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"Barriers to" and "Recommendations for" providing care and support for children living as AIDS orphans in township communities in the Eastern Cape South Africa: A cluster analysis

Sharron Frood[a], Edward Purssell[b]

[a] Department of Child Health and Family Health, Kings College London, United Kingdom
[b] School of Health Sciences, City, University of London, United Kingdom

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ABSTRACT

Background: Orphan-hood is a major consequence of the Acquired Immune Deficiency Syndrome (AIDS) pandemic globally. In South Africa most children who are AIDS orphans live in township communities. They are often uncared for and unsupported by the community, and experience recurrent psychological trauma and much personal suffering. Identifying the "barriers to" and "recommendations for" providing care and support to these vulnerable children is vital to enable the development of comprehensive implementations to meet these children's unique care and support needs.

Objective: Using empirical data from health and social care professionals and cluster analysis to identify "barriers to" and "recommendations for" providing care and support to children living as AIDS orphans in township communities in Nelson Mandela Bay South Africa.

Design: Data was collected using a descriptive phenomenology research design incorporated an exploratory, contextual and descriptive approach. In-depth unstructured interviews were used to collect data from participants.

Participants: The primary health care nurses (PN) (n = 10) and social workers (SW) (n = 8) were selected using criterion-based purposive sampling, whilst snowball sampling was used to select psychologists (Psy) (n = 6). Participants are referred to as health and social care professionals.

Setting: Participants were selected using purposive sampling (nurses and social workers) and snowball sampling (psychologists) from four primary health care clinics and twelve satellite health care clinics, all located in township communities in Nelson Mandela Bay, South Africa. The participants were all caring for and supporting children who are AIDS orphans living in these communities.

Methods: In-depth individual interviews occurred between April and Nov 2013 which were recorded and transcribed verbatim. All data was then analysed using cluster analysis to identify "barriers to" and "recommendations for" providing care and support to these vulnerable children as identified by these research participants.

Results: All "barriers to" and "recommendation for" are represented in this cluster analysis. There were six identified clusters illustrating "Barriers to" and four visualised clusters illustrating "Recommendations for". The barriers can be identified using the following broad themes; B1, fundamental barriers; B2, primarily related to legislative and policy frameworks, B3, lack of human and financial resources also included stigma and communication. B4, grief, high risk behaviours and cumbersome bureaucratic processes and included loss of trust in adults; B5, barriers related to poverty B6, barriers related to poverty also included non-disclosure of HIV status. Regarding the "recommendations for" these can be identified using the following broad themes; R1, developing the resilience of health and social care professionals. R2, developing interventions, to meet the unique needs of these AIDS orphans. R3, developing, empowering and capacitating professionals and R4, facilitating an empowering working environment for professionals.

Conclusions: Significant clusters emerged and the "barriers to" and "recommendations for" were identified in this research which could be used to inform the development of an intervention to provide "best practice" care and support to these vulnerable children living in these township communities.

E-mail addresses: Sharron.frood@kcl.ac.uk (S. Frood), Edward.Purssell@city.ac.uk (E. Purssell).

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What is already known about this topic?

- There are high numbers of children living as AIDS orphans in townships in South Africa
- Many studies have been conducted about the difficult circumstances in which these children live
- There is a paucity of empirical studies reflecting the self-reported experiences of health and social care professionals in identifying "barriers to" and "recommendations for" providing care and support to these children.

What does this paper add?

- Robust data giving detailed insight regarding the "Barriers to" and "Recommendations for" providing care and support to children living as AIDS orphans in township communities in South Africa.
- Empirical data concerning these professional's experiences was used to identify "barriers to" to and "recommendations for", providing care and support to children living as AIDS orphans in township communities in the Eastern Cape South Africa.
- This data can be used to inform and develop interventions to provide improved care and support to children living as AIDS orphans in these township communities in South Africa.

1. Introduction

The Human Immunodeficiency Virus (HIV) is a virus that preferentially infects T-helper cells in the immune system, and if untreated in most people will result in Acquired Immune Deficiency Syndrome (AIDS). Since the introduction of combination antiretroviral therapy (ART) in the mid-1990s HIV has become a chronic condition although it remains incurable, and access to therapies is far from universal. Furthermore, HIV and AIDS are associated with significant stigma which can deter people living with HIV from accessing treatment, care and support.

South Africa commenced ART role out in 2004, but despite South Africa facing the world's largest paediatric HIV epidemic, only one in four children have access to combination ART (Morsheimer, Dramowski, Rabie, & Cotton, 2014). South Africa is listed as 58th out of the 100 countries with the highest under 5-year-old mortality rates worldwide and has an estimated 360 000 children living with HIV (Maartens & Goemare, 2014). Unique considerations exist regarding ART for HIV-infected infants, children and adolescents, with many barriers existing which hinder access to this treatment (UNAIDS, 2017). HIV infection in children is a life-threatening disease. Without treatment, and specifically adherence to treatment, HIV-positive children in resource-poor settings have a 45%–59% mortality rate by 2 years of age (Daviaud & Chopra, 2008).

In addition to its direct effect on infected children, AIDS has devastated the social and economic fabric of African societies and made orphans of a whole generation of children who have, as a result, become an often-unseen epicentre of the HIV/AIDS pandemic (Fassin, 2007). People living in South Africa has suffered significant burden from HIV; the total number of persons living with HIV increasing from an estimated 4.72 million in 2002 to 7.03 million by 2017 (Stats SA, 2017), and it has the largest number of HIV infected people in the world (UNAIDS, 2017).

In 2017, an estimated 12.6% of the total population of South Africa (56.5 million) was HIV positive (Stats SA, 2017). Although more recent statistics are lacking, it is known that there is significant variation in HIV prevalence across the nine provinces. The Eastern Cape Province, where Nelson Mandela Bay is situated, reportedly had an average prevalence among pregnant women of 30.4% in 2013 (South African National AIDS Council, 2016). The HIV burden on children is twofold; firstly, if they contract HIV, they suffer direct morbidity, and even if they do not, they may still suffer the consequences of parental ill health and possibly bereavement. Further, it is estimated that this pandemic affects approximately 280, 000 South African children from the age of 0 to 14 years (Hayman & Kidman, 2009; UNAIDS, 2017). If left untreated, morbidity and mortality as a result from tuberculosis, pneumonia, and severe bacterial infections is high, especially in Sub-Saharan Africa where essential resources for adequate testing, paediatric ART and child-friendly prevention programmes are often lacking (Avert, 2018; Frigati, Archary, Rabie, Penazzato, & Ford, 2018; Njuguna, Cranmer, Otieno, et al., 2018).

