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**Citation:** Frood, S., Ricks, E. & van Rooyen, D. (2023). The Development of a Conceptual Framework for the “Steps of Progression Strategies” to improve care and support to children who have become AIDS orphans and who are living in township communities in South Africa. *International Journal of Child Health and Human Development*, 16(1), pp. 53-72.

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# **The development of a conceptual framework for the “Steps of Progression Strategies” to improve care and support to children who have become AIDS orphans and who are living in township communities in South Africa**

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## **Abstract**

Orphanhood is a major consequence of the AIDS pandemic in South Africa. Most children who are living as AIDS orphans in township communities experience recurrent psychological trauma, a lack of care and support, and much suffering. Aim: The development of a conceptual framework upon which the “Steps of Progression” strategies were developed for primary health care nurses, social workers, and psychologists to improve care and support to children living as AIDS orphans in township communities in Gqeberha, South Africa. Methods: This conceptual framework was developed using the Survey List of Dickoff, James and Weidenbach. Data to develop this conceptual framework was collected from an in-depth literature search, to determine the legislative and policy frameworks influencing the South African Government’s policies concerning these vulnerable children, and from in-depth interviews with primary health care professional nurses (n = 10), social workers (n = 8) and psychologists (n = 6) who provide care and support to these children. Results: The results from the in-depth literature review and empirical data enabled the development of this conceptual framework. The four aspects of the procedure part of this conceptual framework were identified as: strengthening the existing legislative and policy frameworks in which the primary health care nurses, social workers, and psychologists practice; enhancing the resilience of these professionals; enabling interdisciplinary collaboration; and the facilitation of an empowering work environment. These became the essence of the “Steps of Progression” strategies which were subsequently developed. Conclusions: This conceptual framework enabled the development of the ‘steps of progression strategies’ which could improve care and support to these vulnerable children.

**Keywords:** Development, conceptual framework, strategies, care, support, AIDS orphans, townships, South Africa

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## Introduction

Children living as AIDS orphans in township communities in South Africa live uncared for and unsupported (1). In 2017, an estimated 12.6% of the total population of South Africa (56.5 million) was HIV positive (2). Although recent statistics are lacking, there is significant variation in HIV prevalence across the nine provinces in South Africa. The Eastern Cape Province, where Nelson Mandela Bay formally known as Port Elizabeth (PE) and now known as Gqeberha is situated, reportedly had an average prevalence rate among pregnant women of 30.4% in 2013 (3).

The HIV burden on children is twofold. Firstly, if they contract HIV, they suffer direct morbidity and, even if they do not, they may suffer the consequences of parental ill health and possibly bereavement. It is estimated that the HIV/AIDS pandemic affects approximately 280, 000 South African children from the age of 0 to 14 years (4). If HIV is left untreated, morbidity and mortality because of opportunistic infections such as tuberculosis, pneumonia, and severe bacterial infections is high. This is especially the case in Sub-Saharan Africa, where essential resources for adequate testing and treating both HIV and its resultant co-morbidities and child-friendly prevention programs are often lacking (5).

An important consideration when developing interventions to provide care and support to children who are living as AIDS orphans in township communities is the conceptualisation of what is required to help policy makers and primary health care nurses, social workers and psychologists meet the complex and unique needs of these vulnerable children. Health and social care policy makers in South Africa have been motivated by a 'top down' approach, often driven by ambiguous policy targets that are rooted in international law ratifications, such as the Convention of the Rights of the Child, and through the Bill of Rights Section 28 of the South African Constitution and the South African Children Act of 2005.

In 2011 research was conducted by the Children's Institute at the University of Cape Town; Funding of services required by the Children's Act. High implementation of this Act, defined as "good practices and norms for all services," would cost \$5.92 billion

(6). The Eastern Cape was allocated 3% of the budget necessary for high implementation the Act by the Department of Social Development (6).

The gap between policy and service delivery is significant. The need for a conceptual framework informed by the 'lived experiences' of primary health care nurses, social workers and psychologists caring for and supporting these children, was seen as necessary so that interventions for these vulnerable children could be developed using a 'bottom-up' approach to inform policy interventions that would meet the unique needs of these children. The approach to developing this conceptual framework was considered vital as it was based on 'lived' rather than perceived experiences and provided a solid base for the development of the strategies" (7).

The conclusion of a study by Frood et al. (7) was that these professionals experienced complex challenges in operationalising the care and support response initiatives mandated by health and social care legislations in South Africa, resulting in different forms of anguish and challenges in providing care and support for these AIDS orphans. Although health and social care interventions for such vulnerable children are comprehensively provided for in government legislation and regional government policy, the mobilisation of the required responses remains inadequate, resulting in the professionals in this study indicating the need for the development of comprehensive strategies to improve care and support for children living as AIDS orphan in township communities in South Africa, Frood et al. (7). This article will present the development of this conceptual framework upon which the so called "Steps of Progression" strategies were developed.

## Methods

The process for developing the conceptual framework was accomplished by, firstly, conducting an in-depth literature review to establish the current international, national, and provincial legislative and policy frameworks concerning the rights of children living in South Africa. This identified the legislative and policy frameworks which guide the PHC (public health care) nurses, social workers, and psychologists in the provision of care and support to children living as

AIDS orphans in township communities in South Africa. Secondly, an empirical study was conducted utilising a qualitative, explorative, descriptive, and contextual study design to establish the experiences of these professionals regarding the care and support provided to children who are AIDS orphans living in townships. In the instance of this article health care professionals will refer to primary health care nurses, social workers and psychologists who provide care and support to children living as AIDS Orphans in township communities in South Africa and children will refer to children living as AIDS orphan in township communities in South Africa.

Ethical approval for the empirical aspect of this study was granted by the ethics committee at the Nelson Mandela University, Ref Number H12-HEA-NUR. Further ethical approval was granted by the Executive Directors from the Departments of Health and Social Development in the Eastern Cape, South Africa.

Data collection involved recording in-depth interviews undertaken with primary health care professionals ( $n = 10$ ), social workers ( $n = 8$ ) and psychologists ( $n = 6$ ) providing care and support to children living as AIDS orphan in township communities. Data were then transcribed verbatim by the researcher and coded by the researcher and an independent coder. The data were analyzed according to the steps suggested by Tesch (8). The data collected from the in-depth literature review and empirical study were used to elaborate the conceptual framework (described below) which identified the key domains upon which the 'Steps of Progression Strategies' were developed. A description of the 'Steps of Progression Strategies' developed using the conceptual framework are not included in this article.

The development of this conceptual framework, using the survey list of Dickoff, James and Wilbenbach (9), will be described in terms of concept identification and analysis, and description of the conceptual framework.

*Concept identification and analysis* are the first steps towards theorising phenomena. Concepts are vehicles of thought which involve images and are important for organising thoughts, allowing a summarised representation of a view of the world

(10). Concepts are also words which describe objects, properties or events and are basic components of theory (11). Since concepts convey different meanings in different theoretical systems, it is important to consider concepts within the theoretical systems from which they are derived and in which they are rooted (12). Concept analysis refers to the approach adopted to identify the main attributes which are fundamental to the definition of a concept or concepts (13).

The concepts used to construct the framework which underpinned the development of the 'steps of progression strategies' were identified from an in-depth literature review and an empirical qualitative study.

## Results

*In-depth literature review.* The aim of the in-depth literature review was to answer the following broad research question: What are the legislative and policy frameworks which guide South Africa Government policy concerning the care and support of children living as AIDS orphans in township communities in South Africa? The in-depth literature review was undertaken using the research platform EBSCO Host.

