

1-1-2008

Creating hope : psychosocial intervention for young children infected and affected by HIV/AIDS

Natalie Wilson
Ryerson University

Follow this and additional works at: <http://digitalcommons.ryerson.ca/dissertations>



Part of the [Pediatrics Commons](#)

Recommended Citation

Wilson, Natalie, "Creating hope : psychosocial intervention for young children infected and affected by HIV/AIDS" (2008). *Theses and dissertations*. Paper 934.

This Thesis is brought to you for free and open access by Digital Commons @ Ryerson. It has been accepted for inclusion in Theses and dissertations by an authorized administrator of Digital Commons @ Ryerson. For more information, please contact bcameron@ryerson.ca.

RJ
387
A28
WSS
2008

CREATING HOPE: PSYHCOSOCIAL INTERVENTION FOR YOUNG CHILDREN
INFECTED AND AFFECTED BY HIV/AIDS

by

Natalie Wilson
B.A. (Honours), Brock University, St. Catharines, ON, 2007

A Major Research Paper
Presented to Ryerson University

In partial fulfillment of the requirements for the degree of

Master of Arts
In the Program of
Early Childhood Studies

Toronto, Ontario, Canada, 2008

PROPERTY OF
RYERSON UNIVERSITY LIBRARY

© Natalie Wilson 2008

Author's Declaration

I hereby declare that I am the sole author of this major research paper.

I authorize Ryerson University to lend this major research paper to other institutions or individuals for the purpose of scholarly research.

Signature

I further authorize Ryerson University to reproduce this major research paper by photocopying or by other means, in total or in part, at the request of other institutions or individuals for the purpose of scholarly research.

Signature

CREATING HOPE: PSYCHOSOCIAL INTERVENTION FOR YOUNG CHILDREN INFECTED AND AFFECTED BY HIV/AIDS

© Natalie Wilson 2008

Master of Arts
Early Childhood Studies
Ryerson University

Abstract

Young children who are infected and affected by HIV/AIDS are at risk for psychosocial difficulties due to the confounding variables associated with the diagnosis. Research is needed to understand what makes psychosocial intervention successful for children who are infected and affected. An ethnographic study of an intervention program in the Southern United States was conducted in an attempt to understand what makes this intervention successful from the perspective of the children, their caregivers, and their intervention providers. Interviews and observations with all three groups took place over a three week period. Results were analyzed from both an ecological and a child rights perspective, which suggest that combining social services with a childcare program, the implicit ecological perspective of staff and their knowledge of HIV-related variables, and the development of positive relationships are essential components of a successful program. Recommendations for effective practices are made, and future research needs are discussed.

ACKNOWLEDGEMENTS

I would like to thank the families and staff at Hope House for their contribution to this research study. Their kindness, cooperation and insight enabled a study that may not have been possible without them.

It is also with gratitude that I thank the Ryerson University Consultative Group on Early Childhood Care and Development, who provided the means to travel and collect such valuable data.

I would also like to thank my research supervisor, Dr. Rachel Berman, who provided the guidance, patience and knowledge to make the study a success.

I would further like to thank my father and my friends. It is with your support, encouragement and humour that helped make this experience memorable and worthwhile.

TABLE OF CONTENTS

Abstract	v
Acknowledgements	vii
List of Figures	xi
List of Appendices	xiii
Introduction	1
Literature Review	5
Variables Affecting Psychosocial Health	5
Why the Lack of Psychosocial Intervention for Young Children In North America?	8
Psychosocial Intervention: Tools and Approaches	10
Implications for Research	11
Research Design	13
Participant Recruitment	14
Participants	16
Ethnographic Approach	16
Data Collection	18
Location	20
Data Analysis	21
Results	22
“They Help You Kind of Better Your Life:” Combining Social Services with Childcare	23
Housing Program	25
Play Therapy	27
“You Can’t Educate a Child who is Not Emotionally Ready:” The Implicit Perspective Of Staff and Their Knowledge of HIV-related Variables	30
“She My Friend:” Positive Relationships	37
Staff-Caregiver Relationships	37
Staff-Child Relationships	39
Child-Child Relationships	42
Validity	44
Additional Dimensions of Credibility: Reflexivity	45
Discussion	46
Recommendations for Effective Practices	49
The Next Step for Psychosocial Intervention?	55
Limitations and Suggestions for Future Research	58
Conclusion	60
Appendix A	61
Appendix B	72
References	76

List of Figures

<i>Figure 1. Social Ecological Theory Model.....</i>	<i>3</i>
<i>Figure 2. Variables Contributing to Successful Psychosocial Intervention for Children Infected and Affected by HIV/AIDS, Depicted Through the Social Ecological Lens.....</i>	<i>23</i>

List of Appendices

Appendix A: Consent Forms.....	62
Appendix B: Sample Interview Questions.....	73

Introduction

By the end of the day, approximately 1, 100 children in the world will be newly infected with HIV (Elizabeth Glasser Pediatric AIDS Foundation, p.2). With estimates of 2.9 million people to die from AIDS this year, chances are high that these already-compromised young people will lose caregivers or family members who are also infected (Thomas & Foster, 2006). Although the incident rate of families living in North America is low, in comparison to parts of Africa, there are still approximately 58, 000 people infected with HIV/AIDS in Canada (Public Health Agency of Canada, 2005). This is significant, as increasing survival rates of infants and young children in North America, due to antiretroviral medication, create new health risks, such as social and emotional difficulties (Roberts & Cairns, 1999), for those infected, and those around them.

Furthermore, the confounding variables of HIV/AIDS include poverty (Roberts & Cairns, 1999), being a visible minority (Owens, 2003), living in an unsafe neighbourhood (Lesar, Gerber & Semmel, 1995), parental mental health issues, and stigma (Goicoechea-Balbona, 1998). Any one or combination of these variables puts a child at risk for psychosocial difficulties, which is defined as the inability to successfully cope with aspects of one's life, resulting in changes in personality, due to prolonged emotional stress, and a lack of social functioning (Barry, 1996). Given these statistics and the confounding variables discussed, intervention programs for children infected and affected¹ by HIV are crucial in order to create better outcomes for these children and their families. However, what makes a successful intervention program? Moreover, what makes a successful intervention program from the viewpoint of participants and of the

¹ Children who are infected are HIV-positive and may or may not have family members who are positive. Children who are affected are not HIV-positive, and have at least one family member with the diagnosis.

workers who provide it?

The purpose of this study is to explore a psychosocial intervention program for children infected and affected by HIV/AIDS, aged 3-5. Psychosocial intervention is described as the continuous, nurturing support that strengthens the social, emotional, developmental (Richter, Foster & Sherr, 2006), behavioural and psychological aspects in one's life (Duncan & Arnston, 2004). It may be in the structure of formal programming, counselling (Richter, et al., 2006), games, songs, play, art, and/or age-appropriate education (Duncan & Arnston, 2004).

The research question addressed in this study is as follows: "What is a successful psychosocial intervention program for children infected and affected by HIV/AIDS, according to infected and affected children, caregivers and intervention providers?" The voice of the researcher is also present.

In order to carry out this research, an ethnographic approach was employed. This involved spending time with participants in their own environment (Cresswell, 2008). Qualitative data was collected through interviews and observations in attempt to understand this population's "culture-sharing behaviours, beliefs, and language" (Cresswell, 2008, p. 473). It is the hope that the combination of participant views, researcher observations and interpretations, and their comparison with current research literature will create meaningful results. This will provide information that may be used when developing future intervention programs for this population.

The theoretical lenses employed in this study include the ecological perspective and the rights of the child. Kmita, Baranska and Niemiec (2002) argue that in order to best empower families affected by HIV/AIDS, the child must be considered only in the

context of the family when intervention is taking place. Although this may be effective on some level, the approach fails to recognize the child as an individual, and the individual needs that may apply, which is achieved with the rights-based approach. Nor does it consider the larger societal context in which the family exists. Bronfenbrenner's (1979) social ecological theory outlines how the combination of one's surroundings all play a role in development and health. The model consists of four levels, all of which affect the individual:

- Microsystem - The relations, activities and roles directly experienced by an individual
- Mesosystem - The combination of two or more microsystems which the child is in, and the relations that develop as a result
- Exosystem - The indirect environments that an individual does not experience first-hand, which affect the individual's meso and microsystems, which in turn affect the individual
- Macrosystem - The larger, more indirect societal, political and cultural factors that influence the exo, meso and microsystems, which in turn affect the individual (Bronfenbrenner, 1979)

By viewing the child through the ecological lens, as seen in Figure 1, the family is still considered, as they play a key role in the child's quality of life (Hough, et al., 2003), but the larger context in which the family lives is also considered.

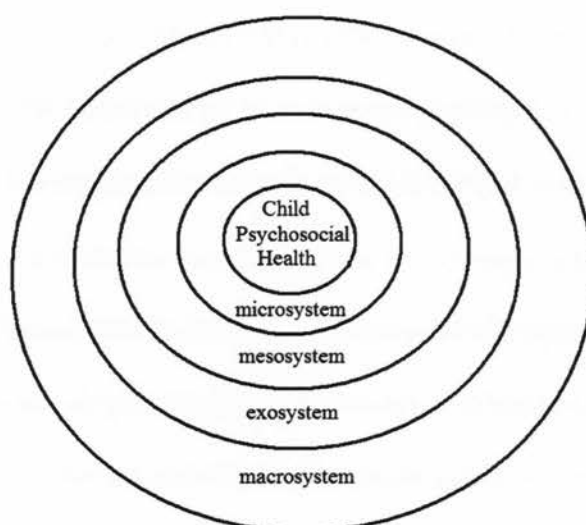


Figure 1. Social ecological theory model

In addition to an ecological lens, this study incorporates the principles contained within the United Nations Convention on the Rights of the Child. The convention is comprised of 54 Articles, in an attempt to ensure rights pertaining to the best interest of the child, development and basic survival, participation in their own world, and non-discrimination (United Nations, 1991), to all children in U.N. countries.

Although current research on HIV-positive adults has adopted the ecological lens (Barrio & Shoffner, 2005), there are no studies that use this approach, or a rights-based approach, to study psychosocial intervention programs for children infected or affected by HIV. Indeed, there is a scarcity of research on the psychosocial health of this population of children under the age of 6. There also appears to be a scarcity of intervention programs. For example, it was extremely difficult to find a program offering intervention for this age group, despite the alarming rates of psychosocial difficulties in children aged 5-18 who are infected or affected (Bacha, Pomeroy, & Gilbert, 1999; Mialky, Vagnoni, & Rutstein, 2001). Thus, employing a combination of the ecological theory and the rights of the child is unique in research on HIV intervention programs for children and families. Such an approach allows the child to be viewed in the context of her/his world, while also recognizing him or her as an individual with given rights.

As will be discussed, key findings include the combination of social services with child care, the ecological perspective of staff combined with their knowledge of this population, and the development of positive relationships. It is hoped that the information gleaned from this ethnographic study may provide grounding for similar programs to be initiated in Toronto, Ontario, where research and services for the young population infected and affected by HIV, are lacking (Husbands, et al., 2005).

Literature Review

Variables Affecting Psychosocial Health

Over 50% of those infected by HIV/AIDS in the United States are African-American women, at a rate that continues to increase (Owens, 2003). These visible minorities are less likely to have a high school diploma and are more likely to be a lone parent (Owens, 2003), with approximately 96% requiring financial support (Hough, et al., 2003).

Even if a woman attends individual therapy, having access to psychosocial-based therapy is not always enough, as the relationship an African-American mother has with family members, including support and involvement, affect her adherence to treatment (Mitrani, Prado, Feater, Robinson-Batista, & Szapocznik, 2003). This is significant because regardless of actual support, the perception of social support felt by infected women affects their mental health (Serovich, Kimberly, Mosack, & Lewis 2001).

In turn, a mother's ability to cope with the diagnosis, as well as her social support network and the environment, all affect her child's psychosocial health (Hough, et al., 2003; Bronfenbrenner, 1979). What is more, a child with HIV may be medically compromised due to their caregiver's own psychosocial state, as this is connected to the child's adherence to their antiretroviral medication (Marhefka, Tepper, Brown, & Farley, 2006).

Cultural variables, found in the macrosystem (Bronfenbrenner, 1979), are further shown to play a role when demonstrating the need for psychosocial intervention for young children who are infected and affected. African-American women are more likely to continue having children after being diagnosed with HIV, perhaps because

childbearing and mothering are signs of respect in African culture (Bungener, Marchand-Gonod, & Jouvent, 2000). This increases the number of children who are infected and affected, living in a minority race and culture, who may be compromised psychosocially, and need intervention. It is thus imperative that cultural traditions of a family are considered when assessing psychosocial health, as family structure, child care traditions and social support will ultimately be defined in these contexts (Barry, 1996). This is especially important when addressing issues around a chronic illness such as HIV/AIDS, as a caregiver's beliefs about death significantly shape a young person's understanding of the subject (Willemsen & Anscombe, 2001).

Stigma associated with HIV, which can also be located in the macrosystem, is further increased for this population, as African-European women are less likely to disclose their HIV status to family and friends when compared to infected Caucasian women (Bungener, et al., 2000). Many infected African-American mothers report feeling isolated from family members due to stigmatization (Mitrani, et al., 2003), which increases their struggle of disclosing their or their child's diagnosis to the child. This is likely to lead to confusion for the child and false knowledge about their or their caregiver's health, which, if not addressed early through intervention, may present psychosocial difficulties later on (Blumenreich, 2003).

