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Beneath the Mask: A Group Therapy Model Supporting Children Infected With and Affected by HIV/AIDS

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In 2007 a study was conducted to identify the outcomes of an activity-based psychosocial intervention called Leading the Way, a program designed for children infected with and/or affected by HIV/AIDS, based in Toronto, Canada. Qualitative and quantitative data showed that children who were unaware of the HIV status of their families experienced heightened anxiety and depression when compared to children who were aware of the presence of HIV in their families. Furthermore, data indicated that though the intervention positively influenced children's senses of self and their ability to cope and problem solve, deep social stigma surrounding HIV continued to profoundly affect the lives of these children. The ethical dilemmas involved in serving populations of children who have not been disclosed to regarding their own or a family members' HIV status came to light in the development of the program and are discussed in the analysis of data.

KEYWORDS children, HIV/AIDS, disclosure, social work, activitybased therapy

[Having HIV] is like wearing a mask on top of a mask. You can never take it off because you are so used to hiding things. (Age 15, disclosed youth)

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Since the beginning of the HIV epidemic, secrecy, stigma, and discrimination have characterized the experiences of people infected with or affected by HIV/AIDS. Stigma is manifested through discrimination and social ostracism, not just against the individuals who have HIV, but against their families and those who support them. Deep social stigma surrounding HIV/AIDS continues to inhibit disclosure among peers, family members, faith groups, schools, and places of employment, consequently disconnecting people from informal and formal systems of support (Cree, Kay, Tisdall, & Wallace, 2006; Forehand, Jones, & Kotchick, 2002; Woodring, Cancelli, & Ponterotto, 2005). The psychosocial impact of stigma on individuals has become such a profound barrier to education and prevention efforts, treatment, and coping mechanisms that it has been termed by some as the "secondary epidemic" (Lamptey & Gayle, 2001).

In Canada, the nature of the HIV/AIDS epidemic has changed from one that primarily affected men who have sex with men (MSM) to one that increasingly affects other populations such as injection drug users (IDU) and heterosexuals. The growing rates of HIV/AIDS and the shift in the nature of the epidemic have led to increases in children who are born with HIV and with HIV in their families (Public Health Agency of Canada, 2007).

In 1990 a community-based charitable organization, The Teresa Group, was formed in response to the need for holistic, family-centered support for families affected by HIV/AIDS. Based in Toronto, Canada, The Teresa Group provides a spectrum of practical and emotional support for families and serves 390 families and 770 children. In 1996, to address the psychosocial needs of children and youths infected with and/or affected by one or more family members' diagnosis of HIV, the Teresa Group designed and launched a group therapy program called Leading the Way. In 2007, an external program evaluation was conducted to determine best practices of psychosocial support systems for children infected with or affected by HIV/AIDS and to gain a deeper understanding of the differences in psychosocial functioning between children who were unaware and those who were aware of the presence of HIV/AIDS in their lives (undisclosed vs. disclosed). This article outlines the results of that study and provides insight into group therapy approaches for a growing population with unique and complex needs.

BACKGROUND: THE "LEADING THE WAY" APPROACH

Leading the Way (LTW) is a 9-week psychosocial support intervention offered twice a year by trained social workers in Toronto. It operates in conjunction with other Teresa Group programs designed to meet the psychosocial needs of families who are affected by HIV. Other program components are designed to address the needs of pregnant women, new mothers, and mothers and infants. A parenting and tutoring program are offered, as well.

Leading the Way uses activity group therapy, an approach derived from play therapy that includes a mix of guided conversation and activities that allow for direct and indirect self-expression. The history of social work with groups provides a wealth of knowledge on the "use of activity" and play in group work (Bratton & Ferebee, 1999; Middleman, 2006). A number of quasi-experimental and qualitative accounts also confirm that activity group therapy with children and adolescents can help reduce anxiety, aggression, and delinquent behaviors; increase performance at school and engagement in groups; and help youths to feel in control of their lives (Ciardiello, 2003; Packman & Bratton, 2003; Paone, 2006; Wright, 1999).