In-depth reviews do not aim to produce a critically appraised and synthesized results or answers to a question, but to provide an overview or map of the evidence (14). The general purpose of conducting an in-depth review is to identify and map available evidence or literature regarding a topic or concept. Arksey and O'Malley (15) provided four reasons for conducting an in-depth review. They are: 1) identifying and answering the research question, which is generally broad in nature; 2) identifying relevant studies, a process that is as comprehensive as possible; 3) study selection, with the establishment of inclusion/exclusion criteria, based on familiarity with the literature; 4) charting the data, including sifting, charting, and sorting information according to key issues and themes identified in the review (15). Figure 1 presents the overview of the legislative and policy frameworks identified in this in-depth literature review.

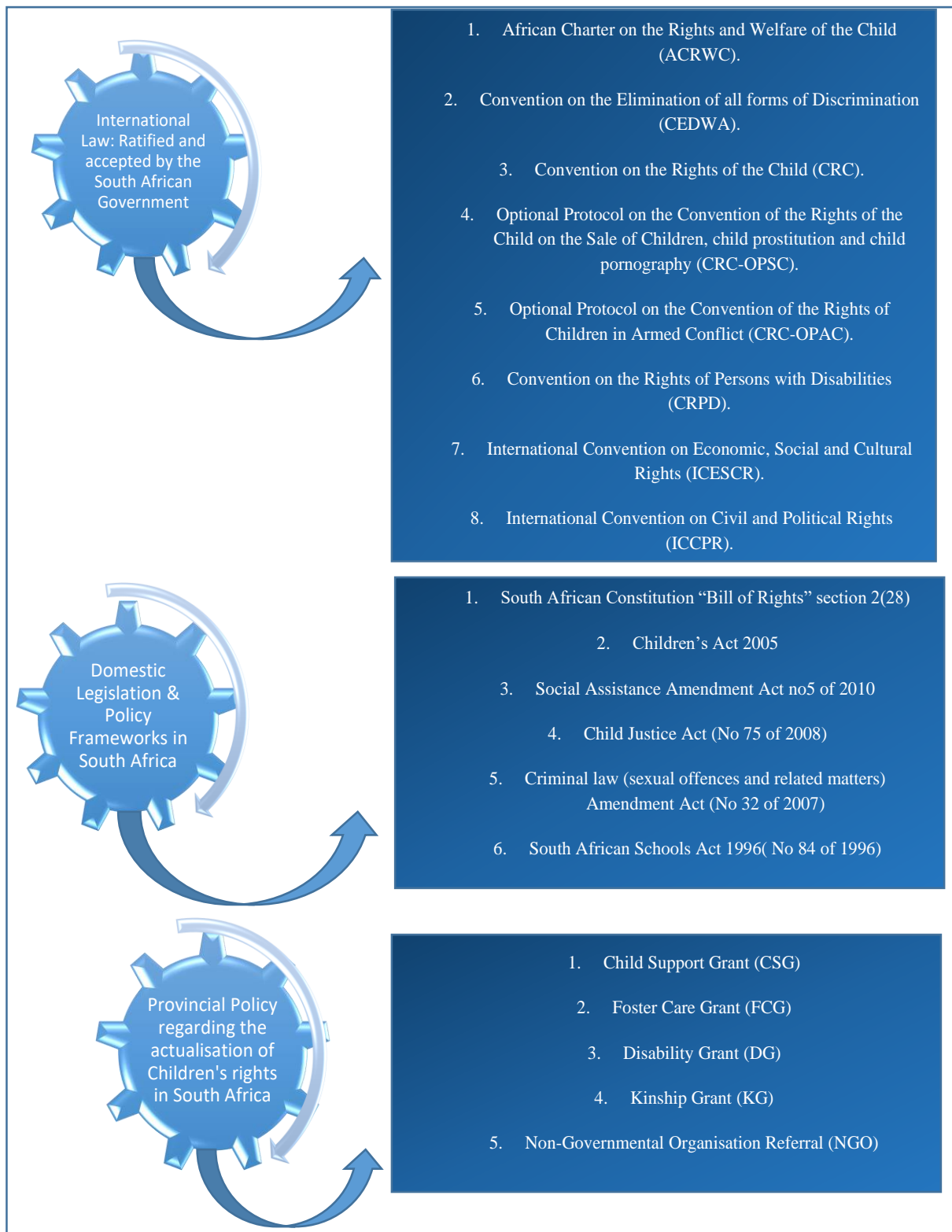


Figure 1. An overview of legislative and policy frameworks concerning children in South Africa, identified in this in-depth literature review.

The key findings of this in-depth literature review are that South Africa has one of the most progressive constitutions in the world and has made significant progress in fulfilling the rights of its children including a system of laws and programmes to ensure the realisation of children's rights through the delivery of services to children. Yet despite the gains made in expanding services, inequalities persist which negatively affect the health and welfare of children who are unable to access the opportunities that are mandated in instruments ratified by South Africa for the fulfilment and realisation of children's rights (16). Fulfilling children's rights through comprehensive service delivery to meet their needs and reduce vulnerabilities is a moral imperative and necessary for the total development of South Africa (Department for Women and Children and People with Disability (17).

The principle of the 'best interests of the child' is a central and all-embracing principle throughout all legislative and policy frameworks concerning children living in South Africa. It stipulates that "in all actions concerning children, the "best interests" of the child shall be the primary consideration" (17). South Africa's ratification of international treaties relating to children's rights obligates the country to ensure that its domestic legislation is in harmony with international laws and commitments. Although the National Plan of Action for Children (NPAC) is developed within the context of these treaties, it is firmly rooted in the provisions of the South African constitution as well as in domestic legislation and policies (17).

What is apparent is that children who are AIDS orphans living in township communities are very vulnerable and most are uncared for and unsupported. This situation requires of policymakers in South Africa to have a child-centred approach when planning and developing government programmes, budgets, and monitoring systems. There is still a need for policymakers to redress the inequalities of the past as well as tackling the substantial barriers that children still face today in accessing care and support to meet their needs as they live in the vulnerable circumstance of being AIDS orphans in township communities (17).

The National Plan of Action for Children (NPAC) 2012-2017 aimed to bring together existing international and national priorities in one coherent framework for the survival, protection, and develop-

ment of children in South Africa. The NPAC provided, within the broader context of the South African Human Rights Framework, a children's rights impetus to national planning, and to the implementation, monitoring and evaluation of national policies. The overall vision of the NPAC is to "put children first" (17), and its mission is "to promote the realisation of children's rights and to mobilise resources on all levels to enable this" (17).

The implementation activities of the strategies in the NPAC are not stated, resulting in implementation of the strategies remaining weak. There is a need to engage with professionals and children's lived experiences to inform the development of interventions designed to actualise children's rights in the homes of very vulnerable children living in township communities, (16). The creation of this conceptual framework and the subsequent development of "Steps of Progression Strategies" gives detail to the ambitious intention of the South African Government to provide care and support to meet the unique needs of these vulnerable children.

## Results

### *Empirical qualitative study*

The empirical qualitative study explored and described the lived experience of primary health care nurses, social workers, and psychologists, regarding their provision of care and support to children living as AIDS orphans in township communities in South Africa. The recommendations made by these professionals for improving care and support of vulnerable children were identified in the data analysis are discussed below.

### *Theme one: Barriers to providing holistic care and support to children*

Professionals highlighted the prevailing challenges they experienced when providing care and support to children who are living as AIDS orphans in townships communities. Professionals further identified a lack of support services for AIDS orphans living in the township communities, which caused them to feel

overwhelmed at times, and to experience severe stress, anger, depression, and fatigue. Professionals felt that lack of health and social support services was not

conducive to the provision of *holistic care and support* to children living as AIDS orphans in these township communities.