For example, when a sample of 11-16 year old children living with an infected parent are compared to children who are not infected or affected, the sample of affected children are found to have greater psychological stress, lower self esteem, and greater parent-child conflict (Reyland, McMahon, Higgins-Delessandro, & Luthar, 2002). These are thought to be related to families living in a lower socioeconomic class, and being a

visible minority, located in the child's macrosystem (Bronfenbrenner, 1979), as well as stigmatization, and the child's resulting social environment on the microsystem level; all of which are characteristic of an family living with HIV/AIDS (Reyland, et al., 2002).

In addition to external characteristics, mental health is an issue, as Mialky, et al. (2001) find that nearly 20% of children with HIV, aged 7-9, are diagnosed with a mental health malfunction such as depression, and 43.5% with an emotional disorder. Because mainstream preschools and elementary schools do not include a psychosocial-based curriculum (Franks, Miller, Wolff, & Landry, 2004), the psychosocial health of children is put at risk. These issues could be addressed earlier to prepare young people, with the proper psychosocial intervention (Mialky, et al., 2001).

Along the same lines, outlets for expression are not always available for children, as most parents do not disclose their or their child's HIV/AIDS status to the child's school, due to fear of stigmatization and disclosure to other parties (Mialky, et al., 2001.; Roberts & Cairns, 1999). When the status goes unknown to the teacher, psychosocial support is not offered on this meso and micro level. Although parents choose not to disclose in order to protect the child and family, they also feel that by doing so they are unable to advocate for their child for support in the classroom (Roberts & Cairns, 1999).

However, even if a parent does disclose her/his status, there is only a minor chance that such psychosocial support would be incorporated into the curriculum (Roberts & Cairns, 1999). Teachers themselves do not feel experienced or trained to successfully include a child infected or affected by HIV/AIDS into a mainstream class, and integrate their social, emotional, psychological and physical needs (Franks, et al., 2004). Significantly, Franks, et al. (2004) show that teachers are an essential variable in

how other children and staff view a child infected or affected by HIV/AIDS, and teachers without previous experience with this illness are less likely to hold an accepting attitude (Greenland & Masser, & Prentice 2001).

From the ecological perspective (Bronfenbrenner, 1979), we see how children are impacted psychosocially whether they are infected or affected, due to afore mentioned characteristics, demonstrating the need to focus on children in both circumstances. As stated at the outset of this paper, little research exists on children infected and affected by HIV/AIDS in the early years. That which does exist surrounds medication adherence and the effects on caregivers (Boyd-Franklin, Steiner, & Boland 1995), leaving out the psychosocial health and evaluation of interventions for young children.

While psychosocial interventions are lacking, they are greatly needed by young children infected and affected by HIV/AIDS, for not only does it provide support for an at-risk group, it aligns with Articles 12 and 13 in the Convention on the Rights of the Child (CRC), enabling information and participation of the child in his/her life (United Nations, 1991).

Why the Lack of Psychosocial Intervention for Young Children in North America?

Many medical professionals claim a major reason why children are not involved in the explanation of their own health issues is due to their *limited cognitive ability* to understand and grasp what is being said (Alderson, 2002). However many now believe that all human beings, regardless of age, learn to understand the unfamiliar the same way, as long as they receive the proper information in an appropriate way (Rushforth, 1999). According to Rushforth (1999) the focus must, therefore, be on ways to foster and

increase children's ability to understand, so they may be active members in their health care and the variables associated with HIV/AIDS which affect them.

Some progress has been made to include children in knowledge surrounding their healthcare, although this varies across time and place. Europe now has an umbrella organization followed by 16 countries, titled the "European Association for Children in the Hospital," which stresses the right of children to be informed and participate in their medical care (Hallstrom, 2004). Although considered a liberal democratic country, Canada is far behind other nations who are providing children with age-appropriate education about HIV/AIDS. For example, the "HIV Psychosocial Care and Social Work Practice" (Canadian Association of Social Workers, 1997) policy for social workers in Canada focuses mainly on adults, and advises against disclosing information about illness to children under 6 years old. Although it mentions psychosocial assessment for HIV-positive adults, the document leaves out afore mentioned variables that put an individual at risk. What is more, "Canada's Child and Youth Health Charter" (2007) fails to mention psychosocial health, as well as HIV, despite its collaboration between the "Canadian Medical Association," the "Canadian Paediatric Society," and "The College of Family Physicians of Canada."

This is in contrast to other nations who are educating young children about HIV/AIDS via an infected Muppet child on Africa's version of *Sesame Street* (Hawkins & Goldstein-Knowlton, 2006). In addition to standard topics, preschoolers are educated about issues such as transmission, stigmatization, friendship, and losing a parent to AIDS (Hawkins & Goldstein-Knowlton, 2006).

Interestingly, other chronic conditions such as diabetes hold an open-

communication policy in Canada and North America. Although we do not have an infected Muppet on Sesame Street in North America, the emergence of story books available to educate young children about HIV/AIDS in effective ways do exist (Merrifield & Collins, 1998). Unfortunately they are not accepted in most classrooms in North America due to the stigma associated with this subject (Roberts & Cairns, 1998).

Psychosocial Intervention: Tools and Approaches

Although stigma continues to exist, it does not mean that story books and other props should not be used as tools during psychosocial intervention to aid in the education of children infected and affected, to increase their understanding of their lives (Alderson, 2002), and empower their rights as a child. For example, Willemsen and Anscombe (2001), whose approach aligns with the CRC (United Nations, 1991), demonstrate through appropriate psychosocial intervention, that children as young as two understand and adapt to issues surrounding death. Willemsen and Anscombe's (2001) method of artistic and dramatic play with children infected and affected by HIV/AIDS, is based on the belief that those aged 3-5 are capable of expressing their inner emotions and thus benefit from intervention.

The purpose of play and art therapy is to restore internal structures of psychosocial health by enabling an outlet for expression and empowerment (Tate & Longo, 2002). This unobtrusive approach of play and art allows for general goals to be applied to a group, such as social expression, while individual goals may be applied to a child to meet their specific need (Tate & Longo, 2002).

Through dramatic play, child participants in Willemsen and Anscombe's (2001)

study reveal many hidden emotions such as anxiety, shame, and grief. The displacement of emotions by one child participant, leading to aggression, shows an area of intervention a child affected by HIV/AIDS may need (Willemssen & Anscombe, 2001). Fortunately, this child attends a specialized preschool for children infected and affected by HIV/AIDS (Willemssen & Anscombe, 2001), as a mainstream school environment may mistake his emotional state for a behavioural problem.

Although psychosocial intervention may be applied individually, interventions such as play and art therapy in groups build trust and promotes risk taking, while allowing the group to bond through shared feelings and emotions when expressing their work (Tate & Longo, 2002). Kmita, et al. (2002) attest to this, as observations reveal children expressing their emotions the most when involved with group activities, such as dramatic play, with other children. Sadly, the general divide between caregivers and professionals in mainstream preschools and health centres (Franks, et al., 2004) make it unlikely that a child would benefit from this type of group-based psychosocial intervention.

Implications for Research

The majority of research involving children and HIV/AIDS revolve around prevention of infection. Boyd-Franklin, et al. (1995) note that teachers relate the subject to drug use, which reproduces the stereotypes of those infected, and creates a sense of fear surrounding the virus. This is even more detrimental to the psychosocial health of young children infected and affected by HIV/AIDS, as social and emotional issues are likely to arise from stigmatization (Boyd-Franklin, et al., 1995). Fortunately, a slow

emergence of programs, designed for this population of young children, are incorporating a psychosocial-based curriculum (Hope House staff, personal communication, June 10, 2008). However few have been evaluated, and thus research is needed to explore successful methods of implementing psychosocial intervention for children infected and affected by HIV/AIDS under the age of six years old.

Research Design

This ethnographic study involved a two-stage sampling process (Cresswell, 2008). After receiving approval from Ryerson University's Research Ethics Board, a centre was selected by researching organizations world-wide that provide psychosocial intervention for infected and affected children under the age of six. Due to the advanced participation of children in their medical care in England (Willemsen & Ancombe, 2001), and to a lesser degree the United States (Boyd-Franklin, et al., 1995), these were the countries of focus. Centres were identified based on information they advertised via the internet, through word of mouth, and by contacting child health organizations. Specific centres were contacted through phone and email, and were provided with information about the study, and an invitation to participate.

Hope House, a daycare and social services program for children and families infected and affected by HIV/AIDS, located in Memphis, Tennessee, was selected based on the services they offer and the centre's interest in participating². The services include daycare, respite care and play therapy for infected and affected children, and a social services program encompassing parenting classes and a housing program for caregivers (The Hope House, 2008). In addition, Memphis holds the highest rate of HIV infection out of all American cities, with similar variables that infected and affected populations face in Toronto, Canada, such as poverty and living as a visible minority (McGowan, in press). The combination of services and population characteristics thus made this research site significant for data collection.

² As the founder of Hope House requested that the name of the centre be used in the study, this information was added by hand at the end of each consent form, by which consenting participants signed their initials.

Participant Recruitment

Staff, caregivers and children from Hope House were sought for inclusion in this study. Thus, participants were the result of purposeful sampling (Cresswell, 2008). It was anticipated that staff members would provide insight into the psychosocial curriculum at the centre, as well as the attitudes, beliefs and goals of the staff and centre. This is important information for future organizations to be aware of when developing their program. Caregivers of the child clients were sought out as participants, as they hold an understanding of the issues and environments of the child, which ultimately affects their psychosocial health (Bronfenbrenner, 1979).

Finally, data would not have been complete without the voices of the children themselves. Despite traditional research about children, which gives approximate insight at most, Alderson (2002) shows that research may be done *with* children, who understand and articulate complicated medical aspects of their lives, even at age two. Aside from it being their right to be involved and express opinions on aspects of their lives (United Nations, 1991), young people's ability to contribute to research is highly underestimated and may provide an understanding of their lives that only they can give.

This qualitative study was the ideal opportunity in which to include children as participants, as viewing them from a rights-based perspective--in which they are entitled to the same rights as a participant and a citizen--further breaks down power relations between adult and child (McNaughton & Smith, 2005). It was imperative that this issue was addressed, as there lay an expected power relationship between adult and child, which may have affected the comfort level of child participants (Greene & Hogan, 2005). This was further significant for this population in general, as the stigma internalized by

infected and affected individuals may have created an additional imbalance of perceived power by participants (Boyd-Franklin, et al., 1995).

In the second stage of sampling, participants were recruited by making staff members and caregivers aware of the study via a Hope House social worker, who was encouraged to approach the subject in a sensitive fashion. After arriving at the research site I was then introduced to all children, staff and caregivers. Private meetings were conducted with each interested participant to explain the study and provide them with consent forms. This was done in an empty staff room at Hope House to limit the knowledge of who was or was not participating in the study so to maintain their right of privacy (Cresswell, 2008).

Consent forms, as shown in Appendix A, were presented to all interested participants, including children. This was important in order to ensure the rights of the child, as outlined in Article 4 of the CRC (United Nations, 1991). Children had their forms read to them, and were asked questions about the content, such as “what happens if you don’t want to answer a question?” to ensure their understanding of their rights (Greene & Hogan, 2005).

Participants were given as much time as needed to review the forms and present questions and/or concerns to the researcher. They were also reminded that their contribution was voluntary, and had the choice to stop the process at any time without penalty (Cresswell, 2008). Individuals received a small, inexpensive appreciation gift for participation, whether they completed the process or not, to avoid coercion (Cresswell, 2008).

Participants

Participants included two staff members from the centre, five children infected or affected by HIV/AIDS ages 3-5 who attend the centre, and their primary caregiver(s). This allowed for a triangulation of information to be collected, increasing the richness of data (Cresswell, 2008). Although not planned, all children and caregivers were African American, having lived in Memphis their entire lives, and were of a lower social economic status. Four of the caregivers were the biological mothers of the child participants and one was the sister of a child participant. All five caregivers were HIV-positive and four were the lone guardians of the children. Staff were Caucasian, both of whom had lived in the suburban area around Memphis for more than a decade, and appeared to live in a mid-range socioeconomic class. One participant was a social worker, who provided services to caregivers and play therapy to children, and another was a preschool teacher who worked directly with the 3 to 5-year-olds. Caregiver participants were under 30 years of age, with most being under the age of 25, some of whom were still treated at the local children's hospital. Staff were between the ages of 35 and 50. The ratio of children affected versus infected was 4:1, which was the result of whom showed interest in participating. Due to the ethnographic nature of the study, a smaller sample size was desired in order to gain an in-depth understanding of the strengths and limitations of the centre's programs, in relation to the child's psychosocial health (Cresswell, 2008).

Ethnographic Approach

In order to build a rapport and a feeling of trust between researcher and

participants, a three-week time-frame was allotted for data collection, in which each day was spent in the preschool classroom, to allow the children, staff and caregivers to become accustomed to my presence. Gaining knowledge about the research field before entering it was important to prepare for this ethnographic approach (Berg, 2004). This included learning the statistical variables likely to be associated with the participants, and the routines of the childcare centre, which was provided by a Hope House social worker before entering the site. As will be discussed, reflexivity was also applied throughout the ethnographic research process.

Staff interviews were planned near the end of the first week; the caregiver interviews during the second and third week, and the child participant interviews during the third week. This was done to give the most vulnerable participants the maximum time to build rapport and trust with the researcher (Greene & Hogan, 2005). It was particularly important for this population, as families infected and affected by HIV/AIDS are already compounded by feelings of distrust from stigmatization and the taboo approach society takes regarding this illness (Mialky, et al., 2001).