Four distinct and complementary methodologies constitute the program structure and guide the activities of LTW: (1) socio-recreation: activities such as games, art, music, and/or drama that tap into members' strengths, foster creativity in problem solving, and provide mediums to externalize thoughts, experiences and feelings; (2) psychotherapy: guided discussions to explore difficult issues and feelings; (3) peer modeling: opportunities to learn by observing and interacting with other group members; and (4) psychoeducation: education about HIV/AIDS and risk-reduction behaviors, combined with behavioral counseling focused on self-esteem, coping, and social skills.

To ensure that activities and discussions address the needs of specific age groups, children/youths are subdivided by age: undisclosed groups are held for ages 5 to 7 and 8 to 10, and disclosed groups are held for ages 10 to 12 and 13 to 18 (age ranges vary according to the population of a given year). Undisclosed groups are not held for children older than age 10. These groups are for children who are unaware that they have or a family member has HIV or AIDS, whereas disclosed groups are for those who are aware of their HIV-positive status and/or that of a family member. The same program structure and blended methodologies are used in both groups.

AN ETHICAL DILEMMA

Working with "Undisclosed" Children

The decision to offer a group for children who are undisclosed evolved after much debate about how best to balance the ethics surrounding the issue of disclosure, treatment, and The Teresa Group's mandate to serve the whole family. Group facilitators first considered the issue of whether it was ethical to work with children when the facilitators, and not the children, knew about the presence of HIV in the childrens' lives. Although infected children are informed of their HIV status in a hospital setting, generally by the age of 12 or 13—in collaboration with parents and medical practitioners—the policy of the Teresa Group is to respect parents' decisions about disclosure to affected children (children who are not infected but are affected by a

family member's HIV status). Staff also struggled to consider the ethics of disclosure, given their mandate to treat the psychosocial needs of all family members who came to the centre.

Over time it became evident through regular interactions with families who participated in Teresa Group programs that undisclosed children were reacting with symptoms of depression and/or anxiety. In developing the Leading the Way program the discussion shifted to the ethics involved in providing treatment or not providing treatment. After careful consideration Teresa Group staff members concluded that it was not an option to deny treatment to this group of infected and affected children who did not know about the presence of HIV in their lives but were struggling to cope with anxiety and depression. Parents reported that the deep fear of social stigma fueled their desire to keep their HIV status private and inhibited them from seeking support and treatment for their undisclosed children. However, because a trusting relationship had already been established with Teresa Group staff members, parents said that they were receptive to their undisclosed children participating in a group therapy program with them, providing that HIV was not openly discussed, and their decision about disclosure was respected. Consideration was further given to the principle of "do no harm." Staff members concluded that these children were subject to more harm if the treatment was not provided and that they had a greater obligation to assist these children.

Addressing the Question of Disclosure

To address the complexities involved in designing the Leading the Way program for infected and affected children, it was agreed that staff members needed to address the issue of disclosure from different angles: (1) continue to work with parents in counseling by addressing the fears, concerns, and challenges encountered regarding the issue of disclosure; (2) offer support groups to undisclosed children; (3) through observations and regular interactions with children, determine which ages should be included in the undisclosed group.² It was decided that undisclosed groups would only be offered to children between the ages of 5 and 10, and groups for disclosed children would start at age 10. This appeared to be the age that parents were choosing to begin to disclose to infected and affected children (as noted disclosure to infected children generally takes place in a hospital setting by age 12 or 13).

Staff members determined that the age division between the disclosed and undisclosed groups was appropriate based on clinically documented interactions with families over time, where it was observed that children in the undisclosed groups developed a natural and age-appropriate tendency to become more inquisitive about their surroundings between ages 11 and 12. Dividing the groups in this manner meant that younger children understood

that there were groups for older children and groups for younger children. It was felt that children who were affected and not disclosed to would question this division if they were, for example, 11 or 12 and children of the same age were in another disclosed group. It would be natural to ask why they could not be in the same group, especially if they were the same age.

It is important to note, that even though children who are not disclosed to are no longer offered group therapy after age 10, other programs at The Teresa Group are available to them. They include tutoring, summer camps, and various activity days offered during the year. This allows them continued contact and support that still respects the parents' decision regarding disclosure to an affected child. Parents are always advised regarding other counseling services that they can obtain for their children when the group ends. Given the lack of research available about how disclosure influences affected children's psychosocial functioning, staff members concluded that it was imperative that they collect information about the impact of the Leading the Way program throughout its implementation, to learn and engage in ongoing dialogue about how best to serve this largely underserved and underresearched population (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001).