In South Africa, there are an estimated 3.7 million orphans, about half of whom have lost one or both parents to AIDS (UNICEF, 2016). Children who are AIDS orphans living in South Africa, as in other African countries, suffer from recurrent psychological trauma which starts with the illness and death of their parents (van Dijk, 2008). Given the prevailing conditions, orphans in these township communities are particularly vulnerable.

Many orphaned children living in Africa are from impoverished households (UNAIDS, 2009). In South Africa, these children often live in informal housing termed 'townships', or informal settlements (made up of tightly clustered informal shacks, often built as an extension of a township). In this study, townships are referred to both formal and informal housing structures within these designated township areas. People living in these areas have limited access to water and lack sanitation, with only 46.7% of the South African population having piped water in their dwellings and 60% with a flush or chemical toilet. Unemployment in these areas is high (up to 60%) with household consumption expenditure of less than R16, 406.28 (approximately $1,316.72) per annum. Correspondingly 25.7% of all households have indicated that their standard food consumption was less than adequate (Mahajan, 2014; Stats SA, 2012).

Children living as AIDS orphan in these communities often experience a range of privations, including inadequate access to health care services and social security, insufficient food, restricted access to water, poor housing and limited educational opportunities. Conditions result in these children becoming ill, or living on the streets, where they are exposed to forced labour, organised crime, substance use and sexual and physical abuse (Molepo, 2015:1; Wagstaff & Therivel, 2017).

If the orphans living in the townships are not appropriately cared for, there will be a significant direct cost incurred in caring for and supporting them in the longer term; and indirect effects on the economy. Such costs will include increased numbers of children living on the streets or in child-headed households, increased levels of juvenile delinquency and reduced literacy. Consequently, an increased economic burden will be placed upon the state (van Dijk, 2008; UNICEF, 2015; Wagstaff & Therivel, 2017).

In South Africa children living in township communities as AIDS orphans; in the first instance, receive care and support through primary health care nurses who are employed by the Department of Health, and social workers and psychologists who are employed by the Department of Social Development. These professionals, referred to as health and social care professionals in this study, are based in clinics and satellite clinics in the communities and provide care and support to these vulnerable children. They are employed to make visible to these children the government mandates of care and support, as constituted in the Bill of Rights in the Constitution of The Republic South Africa, in which it is stated that "that every child in South Africa has the right to basic nutrition, shelter, basic health care and social services" (section 29(1) (c) (RSA, 1996). In the township community's primary health care centers and satellite offices house these professionals employed by the South African Government to treat and refer these children accessing them for care and support. These professionals were able to identify "barriers to" and "recommendations for" providing care and support to these children and will be presented in this paper.

Health and social care professionals should be empowering, facilitating and enabling to help these children adapt to the new life reality of living as AIDS orphans in the township communities. To do this, it is

essential that health and social care professionals sensitively care for and support the children's unique needs in an informed, professional and well-resourced manner (HM Government, 2015). However, providing care and support to children living as AIDS orphans in township communities is complex due to these children's unique needs.

The aim of this study was therefore to use empirical data from these health and social care professionals and cluster analysis to identify "barriers to" and "recommendations for" providing care and support to children living as AIDS orphans in townships in the Eastern Cape in Port Elizabeth South Africa. The identification of these "barriers to" and "recommendations for" could help to inform the development of interventions to meet the unique care and support needs of these vulnerable children and improve the health and social well-being of these very vulnerable children.

2. Analysis

The population of interest comprised three groups: primary health care nurses, social workers and psychologists all registered with their own professional bodies in South Africa and working in township communities to provide care and support to children living as AIDS orphan in these townships. The sample comprised; primary health care nurses (PN) (n = 10), social workers (SW) (n = 8) were selected using criterion-based purposive sampling, whilst snowball sampling was used to select psychologists (Psy) (n = 6). Participants are referred to collectively as health and social care professionals. All those invited agreed to participate in this research study. These data were collected from a wider study reported elsewhere (Frood et al., 2018),

2.1. Data collection

Participants were interviewed between April and Nov 2013 and were each asked the following open-ended questions.

How do you experience providing care and support to children who are AIDS orphans living in the township communities?

What recommendations would you like to make to improve the quality of care and support provided to children who are AIDS orphans living in the townships?

All in depth interviews were transcribed verbatim. Interviews were unstructured and lasted for approximately 90 min per participant. Interviews were audio recorded and subsequently transcribed verbatim. The data collected was rich and deep these transcripts were then examined and using the Framework Method (Gale, Health, Cameron, & Rashid, 2013:117) themes regarding "barriers to" and "recommendations for" providing care and support to children living as AIDS orphans in township communities were identified were using this framework method (see Table 1).

2.2. Data analysis

All "barriers to" and "recommendations for" were identified. Data were coded 0 for absent and 1 for present this was then analysed using the heatmap.2 command in the R package gplots (R Core Team, 2017; Warnes, Bolker, Bonebakker, Gentleman, & Huber, 2016) which used Euclidean distance and complete linkage to cluster the pattern of responses given by the participants; thus, clustering has been done to categorise similarity of responses rather than similarity of responses by different practitioners. In the resulting heatmap black indicates the presence of a barrier or recommendation was used to both cluster the data according to similarity pattern of the statements and to produce the dendrogram and heatmap shown in Fig. 1. Each cell represents the presence or absence of a statement in an individual's transcript, these are then clustered using an agglomerative approach based on the euclidean distance between each set of responses. In this approach each response starts as its own cluster, it is then merged recursively with the next nearest until there is one overall cluster. No clustering was done on the columns, so individual practitioners appear as they were on data entry and are not reordered.