The same gradual approach was taken with observations in the childcare centre, as a more passive role was taken during the first week of observations in order to learn the daily routines of the preschool and allow time for the children, staff and caregivers to become familiar with my company (Berg, 2004). Once individuals were more comfortable, a participant-observer role was taken during the second and third week (Cresswell, 2008). I attempted to accomplish this by becoming part of the environment as much as possible, by spending each day in the preschool classroom, and engaging in activities, conversations and routines with the children. It was hoped that this approach

would instill a sense of normalcy regarding my presence, while still respecting the boundaries between researcher and participants.

Upon completion of the three weeks spent in the childcare centre, children were shown a map and a miniature airplane, to help explain my leaving the research field. Attention was also drawn to flying airplanes that were visible in the playground of the centre, to further explain that I would be leaving, and travelling home.

Data Collection

As mentioned previously, data collection consisted of interviews and observations of participants which allowed for the participants' voices to be heard, without a predetermined hypothesis of findings by the researcher (Greene & Hogan, 2005). Semi-structured interviews were developed for staff members, caregivers and children, to enable flexibility in the way questions were worded, to include probes if needed, and to allow for follow-up questions (Berg, 2004). This approach enabled the needs of the child participants to be met by breaking the interview into segments for some, and providing verbal prompts for others (Irwin & Johnson, 2005). These needs were learned by building a rapport with each child participant during the first two weeks at the daycare, while observing and speaking with the child to learn their preferences and strengths.

As shown in Appendix B, questions began and ended with easy, 'light-hearted' subjects, to ensure the participants' comfort and to end off on a positive note. This lessened the risk of negative emotional or psychological feelings lingering from discussing such a sensitive subject (Cresswell, 2008). Questions for children and caregivers were designed in a way to shed light on their psychosocial health, and to

understand their experience with Hope House. Questions for the staff were written with the goal of learning the assumptions, goals and beliefs of the program and facilitators, and to understand how the program goals are put into practice, to meet the psychosocial needs of the children. There was also an opportunity at the end of the interview for participants to provide additional information, to empower them as partners in the research (Greene & Hogan, 2005). Because interviews were recorded to allow for verbatim data, children had time before hand to play with the tape recorder for maximum comfort and trust (Greene & Hogan, 2005).

Observations were conducted in a non-participatory manner (Cresswell, 2008) during play therapy sessions between child and staff participants, to better understand this type of psychosocial intervention, as well as the staff member's approach, and the children's responses. Less formal, participatory observations (Cresswell, 2008) were done throughout the three weeks spent at the centre, while spending the mornings and part of the afternoons in the preschool classroom. Observational data included descriptions of settings, actions, quotes and behaviours of participants, and reflective notes (Berg, 2004), which were written in a private notebook. This unobtrusive technique was of particular advantage for child participants (Cresswell, 2008), as not all demonstrated strong verbal skills during interviews. Observations also allowed for the researcher's perceptions, which were compared with current research during analysis. Photographs were also taken of consenting participants, to add to the expression of findings (Berg, 2004), however they were not analyzed for the purposes of this particular study, but may be employed in future work.

In order to maintain the privacy of participants while data collection took place,

discretion was taken as to not make obvious who was the focus of study. As stated at the outset, the combination of the two methods were applied (Cresswell, 2008) with the goal of understanding what makes psychosocial intervention for children infected and affected by HIV/AIDS successful, from the point of view of the children, caregivers, staff and the researcher.

Location

All participants were asked their preference of where in the centre or their home they would like to do the interview, and child participants were given the choice of whether they would like a caregiver, staff member, or friend present, and their choice of activity while the interview took place. These additional measures were taken to ensure the comfort of all participants, in an attempt to reduce power between researcher and participant, and particularly between adult and child (Greene & Hogan, 2005).

Interviews for all participants, with the exception of two caregivers, took place at Hope House. It is likely that this location further lessened the risk of child and caregiver participants carrying away negative feelings as a result of the interview, as they were in an environment that is designed to help individuals work through their emotions. Due to issues surrounding disclosure and stigma, this setting also ensured a safe environment for participants, as this is where they are used to sharing information with trusted individuals about issues surrounding HIV/AIDS. To accommodate the needs of participants, the other two interviews with caregivers took place in their home. Both locations provided a familiar and accessible setting (Irwin & Johnson, 2005).

Data Analysis

Interviews were transcribed by the researcher after leaving the research site each day, and reviewed a number of times in a reflective manner to ensure the quantity and quality of data (Cresswell, 2008). This review provided an opportunity for clarifications to be made as I was still in daily contact with participants (Cresswell, 2008).

Observations were re-written with reflective notes to prepare for analysis (Cresswell, 2008). Transcripts and observations were then coded for emerging themes, followed by further reflection on how themes connect to psychosocial health, and the impact of the centre's intervention on participants (Cresswell, 2008). In keeping with the ecological approach, attention was paid to the cultural and contextual themes within the data (Berg, 2004), with an eye to what makes psychosocial intervention for young children infected and affected by HIV/AIDS successful. Attention was also given as to whether children were validated with their rights, as outlined in the CRC, despite the fact that the United States has not signed the Convention.

Results

Hope House is a not-for-profit childcare and social services centre, working to “be a catalyst for change in the lives of HIV impacted preschool-aged children and their families, to facilitate positive life-long changes” (Hope House Daycare, p.1). Founded in 1993, the centre provides day care and respite care to children who are infected or affected by HIV/AIDS. The centre consists of three houses on the residential street, which are divided into a preschool program, a toddler and infant program, and a social services program. Two staff, holding their Master of Social Work degrees, work in the social services house, along with administration staff. Preschool staff have varying levels of educational backgrounds, ranging from work experience to a Bachelor of Arts degree. If caregivers do not have transportation, children ride to and from the centre on one of two school buses that Hope House uses, driven by their own staff.

The cost of care is dependent on a family’s income, unless families qualify for childcare assistance from the government, in which Hope House is paid in full for the cost of a child (Hope House staff, personal communication, June 12, 2008). However, as a social worker explains, most caregivers are required to pay \$5 per week, and many do not pay. Hope House receives 10% of their costs from government funding, and rely on donations and fundraising for the other 90%.

Social services for families include play therapy for children, classes about raising children, and employment assistance for caregivers. Transportation is provided to and from the centre for these services as well, if needed. Hope House also offers a two-year housing program, which will be discussed in more detail.

After analyzing the data it appears that there are three main aspects of the centre

that make psychosocial intervention for young children infected and affected by HIV/AIDS successful. These include: Combining social services with childcare; the implicit ecological perspective of staff and their knowledge of HIV-related variables; and the positive relationships developed and nurtured within the centre. These three themes are further broken down into sub themes, as shown in Figure 2.

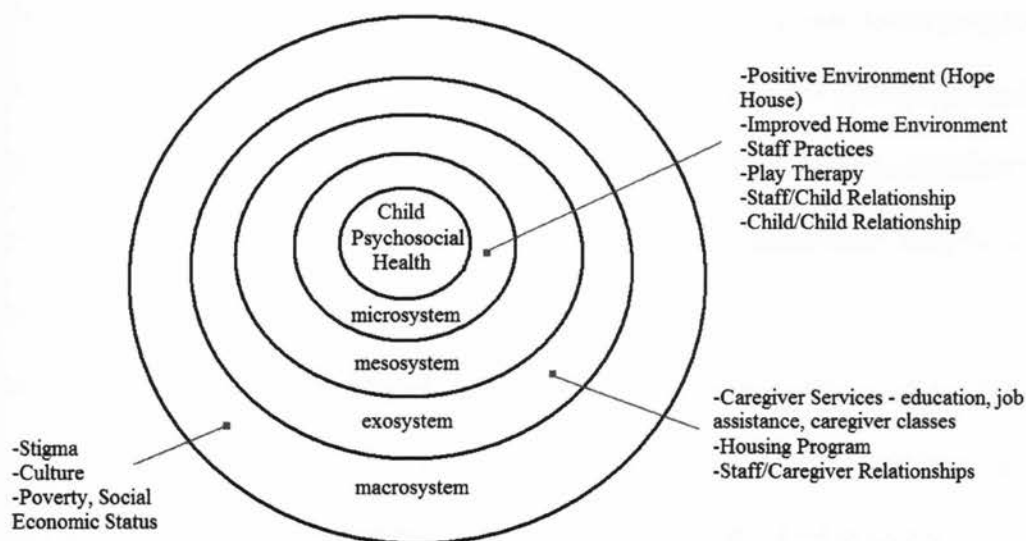


Figure 2. Variables contributing to successful psychosocial intervention for children infected and affected by HIV/AIDS, depicted through the social ecological lens.

"They Help You Kind of Better Your Life:" Combining Social Services with Childcare

Although at first glance Hope House appears to be a typical childcare facility with a focus on early learning, with the exception of all children being infected or affected by HIV/AIDS, a closer look reveals a multidisciplinary compilation of services that exist within this program. In addition to a stimulating program for young people, Hope House provides services for caregivers, which work to successfully intervene for children infected and affected, on the exosystem level of the ecological model (Bronfenbrenner,

1979). As a social worker explains, “[they] can provide great early education for the children, but [they] wanted to do something that would affect the child long term.” They seem to have done just that with the implementation of a caregiver class, titled “Strengthening Ethnic Families and Communities;” a 13-week program caregivers attend as a requirement for receiving child care, which provides insight into discipline, role modeling, rights of passage, and domestic violence (Hope House staff, personal communication, June 10, 2008).

Such a service is likely to be valuable, as most Hope House caregivers are lone parents, without other educational resources, as is typical with this population (Owens, 2003). One caregiver, who is raising her younger sisters, says that the class has been beneficial, while another mother explains that it has helped her in parenting her oldest daughter. And, as Hope House provides an opportunity for parents to improve their income and afford safer housing, children’s risk of domestic abuse may lessen, given the link that is found between poverty and domestic violence (Dematteo, Wells, Goldie & King, 2002). This program reflects the implicit ecological approach that is evident throughout Hope House’s practice and programming.

Furthermore, Hope House enables caregivers to achieve their General Educational Development (GED) diploma, by providing the course at the centre. One mother explains this program, though she says that she did not take it because she graduated from high school. This is said with a sense of pride, perhaps indicating that it is not a typical achievement in her environment; a fact which coincides with current research on this population (Owens, diploma2003).

Services to empower caregivers do not stop at a high school diploma, as

computers and references from social workers are provided to assist caregivers in finding a job (Hope House staff, personal communication, June 10, 2008). This is significant, as a lack of, and low income is among one of the highest of concerns for infected mothers living in Canada (DeMatteo, et al., 2002). Such concerns are warranted for these mothers attending the program in the United States as well, as most caregivers attending Hope House earn less than \$10,000 (USD) per year, which matches statistics found in current research (McGowan, in press). The benefits of caregiver employment are infinite to their children's psychosocial health, as the stress felt by parents, due to poverty, significantly affects the care and social support a child receives. As one mother states, "They help you kind of better your life."

Housing program.

The social services component of Hope House provides a housing service, which families may qualify for after their children have attended the daycare program for at least six months and caregivers have tested negative in a drug test (Hope House staff, personal communication, June 10, 2008). It is a two year program, in which social workers provide guidance for families to move to safer neighbourhoods, where they will pay a reduced rent fee for the remainder of the two years, with the goal of being self sufficient after this time. The assigned social worker acts as a case manager during this time period, and makes visits to the house to assess the progress of the families (Hope House staff, personal communication, June 10, 2008). Although some of the new areas are not considered the safest in the city (Hope House staff, personal communication, June 10, 2008), as witnessed first-hand when accompanying a social worker on a home visit,

they are in a much improved environment, as one social worker recalls:

One time the bus driver was dropping off the kids in a neighbourhood and he could not drop off these kids because there was a gunfight going on in the street and he had to go around the block a couple times before he could drop off the kids.

Benefits of the program are obvious, as some families who attend Hope House are homeless, or do not have a permanent residence. One caregiver shares that before she came in contact with Hope House she was struggling to raise her siblings while living with a friend in an unsafe neighbourhood, filled with poverty and crime. Another mother says she was homeless with her daughters, while living in a shelter and “barely getting by.” Both women are now the proud occupants of homes in neighbourhoods they feel they can raise their children in. A third mother, while sitting in her clean, quiet house, reflects on how peaceful her new neighbourhood is. She seems almost amazed that her children are able to play outside in the yard, as this was not a possibility in her previous home, due to the violent and unsafe environment. A four year old says that when he is at home he likes to ride his bike, which is also unlikely to have occurred in his previous living environment, as social workers say they do not feel safe travelling to many of the original neighbourhoods families lived in.

Although the program is just over one year old, more than 13 families have had their neighbourhood environments upgraded due to this program (Hope House staff, personal communication, June 10, 2008). Time will tell how truly successful the program is when the first families of the service reach their two-year mark and are responsible for taking over the entirety of their housing payments. For the time being, this type of family

intervention works to influence children's psychosocial health indirectly, according to the ecological model, as the housing program that caregivers are enrolled in changes the variables in the child's exosystem, as well as the child's microsystem (Bronfenbrenner, 1979), once the child is living in an improved environment. It also coincides with Article 27 of the CRC (United Nations, 1991), by creating a higher standard of living for the child.

This approach is in contrast to the National Human Services Assembly (Family Strengthening Policy Center, 2007), who suggest that economic assistance, in regard to living environments, should be targeted to families' original neighbourhood. This may be helpful for some families, such as one mother from Hope House who refuses to leave her unsafe neighbourhood, due to her strong connection with her surrounding social network (Hope House Staff, personal communication, June 10, 2008). However, attempting to change a neighbourhood, rather than relocating families, would involve far more government funding, which may not have the immediate results that children in the Hope House program have experienced (Hope House staff, Personal communication, June 12, 2008).