METHOD

Qualitative and quantitative data were used to gain insight about the psychosocial characteristics of children in the Leading the Way program (LTW), how they cope with HIV/AIDS in their lives, and the outcomes of their participation in LTW. Quantitative data sources included the Child Depression Inventory (Kovacs, 1992) (collected from 2002–2006), the Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 1985) (2002–2006), participant pre and post surveys (2004–2006), and participant retention rates (1999–2006). Qualitative data sources included narratives and visual and audio ethnography generated from LTW activities (2004–2006) and weekly facilitator reports (1998–2006). All qualitative data, including facilitator reports, children's answers to open-ended pre and post surveys, artwork, stories, and songs were carefully examined for common themes and a coding scheme was developed. Quotations and illustrations included in this article were selected to demonstrate the dominant themes that emerged in the analysis.

Strengths and Limitations

It should be noted that without a control group, it is difficult to determine if changes in psychosocial functioning, particularly in anxiety and depression, can be attributed directly to the group or are brought about by other external factors. Because of the structure of the groups, it was not possible to compare data between undisclosed and disclosed groups of children of the same age, thus making it impossible to determine the extent to which age may have influenced differences between the two groups or changes over time. However, rich qualitative data collected over 8 years, combined with quantitative data from anxiety and depression instruments, provided a number of lenses through which researchers could view the program and its affect on the undisclosed and disclosed groups of children.

FINDINGS

Experiences of Depression and Anxiety

Data was analyzed to determine the differences in depression and anxiety between disclosed and undisclosed groups of children.³ The Child Depression Inventory (CDI; Kovacs, 1992) results indicated that LTW participants experienced high levels of depression; almost 60% of the children in LTW scored above the 50th percentile for depression, and 15% scored around the 80th percentile. Furthermore, a cross tabulation of CDI scores revealed that not disclosing to a child was associated with higher rates of depression. All of the children in the undisclosed group scored over the 50th percentile for depression, whereas approximately one half of the children in the disclosed group scored over the 50th percentile (100% vs. 45% respectively, p = 0.024, Fisher's exact test).

Results from the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985) similarly indicated that children who were unaware of HIV in their families experienced higher levels of anxiety. Data indicated that children who were aware of the HIV status in their family were less likely to be anxious than children who were unaware that there was HIV in their family, although this correlation did not reach statistical significance (Fisher's Exact Test, p = .537).

To further investigate this finding, the Lie Scale items were analyzed. The Lie Scale is integrated into the instrument to detect acquiescence and social desirability, which is particularly important when survey respondents are asked to self-report thoughts or behaviors that are considered to be "socially undesirable." All children in LTW tended to score higher than average on the Lie Scale than the norm, with 67.4% of the LTW children scoring over the 50th percentile. In particular, children who had been disclosed to were more likely to score higher than the 50th percentile on the Lie Scale than the children had not been disclosed to ($\chi^2 = 4.723$; df = 1, N = 45, p = .03), indicating higher social desirability.

Given the indication that all children, particularly disclosed children, were more likely to provide socially acceptable answers than the norm on the RCMAS, the differences in anxiety between the disclosed and undisclosed groups may not be as large as the numbers would initially suggest.

More investigation is needed to determine what psychosocial factors may contribute to the differences on the Lie Scale between undisclosed and disclosed children. That undisclosed and disclosed children reported higher levels of anxiety and depression than the norm is reflected in the qualitative data, where children expressed significantly high levels of anxiety. This finding is examined in more detail below.

Coping with Loss and Uncertainty

Qualitative data provided rich insight into the complex and changing factors that contribute to anxiety and depression among children infected with and affected by HIV/AIDS. Data showed that children's experience with HIV/AIDS was not a one-time event or linear process. As Figure 1 illustrates, depending on the biomedical stage of HIV/AIDS, children experience one or more events: separation from parents for an extended period, separation from siblings, loss of siblings, death, coping with medications, and so on. Furthermore, depending on their age and developmental stage, children have different ways of coping and may also have different concerns about HIV/AIDS (e.g., older children are more concerned about how to develop relationships or how to negotiate choices about sexual health).

