular perceptions of their quality of life re living conditions at the Drop In-centre and at home as linked to their social, economic, emotional and biological perceptions of living conditions. Exploring the living conditions at the centre indicated the reasons for why they attended, which was mainly for a biological need for all – food, a social need – play and an emotional need – attention for some of the children. These reasons were independent of the age and gender of the children. What was significant was that the children engaged in gardening activities at the centre so that they could learn how to do this and grow their own food at their homes, thereby increasing their knowledge and skill on how to grow their own food, thereby increasing their access to quality food and nutrition (Richter *et al.*, 2004). Senzo, was the only child who did not see the need to have a garden, since the dust irritated his sinusitis, a medical reason was given.

The children’s understanding of what forms part of living conditions clearly indicates the importance of a number of aspects, mainly food in their lives. If they did not lack food then it probably would not have been stated by all the children. Food is a basic necessity for life and all the children attended the centre for food (a meal). The meals that they received were nutritionally balanced and at least they could be able to practice healthy habits linked to feeding (Najemy, 2010). The inclusion of money as a part of living conditions is due to the fact that there was a lack of it and the children saw the possession of money as a possible solution to their conditions. The thinking was that if you have money you can buy food and the other necessities like clothes. The children all stated that their living conditions at home were not good and the main reasons given were the lack of food and money. These children wore shoes that had holes in them and on a cold day some of them did not even have a proper jersey/jacket to wear.

Quality of life onditions can also be described in terms of the type of structure that you live

in, members in the family, is it an adult or sibling responsible for you and access to resources like water and electricity. Since this context is such that there is a high prevalence of HIV positive adults and children, high poverty and unemployment, the living conditions are clearly not the ideal. Many family members would be living in one place so that they can share the minimal resources that they have. It is an amazing 'sharing in poverty' experience that makes it possible for them to sustain their lives. The lack of employment, low education levels and the impact of HIV, death of parent are some of the factors that definitely compromise the living conditions of the children. The fact that using a paraffin stove is so dangerous in causing fires, children getting burnt and the death of people does not stop the use of this resource since paraffin is accessible and is a cheap fuel.

The finding of this study raises the issue of the necessity for the national departments of social welfare to take responsibility for supporting the development of young children. The National grant system for young children is in place but many children do not receive the grants because they do not have the required documentation for this access. While the community organizations (centres) are doing the best that they can with support from various donors and sponsors, there are still so many children who cannot attend the centres because they cannot be accommodated. The development of more centres to contain this problem is not a solution. What is required is a holistic approach where education and job opportunities are available to adults and community upliftment projects are conducted by members of the community, government organizations and community organizations in and around the area.

Conclusions

The findings indicate that these children require both material and non-material needs in the living conditions at home. If the centres were not there to provide these needs these children would be experiencing extensive problems on all fronts, especially those that live in child-headed homes. Even during the holidays when the children do not attend the centre they can fetch food parcels to take home so that they do not go hungry. Their most basic need is met and this is how these children live.

Even though this study on young children had a limited sample size, the voices of the children are present. They clearly have ideas about their quality of life and the possible changes that could enhance it. The children saw the purpose of a vegetable garden at the centre but their engagement in developing one at their homes would require the input of persons at home. This would be a challenge for the children from child-headed homes, but not one that could not be overcome with proper guidance and support from community members.

The government should take note of these children's voices as it has a responsibility towards its citizens in terms of the implementation of a democratic culture. South Africa is nineteen years into democracy but the constitutional rights of these children are still not met or provided for by the government. The role of these NGOs are crucial for providing the children with a very basic quality of life, in a particular context.

References

- Cohen, L., Manion, L., & Morrison, K. (2000). *Research methods in education*. London: Routledge Falmer.
- Department of Education (2001). *Education White Paper 5 on Early Childhood Education*. Meeting the Challenge of Early Childhood Development in South Africa. Pretoria: Government Press.
- De Vos, A. S., Strydom, H., & Delpont, C. S. L. (2002). *Research at Grassroots for the social sciences* (2nd ed.). Pretoria: Van Schaik Publishers.
- Hassink, W., & Kliver, H. (2007). Age-dependent Effects of Socio-economic Background on Educational Attainment - Evidence from Germany. *Discussion Paper Series / Tjalling C. Koopmans Research Institute*. Retrieved on 20 October 2012 from <http://igitur-archive.library.uu.nl/CTK/2008-1126-201328/UUindex.html>.
- Lane, R. E. (1996). Quality of life and quality of persons: A new role for government? In pursuit of the quality of life, edited by A. Offer. 256-293. New York: Oxford University Press.

- Meintjes, H., Hall, K., Marera, D., & Boulle, A. (2010). Orphans of the AIDS epidemic? The extent, nature and circumstances of child-headed households in South Africa. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 22 (1), 40-49.
- Najemy, R. E. (2010). *Our Children's Needs*. Retrieved on 22 October 2012 from <http://www.healthychild.com>.
- Organisation for Economic Co-operation and Development (2009). *Doing Better for Children*. Retrieved on 20 October 2012 from <http://www.oecd.org/els/familiesandchildren/doingbetterforchildren.html>
- Organization for Economic Cooperation and Development. (2011). Better Life Compendium of OECD Well-being Indicators. Retrieved on 26 April 2013 from <http://www.oecd.org/els/family/43570328.pdf>
- Punch, K. F. (2009). *Introduction to Research Methods in Education*. London: Sage.
- Richter, L., Manegold, J., & Pather, P. (2004). *Family and Community Interventions for Children Affected by AIDS*. Capetown: HSRC Press.
- Sommer, D., Samulesson, I., & Hundeide, K. (2010). *Child Perspectives and Children's Perspectives in Theory and Practice*. New York: Springer.
- Statistics, South Africa (2010). Social profile of South Africa, 2002–2009. Report No. 03-19-00 *Annual Report 2010/11*. Retrieved on 20 October 2012 from <http://www.statssa.gov.za>.
- United Nations Committee on Education (1990). *Plan of Action for Implementing the World Declaration on the Survival, Protection and Development of Children in the 1990s*. USA: UNICEF.
- UNAIDS (2006). Report on the impact of HIV/AIDS on Children. Retrieved on 23 October 2012 from <http://www.unaids.org/imp/hiv>.
- Witt, J. A. (2001). *Children's Needs, Societal Consequences*. Retrieved on 23 October 2012 from <http://www.angelfire.com>.
- Republic of South Africa (1996). The Constitution of the Republic of South Africa. Act No. 108 of 1996. *Government Gazette*, 378 (17678) - 18 December 1996. Cape Town: Government Printer.
- UN General Assembly (1989). Convention on the Rights of the Child. United Nations, Treaty Series, 1577:3. Retrieved on 8 October 2012 from <http://www.unhcr.org/refworld/docid/3ae6b38f0.html>.

Advised by Judita Stankutė, SMC "Scientia Educologica", Lithuania

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