Play therapy.

In addition to the indirect ways of intervening for children infected and affected, play therapy, provided at Hope House, makes psychosocial intervention successful to parents, children and staff. The play therapy room, located two houses over in the administration house, includes a play kitchen, a puppet theatre, a play workbench with tools, an array of stuffed animals and small plastic toys, dress up clothes and a sand table.

Toys for the sand table include everything from small plastic animals, to trees and marbles, to a multitude of people figures, most of whom have a brown or black skin colour, matching that of the children. Although a seemingly small detail, it shows that social workers are in tune with the effects of cultural and racial differences when engaging in play therapy, and how they may affect the child (Goicoechea-Balbona, 1998), thereby reflecting the macrosystem level of the ecological model.

As the preschool teacher notes, she cares for “children with some behaviour that [they] have a really hard time with.” Although not all children in the centre receive this service, social workers provide it based on behaviours in the classroom, reports from preschool teachers, and knowledge of what the child is experiencing at home (Hope House staff, personal communication, June 10, 2008). Three of the five child participants are either receiving play therapy or have in the past, all of whom say they enjoy going to the play room. The two children currently receiving the service, one male and one female, say that their favourite part of going to the play room is “playing with guns,” which is observed during sessions in which each child uses play guns to shoot and hit stuffed animals and the therapeutic punching doll. This is in contrast to a five year old female child who received play therapy in the past, who now says that she likes to “play with baby dolls and books” in the playroom. This, in addition to the behavioural and emotional progress the social worker says this child has made, gives hope that the current recipients may progress and not require such negative means for expression and play.

The children currently in therapy are also two who appear to have more problematic home environments, as one mother speaks of the criminal background she has come from, and that her 4-year-old son witnessed the murder of his father at age two,

while it is suspected that a child from the other family may have been abused. Also, during interviews, all children say that there is someone who they are afraid of and who makes them sad. All have trouble verbally communicating what it is, though one three-year-old answers the question by saying "My daddy...he says read your own book." Another child says "He push me" when speaking about home, though she becomes too distracted with her painting activity to say who "he" is. A third child's demeanour quickly changes during his interview, when he picks up a ruler and aggressively says "You better not try to kill me. I'll take that knife and choke you...He'll be dead like a dog." These revelations are powerful testimonies to the negative environments children may be immersed in outside of Hope House, which create an obvious risk to their psychosocial health. Not surprisingly, caregivers are grateful for this service for their children, as demonstrated when one mother speaks about her daughter:

A lot of times she'll hold stuff in and she doesn't know how to express how to get it out and I think with [the social worker] working with her makes it a little easier for her to say, you know, "I'm feeling sad" or "having a bad day" versus just acting out.

The purpose of the play therapy is also evident while observing child participants in their individual play therapy sessions, as both children play out the typical cycle of domestic violence (Evans, Davies, & Dilillo, 2008). This includes extremely aggressive actions with toy guns and yelling at dolls, before apologizing to the doll or figure and becoming very affectionate, while doing domestic chores in the play kitchen. Both children also exhibit male-to-female aggression in their play, with the female child using two dolls, and the male child acting out the role of the male. As one caregiver reveals

details of their violent home life, it is logical to suspect that the child may have been playing out a real experience he had witnessed. However, because the 4-year-old speaks openly during an interview about the violent video games and videos he engages in at home, it cannot be certain whether he is playing out a lived experience. Nonetheless, the play therapy works to intervene on a direct, microsystem level, to allow the child to work through negative emotions and experiences gained from all levels of the ecological model.

The social worker who provides play therapy, says the “goals [for the children] are that they learn some control...and they improve their self esteem and self regulation...and their aggression decreases.” It is seen through observation that the social worker narrates the child’s actions and words in the play room, and praises the child when he or she accomplishes a task. There is not a lot of interactive conversation or discussion of actions from the social worker, to understand the child’s intentions or feelings. Although this practice coincides with Axline’s (1947) eight principles of non-directive play therapy, it is questionable as to whether social workers are missing key opportunities to engage in conversation with the child, and possibly gain insight into the source of the child’s behaviour.

“You Can’t Educate a Child Who is Not Emotionally Ready:” The Implicit Ecological Perspective of Staff and Their Knowledge of HIV-related Variables

The holistic approach to care at Hope House takes into account the microlevel of the ecological model, which further makes psychosocial intervention for children infected and affected by HIV/AIDS successful. It is evident to me through observations in the classroom and interviews with participants, that staff, particularly the preschool teachers,

implicitly work in an ecologically based way to meet the specific needs of a population infected and affected by HIV. This starts when children walk through the door of Hope House, as the first order of the day is always breakfast. Although children are not required to eat, most do, as a teacher explains that “a lot of children have not eaten breakfast; they get up early to take the bus in, or they get up early to ride in with a parent...so they rely on us to feed them.” The low socioeconomic status of families interviewed at Hope House match families living with HIV/AIDS in other research (Weinreb, Goldberg & Perloff, 1998; Goicoechea-Balbona, 1998), which often results in nutritional issues for children (Alaimo, Olson, & Frongillo, 2001). Thus, incorporating seemingly simple practices such as breakfast into the process of psychosocial intervention, is likely to add to the success, as food insufficiency is linked to psychosocial malfunction in young children (Alaimo, et al., 2001). Meeting these needs also align with Article 27 of the CRC, which states a child’s right to an acceptable standard of living (United Nations, 1991).

The approach is evident in many other places in the centre and specifically can be seen through one teacher’s passion for her students and their greater well being. She understands that children will not be ready to learn their letters and numbers if they have had a rough night at home, or are experiencing ongoing difficult circumstances, thus reflecting an ecological perspective of children’s lives. Through my observations I see that she does what is necessary to meet each child’s needs, whether it be some alone time, a hug, or communicating with social services, and still manages to fit in the lessons of a preschool curriculum. The teacher explains that Hope House is “safe for the children that are within the facility itself; it’s a safe place for parents to come and discuss any

issues...or problems they may have.” The caregivers seem to agree as a mother states that “their main goal is about the kids, and it’s not all for the kids; it’s for the parents too.”

What is more, an ecological approach that is targeted for children that are both infected and affected by HIV/AIDS, is likely to improve the psychosocial health of more children, as variables that place children at risk are the same, regardless of whether they are infected or affected (Dematteo, et al., 2002; Goicoechea-Balbona, 1998; Roberts & Cairns, 1999). One mother, who sends her two affected children and one infected child to Hope House, speaks of the benefits of this approach by saying that when “the school is for affected and infected...I think they’ll feel more comfortable around their sisters, so even though they [are] in different classes...they feel more comfortable getting off the bus all together.” Her oldest daughter at Hope House, aged three, is very aware that her two siblings are in the toddler program next door to her, and shows excitement when she has the opportunity to play on the playground with them. She is also aware when her brother or sister miss a day at the centre, as she says that they “go to the hospital and...[they] didn’t go to school.” Staff agree with combining the children, as both the teacher and social worker say that the care and services the children require do not differ whether the child is infected or affected. This appeared to be the case during observations, with the exception of a select number of children who are infected, who receive medication when they come off the bus in the morning. A preschool teacher, who was initially a volunteer when Hope House opened, before becoming staff, says she remembers thinking that it was “nice to know that there was going to be a facility to cater to children who are infected and affected.” And, as the social worker states, “these kids come from poverty, from dire situations...whether they are infected or affected,”

suggesting that the variables putting children at risk for psychosocial difficulties are similar regardless of the child's HIV status, resonating with current research (Boyd-Franklin, et al., 1995).

Additionally, the ecological approach implicitly taken at Hope House is reflected in the fact that staff understand that children infected and affected may not be able to participate in various events and holidays, such as Thanksgiving dinner, trick-or-treating, or receiving Christmas gifts, as most families live in poverty (Hope House staff, personal communication, June 10, 2008). This is similar to statistics showing that the majority of affected families living in Memphis (McGowan, in press), as well as in Canada, are living in poverty (Roberts & Cairns, 1999). The centre, therefore, hosts dinners, parties and outings for all family members, which is likely to increase the psychosocial health of these young children by being exposed to positive experiences that they share as a family and with other families (Fisher, 1999).

Children's medical needs are also attended to, as one mother remembers that when she would give her daughter her antiretroviral medication before getting on the bus to go to Hope House, the 3-year-old would become sick to her stomach. Thus, parents arranged with staff for the child to receive her medication upon arriving at Hope House by a nurse who works at the centre. Although other daycares allow for the dispensing of medication, this mother notes that she would not feel comfortable relying on staff in a typical daycare to provide this service, due to disclosure and stigma issues of HIV. Hope House, thus, provides a feeling of safety and comfort for family members, which enhances a child's physical and psychosocial wellbeing.

Flexibility of the staff work to meet the needs of these children as well, as a Hope

House teacher speaks of this accommodating schedule by saying

If we have a child that has had a traumatic event, play therapy is there for that, as well as...if there's something while they're in the classroom that we can do to make the child feel more comfortable or deal with that issue, we will. If that means that they need more one on one time with an adult...or if they want to play alone, we will allow that.

Both the social worker and teacher agree that this need for extra support is usually recognized through a behavioural difference in the child, though observations of the teacher also reveal her awareness of the child's life, that allow her to anticipate and better meet the needs of each child. This includes communicating with a child's caregiver to know when she will be seeing her biological mother, at which time the teacher can prepare for a regression in behaviour that was likely to occur in this particular child.

Although the ecological perspective is never mentioned by staff, it is evident that its principles work to shape their practices, as the preschool teacher states that

you can't educate a child who is not emotionally ready. And our children come from such traumatic events in their lives from the situations they live in or the neighbourhoods that they live in, that they're not going to be emotionally ready. So we probably cater more to their social and emotional needs and education just kind of comes along with it.

The experiences mentioned by this teacher demonstrates her awareness of the children's living conditions, as these variables match current research, showing the additional psychosocial stress placed on children infected and affected, in the home environment, due to poverty (Dail, 1990). By understanding the variables affecting this young

population, staff are able to cater to the child's specific needs on the microsystem level and intervene in a successful way.

It should, however, be noted that this teacher has a considerable amount of experience with this population, after working at Hope House for 11 years. If a new staff member, particularly a preschool teacher, joined an intervention team to work with these children and families, it would seem a beneficial asset to have a background in this population or at least psychosocial health, to enable as strong of an impact that this teacher is able to provide for her young students.

As mentioned previously, the stigma associated with HIV makes those living with it another variable that threatens psychosocial health (Roberts & Cairns, 1999) on the macrosystem level (Bronfenbrenner, 1979). Although neither staff member says they had any hesitations working with HIV-positive clients at Hope House, the social worker demonstrates the progression the centre has made, as she says that seven years ago Hope House did not publicly advertise, nor did it display a sign outside the centre. This is in contrast to today, with a Hope House sign, a website and several public fundraisers throughout the year (Hope House staff, personal communication, June 10, 2008). This coincides with the "Family Strengthening Policy Center's" (2007) recommendation to improve "the macrosystem in which parents and caregivers are raising children,...[including] media campaigns to change social norms" (p. 12).

This openness appears to be beneficial, as one mother recalls that "when [she] first walked through the doors...[she] hadn't been infected that long and so...[she] wasn't used to all this," as she speaks of the comfort level of the centre. It reveals how normalized it has become for caregivers to feel stigmatized, which creates a reluctance to

advocate for their child's health, in fear of disclosure. However, the comfort caregivers say they feel around staff seem to have diminished some of their feelings of stigmatization, affecting the child's psychosocial health on the exosystem level. Children are further impacted directly, on the micro-level, as the hugs and affection shared between staff and children also help breakdown stigma, according to parents and staff. Equally important, children enjoy attending Hope House, as one child says "I really like coming to school", while another child says that if she was given the choice of how often she attends, she would come "a lot of times."

The comfort level of caregivers is again shown as a preschool teacher notes, A lot of our clients have not disclosed [their HIV status] to their own family members. And...they have a lot of fears, and the disease itself has so many stigmas attached to it that they need someone to be able to come and talk to and to know that their children aren't going to be treated differently.

That is why one caregiver says she "probably wouldn't put [her infected daughter] in [mainstream] daycare because of the situation, because you never know how a person in a certain daycare [will] treat your children." This fear is warranted, as a teacher shares her outrage when finding out that two former children of Hope House, now attending a mainstream after-school program, were forced to sit away from the group, because it was known that their mother was infected.

It appears that the experience staff have in working with this population, their knowledge of HIV transmission, and their passion for helping families, all work together to break down the stigma within Hope House. That is not to say that the centre is completely void of stigma, as there is always room for improvement, which will be

discussed later on.

“She My Friend:” Positive Relationships

The third and equally significant theme found to make psychosocial intervention successful for children infected and affected by HIV/AIDS is the theme of positive relationships. Whether it is relationships between staff and caregivers, staff and children, or children and children, these young people seem to have benefited psychosocially at Hope House through their relationships. Relations between staff members are not included in this section, but will be discussed at a later point.

Staff-caregiver relationships.