3. Results

There was a total of 92 "barriers to" identified and 70 identified "recommendations for". These are represented in Table 1. Main Clusters were visualised; 6 clusters for "barriers to" and 4 clusters for "recommendations for", which are shown in Figs. 1 and 2 respectively.

3.1. Barriers

The identified "barriers to" and the detail thereof comprised 6 clusters. It was particularly notable there was agreement amongst all participants in identifying the "barriers to" in cluster 6. The "barriers to" in this cluster related to poverty and stigma. This contrasts with B1 which identified low morale amongst health and social care professionals as the main barrier and B2 where legislative and policy frameworks, poor medication compliance, and the requirements of the Children Act 2005 as being cumbersome, were identified as "barriers to". Within both of these clusters where there was only a sporadic mentioning of these "barriers to" by participants. There was also a difference in responses from some social workers and psychologists to the identified barriers comprising B1. These different responses were identified and related to different barriers identified respectively to each profession.

Cluster B3 and B4 were characterised by a mixed response. These clusters identified barriers relating to the lack of human and financial resources and included stigma and communication difficulties relating to becoming an AIDS orphan. B4 comprised identified barriers relating to complex grief, high risk behaviours of these AIDS orphans and cumbersome bureaucratic processes related to referrals to other health and social care services and accessing immediate grant support. Further this cluster included the loss of trust in adults. The remaining cluster B5 all barriers were identified by all participants except for 1 primary nurse who was geographically located in a clinic on the edge of a township community as opposed to the others which were located within the township communities. B5 comprised identified barriers related to poverty included stigma on being an AIDS orphan. All barriers in this cluster were identified by all participants apart from one. This was the distinction between B5 and B6 clusters. Otherwise all identified barriers were mentioned by all research participants.

3.2. Recommendations

Recommendations were also characterised by a large cluster because of complete agreement amongst participants in the cluster R4. This cluster included recommendations relating to the facilitation of an empowering working environment for health and social care professionals. This complete agreement contrasted with cluster R1 which had a much more mixed pattern visualised within this cluster, the recommendations identified within this cluster included developing the resilience of health and social care professionals.

Cluster R2 was formed by recommendations identified by most respondents except for a small group of primary health care nurses and social workers. This can be explained by these participants being geographically located next to a well-resourced NGO which provided care and support specifically for children living as AIDS orphan in township communities. The recommendations identified within this cluster broadly relate to the development of interventions to meet the unique needs of these AIDS orphans. Cluster R3 comprised recommendations primarily relating to developing, empowering and capacitating professionals and enabling better collaborative responses and were identified by everyone except primary nurse (PN) 1, Psychologist (Psy) 4 and social worker (SW)1. This could also be explained by the geographical location of the clinic and satellite office in which these professionals

Table 1
"Barriers to" and "Recommendations for" Providing Care and Support for Children Living as AIDS Orphans in Township Communities in the Eastern Cape South Africa; a Cluster Analysis.

"Barriers to"		
B Cluster 1	B 64	Poor Communication between DOH and DSD
	B 20	Low Morale Amongst Professionals
	B 10	Travel costs to attend appointments with Professionals using buses or traditional Taxis
	B 3	Lack of extended family support
	B 8	Difficult to Locate Professionals in the Township Communities
B Cluster 2	B 71	Poor Medication Compliance
	B72	Irregular Medication Administration
	B160	Managers Devalue the role of Psychologists
	B122	Orphaned Teenagers Becoming Pregnant to Attain a Child Support Grant
	B123	Manipulate ART compliance (to reduce CD4 count) to attain Disability Grant
	B50	Exploitation by Extended Family, For Financial Gain in the Form of CSG or FCG
	B56	Demotivation in Professionals due to loss of hope in Health and Social Care Systems
	B44	Not being able to Locate Fathers Therefore Grant Applications Delayed
	B73	Exposure to TB in Overcrowded Homes and Over Crowded Clinics
	B46	Compassion Fatigue in Professionals
	B22	Too few Magistrates to Place Orphans in Foster Care
	B16	Orphans using prostitution for survival "Survival Sex" (sex for food and school fees)
	B97	Resentment in Grandmothers due to their own Grief and Financial Hardship
	B55	Lack of Safe Foster Care Placements
	B58	Writing lengthy reports to refer orphans to specialists and evaluation of FC placements.
	B66	Limited availability of medications
	B65	Children's Act requirements cumbersome.
	B19	Poor confidentiality due to overcrowded working conditions in Clinics and Satellite Offices
	B9	Iliteracy in orphans and family members caring for them
	B6	Difficulty in locating documents namely birth and death certificates
	B1	Births not being registered so no birth certificate
	B2	No clinic cards available for orphans due to being lost by family
	B13	Government corruption stopping investment in health and social care systems
	B18	Orphans being vulnerable
	B140	Backlog of cases to be heard by magistrates re awarding FC placements
	B152	CHH grant applications complex if parent child below 18 years old.
B Cluster 3	B53	Lack of immediate resources to help children who become orphans (i.e. food parcels)
	B69	Cross Cultural Communication difficulties
	B68	Language barrier between professional and orphan
	B34	Professionals leaving the profession due to "burn out"
	B21	Long term sickness in professionals (PTSD, TB, HIV)
	B15	Poor School attendance by orphans
	B17	Orphans experiencing physical hunger
	B38	Non-disclosure of HIV status in professionals
	B39	Movement of family members between township communities and SA provinces
	B119	Professionals feel "Soul Destroyed" due to being overwhelmed and feeling ineffective.
	B118	Bureaucratic bounce in the DOH and DSD
	B117	Lack of availability of resources for psychologists (pencils, paper and toys)
	B112	Orphans not coping at school or in peer relationships due to fear and shame
	B116	Professionals struggling to build therapeutic relationship with orphans
	B115	Orphans "acting out" due to anger experienced due to their experience of loss
	B113	Hopelessness and Depression in orphans causing a lack of motivation in them
	B114	Living in imporversihed and violent commmunities overwhlemed by need, poor infrastructure and insufficient resources to meet these children's basic needs.
B Cluster 4	B14	Orphans experience complex grief which makes it difficult to build relationships with professionals
	B80	Loss of belonging causes deviant high-risk behaviours in orphans
	B83	Orphans repress grief so don't engage with professionals
	B82	Orphans experience overwhelming loss and isolate themselves due to this pain.
	B81	Practical difficulties, long walks in the community to locate professionals, aged grandparents who are not mobile and expensive travel costs.
	B98	Cumbersome bureaucratic process for grant administration
	B96	Complex forms to fill in to fill in with hard to locate supporting documentation
	B103	Delays of up to 2 years in processing FCG's
	B95	No immediate financial assistance availed for children who become orphans
	B101	Delays in processing CSG's due to complex forms to fill in and difficult to locate supporting documentation.
	B90	Difficult to locate and access social workers due to big care loads
	B94	Orphans lose trust in adults
B Cluster 5	B12	Grant processing delays
	B24	No finance available to pay school fees
	B25	Professionals experiencing suffering due to hopelessness and despair of orphans
	B5	Professionals have too many patients to see every day
	B77	Poor nutritional status of orphans due to poverty
	B67	Orphans experience physical neglect due to overcrowding and poverty
	B43	Over dependence on grandmother's government pension
	B128	Overcrowding in clinics and office spaces of professionals
	B70	Orphans emotionally withdrawn so struggle to engage with professionals
	B4	Lack of food in orphan's home
	B11	Lack of collective resources
	B76	Poor living conditions particularly in informal settlements

