

Loob-Kapwa-Diwa: A Community based Mental Health Model Based on the Circle of Hope (COH) Program

Cherie Ann Lo, MA, MSc, RPsy

INTRODUCTION

Research in pediatric care setting has been going on since the 1970s since learning about the impacts of childhood cancer allowed psychologists to understand the effects of such stressful events on children and their families (Kazak and Noll, 2015). Issues faced by childhood cancer patients encompass health behavior, neurocognitive, and psychosocial challenges (Brier, Schwartz, & Kazak, 2015).

According to a phenomenological study of families facing childhood cancer (Harrington, Kimball, & Bean, 2009), the “culture of cancer” encapsulated the changes that were observed in family interactions before and after the diagnosis. The implication of these changes is that these family are more likely to be at risk for secondary trauma, poor treatment adherence, among other complications (Harrington et al., 2009). This means that the child with cancer develops in bigger systems apart from the self so that other systems such as the family are affected by this life change.

A Socio-ecological Framework

Because of this, a socio ecological model was identified as an appropriate model in providing psychological support for children with cancer (Kazak & Noll, 2015). Using a social ecological model highlights the importance of looking at the child’s social world subsystems (e.g. families) that contribute to his/her adjustment (Kazak and Noll, 2015). According to this framework, a child’s well-being is affected by distal interacting systems (Kazak, 2006). Using this, the child’s medical condition is included as a microsystem in the social ecology. The interaction among school and peer microsystems is also central to the framework (Kazak, 2006).

Most studies described communication among patients, families, and staff, as well as early models of consultation (Kazak and Noll, 2015). Overall, “clinical care in pediatric cancer is an inherently multidisciplinary endeavor, with hospital-based psychosocial teams comprising of social workers, child life specialists, psychologists, creative arts therapists, clergy, and psychiatrists”. More so, the socio-ecological framework would also necessitate considering culture in understanding the phenomenology of these patients and their families. This context would also be a better lens in evaluating the existing resources as well as gaps between the needs and the psychosocial support provided.

Psychological Care in the Philippine Setting

In the Philippines, there are around 250-300 children and teenagers diagnosed with cancer, in the Philippine General Hospital alone (Reference). The effect of childhood cancer on patients and their families is pervasive and profound. Childhood cancer confronts the child or adolescent and their family with a new reality, one that

includes physical (i.e. hospitals, chemotherapy, doctors, radiation, surgery) and psychological (i.e. trauma, loss, change, grief, and in some instances death and mourning) challenges. Patients whose families have no financial means to support their treatment, experience considerably more stress and are at higher risk for emotional problems. They are more vulnerable to feelings of hopelessness and despair, helplessness, and loss of will to live. There has been a high incidence of suicidal ideation for teens receiving cancer treatment at PGH reported by the Pediatric Oncology Team.

More so, the Philippines has a shortage of mental health professionals (Tuliao, 2014). Studies on the mental health services in the Philippines show that aside from economic factors such as the general lack of accessibility and affordability of such services, cultural beliefs may also affect Filipinos' mental health help seeking behavior (Tuliao, 2014). Specifically, culturally-influenced beliefs on the etiology of mental illnesses are found to be inconsistent with the more Western approach involving a medical model. In the Philippines, these illnesses, whether physical or mental, are still believed to be a result of magical intervention (Lee Mendoza, 2009). It is precisely these gaps between cultural views and theoretical framework that have led social scientists to advocate for models of thought that reflect the nuances and subtleties unique to specific cultures (Pe-Pua).

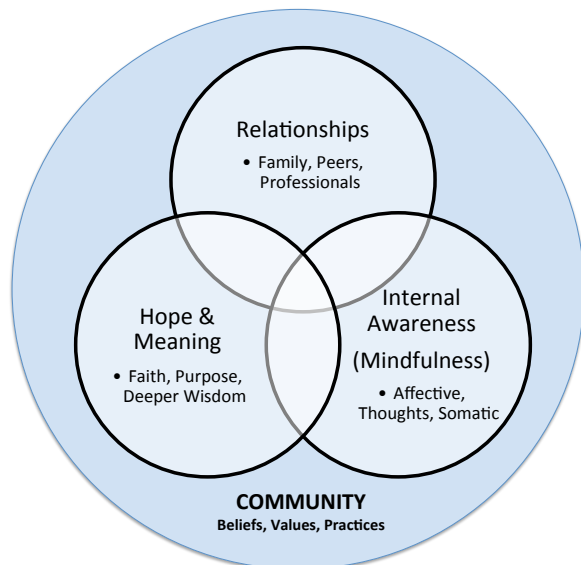
Towards a Culturally Appropriate Mental Health Model