The relationships built between staff and caregivers appear to have been transformative for the caregivers, thereby altering a child’s meso and exosystem and positively impacting the psychosocial health of their children. A preschool teacher admits that it is not always easy to create a relationship with caregivers, as she is a Caucasian woman. And, as the majority of those infected in North America are African American, it is likely they may already feel stigmatized from being a visible minority. The population is also likely to be feeling the negative effects of being of a different culture and social class, in addition to their HIV status, and thus may be less likely to trust others. This teacher says that patience, and maintaining an open line of communication helps some to build trust with her. Her approach is observable on a daily basis at Hope House, as the teacher greets all caregivers who drop off their children, and usually engages in conversation about the happenings in the centre and with the child, and allows caregivers

an opportunity to share any concerns.

The social worker communicates more with parents in regard to their social service needs, and thus develops relationships with caregiver clients this way. The frequency of meetings between caregivers and social workers varies, depending on each caregiver's individual need (Hope House staff, personal communication, June 10, 2008). These relationships often go beyond the call of duty on the staff's behalf, as the very experienced social worker reflects that she has "been in a delivery room for a client, [she has] been at the hospital with them at 10:00 at night, [she has] been available to them at 6:00 in the morning, [and] so they know that [the social workers] are there for them." All caregivers validate this, as a mother says that "if there's anything you need...you have a problem, you can call and talk to them". Another mother proclaims

If I'm having a situation at home that I need someone to talk to I can call the social worker and I can actually talk to them...I used to see a psychiatrist but, since I been going to Hope House I really don't need a psychiatrist because...I feel like I can talk to them about anything...They're good listeners...and they feel like family to me.

Along the same lines, direct psychosocial intervention for caregivers, provided by the social workers at Hope House, makes a significant difference in many caregivers' mental health. This is evident when one mother remembers back to when she first brought her children to the centre:

I'd been really sick. And it had been times when I just, I needed time to realize what I had and I just refused to take medicine at the time...and these are things you don't tell people because some doctors, some social workers, as soon as you

tell them [they are] gonna go call somebody...and you talk to [the social workers at Hope House] and...they gonna convince you and work with you, in any kind of way to take your medicine. And, I did.

This mother's testimony shows that it is the specific relationship between her and the Hope House social workers that has made the difference in her life, which appears to be due to the openness and lack of stigmatization she feels from them.

As mentioned earlier, the support a mother with HIV feels she has directly affects her infected or affected children, which is likely to contribute to her psychosocial health (Owens, 2003). This support may be social-emotional or physical, as one mother recalls social workers calling her to offer transportation to and from her parenting classes. This may result in a higher rate of attendance, enabling the positive effects of the class to transfer to the child. It can thus be assumed that the relationships staff develop with the caregivers of these children, and the support they provide, contribute to the success of psychosocial intervention for young children infected and affected by HIV/AIDS.

Staff-child relationships.

Possibly one of the most significant relationships observed is the relations between staff and children. When research was conducted the preschool staff ratio to children was approximately 3:12. Although attendance was about half than what is typical, due to the summer months in which the study took place, staff say they work as a team so ensure children receive the attention they need. The preschool teacher, who implicitly views staff-child relationships from the ecological perspective (Bronfenbrenner, 1979), states that

Children will and can be as good as the person that they're modelling...If they never have that [positive] encounter...then that child is not going to know how to be better than that unless someone tells them they can be.

At Hope House there lies an obvious connection between each child participant and the preschool teachers, as when children are asked about their friends, all of them list at least one of the three teachers. And, when asked about individual teachers, the common response is "she my friend." Social workers, who have more of a therapeutic relationship with the children receiving play therapy, are also listed as friends by two of the five child participants in addition to teachers and children. It is further observed through the positive reinforcement used by teachers, and the countless hugs exchanged between children and staff, that it is the staffs' passion to better the lives of the children. One mother also speaks about the one-on-one attention children receive, as she compares her experience working in another daycare, where staff in contrast, did not work to meet the social and emotional needs of each child.

The benefits of building child-staff relationships is clear when one child speaks about her fears, and says there is a person she is afraid of, and becomes quiet and reluctant when asked who it is. Although she is told that she does not have to talk about it, and the conversation moves on, it suggests that her environment outside of Hope House may include a negative relationship. Another child, when asked about her favourite part of Hope House, responds with "I like about coming to school and be good so my Grand Daddy don't woop me." Granted, some of these children will already have positive role models in their home life, as is evident in two of the child interviews, however staff create a protective environment regardless, that can only help the child in

terms of their psychosocial health (Willemsen & Anscombe, 2001). Masten (2001), who views resilience as “a common phenomenon that results...from the operation of basic human adaptation systems” (p. 227), explains this link between positive relations and health, as one single person may act as a mediator between a child and the variables causing psychosocial difficulties.

The result of the positive relationships between Hope House staff and children is evident through observations, as it is common for children, whether it be while sitting at the lunch table or playing outside, to call the attention of a staff member in order to say “I love you.” Whether this is said while sitting quietly or after exhibiting challenging behaviour, the staff member always responds with “I love you too.” When asked about this common practice, the teacher explains that although most children want attention, at Hope House

children crave the physical touch of an adult...they need to know that they are loved, that they are accepted...their body craves it, their mind craves it and I think if we were to deprive them of that it would drastically affect how they’re going to learn.

This is a logical connection in accordance with the ecological perspective, as when one aspect of their life is compromised, other aspects are likely to be affected. The connection between myself and the children while in the field also shows the value children place on these relationships, as one three year old states “You need to go home with me”, before getting on the bus at the end of the day. Having such a positive relationship with an adult outside of their home environment is vital for this population of children, as it is likely to contribute to the child’s psychosocial health, by creating a positive relationship in his or

her microsystem.

Child-child relationships.

Finally, the relationships that children infected and affected by HIV/AIDS develop at Hope House add to the success of psychosocially intervening in their lives. Observations show that all of the preschool-aged children at the centre share a special friendship, which often includes hugging each other good-bye at the end of the day. When asked her favourite activity at Hope House, one child says "I like playing with my friends," before listing the various activities she likes doing with them. Although the 3-4 year-olds are technically in a separate class from the 5-year olds, much of their free-play is combined, which allows for additional friendships to be made. One of the child participants, aged three, also takes on a very obvious care-giving role whenever she comes in contact with her younger sister, aged two, who attends Hope House in the toddler program. Another child says "[My brother] is in the daycare" when asked who his friends are. This again validates the benefits of services for children who are both infected and affected, to prevent siblings and "friends" from being separated.

Friendships are mentioned by all child participants, in which they also name their peers at Hope House in addition to their siblings. Significantly, one child says that another one of his friends is "Snoop Dogg", who is notorious in the media for being a negative role model to young people through his rap lyrics (Armstrong, 2001). This reveals an obvious benefit to positive relationships created at Hope House.

These friendships not only strengthen psychosocial health (Gifford-Smith & Brownell, 2003), but are significant for children infected and affected because most

caregivers say that without Hope House, their children would most likely not be in childcare, due to variables mentioned earlier. And, because caregivers say that for the most part, they are isolated from other family members and friends, due to disclosure issues, the friendships children make in Hope House are often the only ones these they have. Clearly, this positive addition to their lives, on the microsystem level, contributes to the success of a psychosocial intervention program for young children.

Validity

Given that this is a qualitative study, and due to the uniqueness of this program, findings cannot be generalized to the wide population of children infected and affected by HIV/AIDS, their caregivers, and care facilitators. However, this study has attempted to provide an in-depth view of the participants', staff's and caregivers' experiences of one program from an ecological and child rights perspective; experiences which may prove useful for organizations designing psychosocial interventions for young children and families, particularly those that employ an ecological framework.

Moreover, many studies reveal similar characteristics of caregivers of children who are infected and affected by HIV/AIDS, such as a lack of higher education, having a low income, and being a lone female caregiver (Lesar, et al., 1996; Hough, et al., 2003). DeMatteo, et al. (2002) find that from a sample of Canadian mothers with HIV, 73% have significant concerns regarding income, 65% are concerned about their affected child's emotional health, and 50% about their housing. This suggests that although the population of American children infected and affected may be faced with differing variables, such as parental drug abuse (DeMatteo, et al., 2002), many variables are the same. Services are needed to attend to these and other specific variables faced by Canadian families, as the number of women infected with HIV have almost doubled in the past 20 years, to 24% of all HIV diagnoses (AIDS Committee of Toronto, 2008). Therefore, what has been learned in regard to psychosocial intervention from the current sample of children may also be beneficial to Canadian groups, despite the need for further research.

Additional Dimensions of Credibility: Reflexivity

Attempting an ethnographic study could not have been done without reflexivity, to recognize the components that shape my perspective as a researcher (Cresswell, 2008). First, a degree in higher education has significantly shaped my rights-based perspective on children, with validation for their ability to contribute to research and to their world. This helped shape the design of the study and the decision to include children as participants, with the belief that their voice would increase the richness of the data. Additionally, this perspective on children and my higher education may not have been possible without my specific sociocultural position, as a young middle-class Caucasian woman, living in Canada. These factors must be considered, particularly with this research, in which the population and social location of focus is vastly different. This included living in Memphis for three weeks, in a country that has not signed the CRC, and where I felt very aware of my skin colour, due to the candid racial segregation in the city. It was thus to my benefit to try to learn as much as possible through research and the Hope House social worker, about infected and affected families as a population before entering the site, and about participants individually before collecting data.

Becoming familiar with participants through time spent at the centre, and learning of their struggles with being infected or affected, required an open mind and personal reminders to keep researcher-participant boundaries, so not to become emotionally involved. The combination of these factors played a role in every aspect of the research, and it is the hope that the open perspective on children, my approach to methods, and my academic ability to analyze and report findings, have made the project successful.

Discussion

The time spent at Hope House sheds light on what makes psychosocial intervention successful for young children who are infected and affected by HIV/AIDS, according to the children themselves, their caregivers, and their intervention providers. Through observations and interviews with participants, it appears that the blend of combining social services with child care, the ecological perspective of staff paired with knowledge of affected family variables, and the development of positive relationships, enable successful psychosocial intervention for 3-5 year olds who are infected and affected. Viewed through the ecological perspective, as well as a child rights-based approach, it is seen how these components work to benefit this population of children, and reveal areas for improvement.

Much of the findings relate to current research, as Lesar, et al. (1996) state that “any comprehensive model needs to treat the child as part of the family, and that this family, as a unit, be recognized as having needs for support services that may be different from those of the child” (p. 225). This is one of the strengths that Hope House has established, through their holistic approach, enabling services for specific family members, which in context of the family strengthen all members as a whole in regards to psychosocial health.

Also, the lack of family and social support felt by caregivers outside of Hope House correlates with research on Canadian families living with HIV/AIDS (Roberts & Cairns, 1999). It suggests the importance of support services for caregivers, in addition to the children themselves, as this support affects the caregiver-child relationship, and in turn the child’s psychosocial health (Owens, 2003). Similar patterns of support services

were found in research, in which caregivers become withdrawn upon diagnosis, and with the appropriate support, begin to seek out support services for their children, and become advocates for their families (Lesar, et al., 1996). As Kmita, et al. (2002) say, “the difference between care and empowerment is that only the latter makes it possible for the family to make its own choices and restore self-efficacy and self-esteem” (p.279).

In terms of housing, the program at Hope House, works to indirectly improve the psychosocial health of children, as it alters the impoverished environment that they are raised in. This correlates with research showing that 50% of Canadian mothers who are infected with HIV have an ongoing concern about their housing (DeMatteo, et al., 2002).

In regard to play therapy, many characteristics of children receiving the service, such as unstable home environments and domestic violence, are variables found in current research with affected families (Hough, et al., 2003), validating the need for this type of psychosocial intervention for this population. One child who is about to leave the centre to enter kindergarten, appears well adjusted, compared to how her teacher says she was before intervention took place, suggesting the positive influence of the program at Hope House, of which play therapy was a component. She may now be more successful in kindergarten from receiving this support, which aligns with Article 39 of the CRC, requiring rehabilitation for those who have been victims of conflict (United Nations, 1991).

When evaluating the findings of relationships, Hope House not only validates Articles 27 and 30 (United Nations, 1991) by providing a stable and stimulating environment for children infected and affected, but builds relationships that appear to be a component in successful psychosocial intervention for this population. The supportive,

unconditional relationships provided by staff, which caregivers speak about, greatly add to the success of psychosocially intervening for these children, as many caregivers describe the complete transformations they have made, due to this support. This is similar to current research, as over 90% of infected Canadian mothers say that having a professional aid to mediate between them and other professionals is among their most desired personal needs, as well as having a professional to confide in, and a resource for counselling (DeMatteo, et al., 2002). Lesar, et al. (1996) suggest that although caregivers may feel isolated from family members due to an HIV status, other social supports develop as a result, which works to decrease stress levels in caregivers. This is shown in this study, as caregivers all cite Hope House staff as a tremendous support, while mentioning that their relationships with family have decreased.

The direct relationships experienced by children at Hope House with their peers, also appear to add to the psychosocial interventions of these young people. Kmita, et al. (2002) find that the most successful intervention are those that involve a group of children and incorporate various group activities, which is similar to the experiences expressed by the child participants at Hope House, who state that playing in the playground, going to the waterpark, and playing with friends are among their favourite activities. Masten (2001) says it is these components that bring out resilience in children, which include “connections to competent and caring adults in the family and community, cognitive and self-regulation skills, positive views of self, and motivation” (p. 234), all of which Hope House works to do.

Recommendations for Effective Practices

In addition to the initial findings in this study, further analysis of the data reveal components that, in an ideal program, may add to the success of psychosocial intervention for young children infected and affected by HIV/AIDS.