(*continued on next page*)

Table 1 (*continued*)

	B23	Professionals experiencing psycho social suffering or orphans
	B78	Overcrowding in clinics exposing orphans attending clinics to TB and other adults who are in the terminal stages of HIV/AIDS
	B146	Stigma due to becoming and living as being an AIDS orphan
	B143	Misspending of grant money by foster carer
	B137	Alcoholism in orphans and due to despair (local brewed alcohol)
	B138	Drug taking in orphan's due to despair
B Cluster 6	B162	Orphans confused as to why taking ART as don't know they are HIV positive
	B157	Anti-social behaviour of children living in CHH
	B156	Incompetence of managers in DOH and DSD in Bisho
	B153	Delinquent behaviour of orphans due to neglect
	B141	Orphans become an additional burden to already impoverished families
	B142	Exploitation of orphans by community members (menial jobs undertaken for little financial reward)
	B36	Escalating poverty
	B7	Lack of health and social care professionals
	B155	Stigma due to orphans being HIV positive
	B154	Unending cycle of poverty affecting health and well-being of orphan's
	B150	Volatile communities affected by municipal strikes and violence
	B148	Iliteracy in professionals due to immigration from SADEC countries
	B145	Caring for elderly grandparents in whose home orphans now live
	B147	Orphans live a long way from clinics and satellite offices in the township communities, therefore difficult to access professionals
"Recommendations for"		
R Cluster 1	R120	Develop he philosophy of "Ubuntu"
	R92	Assist in collecting documents from the grant application processes
	R37	Facilitate support groups to teach financial management through Budgeting
	R121	Develop and facilitate homework groups for orphans
	R89	Help orphans develop communication skills so they feel heard
	R63	Improve management at DOH and DSD so less Bureaucratic
	R57	Improve professional's literacy through workshops
	R60	Locating NGO 's who facilitated child sponsorship for Orphans
	R59	Facilitate MDT meetings through case conferences
	R158	Improve resources in clinics and satellite offices
	R127	Keeping comprehensive well written records
	R35	Supporting the existing community network through education re the unique needs or orphan's
	R79	Initiating orphan home visits through incentivising community members.
	R75	Facilitating parenting worships re the unique needs of orphans.
	R74	Facilitate medication administration workshops
	R26	Implement and facilitate for psychologists and social workers re the "lived Experience" of orphans living in township communities in SA.
	R88	Helping orphans to create memory boxes re their parents
	R52	Facilitate orphan adoption into extended family
	R49	Workshops to help professionals identify different funding streams to build their capacity to help orphan's
	R41	Facilitate workshops to educate professionals regarding how the townships communities work
	R32	Create a comprehensive but simple NGO system of referral
	R93	Provide venues for grannies leading GHH to have support groups and to pray
	R28	Start cluster homes for orphans
	R27	To assist professionals in compiling a comprehensive NGO directory
R Cluster 2	R40	Develop trust frameworks between orphans and professionals and between professionals.
	R42	Develop programmes to help restore hope to orphans and their families
	R126	Locate safe spaces for keeping records of orphan's and their families
	R125	Start after school support programmes related to understanding and coping with grief
	R107	Implement developing resilience workshops for Orphans
	R91	Develop a comprehensive data base re GHH.
	R105	Provide immediate support for children who are orphaned
	R85	Help orphans understand the benefits of talk therapy to cope with grief
	R111	Facilitate life skills workshops to help children make healthy choices
	R87	Teaching Foster Care families about the process of grief
	R110	Train Xhosa speaking psychologists and social workers
	R108	Provide an emergency orphan grant through DSD
	R109	Help communities develop food gardens in secure spaces around clinics and satellite offices in township communities
	R100	Develop NGO support to orphans through collaboration
	R102	Lobby for a specific orphan care grant
	R104	Place MDT in one place and thus develop orphan care team
	R99	Develop comprehensive psycho social support through understanding unique needs of orphans living in township communities
	R84	Help professionals develop language in their conversations with orphans to develop hope (I am, I have, I can)
	R86	Coordinate orphan support groups for "rediscovering hope"
	R164	Implement a porridge scheme at the clinic for HIV positive orphans who are on ART and TB treatment.
R Cluster 3	R54	Transition to electronic systems to process grant applications
	R33	Provide food parcels for orphans prior to grant monies being allocated
	R30	Commence orphan support groups in schools, where a nutritional meal can be provided.
	R51	Identify local businesses to financially support; support group initiatives for orphans
	R47	Train more professionals
	R48	Incentivise graduates to undertake a master's degree in Social Work
	R31	Enable HIV positive parents to develop planned responses to enable care and support for their children who will become AIDS orphans
	R29	Create professional space for collaborative meetings between health and social care professionals
	R129	Provide food for orphans attending orphan support groups
	R144	Provide private office space to enable private conversations between professionals and orphan's and their families