According to Enriquez (1975), "sikolohiyang Pilipino" might be able to capture the Filipino as it is based on his own thoughts, feelings, and experiences. It was later defined as the study of *diwa* or the psyche. Studies also showed that the Filipino concept of *kapwa* largely affects Filipinos' preference to seek help from lay people rather than professionals due to the value they give to relationships in their social interactions (Tuliao, 2014). *Kapwa* is the "other", which is its straightforward English translation (Reyes, 2015). However, according to Reyes, it is better translated as "relational will", meaning that it is the self in the context of the other. *Kapwa* is said to be the core of different Filipino values (Pe-Pua & Protacio-Marcelino, 2000). It is the root word of another Filipino value called *pakikipagkapwa* which means relating and treating the other as a "fellow human being" (Pe-Pua & Protacio-Marcelino, 2000). There are also other Filipino psychological concepts that are not captured by the western model. Our collectivist inclinations have borne values that are relational in nature, rather than as a single individual. *Loob* is another Filipino value that is in the context of relationships. It is literally translated as inside but in essence, when referring to Filipino values, it refers to will that is directed towards others (Reyes, 2015). *Loob* is also the way we make sense of the other. According to Miranda (1992, p. 84), "*Loob* needs *kapwa* even to be *loob*: its continued responding to *kapwa* is the condition for its own existence and authenticity as *loob*." These two values should therefore be regarded together, rather than examined in isolation.

Providing psychological care for paediatric cancer patients as well as their families would then be quite different in the Philippine setting. These Filipino values should be taken into account in ensuring that the support provided is appropriate for these families.

Loob-Kapwa-Diwa: Circle Of Hope

Circle of Hope (COH) has sought to provide a culturally appropriate model of mental health care to its clientele of adolescents with cancer, and their families. COH was founded in 2013 with the aim to provide this kind of psychosocial support. It is a weekly group psychotherapy program for teens with cancer. Group therapy is also provided for the parents of these patients. As the model of care is founded on the interrelation amongst *loob*, *kapwa*, and *diwa*, the initial approach towards the program was very relational. This meant that the focus of the program was to develop relationships with its stakeholders. It was through these relationships that several needs have been identified, and thus has become the prime mover for the evolution of the program. Each component of the model was developed using different psychotherapeutic approaches. To develop the *loob*, internal awareness was developed through mindfulness practice, emotion regulation skills training as well as cognitive reframing. The *kapwa* was nurtured through the relationships modeled by the staff towards the patients and parents, as well as the relationships amongst participants. Collaborative helping was emphasized and an attachment-based family therapy approach was used. Interpersonal effectiveness was also targeted through modeling communication. Parent coaching was also provided. In order to link the relationship between the *kapwa* and *loob*, hope and meaning were important themes in the interventions. This was done through logotherapy, narrative therapy integrated with spirituality such as including prayer in the activities. Finally, all these components should contribute to the “*diwa*” of the community so that the participants themselves can be models of relationships to others and instill the value of collaborative helping in their own communities. The following figure illustrates this model:



Through this sharing of the self, between staff and participants, as well as between participants, the following outcomes were sought for the program:

- Decrease incidence of chronic depression and anxiety among youth cancer patients.
- Increase awareness and utilization of tools and practices that promote psychological wellness, adaptation to life changes, and coping with stressors related to cancer treatment.
- Strengthen community support for young cancer patients by helping parents and professional care providers manage stressors related to caring for these young patients.
- Strengthen the patient's and family's capacity to cope with significant transitions in the diagnosis and treatment process.

As the *loob* and *kapwa* are developed through Circle of Hope, a greater vision for the program is to develop community leaders out of its current participants, further propagating the collective *diwa*, or the Filipino psyche is rooted deeply in relating with the other. It is through this relational approach that these families gather their strength in coping with the challenges of cancer.