Similar to the approach at Hope House, an implicit ecological perspective of staff may help improve the success of psychosocial intervention for children infected and affected. This is particularly so for those in Canada, as “growing numbers of [HIV-affected] Canadian families lack well-established networks of social support due to high rates of immigration and internal migration” (Dematteo, et al., 2002, p. 274). Attending to these psychosocial needs also align with Article 24 of the CRC, which validates a child’s right to the most optimal health (United Nations, 1991). Fortunately, this is despite the primarily biomedical model of health that many care facilities embrace, which fails to recognize psychosocial health when applying health intervention (Haynes, 2002).

Many components of the housing program at Hope House match the recommendations in other research, regarding how to intervene psychosocially for mothers and children who are homeless. This includes subsidized rent, educational and mental health support, and employment assistance (Dail, 1990). Interestingly, it is suggested by Dail (1990) that these services be offered by governments, which shows the power of Hope House, who receives funding from the federal government that covers only 10% of total costs (Hope House staff, Personal communication, June 10, 2008), and suggests that other organizations may aspire to this level of care for affected families.

One organization may include the Teresa Group, which works to meet the physical, and to some extent, emotional needs of up to 350 infected families in the

Toronto area (The Teresa Group, 2008). Although they aspire to open a daycare for children who are infected and affected, and provide psychosocial intervention, the plans are currently on hold, due to the lack of government funding (Teresa Group staff, personal communication, May, 2008). However, if plans start on a smaller scale, as Hope House did in 1993, and this organization takes into account findings and recommendations from studies such as this one, the implementation of a program may be more successful.

In addition, the explicit ecological lens of staff may improve play therapy techniques, as Axline's (1947) non-directive approach comes from a developmental perspective, in which children are not capable of engaging in conversation or answering questions about their play and emotions (Abadia-Barrero & LaRusso, 2006). While holding a belief of children's abilities, play therapy seems like a very appropriate setting to speak with children about their feelings and their own interpretations about their play. This would coincide with Article 12 of the CRC, by not only allowing the voice of the child to be heard, but for it to be considered valid and worthy (United Nations, 1991). This may further enable psychosocial intervention to actually take place, by addressing the cause of behaviour, in addition to providing a safe place for children to release the behavioural symptoms.

Along the same lines, a Hope House social worker says that improvements in behaviour and emotion, due to play therapy, do not happen quickly, and the child must receive a minimum of 20 sessions. It is thus imperative, in an ideal program, for play therapy to be consistent and to work around the needs of the child and the child's schedule. Sessions which occur at the same time of day for each session will also enable

children to become accustomed to a schedule, which is shown to help regulate emotions and behaviour (Willemsen & Anscombe, 2001).

Furthermore, it is recommended, in light of these findings, that the ideal program recognize whether services are built from a strength-based or deficit-based model, or a combination. The simultaneous approach taken at Hope House to intervene with families includes mandatory drug testing of caregivers in the housing program, and required night classes for caregivers whose children are in the daycare program, which may carry with them negative connotations about these individuals. Understandably, statistics show that narcotic abuse and problematic parenting of children are prevalent in infected caregivers in the United States (Mitrani, et al., 2003), and are issues the social worker at Hope House candidly discusses. And, as Hope House is a not-for-profit organization, with a waiting list of families, it can be understood why such requirements are put in place. However, the negative assumptions placed on caregivers and its effect on their ability to thrive is worth noting, when viewing the issue through the self-fulfilling prophecy model, in which individuals internalize and amount to the beliefs of others around them (Bond & Omar, 1994). Requirements such as drug testing may not be needed for a program in Canada, due to differing statistics (Roberts & Cairns, 1999), however further research on Canadian families may reveal additional requirements.

On the other hand, because psychosocial health is an enabler in almost all aspects in life (Attride-Stirling, Davis, Markless, Sclare, & Day, 2001), it may be argued that psychosocial intervention, as provided at Hope House, gives children and families the “tools” of social, emotional, behavioural, spiritual and psychological health that may enable them to live a positive life. This way of thinking is portrayed by the preschool

teacher who states that she wants the “families to be in a position where they are confident to better themselves,” suggesting that if they are given the assistance, families may have the power to take the lead in improving their lives. An ideal program which intervenes with children and their families would thus operate from a strength-based model when possible, as Hope House has done in several areas.

In addition, many programs serving families are multidisciplinary³ facilities, which employ an arrangement of expertise to serve children and family members in various areas (Duncan & Arnston, 2004). However, the multiple services, from multiple areas of expertise, do not ensure a *transdisciplinary* approach to care. Through observations it is evident that although teachers at Hope House often relay information and concerns about the children to the social workers, information that social workers hold is not often communicated to teachers, affecting their care for the children. It would be recommended that in an ideal, transdisciplinary intervention program, staff from all disciplines work together to share knowledge and hold a team approach to confidentiality. This may enable intervention to run smoother, as it will avoid one staff team from “undoing” intervention progress or contributing to a child’s difficulties, due to the lack of communication from another staff team.

Along the same lines, including caregivers as part of this transdisciplinary team may allow positive care to continue once families have left the intervention centre, such as revelations in play therapy, when appropriate. Other studies show the benefits of group play therapy, which includes family members, and enable the caregiver to be aware of the child’s emotions, and to parent the child accordingly, when at home (Wittenborn, Faber,

³ Multidisciplinary is considered an array of services from multiple disciplines, which work separately to provide care. Transdisciplinary is considered an array of services in which professionals share knowledge, and care from various disciplines are intertwined (Atkins-Burnett & Allen-Meares, 2000).

Harvey, & Thomas, 2006). Perhaps this would be a beneficial addition to individual child play therapy.

As a researcher with a background in child rights, and the belief in validating children's ability, it is further recommended that in an ideal intervention facility, children who are infected and affected be educated about HIV. One primary reason why children are not disclosed to at this age is the belief that they are unable to understand the diagnosis (Abadia-Barrero & LaRusso, 2006). Alternatively, Alderson (2002) points out that children of similar age, in other parts of the world, successfully run households and work fulltime, and thus undermining the ability of children to be involved in their world is giving in to the negative discourses of childhood.

Importantly, Kmita, et al. (2002) find that in their sample of children aged 2-15 who are infected or affected, they too have not been told about HIV in the family, and nonetheless "reveal indirectly some knowledge of [HIV] in their play and drawings" (p. 282), such as stating that a stuffed animal has AIDS. This is evident in one infected child at Hope House, who at the age of three, speaks about various family members and their need to "go to the hospital 'cause they sick." Although she exaggerates the actual medical issue of her sibling or mother, as the teacher is aware of the actual ailment, her awareness and communication about it shows her ability at this young age (Alderson, 2002). The very fact that this child is exaggerating her family's medical issues reveals a possible, and unnecessary, source of stress, as Rushforth (1999) shows that when children are not informed, they learn false information on their own. In this light it is understandable why children who are infected and affected do better psychosocially when they are raised with the information, versus being disclosed to in older childhood or adolescence (Abadia-

Barrero & LaRusso, 2006). This can be done in a variety of ways, such as with storybooks that are now available, and age-appropriate videos (Abadia-Barrero & LaRusso, 2006).

Along the same lines, one 3-year old at Hope House, though not typical, took her medicine in front of her classmates during observations. While downing her two syringes of syrup with more ease and professionalism than most adults, it seems like only a matter of time before this child, wise beyond her years, will ask why other children do not need medicine to make them "strong," as this is the current explanation provided to her. After all, "it cannot be assumed that children's silence about HIV/AIDS indicates an absence of causal thinking and/or self-made explanations" (Boyd-Franklin, et al., 1995, p.130). By telling children only part of the truth or avoiding the subject as a whole, children and families are encouraged to embrace the stigma associated with HIV/AIDS. After all, if it is not appropriate to educate and be open about the subject in an intervention facility that caregivers consider most sacred, why would it be anywhere else?

Another reason why young children are not disclosed to is that most of their other family members are unaware of the diagnosis (Hope House staff, personal communication, June 12, 2008). Thus, while respecting the wishes of the parents in regards to disclosure, perhaps caregiver classes and staff-caregiver relationships should incorporate an encouraging attitude from staff, as well as coaching and support, for caregivers to proudly disclose their family's status to family members and friends. In this way they may be empowered to become educators about their condition and continue to decrease the stigma surrounding HIV. This would reduce the chance of an educated child from disclosing new information, which may increase the willingness to educate young

children, and possibly begin a generation of new attitudes towards the condition. Staff keeping silent about the issue around children encourage their caregivers to do the same, which reproduces and validates current stigmatized attitudes of society, which is detrimental to young people on the macrosystem level. It also goes against Article 13 of the CRC, entitling children with the right to information about matters concerning themselves (United Nations, 1991).

Finally, support that continues once families have left the intervention program, such as when children first enter mainstream schools, may enable the psychosocial health of children to remain intact. Due to parents' reluctance to disclose their child's HIV/AIDS status to the school, and teachers' personal biases and feeling unprepared to include these young people, children are compromised in school settings (Franks, et al., 2004). Because teachers act as a significant variable in the acceptance and experience of children infected and affected in the classroom (Franks, et al., 2004), it only makes sense for teachers and staff to receive such enlightenment. Ideally, if staff from the intervention program, who are familiar with the children and families, advocated for the child in the school system and educated school staff, children may make a smoother transition from one type of care to another.

The Next Step to Psychosocial Intervention?

With increasing rates of children infected and affected by HIV/AIDS entering mainstream childcare and school systems, the next step to psychosocial intervention may be to create inclusive programs and provide universal education and intervention to all children. Once teachers hold the correct information and attitudes regarding children with

HIV/AIDS, knowledge may be passed on to parents and community members who are hesitant of their child being in contact with an infected or affected peer (Franks, et al., 2004).

Resources such as books and items for sanitary practices give all children exposure to the subject and enable them to be educated at a young age. With these normalizing resources, children infected and affected by HIV/AIDS, as well as those who are not, are able to identify with aspects of the curriculum on an individual and meaningful level, decreasing stigmatization and social exclusion. And, this exposure to all children works to instill an inclusive attitude, whether the child is infected, affected, or none of the above. This may promote psychosocial health in a child who is infected or affected because stigma is decreased, which is one of the unique variables faced by these families. And, because many of the problematic variables are faced by unaffected families, such as poverty, lone parenthood, and visible minority status, psychosocial intervention in these areas would not segregate specific children.

One approach to implementing this may be *reverse inclusion*, in which programs currently providing services to children who are infected and affected, such as Hope House, open their childcare to all children (Hardin & Hardin, 2002). Granted, this would be a challenge for non-profit organizations, but may provoke an increase in government funding to enable the possibility. This would allow those families who are comfortable with the idea to set an example for others who are more hesitant. It may also reduce feelings of segregation and stigmatization felt by children and families in separated intervention programs. If all goes well, the possibility of providing education and support regarding HIV and its variables may be realized in mainstream daycares and schools.

Staff and caregivers have the opportunity to prepare children to face school systems and society at large, who are not yet ready to embrace those living with HIV/AIDS, when they are educated in an open and appropriate way. Rather than questioning whether children are able to understand, it should be made certain that information is presented to the child in a way that they *will* understand (Alderson, 2002). Thus I recommend that staff take a rights-based and ability-based perspective when providing psychosocial intervention, in which greater success for the child may be achieved. It would allow services to further align with Articles 12 and 13 of the CRC (United Nations, 1991), in which children have a right to express their opinion and to be heard, as Alderson (2002) says that children “are active learners and self-health carers from the start, with wisdom through being in tune with their body” (p. 158). By taking cues from the child, in relation to their emotions and needs, professionals will be in a better position to intervene psychosocially (Alderson, 2002). Also, by incorporating an ecological perspective, the variables in all environments, affecting children’s psychosocial health may be attended to.

Limitations and Suggestions for Future Research

As 21% of families living with HIV/AIDS in Toronto have immigrated from Africa and the Caribbean (AIDS Committee of Toronto, 2008), children are likely to be faced with varying stressors, such as being exposed to foreign medical practices and beliefs, language barriers, and cultural differences, that put them at risk for additional psychosocial difficulties (Boyd-Franklin, et al., 1995) not addressed in this study. Demographics of families living with HIV also vary between Canada and the United States, as many Canadian children live with two caregivers, in neighbourhoods that are not saturated with other affected families, and parental narcotic abuse is not as prevalent (Roberts & Cairns, 1999). Immigration, childcare and healthcare policies also differ between countries, which are likely to alter the experiences of families.

Furthermore, because data collection took place at Hope House, observations of the relationships, between children and their caregivers were extremely minimal, as most children travel to and from the centre on a school bus. Future research that includes observations of the child-caregiver relationship may provide further insight into what makes psychosocial intervention for these children successful.

Furthermore, the time allotted to build a rapport with participants before conducting interviews, particularly with children, was shorter than what would be suggested in future research. This was reflected in the quality of the child interviews, as while waiting until the third week allowed for a rapport to be built, the ability to break the interview into several segments, to meet the needs of certain children, proved difficult when time ran short. Adult participants expressed this issue of time and rapport, as preschool teachers shared that they were sad the three weeks had ended, as they were

now feeling very comfortable with my presence as a researcher. It would be suggested for future studies that at least 4-5 weeks are allotted, and even more to increase the richness of an ethnographic approach (Cresswell, 2008).

Conclusion

This research study is successful in shedding light on psychosocial intervention of young children infected and affected by HIV/AIDS, for many reasons. First, it enables the rare opportunity in research for the voice of the family members, as well as the staff to relay the components of intervention that has been successful to them, in addition to the outside perspective of an educated researcher. More significantly, it includes the voice of young children themselves, which is not typical for this age group (Alderson, 2002). The lack of psychosocial research and services available to this population of children, under the age of six, suggests its rarity and reveals the void of information known about it, thus adding to the importance of this study and future ones like it.