Qualitative data further illuminated differences of anxiety and depression between disclosed and undisclosed groups. Children in the undisclosed group, although not cognizant of the HIV in their families, were more likely to discuss anxiety or fear about death, expressing a sense that something "dark" or unknown was present. Although children in disclosed groups reported lower anxiety than those in undisclosed groups on the RCMAS, they expressed deep anxiety about the future and the impact of HIV on

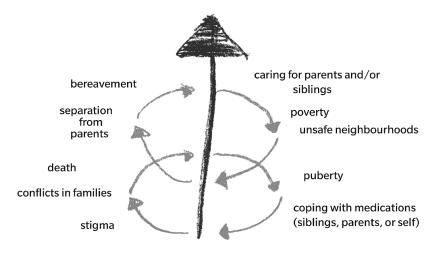


FIGURE 1 Summary of Reported Challenges Facing Children in LTW.

their lives. For example, when children in the disclosed group were asked to use the HIV/AIDS acronym to express their feelings about having HIV or AIDS in their families, some children responded: "Horrible, Invisible, Very worried, Arguments Death, Scared."

Affects of Stigma Related to HIV/AIDS

In addition to fear and anxiety about loss, children in the disclosed group expressed fear and deep concern about what would happen if they or their family member's HIV status was revealed—a fear expressed even among children who reported having a supportive peer group. Children worried that they would be teased, bullied, harassed, rejected, or judged by their friends if it was revealed that they or someone in their family had HIV. HIV was often expressed in relation to something that is "dirty," revealing internalized stigma as well as an understanding of how others perceive this disease:

- "Some people run away and never talk to you again once they know you have HIV." (Age 11, disclosed child)
- "A man would throw a woman out if he found out she had HIV. He would throw her in the trash can. 'You're too dirty for me, get out of my life.'" (Age 12, disclosed child)

Many children in the disclosed group demonstrated a keen understanding of what myths and attitudes contribute to stigma, even if they were not able to articulate the word *stigma*. Through narratives, artwork, and music developed in activities of the LTW program, children reported that stigma in their communities, school and peer groups stem from three dominant beliefs: (1) only "bad" people get HIV and HIV is "dirty," (2) HIV is an "African disease" and therefore an "African problem," (3) and HIV is transmitted by touching someone.

The desire to have a place to express emotions emerged as an important thing for children in the disclosed and undisclosed groups. For disclosed children, fears of disclosure inhibited them from seeking typical forms of support than would be available if they were open about their struggle to cope with HIV in their families. Some children admitted to lying about their parents' HIV and attributing illness to a more socially acceptable disease, such as cancer. Many undisclosed and disclosed children said that they had few, if any, places to express the confluence of emotions triggered by an illness or death in the family: anger, sadness, grief, anxiety about the future, or loneliness. These emotions were expressed in powerful ways throughout their artwork. For example, Figure 2 and 3 illustrate expressions of isolation:

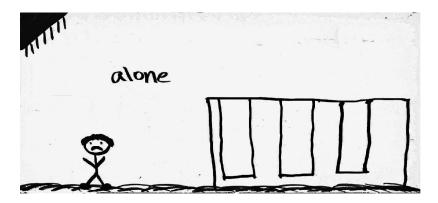


FIGURE 2 Illustration: Experiences of isolation (age 6, undisclosed child).



FIGURE 3 Talk to me photo (ages 13-16, disclosed youth).

"Alone", "Talk to me," "Don't judge a book by its cover," "I'm the same as you," "Don't leave me," and "Don't be afraid to kiss me."

Children's adoption of various caretaking roles throughout different stages of the illness and changing roles in their family further contributed to feelings of isolation and anxiety. Examples of caretaking roles included missing school to care for a parent, caring for siblings, expressing concern over parents' health, paying bills, grocery shopping, enrolling siblings in programs, doing household chores, resolving conflicts, and reminding parents to take medications.

Decrease in Anxiety and Depression

Data from the RCMAS indicated that children's anxiety scores were found to decrease after participation in one or more sessions (from 42.9% to 30.5%) by a statistically significant level, using a paired samples t test (p = .030). A regression analysis of the relationship between the number of sessions attended and anxiety scores did not show significant results. Despite this limitation, analysis revealed a noteworthy trend: though children's anxiety scores varied a great deal at the beginning, scores became lower as time went on.