(*continued on next page*)

Table 1 (*continued*)

	R133	Collate NGO initiatives available in township communities to prevent orphans from becoming socially isolated; grass roots soccer, join library's or church groups.
	R45	Providing professional development opportunities for professionals
	R62	Professional debriefing of professionals caring for and supporting orphan's
	R132	Consider providing orphan key workers to enable continuity of care and support
	R130	Write a Xhosa booklet about the grant application process
	R131	Facilitate grant application writing workshops
R Cluster 4	R163	All orphans to be allocated a SW and Psychologist and Primary Nurse
	R161	Facilitate peer support groups for HIV positive Orphans
	R159	Facilitate support groups for extended families who have adopted orphan's
	R151	Social workers located in department of home affairs to help collect and process documentation required for FCG and CSG
	R148	Implement mobile orphan clinics
	R139	Train local incentivised Community workers to undertake orphan home visits
	R135	Re CHH teach parent children parenting as they have unique needs
	R61	Provide supervision for MDT professionals
	R134	Facilitate MDT support groups for orphans

were located. These participants were located next to an NGO which provided specific programmes and resources for children living as AIDS orphans in township communities. Therefore, these participants didn't make the recommendations identified by other participants within this cluster as these recommendations identified were already being met through the provision of programmes and resources from the NGO located next to these participants clinic and satellite office.

4. Discussion

This study has shown that whilst the intention of the South African government lies in its commitment to provide care and support to these vulnerable children there are many "barriers to" existing which prevent the provision of much needed care and support to children living as AIDS orphans in these township communities in South Africa. Understanding these "barriers to" and supporting the "recommendations for" could enable the development of strategies to overcome these barriers and support these recommendations and therefore begin to help realise these intentions of the South African government as set out in the national plan of action for children (DWCPD, 2017).

The main barriers identified in this study toward providing care and support to these vulnerable children centre around: poverty, poor medication compliance in orphans who are HIV positive; non-disclosure of HIV status in parents, stigma relating to being an AIDS orphan; complex grief due to the multiple losses children experience on becoming AIDS orphans; high risk behaviours of children who become AIDS orphans; geography of the townships creating difficulty and complexity with regard to identifying the location of health and social care professionals. Legislative barriers due to complex bureaucratic procedures, lack of immediate care and support for children who become AIDS orphans, the low morale amongst professionals providing care and support to these AIDS orphans and a lack of human and financial resources. Nearly 51% of children were reported to go without food for one day a week and 41% received between 1 and 2 meals of food per day in this township community (Skinner, Sharp, & Jooste, 2013: 117).

The discrimination often experienced by those with HIV/AIDS may further deprive children who are orphans of basic social, health and education services, (Skinner et al., 2013: 109). There is evidence that children who are orphans may lose many basic material resources which the caregiver usually provides (Cluver & Gardner, 2007: 7). These children may further experience deepening debt and loss of their few assets because of the loss of their breadwinner (Foster, Levine, & Williamson, 2005: 39). This situation can strain the traditional extended family and overwhelm already stretched health, social and education systems (Cluver & Gardner, 2007: 318). This poverty acts as a barrier to care and support as it prevents children accessing care and support from health and social care professionals as they are unable to travel to these professionals. This can result in malnutrition which affects the health of these children and is also linked to poor anti-retroviral therapy compliance (Ridgeway et al., 2018: 1).

Drenth, Alida, and Herbst (2013, p 7) highlight the cumulative losses suffered by children orphaned by AIDS: poverty, poor nutrition and increased work-load beginning with the onset of a parental illness. These children experience the loss of love, guidance, socialisation, and skills transfer by their parents, who often die in quick succession'. Children who are forced, through the death of both parents, to become the sole provider for younger siblings are common in South Africa. Living alone without adult supervision, high poverty levels and hunger almost suggests that grief may be a luxury in the face of survival. This in turn may lead to the development of complicated grief when emotional, social and psychological aspects of this are not adequately addressed (Drenth et al., 2013: 8). Cluver and Gardner (2007: 14) found that children who had become AIDS orphans were significantly more likely compared to other orphans to be depressed, have social problems and demonstrate post-traumatic stress symptoms. There are few support structures available in the township communities to help meet the needs of children who become orphans. With this backdrop of multiple losses these children find it difficult to develop a "trusting" therapeutic relationship with health and social care professionals and often suffer the consequences of complicated grief. The therapeutic relationship is central to all health and social care professionals and is based upon trust and establishing communication which promotes understanding, help and mutual respect. The therapeutic relationship serves as the intervention through which comfort, support, and provision of care are facilitated. Regardless of the setting and clinical situation, the therapeutic relationship always needs to be established" (Grispun, 2002: 5). Lack of ability to develop trust in this relationship is a further barrier in the provision of care and support to these vulnerable children.

Discrimination cased by parental death due to HIV/AIDS and the resultant stigmatisation associated with becoming an AIDS orphan can further add to the deprivation children who are AIDS orphans experience. Children living as AIDS orphans may become socially isolated because of the emotional hurt they experience due to discrimination and stigmatisation (Skinner et al., 2013: 109). This situation is further compounded by the late or no disclosure of HIV status in parents, which causes delay in accessing ART and leads to poor planning concerning the future care regarding their children.