One staff member could not have said it better when reflecting on the goals of such a centre, that shapes lives by providing psychosocial intervention for young children infected and affected by HIV/AIDS: "You can live with HIV; you don't have to die with HIV...I want them to have hope." With continued research to validate the need for services and centres like Hope House, young children may be given just that, to empower them though their current obstacles and their future endeavours. Hope is a word used by all caregivers, a state of mind which staff work to instill, and a feeling that seems to radiate from the children. This, and all of its components, as explained by participants, is what makes psychosocial intervention for young children, infected and affected by HIV/AIDS, successful to them.

Appendix A
Consent Forms

Ryerson University
Caregiver's Consent for Child Participant

Master of Arts in Early Childhood Studies, Major Research Paper

Your child is being asked to participate in a research study. Before you give your consent for your child to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what your child will be asked to do.

Investigator: Natalie Wilson, B.A. MAECS student, natalie.wilson@ryerson.ca

Supervisor: Professor Rachel Berman, PhD, Master of Arts Program in Early Childhood Studies, School of Early Childhood Education, Ryerson University.
rcberman@ryerson.ca 416-979-5000 x7695

Purpose of the Study: This study is for a Major Research Paper that focuses on understanding successful psychosocial intervention strategies for children with and/or affected by HIV/AIDS. Young children are rarely asked about their feelings and emotions, even though their psychosocial health (the social, emotional, spiritual, and intellectual aspects of health) plays a large role in an individual's quality of life. This study will allow a young child to express his or her voice and opinion to gain insight into the state of his or her psychosocial health, and how the centre contributes. By doing so, he or she may help other children like him or her in the future, with the application of psychosocial intervention in the areas found to be significant, in a similar centre.

Description of the Study:

Data will be collected through an open-ended interview facilitated through play and crafts. The child will be allowed to select the activity from the options provided by the researcher. All dialogue will be recorded via-audio-tape. Observations and photographs will be taken to understand what makes the program successful for children and families. Photographs will only be used in presentations about the study.

Sample questions include:

Can you tell me about your family?

Tell me about when you come to the centre.

Location: The early childcare centre for children with and/or affected by HIV/AIDS, which the child attends

Time: Forty-five minutes to one hour

What is Experimental in this Study: None of the procedures used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.

Risks or Discomforts: It is possible that your child may be uncomfortable or wish to stop, but be unsure of how to say no to the researcher. Therefore, prior to commencing the study, the child will be reminded that she/he can say “no” or “stop now” or “next question.” Additionally, the researcher will be alert to non-verbal signs of discomfort and/or fatigue on the part of the child.

Benefits of the Study: This study will allow for a better understanding what makes a psychosocial-based child program successful for families with and affected by HIV/AIDS. It is hoped that your child will benefit by having her/his opinions and ideas validated in the context of a research study. I cannot guarantee, however, that your child will receive any benefits from participating in this study.

Confidentiality: The data and report will be only be viewed Natalie Wilson and Professor Berman. If audio-taping is part of the data collection process, Professor Berman will store the audio-tape, and transcription, if any, in a locked filing cabinet in her office for one year at which time it will be erased. If your child’s participation involves drawings, if she/he requests them, they will be returned in one year (June, 2008). Otherwise, Professor Berman will store them in a confidential manner, in a locked filing cabinet, for one year after which time they will be disposed. If agreed to, photographs will only be used when presenting information about the study.

Incentives to Participate: With your permission, your child will receive a small token of appreciation whether or not she or he completes the study.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to have your child participate will not influence your future relations with Ryerson University. If you decide that your child may participate, know that you are free to withdraw your consent and to stop your child’s participation at any time without penalty or loss of benefits to which you are allowed.

At any particular point in the study, your child may refuse to answer any particular question or stop participation altogether. Your child may communicate refusal verbally and/or non-verbally (signs of fatigue).

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact

Study Supervisor: Dr. Rachel Berman
Telephone Number: 416-979-5000 x7695

If you have questions regarding your child’s rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street, Toronto, ON M5B 2K3
416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree that your child may participate in the study and have been told that both you and/or your child can change your or her/his mind and withdraw consent to participate at any time. It also signifies you agree to have the study tape recorded.

My child may participate in an interview Yes ___ No ___

My child may be observed while in the Hope House Yes ___ No ___

My child may be photographed Yes ___ No ___

You have been given a copy of this agreement to keep.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Signature of Parent/Guardian

Date

Name of Child (please print)

Signature of Investigator

Date

Ryerson University
Child's Consent Agreement

Master of Arts in Early Childhood Studies, Major Research Paper

TITLE OF PROJECT: Psychosocial Intervention for Young Children with and Affected by HIV/AIDS: Improving the Odds

I am willing to talk to, play a game, and/or do a craft with Natalie about my friends and family, and my feelings, and going to the centre.

It's OK by me that:

1. Our conversations will not name or identify me
2. Our conversations will be tape recorded Yes ___ No ___
3. Natalie writes things down about me while I am playing Yes ___ No ___
4. Natalie takes a picture of me when I am playing Yes ___ No ___
5. My picture can be shown to other people, besides Natalie Yes ___ No ___
6. Only Natalie and her teacher, Rachel, will listen to the tapes and read anything Natalie writes. The teacher will protect the tapes by keeping them in a locked filing cabinet for one year and then will make sure if they are not needed anymore to erase them.
7. I can stop the study at any time. One way I can do this is by saying "stop now" or I can say "next question."
8. I can end being part of the study at anytime without any questions being asked.
9. Natalie might talk to someone responsible if they are worried about my safety.
10. I can have my mom or dad with me during the study, or someone who makes me feel safe.

My name

My signature or special mark _____

Today's date _____

Ryerson University
Consent Agreement for Caregiver(s)

Master of Arts in Early Childhood Studies, Major Research Paper

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigator: Natalie Wilson, B.A. MAECS student, natalie.wilson@ryerson.ca

Supervisor: Professor Rachel Berman, PhD, Master of Arts Program in Early Childhood Studies, School of Early Childhood Education, Ryerson University.

rcberman@ryerson.ca 416-979-5000 x7695

Purpose of the Study: This study is for a Major Research Paper which focuses on understanding successful psychosocial intervention strategies for children with and/or affected by HIV/AIDS. Caregivers are rarely given the opportunity to openly discuss what makes a program successful or not successful for their family, especially how it affects their psychosocial health (the social, emotional, spiritual, and intellectual aspects of health). This study will allow you to voice your opinion, and provide insight into the state of your family's psychosocial health, and how the centre contributes. By doing so, you may help other families with children infected or affected with HIV/AIDS in the future, with the application of psychosocial intervention in the areas found to be significant, in a similar centre.

Description of the Study:

Data will be collected through an open-ended interview over refreshments. All dialogue will be recorded via-audio-tape. Observations and photographs will be taken to understand what makes the program successful for children and families. Photographs will only be used in presentations about the study.

Sample questions include:

Can you tell me about your child/children?

How do you think coming to this centre has helped your children, if at all?

Location: The early childcare centre for children with and/or affected by HIV/AIDS, which the family attends

Time: Forty-five minutes to one hour

What is Experimental in this Study: None of the procedures used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.

Risks or Discomforts: It is possible that you may be uncomfortable or wish to stop, but be unsure of how to say no to the researcher. Therefore, prior to commencing the study, you will be reminded that you can say "no" or "stop now" or "next question."

Additionally, the researcher will be alert to non-verbal signs of discomfort and/or fatigue on the part of the participant.

Benefits of the Study: This study will allow for a better understanding what makes a psychosocial-based child program successful for families with and affected by HIV/AIDS. It is hoped that you will benefit by having your opinions and ideas validated in the context of a research study. I cannot guarantee, however, that you will receive any benefits from participating in this study.

Confidentiality: The data and report will be only be viewed Natalie Wilson and Professor Berman. If audio-taping is part of the data collection process, Professor Berman will store the audio-tape, and transcription, if any, in a locked filing cabinet in her office for one year at which time it will be erased. If any materials are produced, such as drawings, if you request them, they will be returned in one year (June, 2008). Otherwise, Professor Berman will store them in a confidential manner, in a locked filing cabinet, for one year after which time they will be disposed. If agreed to, photographs will only be used when presenting information about the study.

Incentives to Participate: You will receive a small token of appreciation whether or not you complete the study.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with Ryerson University. If you decide that you will participate, know that you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed.

At any particular point in the study, you may refuse to answer any particular question or stop participation altogether. You may communicate refusal verbally and/or non-verbally (signs of fatigue).

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact

Study Supervisor: Dr. Rachel Berman
Telephone Number: 416-979-5000 x7695

If you have questions regarding your child's rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree that you wish to participate in the study and have been told that you can change your mind and withdraw consent to participate at any time. It also signifies you agree to have the study tape recorded.

I agree to be interviewed Yes ___ No ___

I agree to be observed while in the Hope House with my child(ren) Yes ___ No ___

I agree to be photographed Yes ___ No ___

You have been given a copy of this agreement to keep.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Signature of Participant

Date

Signature of Investigator

Date

Ryerson University
Consent Agreement for Staff Member

Master of Arts in Early Childhood Studies, Major Research Paper

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigator: Natalie Wilson, B.A. MAECS student, natalie.wilson@ryerson.ca

Supervisor: Professor Rachel Berman, PhD, Master of Arts Program in Early Childhood Studies, School of Early Childhood Education, Ryerson University.
rcberman@ryerson.ca 416-979-5000 x7695

Purpose of the Study: This study is for a Major Research Paper which focuses on understanding successful psychosocial intervention strategies for children with and/or affected by HIV/AIDS. Practitioners/workers providing psychosocial intervention for this population are rarely given the opportunity to openly discuss what their goals and intentions of the program. This study will allow you to voice your opinion, and provide insight into the psychosocial intervention techniques provided by your centre, and how it affects child clients and their families. By doing so, you may help other families with children infected or affected with HIV/AIDS in the future, with the application of psychosocial intervention in the areas found to be significant, in a similar centre.

Description of the Study:

Data will be collected through an open-ended interview over refreshments. All dialogue will be recorded via-audio-tape. Observations and photographs will be taken to understand what makes the program successful for children and families. Photographs will only be used in presentations about the study.

Sample questions include:

What are your goals for your centre?

Can you tell me about a typical day with the child clients?

Location: The early childcare centre for children with and/or affected by HIV/AIDS, which the family attends

Time: Forty-five minutes to one hour

What is Experimental in this Study: None of the procedures used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.

Risks or Discomforts: It is possible that you may be uncomfortable or wish to stop, but be unsure of how to say no to the researcher. Therefore, prior to commencing the study, you will be reminded that you can say "no" or "stop now" or "next question." Additionally, the researcher will be alert to non-verbal signs of discomfort and/or fatigue on the part of the participant.

Benefits of the Study: This study will allow for a better understanding what makes a psychosocial-based child program successful for families with and affected by HIV/AIDS. It is hoped that you will benefit by having your opinions and ideas validated in the context of a research study. I cannot guarantee, however, that you will receive any benefits from participating in this study.

Confidentiality: The data and report will be only be viewed Natalie Wilson and Professor Berman. If audio-taping is part of the data collection process, Professor Berman will store the audio-tape, and transcription, if any, in a locked filing cabinet in her office for one year at which time it will be erased. If any materials are produced, such as drawings, if you request them, they will be returned in one year (June, 2008). Otherwise, Professor Berman will store them in a confidential manner, in a locked filing cabinet, for one year after which time they will be disposed. If agreed to, photographs will only be used when presenting information about the study.

Incentives to Participate: You will receive a small token of appreciation whether or not you complete the study.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with Ryerson University. If you decide that you will participate, know that you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed.

At any particular point in the study, you may refuse to answer any particular question or stop participation altogether. You may communicate refusal verbally and/or non-verbally (signs of fatigue).

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact

Study Supervisor: Dr. Rachel Berman
Telephone Number: 416-979-5000 x7695

If you have questions regarding your child's rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree that you wish to participate in the study and have been told that you can change your mind and withdraw consent to participate at any time. It also signifies you agree to have the study tape recorded.

I agree to be interviewed Yes ___ No ___

I agree to be observed in the Hope House Yes ___ No ___

I agree to be photographed Yes ___ No ___

You have been given a copy of this agreement to keep.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Signature of Participant

Date

Signature of Investigator

Date

Appendix B
Sample Interview Questions

Child Participant Interview Questions

- 1) Can you tell me your name?
- 2) How old are you?
- 3) Do you have any brothers or sisters?
- 4) Who do you live with?
- 5) Tell me about where you live
- 6) Do you have family who don't live with you? Tell me about them
- 7) Do you like coming to the centre?
What do you like about it?
Is there anything you don't like about it?
- 8) Tell me about what you do when you come to the centre
- 9) Do you have friends at the centre? Tell me about them
- 10) What does it feel like when you are on your way to the centre?
- 12) What does it feel like when it's time to leave the centre?
- 13) If you got to choose when you come, how much would you want to come here?
- 14) Do you ever have to miss coming to the centre? How come? How do you feel when that happens?
- 15) Do you ever feel sad? What kinds of things make you sad? What do you do when you are a sad? What makes you feel better when you are sad?
- 16) Tell me about some things that you are afraid of
- 17) Is it ever hard to fall asleep at night? What do you do to help you sleep?
- 18) Has there been anything happen lately that made you sad?
- 19) Tell me about some things you're really good at
What kinds of things do you like to do?