**Table 1. Qualitative Data for Theme 1**

Theme One	Qualitative Data
	"I see children in this clinic every day who are destitute. They are hungry cold and not going to school. It's overwhelming to see these children every day because their lives are full of challenges. They tell me what's happening in their lives and all I hear is that no one cares for and supports them, and they are poor, but we must care for these children they are our future" [Interview 8, pg. 5].
	"The only thing I can do for these children when they come to the clinic is to give to them ART. This is not enough, they have many social, financial, and psychological needs. Many of them can't take their ART because they are hungry: when they say there is no food at home there is no food at home. They need to have a psychologist and a social worker to help them also. There are very few NGO's who we can refer them to; we are very lacking in support services for orphans and vulnerable children; that is why our crime is so high in South Africa, we need to do better and give these children a better care" [Interview 10, pg. 2].
	"When I refer families to court to apply for a foster care grant it takes a long time. On average it takes 18 months through our court system in Port Elizabeth. I tell clients however it is likely to take 3 years. I have one client and it has taken 6 years, we must work together with the social workers and psychologist more to help these poor children" [Interview 19, pg. 1].
	"I see a lot of anger in children who are orphans. They kick out and are rebellious; they don't go to school, and they withdraw from relationships, and they don't do their schoolwork. It takes time for me to build relationship with these children. They must learn to trust me, I feel pressure because of that as there are so many of them to see" [Interview 7p.g 1].
	"Children who are orphans have lost an ability to trust adults. They must regain that ability to trust, and it happened through me and other professionals building relationship with them that are honest, caring, and supportive [Interview 14 pg. 10].
	"This clinic I am working in is meant to accommodate 500 clients per month. Its far more than that now. Currently we are 30 nurses seeing 11000-13000 clients per month. It's very frustrating because we don't have the time or the space to give the services that the community needs like privacy and support groups. You can see we lack space. We have containers in the yard we have converted into rooms for some of our ART patients. An NGO gave us those and converted them and put shading up so people don't have to sit in the sun" [Interview 10, pg. 4].
	"One of the reasons for our frustration is that there are not enough people to do the work. That is why when we refer to others it takes time and why the systems are so slow. As a social worker I must oversee 100 cases. How can I possibly do that and do it well? When the needs are overwhelming of the people I am helping, we need more time to address the multiple needs the children have, we must work together more" [Interview 18, pg. 1].
	"I see children who are thin and bullied every day because they are AIDS orphans. You can't hide AIDS in our communities especially when you are an orphan. Because you become so poor so quickly. Its very difficult because these children are stigmatised every day. They are stigmatised before they are orphans because they are caring for their parents who are dying of AIDS" [Interview 6, pg. 2].
	"Sometimes it is not the medication that makes a child well, it's when they have help from social workers and psychologists too. How do we find these professionals in the township communities to really help these children? I try to make referrals, but I simply can't find these people who are part of the multi-disciplinary team" [Interview 7, pg. 3].
	"You know, I sit here. I fill in referral form for a psychologist, social worker, or dietician. In a few months, these forms come back to me. Meanwhile the child has not been seen" [Interview 22, pg. 4].
	"You see, our township communities are poor, very poor especially in the informal settlements. Look out of my window; you see poverty, you see shacks, no running water, people sitting, and people sick and waiting to die. That is what our communities face. That is what children face living in the townships: unemployment, rape, alcoholism, HIV/AIDS we must be strong to help them" [Interview 11, g: 2].
	"It's so difficult to see children suffering I use the word suffering because they do suffer. When they say they have nothing, they have nothing. Many give up on life and don't bother going to school because they are bullied for being AIDS orphans and they feel less than other children. I hear this story every day, but we must be strong and help them" [Interview 21, pg. 13].
	"When I come to this clinic, I must leave my feelings at the door. If I feel too much, I can't help these children; so, it's best that I don't feel. During the day when I see AIDS orphans, I tell myself they belong to God and I do my best and I pray for them and for His angels to watch over them" [Interview 5, pg. 2].

Professionals further conveyed that when children became AIDS orphans, they experienced physical, psychological, social, and financial distress, which was exacerbated by the inefficient referral systems.

Social workers and psychologists who work in satellite offices within the township communities, complained that the overwhelming numbers of children accessing them for care and support made



it impossible to build a *trusting therapeutic relationship* with the children because of insufficient time available to spend with each child thus adding to the distress the children were already experiencing. Most professionals interviewed felt overwhelmed and frustrated that they were unable to have a meaningful *therapeutic relationship* with children due to time constraints, through which the necessary care and support for AIDS orphans could be facilitated. Professionals experienced the absence of people and material resources in the workplace as a constant source of frustration. Further infrastructure constraints at faculty level led to their feeling enervated. This at times undermined the reasons they had to pursue their respective professional careers.

All professionals indicated that children who were AIDS orphans living in the townships and their extended families delayed accessing care and support because the children experienced shame from community stigmatisation of their status as AIDS orphans.

Professionals felt that lack of *interdisciplinary collaboration* hindered the provision of *holistic care and support* to children who were AIDS orphans, resulting in primary health care nurses, social workers and psychologists experiencing frustration and, at times, extreme anger. Professionals reported feeling devalued and misunderstood, as they felt the quantity of work was more important to management than quality.

Professionals also felt that the care and support they gave to AIDS orphans which they presumed added value to these vulnerable children and was a *quality intervention* which took time was not represented in the statistical data appraised by management personnel.

These professionals also experienced a differing work ethic amongst colleagues, which at times caused frustration and tension in their respective places of work. Both intrinsic and extrinsic factors cause this differing work ethic.

Professionals were challenged to understand and facilitate the provision of care and support to AIDS orphans as their “life world” was beyond the professionals’ own life experience and lived reality. The “life world” of children who are AIDS orphans was experienced as being overwhelmingly challenging and deeply sorrowful.

In concluding this theme, professionals’ experiences indicate considerable challenges regarding the *development of their own resilience*. A process of deep reflection and re-evaluation of their “assumptive world” and of personal and professional adaptation was necessary to enable these professionals to develop the required resilience to enable them to make valuable and necessary contributions to caring for and supporting these vulnerable children.

### *Theme two: Health care professionals had unique in experiences in caring for these children*

When children became AIDS orphans, the psychologists expressed that AIDS orphans experienced complicated emotional needs because of the multiple losses they experienced on becoming AIDS orphans. They further indicated that they learned of the psychological distress these children experienced in watching and caring for their parents as they died of AIDS. Psychologists recounted that a child who become an AIDS orphan experiences anger, depression, sadness, and suicidal thoughts. Psychologists, whilst recognising the complicated emotional needs of children who became AIDS orphans, experienced challenges, and stress in establishing a *trusting therapeutic relationship* with them due to intrinsic and extrinsic factors. Psychologists found situational constraints and the complex emotional needs of AIDS orphans as hindrances to establishing a therapeutic trusting relationship. Psychologists experienced listening to the “lament” of children living as AIDS orphans as unbearable, which led to experiences of stress and anxiety. This was further increased by the lack of resources, which left them feeling hampered in assisting children who had become AIDS orphans in processing their grief and developing resilience.

Primary health care nurses used words such as “disgraceful” when describing how children who were AIDS orphans living in the townships experienced care and support. Primary healthcare nurses explained that a critical lack primary health care nurses, social workers and psychologists obstructed the provision of care and support to children who were AIDS orphans living in the township’s communities. Primary healthcare nurses also experienced feeling

overwhelmed and distressed by *the lack of resources and situational constraints* when assisting desperate families caring for children living as AIDS orphans.