Another barrier identified was low morale in health and social care professionals due to the enervation they experienced due to the large numbers of children accessing them for care and support, few resources and a poor working environment leading them to experience what has been termed 'compassion fatigue'. Compassion fatigue describes secondary trauma stress incurred by helping professionals working with survivors of natural disasters and terrorism. Fidgely (2002: 23) included health and social care practitioners in this definition, since these providers often deal with unrelenting suffering. Although the term compassion fatigue is often used interchangeably with burnout Streit (2013)

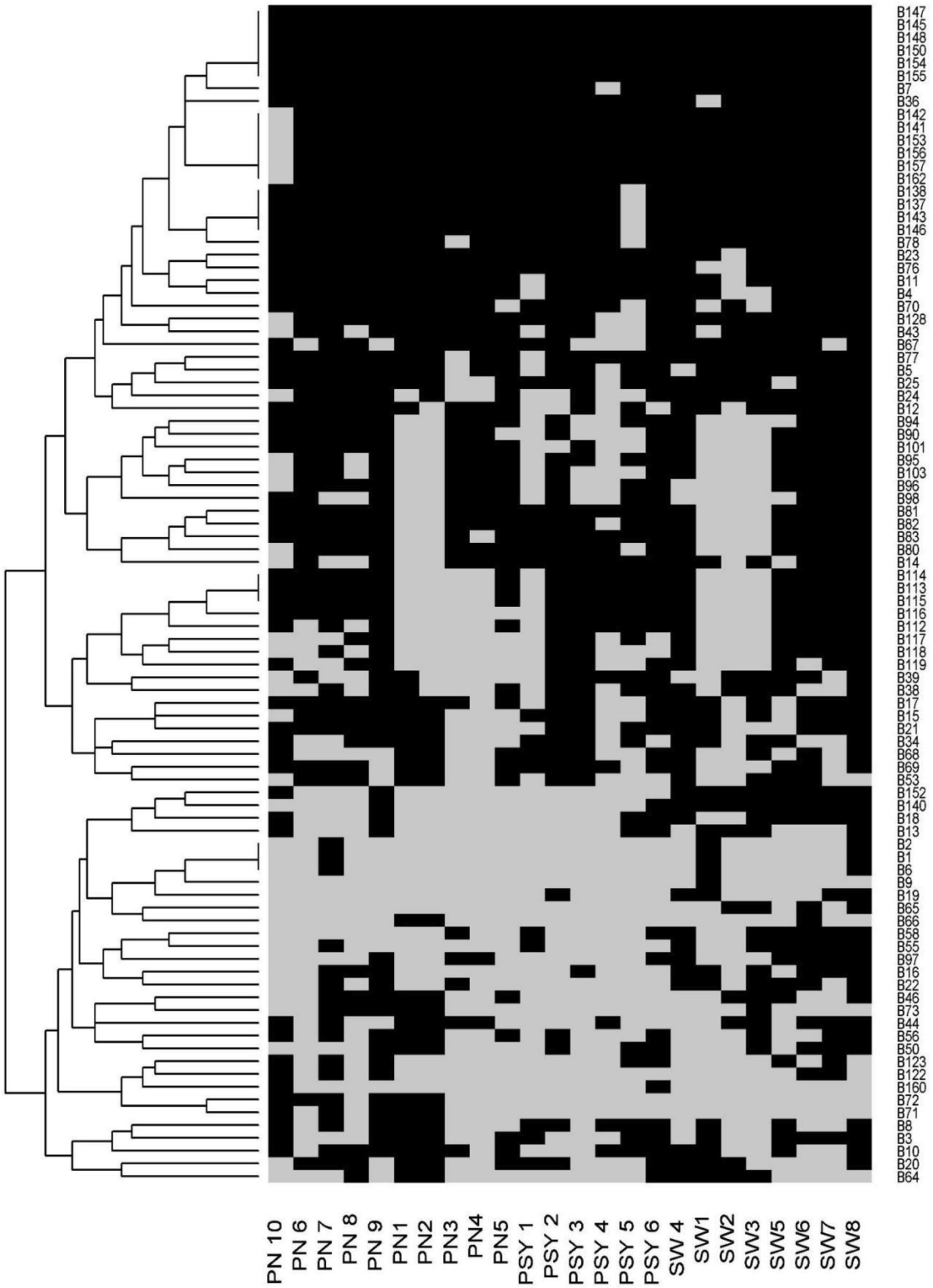

Fig. 1. "Barriers to" Cluster Analysis.

differentiates them by saying that compassion fatigue arises when one is unable to "rescue or save an individual from harm, which leads to remorse and sadness" (2013: 1). In comparison, burnout is thought to "arise from failure to meet personal goals, which results in frustration" (Streit, 2013: 1). According to Landro (2012) cited in Streit (2013: 1), compassion fatigue leads to decreased job satisfaction, decreased job productivity, higher job-turnover rates and cynicism in the health and social care practitioner arena. All these factors can affect patient satisfaction and patient care outcomes. For example, the desirable caseload per social worker is 60 cases, but the Minister of Social Development, Bathabile Dlamini, has conceded that owing to high levels of poverty, deprivation and the high incidence of HIV/AIDS, the actual case load per social worker is much higher (Moloi, 2012: 1). The enervation which social workers, primary health care nurses and