- 20) If you had 3 wishes, what would they be?
- 21) Is there anything you would like to change to make you feel more happy?
- 22) What was the best part of your day today?
- 23) Is there anything you're looking forward to about tomorrow? What about next week?
- 24) If you could tell other kids like you something about this centre, what would it be?
- 25) Is there anything else you would like to talk about or tell me?

Practitioner/Worker Interview Questions

- 1) Can you tell me about your educational background?
- 2) What did you do as work before you started working at the centre?
- 3) Can you tell me about how you came to work at the centre?
- 4) Tell me about what your first impression of the centre was
- 5) Did you have any initial hesitations about working with children and families with/affected by HIV/AIDS? Do you still have any? Do you think they will ever go away completely?
- 6) How would you describe the centre?
- 7) How would you describe the work you do?
- 8) Can you tell me about the relationships between yourself and the child clients, and yourself and the caregivers?
- 9) Can you take me through a typical day with the children you work with?
- 10) Do you see a difference in the children you work with long term? Tell me about it
- 11) What are your goals for the work that you do?
- 12) What are your hopes for the families who attend the centre?
- 13) What does psychosocial intervention mean to you?
- 14) What types of intervention do you provide for the children?
- 15) Everyone has bad days at work. Can you tell me about what a bad day would be for you? (can be real experience or hypothetical)
- 16) How do you think these children would be different if they did not receive the intervention/did not attend the centre?
- 17) Is there anything you would like to add or share?

Caregiver Interview Questions

- 1) How many children do you have?
- 2) What are the ages/sex of them?
- 3) Can you tell me about your family?
- 4) Are you originally from this country?
- 5) Are your children?
- 6) Can you tell me why you decided to move?
- 7) Can you tell me about what it was like to move here?
- 8) What was it like for your children/family before you moved to this country?
- 9) How did you find out about this centre?
- 10) How long have you and your family attended the centre?
- 11) How often do you attend the centre?
- 12) Have you noticed a change in your children since they started attending?
- 13) Can you tell me about your children before and after you started attending?
- 14) How has the centre been beneficial to your family?
- 15) What would you change about the centre to improve it?
- 16) If you could describe the centre in a few words, what would they be?
- 17) (If attend the centre regularly) If your family had to miss a week of attending, do you think it would make a difference in your child? If so, can you explain?
- 18) Would you recommend the centre to other families?
- 19) If so, what would you tell them, and how would you describe it to them?
- 20) Is there anything you would like to add or share?

References

- Abadia-Barrero, C. E., & LaRusso, M. D. (2006). The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS in Sao Paulo, Brazil. *AIDS Patient Care and STDs*, 20(1).
- AIDS Committee of Toronto, (2008). *HIV/AIDS Statistics At a Glance*, 1. Retrieved August 9, 2008 from <http://www.actoronto.org/home.nsf/pages/hivaidsstatsglance>
- Alaimo, K., Olson, & Frongillo, E. A. (2001). Food insufficiency and American school-aged children's cognitive, academic, and psychosocial development. *Pediatrics*, 108(1).
- Alderson, P. (2002). Young children's health care rights and consent. In B. Franklin (Ed.), *The new handbook of children's rights: Comparative policy and practice* (2nd ed.). London: Routledge.
- Armstrong, E. G. (2001). Gnagsta misogyny: A content analysis of the portrayals of violence against women in rap music, 1987-1993. *Journal of Criminal Justice and Popular Culture*, 8(2).
- Atkins-Burnett, S., & Allen-Meares, P. (2000). Infants and toddlers with disabilities: Relationship-based approaches. *Social Work*, 45(4).
- Attride-Stirling, J., Davis, H., Markless, G., Sclare, I., & Day, C. (2001). 'Someone to talk to who'll listen': Addressing the psychosocial needs of children and families. *Journal of Community & Applied Social Psychology*, 11.
- Axline, V. (1947). *Play therapy*. Cambridge, MA: Houghton Mifflin.
- Bacha, T., Pomeroy, E. C., Gilbert, D. (1999). A psychoeducational group intervention for HIV-positive children: A pilot study. *National Association of Social Workers*, 24(4).
- Barrio, C. A., & Shoffner, M. F. (2005). Career counselling for persons living with HIV: An ecological approach. *The Career Development Quarterly*, 53.
- Barry, P. D. (1996). *Psychosocial nursing: Care of physically ill patients and their families* (3rd ed.). Philadelphia, NY: Lippincott.
- Berg, B. L. (2004) *Qualitative Research Methods for the Social Sciences* (5th ed.). Long Beach, California: Pearson.
- Blumenreich, M. (2003). Confidentiality, equity, and silence: A critical look at school policy for HIV positive children. *Equity & Excellence in Education*, 36(1).

- Bond, D. S., & Omar, A. (1994). The kernel of truth in judgements of deceptiveness. *Basic & Applied Social Psychology, 15*(4).
- Boyd-Franklin, N., Steiner, G. L., & Boland, M. G. (1995). Children, families, and HIV/AIDS: Psychosocial and therapeutic issues. New York, NY: The Guilford Press.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by design and nature*. Cambridge, MA: Harvard University Press.
- Bungener, C., Marchand-Gonod, N., & Jouvent, R. (2000). African and European HIV-positive women: Psychological and psychosocial differences. *AIDS Care, 12*(5).
- Canadian Association of Social Workers (1997). HIV psychosocial care and social work practice: Ethical, professional and practical issues. Ottawa, ON: Author.
- Canadian Medical Association, Canadian Paediatric Society, & The College of Family Physicians of Canada (2007). Child and youth health: Our challenge. *Canada's Child and Youth Health Charter*. Retrieved August 9, 2008, from <http://www.ourchildren.ca/images/charters.pdf>
- Cresswell, J. W. (2008). Educational Research: Planning, conducting, and evaluating quantitative and qualitative research (3rd ed.). Columbus, Ohio: Pearson.
- Dail, P. W. (1990). The psychosocial context of homeless mothers with young children: Program and policy implications. *Child Welfare League of America, 69*(4).
- Dematteo, D., Wells, L. M., Salter Goldie, R., & King, S. M. (2002). The 'family' context of HIV: A need for comprehensive health and social policies. *AIDS Care, 14*(2).
- Duncan, J., & Arnston, L. (2004). *Children in crisis: Good practices in evaluating psychosocial programming*. Save The Children Federation, Inc.
- Elizabeth Glaser Pediatric AIDS Foundation (2008). *Full-length Global Pandemic Fact Sheet: Children and HIV/AIDS*, 2. Retrieved February 12, 2008, from [act%20Sheet/The%20Global%20Pandemicas.px](http://act20Sheet/The20Global20Pandemicas.px)
- Evans, G. W., & English, K. (2002). The environment of poverty: Multiple stressor exposure, psychophysiological stress, and socioemotional adjustment. *Child Development, 73*(4).

- Evans, S. E., Davies, C., & DiLillo, D. (2008). Exposure to domestic violence: A meta-analysis of child and adolescent outcomes. *Aggression and Violent Behaviour, 13*(2).
- Fisher, J. W. (1999). Helps to fostering students' spiritual health. *International Journal of Children's Spirituality, 4*(1).
- Franks, B. A., Miller, M. D., Wolff, E. J., & Landry, K. (2004). HIV/AIDS and the teachers of young children. *Early Child Development and Care, 174*(3), 229-241.
- Gifford-Smith, M. E., & Brownell, C. A. (2003). Childhood peer relationships: Social acceptance, friendships, and peer networks. *Journal of School Psychology, 41*.
- Goicoechea-Balbona, A. (1998). Children with HIV/AIDS and their families: A successful social work intervention based on the culturally specific health care model. *Health & Social Work, 23*(1).
- Greene, S., & Hogan, D. (2005). *Researching children's experience*. London: Sage Publications.
- Greenland, K., Maser, B., & Prentice, T. (2001). "They're scared of it": Intergroup determinants of attitudes toward children with HIV. *Journal of Applied Social Psychology, 31*(10).
- Hallstrom, I. (2004). Involving parents and families in clinical nursing: Decision-making during hospitalization: Parents' and children's involvement. *Journal of Clinical Nursing, 13*.
- Hardin, B., & Hardin, M. (2002). Into the mainstream: Practical strategies for teaching in inclusive environments. *Clearing House, 75*(4).
- Hawkins, Costigan, L. (Director), & Goldstein-Knowlton, L. (Director). (2006). *The world according to Sesame Street* [Documentary]. (Available from Participant Productions, 190 Liberty Street, Toronto, Ontario, M6K 3L5).
- Haynes, N. M. (2002). Addressing students' social and emotional needs: The role of mental health teams in schools. *Journal of Health & Social Policy, 16*(1).
- Hope House Daycare (2008). *Vision*. Retrieved August 22, 2008, from <http://www.hopehousedaycare.org>.
- Husbands, W., Braybrook, D., Caswell, J., Buck, K., Browne, G., Roberts, J., Gafni, Amiram, & Taylor, A. (2005). Community-linked evaluation AIDS resource. Toronto, ON: AIDS Committee of Toronto.

- Hough, E. S., Brumitt, G., Templin, T., Saltz, E., & Mood, D. (2002). A model of mother-child coping and adjustment to HIV. *Social Science & Medicine*, 56.
- Irwin, L. G., & Jonson, J. (2005). Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research*, 15(6).
- Kmita, G., Baranska, M., & Niemiec, T. (2002). Psychosocial intervention in the process of empowering families with children living with HIV/AIDS: A descriptive study. *AIDS Care*, 14(2).
- Lesar, S., (1995). HIV infection in children: Family stress, social support, and adaptation. *Exceptional Children*, 62(3).
- Marhefka, S. L., Tepper, V. J., Brown, J. L., & Farley, J. J. (2006). Caregiver psychosocial characteristics and children's adherence to antiretroviral therapy. *AIDS Patient Care and STDs*, 20(6).
- Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, 56(3).
- McGowan, T. G. (in press). The 2008 Memphis TGA Ryan White HIV/AIDS care needs assessment. Memphis, TN: Rhodes College.
- McNaughton, G., & Smith, K. (2005). Transforming research ethics: The choices and challenges of researching with children. In A. Farrell (Ed.), *Ethical research with children*. New York, NY: Open University Press.
- Merrifield, M., & Collins, H. (1998). *Come Sit by Me*. Ontario: Fitzhenry and Whiteside.
- Mialky, E., Vagnoni, J., & Rutstein, R. (2001). School-age children with perinatally acquired HIV infection: medical and psychosocial issues in a Philadelphia cohort. *AIDS Patient Care and STDs*, 15(11), 575-579.
- Mitrani, V. B., Prado, G., Feaster, D. J., Robinson-Batista, C., & Szapocznik, J. (2003). Relational factors and family treatment engagement among low-income, HIV-positive African American mothers. *Family Process*, 42(1).
- Family Strengthening Policy Center (2007). *The Parenting Imperative: Investing in Parents so Children and Youth Succeed*. Washington, DC: National Human Services Assembly.
- Owens, S. (2003). African American women living with HIV/AIDS: Families as sources of support and of stress. *Social Work*, 48(2).

- Public Health Agency of Canada (2005). *Populations At Risk: What Are the Numbers?*. Retrieved February 12, 2008, from http://www.phac-aspc.gc.ca/aids-sida/populations_e.html#pl
- Reyland, S. A., McMahon, T. J., Higgins-Delessandro, A., & Luthar, S. S. (2002). Inner-city children living with an HIV-seropositive mother: Parent-child relationships, perception of social support, and psychological disturbance. *Journal of Child and Family Studies*, 11(3).
- Richter, L., Foster, G., & Sherr, L. (2006). *Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*. The Netherlands: Bernard van Leer Foundation.
- Roberts, J., & Cairns, K. (1999). *School Children with HIV/AIDS*. Alberta, Canada: Detselig Enterprises Ltd.
- Rushforth, H. (1999). Practitioner review: Communication with hospitalized children: Review and application of research pertaining to children's understanding of health and illness. *Journal of Child Psychology & Psychiatry*, 40(5).
- Serovich, J. M., Kimberly, J. A., Mosack, K. E., & Lewis, T. L. (2001). The role of family and friend social support in reducing emotional distress among HIV-positive women. *AIDS Care*, 13(3).
- Sutcliffe, K., Sutcliffe, R., & Alderson, P. (2004). Can very young children share in their diabetes care? Ruby's story. *Paediatric Journal of Nursing*, 16(10).
- Tate, F. B., & Longo, D. A. (2002). Art therapy: Enhancing psychosocial nursing. *Journal of Psychosocial Nursing & Mental Health Services*, 40(3).
- The Teresa Group. (2008). *About us*. Retrieved August 22, 2008, from www.teresagroup.ca.
- Thomas, P., & Foster, J. W. (2006). *AIDS, development and Canadian policy: Achieving universal access by 2010*. Ottawa, Canada: The North-South Institute.
- United Nations (1991). *Convention on the rights of the child*. Minister of Supply and Canada.
- Weinreb, L., Goldberg, R., & Perloff, J. (1998). Health characteristics and medical service use patterns of sheltered homeless and low-income housed mothers. *Journal of General Internal Medicine* 13(6).
- Willemsen, H., & Anscombe, E. (2001). Art and play therapy for pre-school children infected and affected by HIV/AIDS. *Clinical Child Psychology and Psychiatry*, 6(3), 339-350.

Wittenborn, A. K., Faber, A. J., Harvey, A. M., & Thomas, V. K. (2006). Emotionally focused family therapy and play therapy techniques. *The American Journal of Family Therapy*, 34.