Seventy-six percent of participants showed a decrease in their CDI scores within a time range of 6 months to 4 years. However, using a paired samples t test, this decrease did not reach statistical significance (p = .22). Further investigation is needed to determine whether a decrease in depression in these children was a result of their participation in LTW or other factors, such as age.

Although RCMAS and CDI scores indicated a positive impact on anxiety and depression, perhaps a more illuminating finding is that the children reported that they viewed LTW as an important source of continuous support. Retention rates were similarly revealing. The majority of children continued to return to LTW after their first session, although the program was initially envisioned as a one-time intervention. Almost 70% of children returned for at least a second session, and more than one third of LTW children (37%) returned for five or more sessions (representing more than 4 years of attendance).

Data from the survey instruments did not yield an understanding of what specific factors accounted for a reduction in anxiety and depression. However, data from facilitators' reports provided some insight. Undisclosed children seemed to be aware of something going on in the family but could not define what it was. As one child reported: "There is a monster in my house and my mom throws up" (age 7, undisclosed child). When presented with an unknown and at times tumultuous situation (parental mental health or physical health issues, changes in caregivers, etc.), young children often assumed the worst-case scenario (e.g., immediate death), which could have led to heightened levels of anxiety and depression (Tompkins, 2007). Facilitators' observations of the shift from the undisclosed to disclosed groups suggest that disclosure—finding out about "the secret"—combined with the supportive environment in which to ask questions, may have accounted for decreased anxiety and depression reported in the RCMAS and CDI.

Emotional Expression and Open Discussion

The majority of disclosed children in LTW reported that one of the main reasons they came to the program was to talk about HIV/AIDS as well

as to express their feelings and share experiences with others in similar situations. Participation in a group was a way for these children to express their anxieties and fears and voice questions and concerns. Some reported in the postsurveys that they preferred to talk about HIV/AIDS in a less direct way: "camouflaged" or "sideways"; whereas others reported that they wanted to talk about issues more directly. Over the years, facilitators have used numerous activities with children to explore particular themes related to HIV/AIDS, for example: quilt making (bereavement), birthday cakes (celebration of resiliency and personal growth), memory boxes (bereavement), martial arts (self-care and protection), music (stigma and discrimination), role-play (relationships with others, coping with different scenarios), and the "feeling wheel" (articulation and sharing of feelings). Figure 4 illustrates the use of a game to elicit feelings around stigma.

In an analysis of facilitator reports, it was found that the use of activities such as artwork and music were effective in enabling the exploration of feelings for undisclosed and disclosed children. This was particularly so for those who were uncomfortable discussing issues directly. As one participant noted in a postsurvey: "I got to talk about HIV/AIDS from a different perspective." Children also reported a preference for activities that provided fun and allowed them to develop a special skill and a sense of accomplishment and pride about learning something new (e.g., artwork, martial arts).



FIGURE 4 Participants play a game "Don't Trust Your Eyes," which includes a lesson that you cannot know if someone has HIV from their appearance (ages 13–16, disclosed youth).

Improved Coping Skills

Many of the group activities focused on helping children learn and practice coping and social skills in an emotionally safe environment. Reading stories in the group and then talking about the characters was one activity that enabled the group members to observe and evaluate different ways of coping. For example, one child commented on how a dragon in a story that the group read seemed to apply to his problem.

• "The dragon in the story just needed attention . . . it's like a problem. If you run away and ignore it, it gets bigger, but if you face it, it gets smaller." (Age 10, disclosed child)

Although fear about disclosure and how to cope with stigma and discrimination remained a continual source of concern for disclosed children in LTW, over time they demonstrated improved skills to cope with their fears and anger. Qualitative data from the study revealed that coping skills typically evolved through four phases: normalizing feelings, expressing feelings, accepting the situation that led to those emotions (rather than denying the problem), and identifying specific strategies for coping. Some disclosed children displayed an ability to cope with stigma through problem solving and strategizing.