The Present Study

This study explores the phenomenological experience of the stakeholders in the participation in Circle of Hope, specifically, the COH staff, adolescents, and the parents. This study was also used to evaluate the effectiveness of the program, if the model of care has been able to result in the desired outcomes for its clients.

METHOD

Focus group discussions were conducted among three groups: clients, caregivers, and the COH team. Thematic analysis was used as the main data analysis tool.

Participants

The COH team comprised of five individuals, all of whom have been with COH since its conception. All the staff interviewed provide service to COH as volunteers. They also ranged in experience and qualification in providing psychological services. All volunteers have at least a master's level of education in psychology. All of them provide group psychotherapy services to the clients. They are also referred to as the *“ates”* and *“kuyas”* by the participants.

There were a total of 11 participants for the teen groups. Their ages ranged from 16-21 with 6 female participants and 5 male participants. They were divided into two smaller groups, one with 5 participants and the remaining 6 with the other group.

Among the parents, the ages were from 31-61. All participants were female. They were divided into two groups, one group with 7 participants while the other had 6 participants.

Procedures

Each group had a facilitator and a transcriber. Before conducting the discussions, the consent forms were distributed and read to the participants. They were given the time to review the forms and to ask any questions they may have. They were asked to sign the forms if they agree and voluntarily participate. One copy was kept by the research team while a second copy was given to each participant. Each discussion was also audio recorded.

Materials

Group discussions were structured according to the questionnaire assigned. Each questionnaire was designed according to the goals identified by the program. This study also utilized a phenomenological approach in data gathering so that most questions focused on the lived experiences of both participants and service providers. The questionnaire for the COH team was designed differently as it focused more on an analysis on the strengths and weaknesses of the program. The COH team were consulted for additional topics that they would like to be included in the evaluation. Group discussions were at least 1 hour and 30 minutes and done simultaneously, if possible.

RESULTS

The evaluation of each goal was expounded through themes and narratives by the participants. To ensure inter rater reliability, there was an independent reviewer and analyst of the transcripts. The lead investigator and the reviewer conferred to reach an agreement on the results. The discussions had three major components. The first part focused on the experience of the different groups as part of COH. The second part of the discussion focused on evaluating the strengths, weaknesses, opportunities, and threats to the program. Based on these two components, themes reflecting the achievement of desired outcomes comprise the third component.

The COH Experience

“Life changing” was a description that COH staff shared about their experience with the program. Both teen and parent groups also noted that they noticed changes within themselves, as well as their relationship with their family and community, as they got more involved with the program. Overall, the experience with COH was described as positive by all groups, comprising of the following themes:

Makulay at Masaya

According to the teen groups, because of COH, they now look forward to going to the hospital for their treatment and check-ups. They look forward to attending the group

therapy sessions and COH has made them feel that the hospital has become a safe haven for them, emotionally. The parents group describe themselves as “iyak-tawa”, meaning that despite some sharing that they find joy in each other, despite having to share some problems that may elicit negative feelings. Through COH, participants from all groups have also shared that they have become more nurturing and willing to relate with others because of COH. They have learned ways to communicate more effectively such as saying good morning to family members as well as changing the tone of voice during arguments. It is also through COH that they have found people going through the same experience. According to the teens group, they felt a profound loneliness since being diagnosed with cancer as other people their age may have different experiences and problems. Having shared experiences with a group has made them feel that there are people who are going through the same challenges. They shared that the openness and non-judgmental approach of the staff during group sessions helped them share their stories to their peers. The trust that has been developed within the groups has also created a safe space for the participants to share their problems and difficulties, not only with dealing with the cancer, but more so, in managing their other relationships at home.

Mahirap at Makahulogan

According to COH staff, being part of the program has also been a very challenging task. For the program staff, the challenges were mostly due to a lack in resources in terms of finances as well as overall support from other involved stakeholders. On a personal level, being part of COH has also become an opportunity to confront themselves, meaning that they also have to be able to find meaning in loss and suffering as they deal with their patients.

Several losses have also occurred in the recent years. According to the teens, instead of looking at death as a loss, they have started to find meaning in these losses, and instead, look towards celebrating the life of the friend that was lost. Being able to repair their own relationships at home and within themselves have helped them give more meaning to their lives. More so, their identity has gone beyond being a cancer patient, and recognizing themselves as individuals who experience life, love, and loss in the same way that other people would. The parents group have shared that it is also through COH that they started to recognize that a child or teenager with cancer, is still a teenager at his or her core. Because of this, they have learned to balance between caring for them and giving them their independence.