Primary health care nurses described feelings of anger because they saw HIV/AIDS causing much suffering and hardship within township communities. They also felt incensed and enraged by the lack of interventions and the lack of capacity within the health

and social care systems to provide care and support to these children. Professionals expressed that the *inadequacy of management* at both a local and provincial level was a hinderance to the care and support the children receive. Primary healthcare nurses expressed distress at how children who were AIDS orphans living in the township communities experience extreme neglect and continued suffering.

**Table 2. Qualitative data for Theme 2**

Theme Two	Qualitative data
	"I feel like I don't understand the world I live in anymore, when I see how children suffer as AIDS orphans. It's wrong how these children suffer it's just wrong," [Interview 1, pg. 5].
	"I found it difficult to sleep in the night when it's raining. I worried about how the children in the township are. I know they are probably hungry and cold; I don't feel good about this. I appreciate more what I have in my home. I don't take things for granted like I used to. I find myself less critical and many times I say to myself: 'I have nothing to worry about' [Interview 20, pg. 8].
	"Mostly children don't talk, it takes time for them to open up, and to share their sense of loss. I think they have lost all sense of being able to trust, particularly to trust adults because they feel let down abandoned and uncared for by them" [Interview 9, pg. 3].
	"When children begin to talk, they give something away of themselves. If I can trust you enough to tell you this, can I trust you to tell you about how I felt as an 8-year-old boy when my mother died" [ Interview 17 pg.]. "It's unbearable at times to listen and to see the psychological distress children experience when they become AIDS Orphans" [Interview 12, pg. 1].
	"There are so many people needing help. Our referral systems simply just aren't enough to cope with the numbers of people. This is very stressful as it means we are unable to give the care and support these vulnerable children need" [Interview 12, pg. 3].
	"Last week I ran a support group for AIDS orphans on behavioral management related to anger. Three young people had to sit on my desk as there were not enough chairs to sit on. I find the lack of resources we must work with very stressful" [Interview 24, pg.4].
	"Most of the children we see in this clinic aren't eating a balanced diet because of poverty in their homes. It's so distressing to see hungry children. We can't do anything about this because we haven't enough resources" [Interview 5, pg. 3].
	"We fill in forms we apply for milk powder; we fill in forms for food parcels but still nothing comes the government is doing nothing for these AIDS Orphans nothing. And what is worse there are many of them" [Interview 11, pg. 4].
	"The main thing that children who are orphans need is money into the home to buy food and clothes and to enable them to go to school. They need social workers to help them apply for grants. But our processes are complicated to apply for grants and the social workers are few. This is very frustrating" [Interview 23, pg. 3].
	"Mostly the grandmothers they don't apply for the FCG or CSG because they don't know they can; and the application process is too difficult for them" [Interview 9, pg. 5].
	"Sometimes you find 14-year-olds even when they are becoming 17 years, they still haven't received their FCG. I currently have a case where the child will be 20 years old the day after going to court. Our backlog in the Eastern Cape is very, very, very bad" [Interview 22, pg. 4].
	"I can say I am stressed by my high case load. I have over 120 cases on my books" [Interview 21, pg. 4].
	"I didn't know what the Children's Act is till I read it online. It's not possible for us as social workers to do all those things in it because we aren't enough and our resources are too few" [Interview, 1 pg. 4].
	"The reality is this, we expect poor people to take care of more poor people with no extra resources. This is not working which is why we have CHH and street children" [Interview 18, pg. 4].
	"Our system in South Africa is very fragmented. You must go here for this and here for that and even when you have everything you need for applying for a grant or a better house, you must still wait. All I can do mostly is refer these children to HCBC, start a children's court enquiry, refer to NGO's and help out of my own purse. Our system in South Africa is like that for AIDS orphans" [Interview 21, pg. 5].
	"Our management isn't very good in the Eastern Cape. In our office I have the use of a car for one day a month. How can I possibly do a good job when I can only visit the most vulnerable families one day a week? If our management system was more efficient, we could do more" [Interview 22, pg. 8].
	It's terrible that people suffer because of poor and inefficient management. People are fed up with corruption. They need services not managers stealing money" [Interview 13, pg. 4].

Social workers described the appalling and desperate conditions in which they found children who were living as AIDS orphans in township communities. They described their feelings of frustration at the barriers they experienced in helping families access the available financial support for the children through the grant system in South Africa. Social workers spoke about a fragmented and cumbersome social care system which was inadequate to meet the care and support needs of children who are AIDS orphans living in townships communities.

Social workers were weary due to the lack of resources they had to work with and their difficult working conditions. Social workers attributed their high caseloads to there not being enough social workers and viewed this as an obstruction to their efforts to provide much needed care and support to distressed and vulnerable children. Social workers spoke about the challenges of implementing the Children's Act due to the shortage of qualified people and material resources and due to the amount of statutory work which they had to accomplish in their current workloads. Social workers expressed distress and feelings of discouragement which they experienced daily because of the lack of immediate care and support available for these children and because of being unable to intervene in desperate situations to give much needed care and support to children living as AIDS orphans in township communities.

### *Theme three: Short falls in "best practice"*

These shortfalls caused children who were AIDS orphans and on ART for HIV infection, and their caregivers, to receive inadequate education regarding the administration of their ART treatment. Professionals also experienced a lack of collaboration amongst themselves due to situational constraints. When children become AIDS orphans, they experience much grief. However, there are few psychologists available and primary health care nurses and social workers were overwhelmed by the numbers of vulnerable children accessing them for care and support. Accessing a psychologist was considered crucial in the assistance of these AIDS orphans for the processing of their grief. This is seen as "*best practice*" concerning the "*best interests*" of children who had become AIDS orphans. Yet primary health care nurses, social workers, and psychologists, were unable to meet this best practice requirement because of the shortfalls within the health and social systems in which they were working. If "*best practice*" intention regarding management of the health and social care systems is "Whatever we do must be nationally enabling and locally empowering" (18). It is apparent that there is a critical need for improved capacitation and resourcing to enable professionals to provide holistic care and support to these vulnerable children.

**Table 3. Qualitative data for Theme 3**

Theme Three	Qualitative Data
	"I know if they want to implement this Children's Act it will take many more resources and lots more money. If we didn't have the NGOs in Nelson Mandela Bay, then our AIDS orphans will really be in trouble" [ Interview 20, pg. 9]
	"We know what we want to do and should do; but we can't because of the systems in which we work. AIDS orphans and their families suffer because of this" [Interview 12, pg.7].
	"I try to give advice to grandparents to help the health of their HIV-positive grandchildren. It's hopeless, they don't even have money for food, never mind anything else" [Interview 22, pg.16].
	"One young boy told me: 'I am fed up with taking these pills on an empty stomach. We have no food at home, no one works, I am dying of HIV, there is no future no hope. So, I stopped taking my medication because I don't want to be poor anymore, I want to die'" [Interview 14, pg.7].
	"We can't rely on management that isn't there. Sometimes we must just do the best we can and use our colleagues and our own personal experience to help these AIDS orphans" [Interview 19, pg.3].
	"Management tries to tell us what we must do but they don't see the pressure we are under. If they supported us more by giving us resources and employing more people it would help us a lot, I can say that" [ Interview 5, pg.6].
	"To me it's like our managers are invisible, we try to find them to help us with more resource's mores support for us, but they are not there. Sometimes I event think they do not exist" [Interview 22, pg.14].