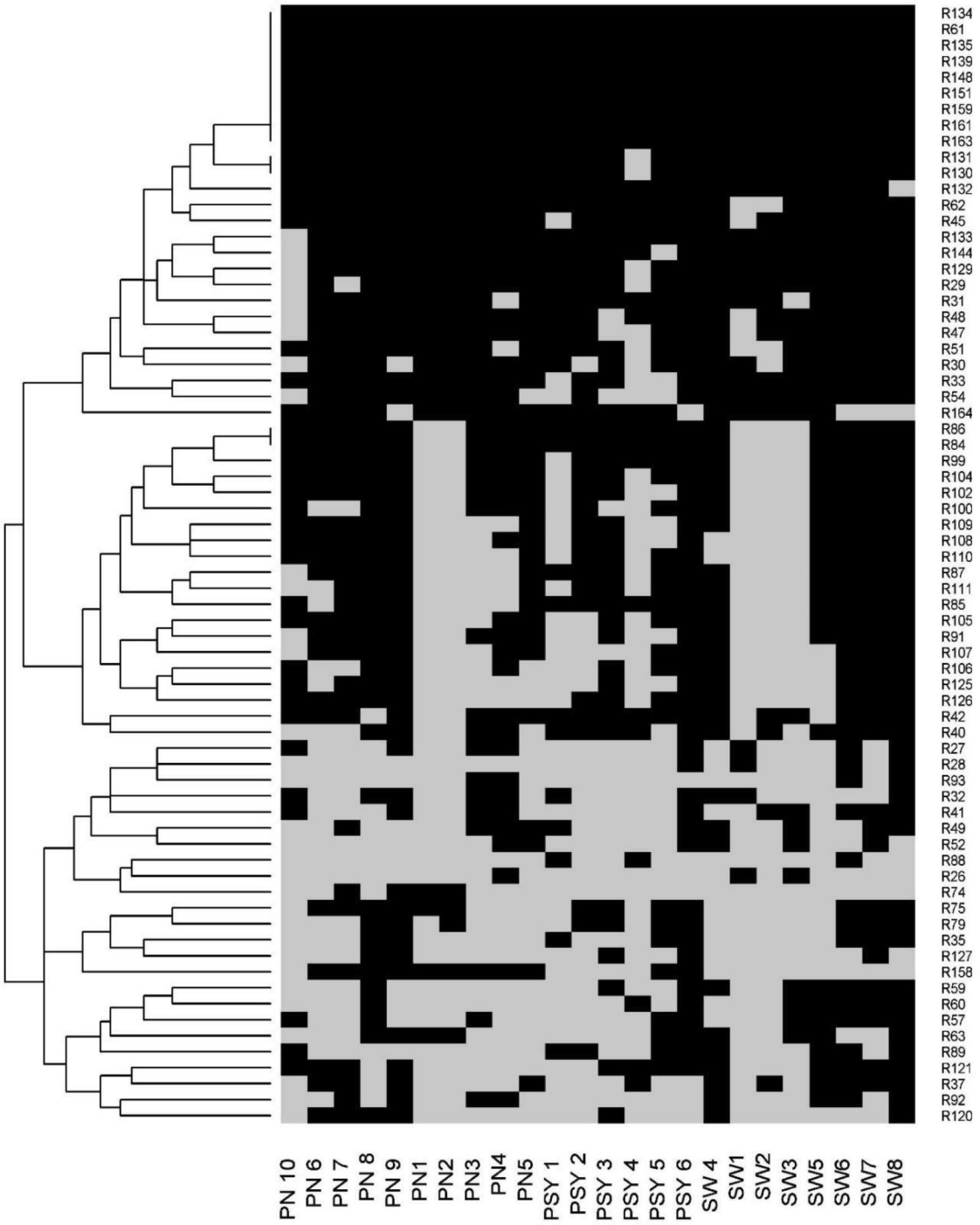

Fig. 2. "Recommendations for" Cluster Analysis.

psychologists experience due to compassion fatigue and having large numbers of children accessing them for care and support in a resource limited setting also causes a further barrier to providing care and support to these children.

The fight against HIV/AIDS "requires leadership from all parts of government" (UNICEF, 2003: 1). AIDS is far more than a health crisis. It is a threat to development itself" Kofi Annan (UNICEF, 2003: 1). This leadership finds direction within the legislative and policy frameworks in South Africa within the National Plan of Action for Children (DWCPD, 2017). The overall objective of the legislative policy frameworks guiding the care and support of children who are AIDS orphans living in townships is to uphold the following statement made by the South African Government: "It is the constitutional obligation of the state to protect and ensure the well-being of orphans through programmatic intervention" (DSD, 2005: 40). Whilst there is government policy in place to direct the course of action of the South African Government regarding the care and support for orphans and vulnerable children, the strategies or overall plan to achieve these aims of government would seem to lack operationalisation and the responsibility is predominantly taken by the NGO sector. The lack of capacity within the systems to operationalise the intentions represented in this government legislation is a barrier which adds to the suffering of these vulnerable children.

In 2011 research was carried out by the Children's Institute at the

University of Cape Town. The research which was titled, "the funding of services required by the Children's Act". This research ascertained the following regarding the implementation of the Children's Act (2005). Implementation Plan low: this was defined as good practice standards and norm for the priority services with lower norms and standards for other services. The cost of this was estimated to be R7.5 Billion. Implementation Plan High: defined as good practice standards and norms for all services. Cost 10.8 Billion. In contrast full cost, low implementation: defined as good practice standards and norms for priority services, lower norms and standards for other services. Cost R30.0 Billion. Full Cost High Implementation: defined as good practices and norms for all services cost R59.2 Billion (Budlender, Williams, Saal, Sineke, & Proudlock, 2011: 3). What is apparent is that the resources required to meet these standards are very high and larger than the budgets held by the provincial departments of Social Development.

The R3.4 billion allocated by the Provincial Department of Social development for the year, 2010/2011 is equivalent to about 45% of the Implementation Plan Low estimate and 5% of the Full Cost High Implementation plan. The Eastern Cape was the worst performer with only 25% of Implementation Plan low and 3% of Full Cost implementation cost funded by the Department of Social Development (Budlender et al., 2011: 3). This means that the resources simply resources simply aren't available for implementation of the Children's Act as the cost of the implementation is simply too high. This cumbersome Act is seen as a barrier to providing care and support to AIDS orphans as the administration to actualise this plan takes time and the resources to implement it are insufficient. This is seen as a further barrier to providing care and support to these children as identified by participants in this study.

The "recommendations for" centre around the following main themes. The development of holistic strategies to meet the unique needs of these AIDS orphans and developing, empowering and capacitating professionals and enabling better collaborative responses to meet the care and support needs of these vulnerable children; facilitation of an empowering working environment for health and social care professionals and developing the resilience of health and social care professionals. By definition "Best Practice" can be defined as anything which works to produce results without using inordinate resource (WHO, 2008: 7). What lies in the core of every health system is the unique encounter between one set of people who need services and another who have been entrusted to deliver them (Frenk, Bhutta, & Cohen, 2010: 1925). The research participants in this research study represent this unique encounter between children living as AIDS orphans in township communities and the professionals appointed to provide care and support to them. If "best practice" intention regarding management of the health and social care systems is "Whatever we do must be nationally enabling and locally empowering" (Doherty & Gilson, 2011: 7) The considering the "barriers to" and "recommendations for" as identified by these participants, would be an important consideration for professionals, managers and policy makers within these systems so that better care and support and be provided to these vulnerable children.