As the children grew older, they raised issues about HIV/AIDS that had direct relevance to their lives: how to date and have relationships if you have HIV and how to disclose. Children in the disclosed group also felt that information about HIV/AIDS helped to mitigate their fears about death, separation, or loss. In particular, children expressed that learning that HIV is not a "death sentence," that women with HIV can have children, and that one can live a long life with medication cultivated feelings of relief and hope for the future. However, data also showed that the same children needed to have these messages reinforced numerous times, suggesting that relief is short lived. This need for repeated reinforcement perhaps points to the power of dominant messages they hear outside of LTW (e.g., perception that HIV is a "death sentence").

Promising Practices in Social Work

The study revealed a number of best practices for programming for this target population. It is evident that the positive outcomes of LTW stemmed not from a particular set of activities or a singular approach to group work. Rather, adaptability, flexibility, and responsiveness to children's changing needs and positive and long-term relationships with children emerged as the most important features of the program. Furthermore, an activity-centered approach proved to be successful in allowing undisclosed and disclosed

children to express complex and difficult emotions. Nevertheless, because some disclosed children preferred direct conversation about HIV/AIDS, an activity-centered approach should be accompanied by open and frank discussion.

Children provided positive feedback about activities that allowed them to counter the stereotypes, myths, and misconceptions that fuel discrimination against people living with HIV/AIDS. For example, through the use of artwork and narratives, they were able to express clear messages that challenged negative representations of people living with this disease. Finally, activity-centered therapy was an effective tool for fostering self-esteem. Consequently, programming in the group should include activities in which children are encouraged to develop new skills that foster a sense of pride and accomplishment.

DISCUSSION

Data gathered for the current study provided important insight into the challenges facing children who are infected with and affected by HIV/AIDS. Stigma continues to dramatically affect how children cope with HIV/AIDS in their lives. The children's experiences demonstrated that stigma around HIV is rooted in the concept of individual blame. This is in contrast to the idea of the social determinants of health that contribute to the spread of the virus. The fear of what would happen if others discovered the "secret" remains a serious point of concern for children in LTW and their parents, who grapple with how and when to disclose to their children. Secrecy and isolation continue to play dominant roles for parents and children struggling with HIV/AIDS. It is critical that they identify social supports to help them cope with the multiple challenges that occur at various stages of the disease.

Data showed that parents' decision to keep HIV/AIDS a secret to protect their children was not always the best solution. Many children who were unaware of HIV/AIDS in their families reported heightened levels of anxiety and depression. This stemmed from a sense that something "bad" was going on of which they had little knowledge. The magnitude of the concern regarding disclosure for LTW families suggests that ongoing support is needed to help parents cope when they undertake the task of disclosing to their children.

The study showed that children infected with and affected by HIV/AIDS needed and wanted long-term and regular support because of the way the disease affects health over time. Children's abilities to cope varied and changed according to their developmental stage. Long-term support is vital because a child's ability to cope with HIV in his or her family is strongly influenced by other factors in his or her life that may include poverty, violence, racism, or family conflict.

Finally, the current study provided a number of insights related to the challenges of gathering data about the psychosocial impact of this intervention. "Beneath the mask" emerged as a dominant theme in the analysis of the quantitative and qualitative data. Children expressed difficulty communicating their ideas through conventional research tools such as the RCMAS and CDI. However, rich qualitative data offered important insights into the complex landscape of their social realities, attitudes, values, and perceptions that may influence their life choices and behaviors.

The current study suggests that more work is needed to strengthen data collection tools that draw from best practices in activity-based therapy and qualitative research methodology. In practical terms this means using a range of media through which children communicate their ideas and experiences: art, storytelling, role-play, music, games, photography, and audio-visual tools, for example.

An aim of the current study is to increase the sensitivities of service organizations to the characteristics and needs of children infected with and affected by HIV/AIDS. By sharing promising practices for supporting these children, it is hoped that service providers and support networks will become better equipped to address the pain and isolation experienced by children who live "beneath the mask."

NOTES

- 1. The proportion of HIV diagnoses of women increased from 1.8% in 1985 to 27%–29% in 2002–2004. In Toronto in 2004, women accounted for 27.8% of adult positive HIV tests (Public Health Agency of Canada, 2007).
 - 2. One of the resources developed and used by the Teresa Group is How do I Tell My Kids (2009).
 - 3. The data analysis of the quantitative data was conducted by researcher Nancy Weir.

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