#### *Theme four: Recommendations for improving care and support to these AIDS orphans.*

Professionals indicated the need to develop comprehensive strategies to provide improved care and support to these children. Professionals identified the need for debriefing for themselves, in view of the effects of the suffering they saw and heard every day when providing care and support to children who were “suffering” as AIDS orphans living in these townships. The professionals identified explained the need for peer support groups for children who were AIDS orphans. Furthermore, professionals identified the need for inter-disciplinary collaboration between

primary health care nurses, social workers and psychologists as being a key to improving care and support to these vulnerable children.

It is evident from the above summary of the literature review and empirical research findings that professionals identified that, in-order for them to care and support children living as AIDS orphans in township communities adequately, they need to be capacitated, resourced, encouraged to work collaboratively, and not held back by situational constraints. The main concepts identified from the in-depth literature review and the empirical data collected from primary health care nurses, social workers, and psychologists are discussed below.

**Table 4. Qualitative data for Theme 4**

Theme Four	Qualitative Data
	“I can say when children become AIDS orphans living in the townships, they become very poor. There are few people and resources to help them and their families and this needs to be improved very quickly” [Interview 12, pg. 6].
	“We don’t have a plan for these children who are AIDS orphans. How we help them most is by writing referrals and by giving from our own pockets. If we have a well-resourced plan, I can say these children who are AIDS orphan will be helped” [Interview 19, pg. 8].
	“Seems we always live in crisis in South Africa. Aids orphans need to be cared for and supported. We must plan for them; they are children, we are adults. We must plan to help AIDS orphans; but we don’t... it’s all ad hoc, so we open our own purses to help them, because they need food to live” [Interview 19, pg. 4].
	“One of the most important strategies a social worker can do is to start support groups for children who are AIDS orphans in the township communities. If we had the resources to start these groups, I can say they would help children who are AIDS orphans a lot” [Interview, 1, pg. 6].
	“Without proper psychosocial support, children who are AIDS orphans will not be able to go forward in life. The need the full support of a coordinated approach of the multidisciplinary team” [Interview 24, pg. 3].
	“What would be good is if we had the multidisciplinary team under one roof, I mean the social worker, psychologist, and us the primary healthcare practitioners. This would help our clients a lot. They would only have to walk down the corridor and not travel across town” [Interview 22, pg. 7].
	“We need debriefing because we are listening to traumatic stories every day” [Interview, 24, pg. 5]. “This is what I have been through... and sharing it with someone. That’s what debriefing is. I just need someone to know what I have been through. Then you don’t have to absorb as much” [Interview 17, pg. 10].
	“I think a lot about how caring and supporting AIDS orphans affects us. I think debriefing would help us a lot ... to manage stress and to not worry about all we see and hear every day” [Interview, 18 pg. 7].

## **Discussion**

The following concepts will be clarified for better understanding: *holistic, care, support, motivated by justice, and therapeutic relationship.*

### *Holistic*

The word holism comes from the Greek word ‘holos.’ The Oxford Dictionary defines it as ‘the theory that certain wholes are to be regarded as greater than the

sum of their parts” (19). It adds that it is ‘the treating of the whole person, including mental and social factors rather than just the physical symptoms of disease’ (19). The South African philosopher and politician who coined the term ‘holism,’ Jan Christian Smuts, introduced this term in his book. “Holism and Evolution.” Smuts saw that matter and life consisted of atoms, cells and units which produced natural wholes that we call bodies and organisms. He observed that the feature of ‘wholeness was characteristic of the universe’ (20). In Urding and Swallow (21), holism, or wholism, is defined as a ‘philosophical concept in

which an entity is seen as more than the sum of all its parts'. Holistic is defined as 'of, or pertaining to, the whole, considering all factors, as in holistic medicine' (21). Most importantly, holistic healthcare is defined as a system of comprehensive or total patient care which considers the physical, emotional, socio-economic, and spiritual needs of the person, the response to an illness and the impact of an illness on the person's ability to meet self-care needs, including all aspects regarding *well-being* (21). Thus, the concept of holism emerges from a deep understanding of the awareness of the parts (22).

### Care

The concept of *care* is defined as the provision of all that is necessary for the health, welfare, maintenance and protection of someone or something, and is woven into the context of safe keeping, protection, and responsibility. In Varley (23) '*care*' is defined as 'in a serious attention or thought condition'; and ranges from avoidance of damage or loss to provision protection of and supervision for someone. Care is an action to be seen or a thing to be done for and a willingness to do or to provide for that which causes concern. Fox, Moon, and Stock (24), define the concept of care as: the importance given to, interest in, concern about, choosing to do something for, the act of consistently providing what a person or a thing needs to keep them in good condition or to maintain their well-being or to keep them well; and making sure that they do not come to harm. To do something with care is to do it slowly, with great attention, to do it professionally and thoughtfully and not make mistakes or damage anything, making sure there is no harm done.

### Support

Support is an important but complex concept of caring and has been described as an interactive process which affects all the health and welfare of an individual (25). Support is linked to the attachment process and attachment roles. Attachment will affect both the individual's ability to interact with other people and the individual ability to trust other people. Both the ability

to provide (provider) and the ability to receive (recipient) support are affected by the person's age, experience, and social environment. The support offered can be either emotional, appraisal, informative or practical (25). There are several aspects related to providing support. Emotional support promotes a sense of safety and belonging, while support promotes a sense of ability and competence. Informative support is provided through giving information regarding helping to solve an issue or problem and practical support is practical help in solving the actual problem. Support which is perceived as positive by the recipient is more likely to have a positive impact. The emotional part of support is described as the most important part for support to be experienced as positive. The environment where support is offered will affect the quality and perception of support (26). To offer adequate support, it is not only necessary to consider what support is required but also when this support is needed.

Support mediates assistance, enabling individuals to cope better with stressful events, thereby reducing some of the effects of stress. Support has been identified as a useful coping mechanism when dealing with stressors and the provision of support has been attributed to preventing burn-out caused through stress (27). To support is to give strength, to bear the weight of, to give assistance to, to endure with, to hold up, and to give approval and encouragement to (27).

Care interventions with professional support should aim to strengthen social support. Social support being offered within the social network, requires reciprocity and relationships whilst professional support does not require reciprocity in the same manner and should be directly available from professionals in the society (26). Professional support is also limited by the professional domain, professional knowledge and professional resources available, but it can and should be empowering (27).

Primary health care nurses, social workers and psychologists need to consider the possible distinction between 'to care for' and to 'give support to.' Etymologically, 'to give support to' is understood as the provider having 'trust' in the capacity of the recipient, expecting that the recipient will 'take charge.' The suggestion is that the provider provides means and that the recipient will be enabled or strengthened to cope with or within his/her given

situation, therefore empowering the recipient. In contrast, to 'care for' could etymologically be understood as the provider expecting to 'be responsible for' and the recipient 'to be taken care of' (26).

Primary health care nurses, social workers and psychologists' support should aim to be empowering, facilitating and have a positive development of the individual's ability to cope with challenging and stressful situations in life. To empower individuals, it is essential that professional support is sensitive to an individual's unique needs (28).

### *Motivated by justice*

Motivation is defined as the process which initiates, guides, and maintains goal-orientated behaviour. It is what causes a person to act according to their perception of rightness, strong conviction, or persuasion. Motivation is seen in actions (29). Justice is a legal, ethical, and ontological word. Aristotle regarded justice as a virtue and the most necessary to a state of welfare. According to him 'just' means lawful, fair, and 'unjust' means 'unlawful and unfair'. According to Aristotle, there are two kinds of justice, natural and legal. Natural justice is 'that which has the same validity everywhere and does not depend upon acceptance' (30). According to Leo Strauss, 'Justice thus understood would seem to be unqualified good for the giver and for those receivers who are good to the giver' (31). What is apparent is that fairness about the rights of human beings is the core aspect of the concept of justice, and goodness, fairness, honesty, legally, rightness, and right action are all aspect of this concept.