Participants identified that care and support to children who are AIDS orphans living in the township communities was fragmented and ad-hoc, and emphasised that a strategy needed to be developed, in order to provide holistic care and support to children living as AIDS orphans in the townships. This was deemed necessary by research participants in order to prevent already vulnerable children from becoming further deprived of this much-needed care and support. 'Holistic' refers to a comprehension of the parts of something as intimately interconnected and explicable only by reference to the whole. Regarding health and social care, it is characterised by the treatment of the whole person, considering the psychological, social, spiritual and physical factors (Dictionary, 2009: 245). The term "Strategy" is about shaping the future and is the human attempt to get to a desirable end with available means; a plan of action designed to achieve a long-term or overall aim. It is a high-level plan to achieve one or more goals under conditions of uncertainty; or a plan of action or policy designed to achieve a major overall goal, or a plan to address a problem: a pattern in a stream of decisions (Dictionary, 2009: 958). In the development of these strategies' participants recommended that providing immediate nutritional and financial support to these children, assisting in collecting and filling in grant application forms for either a child support grant or foster care grant and providing support groups as children living as AIDS orphan in township communities face unique challenges would greatly improve the care and support these children receive. Literature attests that Peer support through support groups for AIDS orphans has been shown to reduce their anxiety-anger and levels of depression (Kumakech, Mantor-Graae, & Maling, 2009: 1039).

A subsequent recommendation made was regarding collaboration. A multidisciplinary care team can be defined as a partnership among health and social care professionals of different disciplines inside and outside the health sector and the community with the goal of providing continuous, comprehensive and efficient quality services (IAPAC, 2011: 2). Most collaboration requires leadership although the form of leadership can be social within a decentralised egalitarian group. Teams that work collaboratively can obtain greater resources, recognition and reward when facing competition for finite resources (Gardner, 2005: 3). In this instance there was agreement across all participants for a collaborative response comprising social workers, psychologists and primary health care nurses to provide a care and support response to meet the complex needs of this unique group of children. A strong recommendation was that professionals be in the same geographical place. In this manner a more collaborative approach to providing care and support to these children could be coordinated and implemented; and this study has shown that location does matter in how professionals see their work and role.

The other broad recommendations made were related to facilitating the development of an empowering work environment and developing the resilience of health and social care professionals. This recommendation comprised; debriefing of the health and social care professionals, providing food parcels so immediate assistance could be provided to these children, compiling an NGO directory so that community support could be accessed to help meet these children needs.

Debriefing can be considered as part of stress reduction and alleviate distress in healthcare professionals facing stressful situations in their place of work (Cant & Cooper, 2011: 34). The 'debrief' is a common form of retrospective analysis of critical incidents in primary healthcare practitioners and related professionals (Raphael & Wilson, 2000: 39). Debriefing has been described as a critical-incident stress reduction technique that includes structured stages of group discussion (Mitchell, 2003: 59). The health and social care professionals experienced desperation regarding their need for debriefing. In this manner the facilitation of an empowering work environment could be created, and professional resilience could be developed. Thus, improving the care and support response to these children.

4.1. Planning interventions

Thematic analysis followed by cluster analysis enabled the identification of those factors that were "barriers to" or "recommended for" providing care and support to children living as AIDS orphans in Township Communities in South Africa. Through looking for and understanding the patterns in these clusters it may be possible to identify interventions or policy changes which could improve care and support delivery to these children. Details represented in these clusters can help to inform the development of interventions to enable "Best Practice" care and support for children living as AIDS orphans in township communities in South Africa. Being cognisant of the details which comprise these clusters can inform development of an implementation to meet the unique care and support needs of these children and therefore progress towards "best practice" interventions.

What is apparent is that overcoming the identified "barriers to"

could minimise the exposure of these children to certain risk factors which increase the vulnerability of these AIDS orphans and prevent these children from receiving care and support. Developing interventions based upon the identified "Recommendations for" could conversely be seen to develop protective factors which would improve the care and support responses to these children. Identifying the "barriers to" is considered significant as specific strategies can be developed to overcome these specific barriers. In this manner specific interventions can be developed to meet the unique needs of these vulnerable children.

4.2. Using process models

Process models such as the Model of Knowledge Translation are used to describe and/or guide the process of translating research into practice. Such models as developed by Huberman and Landry as identified by the Canadian Institutes of Health Research (CIHR, 2017) Such Knowledge-to-Action Frameworks outline phases or stages of the research-to-practice process, from discovery and production of research-based knowledge to implementation and use of research in various settings (CIHR, 2017).

Using the findings of the named "barriers to" and "recommendations for" could inform the development using a process model to guide the development of an intervention. In this manner the unique needs of these vulnerable children can be met through developing strategies to overcome the "barriers to" and strategies to implement the "recommendations for" providing care and support to these children

5. Conclusion

In conclusion, cluster analysis identified previously unseen constellations of "barrier to" and "recommendations for" providing care and support to children living as AIDS orphan in township communities in South Africa. Clusters R3 and 4 and B 5 and 6 could be used in informing the development of an intervention to move towards "best practice" implementation to provide care and support to children living as AIDS orphan in township communities in South Africa. This could enable the development of care and support responses to meet the unique care and support responses of these children. Which in turn would enable the transformation of the political intention of the South African government concerning the care and support of children living as AIDS orphan in these township communities. Into well-planned and effectively implemented evidence-based programmes and services to achieve the lofty goals of the National Plan of Action for Children living in South Africa concerting the care and support of these vulnerable children (Mayosi, Lawn, & van Niekerk, 2012, p2).

6. Implication

Although this kind of analysis is exploratory clear patterns in the responses were visualised both in the "barriers to" and "recommendations for" clusters. The heatmap showing "barriers to" and "recommendations for" demonstrates two clusters where there was a complete agreement with all participants mentioning all "barriers to" and all "recommendations for"; these were B6 and R4 clusters respectively. The "barriers to" and "recommendations for" could be used therefore to inform the development of interventions whereby "barriers to" could be overcome and "recommendation for" enabled. To improve the care and support to these children living as AIDS orphan in these township communities though primary health care nurses, social workers and psychologists.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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