The golden rule concerning justice is an ethical injunction which has been exposed by religious and ethical books. Simply put, one should do to others as one would have them do to us. This golden rule is a precept of justice, though it might not cover all that justice can be construed to be. John Stuart Mill stated the 'Act Utilitarian' that we should always perform that action which will have the best overall result (32).

### *Therapeutic relationship*

A therapeutic relationship can be defined as one which is perceived by patients to encompass caring and

supportive non-judgmental behavior, embedded in a safe environment during an often-stressful time in a patient's life (33). In this instance, the therapeutic relationship is between vulnerable children who are seeking care and support on becoming AIDS orphans from primary health care nurses, social workers, and psychologists. Therapeutic relationships comprise high levels of trust. Typically, this type of relationship displays warmth, friendliness, genuine interest, empathy, and the wish to facilitate and support. Consequently, therapeutic relationships engender a climate for interactions that facilitate effective communication. Therapeutic relationships between health care professionals and patients are associated with improvements in patient satisfaction, adherence to treatment, quality of life, levels of anxiety and depression, and decreased health care costs (33).

### *Description of the conceptual framework*

A conceptual framework is an abstract structure of meaning which guides the development of a theory (34). A conceptual framework is developed by a researcher through the identification and definition of concepts, as well as a proposal of the relationships between these concepts (34).

The survey list proposed by Dickoff et al. (9), guided the development of the conceptual framework which underpinned the development of the Steps of Progression Strategies. Dickoff et al. (9), describe the survey list as a "supplement to present prescription and as preparation for future prescription for activity towards the goal content". In their proposal of a survey list, Dickoff et al. (9), outline six aspects of activity that must be included therein, and related questions that pertain to each activity:

1. *Agent or agency* (Who or what performs the activity?)
2. *Recipient* (Who or what is the recipient of the activity?)
3. *Procedure* (What is the guiding procedure, technique, or protocol of the activity?)
4. *Dynamics* (What is the energy source for the activity?)
5. *Context* (In what context is the activity performed?)

6. *Terminus* (What is the end point of the activity?)

To clarify the concepts which were used in the construction of this conceptual framework, the

researcher adopted the thinking map put forward by Dickoff et al. (9) which is illustrated in Figure 2.

The concepts outlined in Figure 2 will be described below.

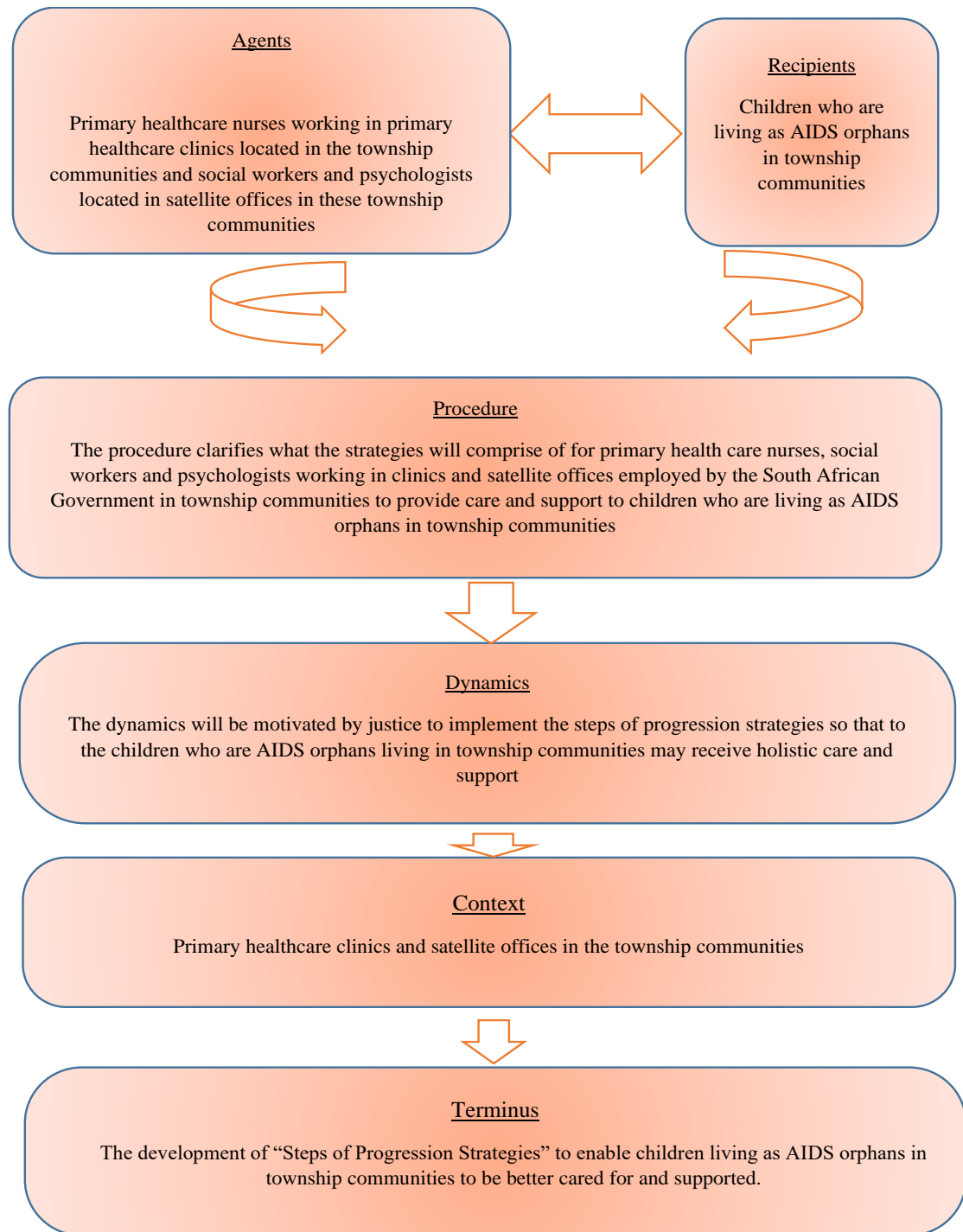


Figure 2. Thinking map for clarifying the concepts.

*The agent*, as described by Dickoff et al. (9), is the person who performs or facilitates the activity which is designed to attain the desired goal or terminus. In this instance, the agents are primary health care nurses, social workers and psychologists caring for and supporting children living as AIDS orphans in township communities in Gqeberha, Eastern Cape in South Africa.

*Primary health care nurses* are professional nurses working in primary healthcare clinics, individuals authorised to practice and capable of practicing nursing or midwifery in their right by virtue of registration in terms of section 16 of the Nursing Act, 2005 (34). Such a person is accountable for evaluating a patient's situation, based on knowledge and skill, taking decisions with discretion, and acting in accordance with such decisions, as indicated in the South African Nursing Council Terminology List. Professional nurses meeting these requirements act as independent practitioners and are expected to accept full responsibility and accountability for their actions. Primary health care nurses form the cornerstone of the primary health care clinics in South Africa.

*Social workers.* The social work profession promotes social change, problem-solving in human relationships and the empowerment and liberation of people to enhance their well-being. Utilizing theories of human behavior and social systems, social workers intervene at the points where people interact with their environments, addressing the multiple, complex transactions between people and their environments. Principles of human rights and social justice are fundamental to social work.

The mission of social work is to enable all people to develop their full potential, enrich their lives and prevent dysfunction. Professional social work is focused on problem-solving and change. As such, social workers are change agents in society and in the lives of the individuals, families, and communities they serve. Social work is an interrelated system of values, theory and practice which grew out of humanitarian and democratic ideals, and its values are based on respect for the equality, worth, and dignity of all people (35). It is understood that social work in the 21<sup>st</sup> century is dynamic and evolving, and therefore no definition should be regarded as exhaustive.

*Psychologists.* A psychologist is a professional person who has completed a programmed of study in

Psychology and is engaged in research, clinical treatment, teaching, or other applications of Psychology. Psychologists specialise in diagnosing and treating diseases of the brain, emotional disturbance, and behavior problems. Since psychologists can only use talk therapy as treatment, they will refer clients to a psychiatrist or other medical doctor to be treated with medication if this is what is professionally required (36).

These agents' roles and responsibilities will comprise of the promotion of health and welfare, and facilitating healing and alleviation of suffering, while providing holistic care and support to children living as AIDS orphans.

### *The recipient*

The term *recipient* in nursing theory refers to any person or thing that receives action from agents (9). The primary recipients of the strategies to be developed are children who are living as AIDS orphan in township communities in South Africa.

- *Children.* There is no single law that defines the age of a child globally. The United Nations Convention on the Rights of the Child (UNCRC) (37), ratified by the South African government in 1991, states that a child 'means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier' Article 1, (37). The Constitution of South Africa defines children as being persons under the age of 18 years. Therefore, for this article children will be considered as persons below the age of 18 years.
- *AIDS orphan.* According to UNAIDS, an AIDS orphan is defined as an HIV-positive or -negative child who, prior to the age of 15 years, has lost either mother or both parents to AIDS (38). For this article, considering that the constitution of South Africa defines a child as a person being under the age of 18 years, the author will consider an AIDS orphan to be a person below the age of 18 years who has lost either one or both parents to AIDS and AIDS-related symptoms.



## *Context*

Context or framework refers to the environment within which the activity takes place (9). For this article, the context is township communities in South Africa. The last census in South Africa was 2011 so that data collected in this census will be used to give detail to the context. The Nelson Mandela Bay Health District known as Gqeberha (formerly Port Elizabeth), is situated in the Western Region of the Province of the Eastern Cape (PEC), South Africa. It has a population of 6.8 million people, which is 13.50% of the national total, making the PEC the third largest province in South Africa (43). According to the latest published census, the mid-2011 estimates from Statistics South Africa, South Africa's population is 50.6 million, with Black Africans in the majority at 79.5% of the population (43). Approximately 1,267,000 people live in Nelson Mandela Bay (NMB) (43), which is one of six metropolitan areas in South Africa. Nelson Mandela Bay Metropole is located on the shores of Algoa Bay and consists of Port Elizabeth, Uitenhage, and Despatch. It covers an area of 1,845 square kilometres, 4% of which is rural. Approximately 250,668 of NMB's population are children under the age of 14 years (43).

The socio-economic profile of the Eastern Cape is marked by widespread and inherent poverty, racial, class and geographical inequality and profound backlogs in public services, (43). The populations in the areas that are serviced by the PHC clinics and satellite offices live in informal settlements, made up of tightly clustered shacks and informal areas termed townships. A shack is a roughly assembled house made with a combination of corrugated iron, wood, and cardboard. Approximately 13.7% of the potential professionals of this study live in this type of housing (42, 43).

People living in township areas have limited access to water supplies and lack sanitation, with only 46.7% of the population having piped water in their dwellings and 60% with a flush or chemical toilet (43), indicates that approximately one in four households in the Eastern Cape (25.0%) registered household consumption expenditure of less than \$1,640 per annum. Correspondingly 25.7% of all households indicated that their standard of food consumption was less than adequate (43). The majority of

local residents are Xhosa-speaking and adhere to traditional Xhosa cultural norms and practices, including traditional healing and veneration of ancestors (43).

The children living in township communities attend local Primary Health Center's where primary healthcare professionals provide care and support and satellite offices where social workers and psychologists work to provide care and support to these children. The clinics and satellite offices in which the researcher performed interviews are situated among people in the Eastern Cape living in extremely low socio-economic conditions. As an example, an estimated 26% of individuals of working age are currently employed in the Eastern Cape. There is no doubt that many people in the Eastern Cape are living under conditions of extreme poverty (43)

## *Dynamics*

The dynamics of an activity refers to the energy source for the agent and patient, or the context of that activity; it could be chemical, physical, biological, mechanical, or psychological (9). The dynamics for this framework, will be motivated by justice, which will be the energy source for both the agent and recipient. The primary health care nurses, social workers and psychologists were motivated by a sense of justice as they wanted to improve care and support to these vulnerable children. They saw these children as the future of South Africa. They were moved by a sense of what was deemed as "just and right" to care for and support these vulnerable children.

## *Procedure*

The procedure provides enough details to enable the activity to be performed (9). The procedure outlines the steps which need to be followed in conducting an activity. The procedure outlined in this article clarifies the procedure for the Steps of Progression Strategies which were developed. The aspects of the procedure were identified by the authors of this paper during the data analysis of the afore mentioned interviews with professionals. Each aspect of the procedure is identified below.

### *Strengthening existing legislative and policy framework*

The legislative policy framework in South Africa concerning the rights of children is rich. However, it remains weak in operation. The National Plan of Action for Children is a prime example of this. It presents the intention of the South African Government regarding what needs to be done, but the how to do it is omitted. The South African legislative policy framework concerning provision of holistic care and support of children who are AIDS orphans living in township communities is guided by the principle of the “best interests” of the child. The development of these named “Steps of Progression” strategies is to assist in enabling the fulfilment of the South African governments legislative a policy framework in meeting the needs of orphans and planning interventions to meet their unique needs which is in their “best interests” (37 & 41).

### *Enhancing resilience of primary health care nurses, social workers, and psychologists*

The results of this study have highlighted a need for primary health care nurses, social workers and psychologists to be resilient in order to provide holistic care and support to children living as AIDS orphans in township communities. The enhancing of resilience requires human and material resources, such as training and employing more primary healthcare nurses, social workers and psychologists, and the redistribution of large sums of money within the health and social care system. These professionals have to be capable of developing resilience in an enabling working environment, but this requires input on a micro level in order to obtain the necessary resources to facilitate the development of an environment which supports the development of their resilience. Capacity-building regarding people and material resources should be advocated for at a macro level, as increased capacity of people and material resources would improve the resilience of the professions who are at risk of high burnout due to being exposed to much suffering in poorly resourced health and social care systems.

### *Development of interdisciplinary collaboration*

Collaboration to “work jointly on an activity or project” is closely linked with coordination (19). Collaboration is a dynamic interpersonal process in which two or more individuals make a reciprocal commitment to interact authentically and constructively to solve problems and learn from one another to accomplish identified goals, purposes, or outcomes. Collaboration which involves joint decision-making is necessary within all aspects of the multidisciplinary team addressing the provision of holistic care and support to children who are AIDS orphans living in township communities (44).

Collaboration of services is recognised by the WHO as an important method regarding the improvement of health and related service provision in low-and-middle-income countries. However, that “collaboration must be seen as beneficial to both parties” (45). which in this instance may include international organisations (such as UNICEF,) government departments and NGO’s. It will also include practitioners from different disciplines in this instance primary healthcare nurses, social workers, and psychologists.

### *Facilitation of an empowering work environment*

Primary health care nurses, social worker, and psychologists spoke about fragmentation of health and social care, and about the frustration they experienced because of hindrances in their current working environment (1). Professionals also spoke about the need for a better resourced working environment, in terms of people and material resources, for care and support needs of AIDS orphans to be met. Professionals spoke about the success of the Thuthuzela approach. Thuthuzela (comfort) centers enable the coordination of care and support for women who have been raped.

At the heart of the success of the Thuthuzela approach is the professional interface and a high degree of contact between the rape victim and the service providers (50). In the same manner coordinated care and support could be provided to children living as

AIDS orphans in township communities through centres which could be named for example “Ithemba Elitsha” (New Hope) centres. These centres could provide coordinated care for these children, by locating primary health care nurses, social workers, and psychologists in one place and through providing resources such as rooms in these centres in which support groups could be facilitated for these vulnerable children.

Figure 3 represents an overall perspective of this conceptual framework. The puzzle pieces at the top of figure 3 highlight the fragmentation children are exposed to when they become AIDS orphans as they experience sorrow, *neglect*, and suffering. The lives of the children who have become AIDS orphans fall mainly into the hands of their extended family and primary health care nurses, social workers, and

psychologists, who try with their professionalism, skills, resources, and capacity to care for and support children who are living as AIDS orphans in township communities.

These blue figures in the second part of Figure 3, represent the primary health care nurses, social workers and psychologists who provide care and support to these children. These blue figures are small to represent their feelings of being overburdened by the lament of these children and being overwhelmed by the weight of providing care and support to these children with few available resources. The cracked white circle on which the blue figures are standing, demonstrates the creaking, broken and inadequate health and social systems (*Context*) within which these professionals work.

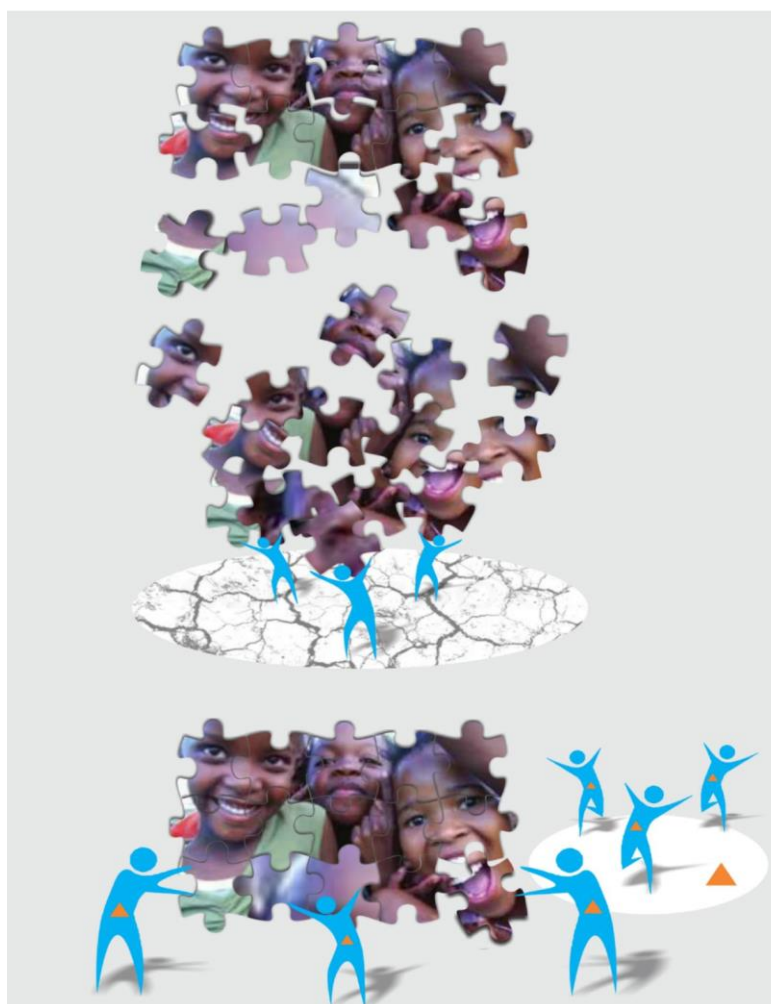


Figure 3. Diagrammatic representation of the conceptual framework.

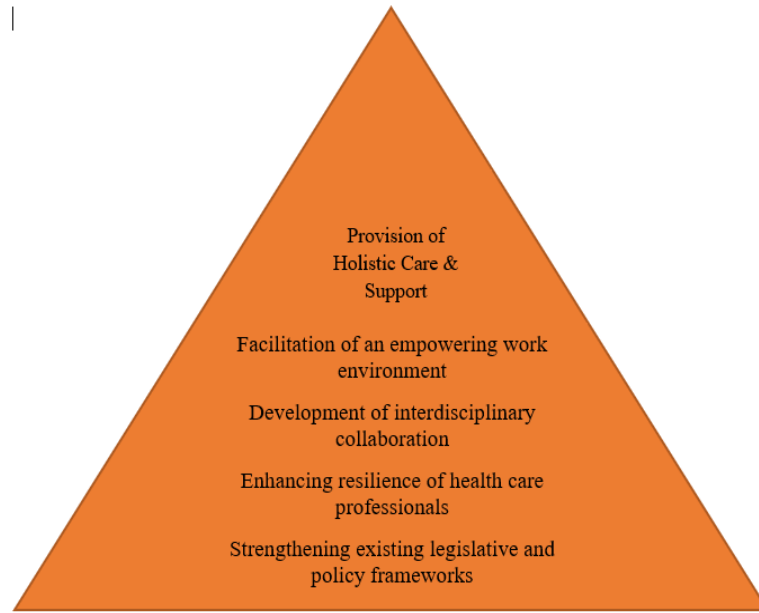


Figure 4. The detail of the procedure.

The puzzle at the bottom of this figure demonstrates what could happen to the health and social systems and the primary health care nurses, social workers and psychologists working in these systems, if they are strengthened and supported through the “Steps of Progression Strategies” which were developed using this conceptual framework. The sole aim of which is to provide holistic care and support to children who are living in township communities as AIDS orphans (*Terminus*).

The orange triangle reflects the procedural aspect of this conceptual framework on which the Steps of Progression Strategies (*Procedure*) were developed to facilitate the provision of holistic care and support to these vulnerable children. The detail of this procedure as presented in an orange triangle which is presented in Figure 4. The developed strategies aim to strengthen the existing health and social systems in which these professionals work and enable capacitation and resourcing of the primary health care nurses, social workers and psychologists working in these systems (*Context*).

The blue figures are now standing taller and standing in a sturdier system, which is represented by a solid white circle. These professionals are no longer overwhelmed and overburdened and are standing in a strengthened system.

## Conclusion

The development of this conceptual framework upon which the “Steps of Progression Strategies” were developed could assist primary health care nurses, social workers, and psychologists to provide holistic care and support to children who have become AIDS orphans and who are living in these township communities. The procedure aspect of this conceptual framework identified the four grand strategies. These four grand strategies were further developed and named the “Steps of Progression Strategies.” A lived experience approach in developing this conceptual framework and the resultant “Steps of Progression” strategies was considered a necessary step to improve the care and support these children receive.

## Acknowledgments

The authors have stated all possible conflicts of interest within this work. The authors have stated all sources of funding for this work. If this work involved human participants, informed consent was received from each individual. If this work involved human participants, it was conducted in accordance with the

1964 Declaration of Helsinki. If this work involved experiments with humans or animals, it was conducted in accordance with the related institutions' research ethics guidelines.

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*Submitted:* December 10, 2022. *Revised:* December 20, 2022.  
*Accepted:* January 10, 2023.