Magaan ngunit Malalim

Although themes of death and loss are part of the program, the participants shared that they still find the group as having a very jovial atmosphere during group sessions. When asked about their favorite topic, the teens group shared that they are most interested when the topic is about romantic relationships. They have also shared that both parents and teens have become more cheerful and talkative during group sessions. More than meaning, the theme of hope was also mentioned. Through COH, both parents and teens have found meaning in their life situations, thereby giving them hope that all these challenges may be worth something in the end. The experience is

described as “malalim” as it has evinced change in all the groups at different levels, from the self, family, and towards the community.

Program Features

Each group was asked to evaluate the program according to its strengths and weaknesses. They were also asked about possible solutions as well as further improvements for the program.

Strengths

The COH staff were identified as the main strength of the program. According to the participants, their authenticity, empathy, and openness have encouraged them to also become more open to change. They are also able to model collaborative helping as well as proper communication for both teens and parents. They have also fostered a safe environment for each group so that the participants have also developed trust among each other. This allows them to share their difficulties as well as problem solve. The safe space has also allowed for each individual, whether staff or participant, to contribute to the program according to each one’s skills and strength. The consistency and the regularity of the sessions were also identified as strengths of the program. Through weekly sessions, relationships are nurtured and it served as a motivation for parents and teens to come to the hospital.

Areas for Improvement

Although the support group is consistent and regular, a more structured approach would benefit the program. This would mean having a set number of sessions as well as activities for group therapy. A systematic evaluation of outcomes through pre and post intervention testing would also be a helpful evaluative tool for the program. Identifying quantitative tests to measure the desired outcomes would provide a basis for changes in the program. The teens and parents group mentioned that they would want to have more activities that highlight their talents and skills. The parent group also wanted to have more activities with their kids such as leisure trips and recollections.

Challenges

Currently, COH is comprised mostly of volunteers as the present financial resources are limited. Although COH is founded on the spirit of volunteerism, the time allotted to the roles as staff of COH could also be restricted. Activities are also limited due to these financial resources. The number of participants for COH has also been increasing so that sometimes, newer members take a bit more time in order to feel comfortable with the current group.

Opportunities

Increased dialogue with other stakeholders such as the medical staff and other members of the family can help strengthen the program. Expanding the service to other paediatric wards as well as hospitals. Nurturing an egalitarian relationship with the donors is also an opportunity to make these relationships sustainable.

Desired Outcomes

COH has four goals namely: (1) decreased depression and anxiety; (2) increase awareness and utilization of tools; (3) strengthen community support and (4) coping with significant transitions and treatment process. Overall, both teens and parents shared that the safe space created by COH have allowed them to create relationships that have helped them feel isolated, thereby decreasing feelings of depression. Exercises and skills such as mindfulness, like *Hingalangin* (a portmanteau of hinga/breathe and panalangin/prayer) were tools that helped them improve stress management as well as their communication style. The group has also become a venue to shift from problem sharing to problem solving. A change in perspective in terms of seeing death as a celebration of life, more than as a loss, have also contributed to their resilience. COH has also allowed them to see that there is more to their lives beyond the cancer, so that parents have started to recognize the developmental needs of their adolescent children, as well as the needs of other members of their family. The teens have learned to relate better with their peers as well as with their parents as the staff served as their models for communicating and relating with others. It is through the nurturance of these relationships within and outside COH that has helped them cope with the changes brought about by their sickness.

DISCUSSION

Using a culturally appropriate model of psychological care may be able to consider subtleties and nuances in culture that western models may not capture. According to Tuliao (2014), Filipinos prefer lay people over professionals when seeking for mental health support. COH has established an egalitarian relationship amongst its stakeholders so that participants view them as “ates” and “kuyas”, apart from their mental health professional status. COH is also hinged on an attachment based therapy so that consistency and reliability were components of the program. Group therapy sessions were done weekly to fulfill this component. According to participants, knowing that a session was expected every week gave them motivation and has changed their perspective of the hospital. Before COH, the visits to the hospital were seen as a chore, but now, according to the teens, they look forward to their weekly checkups because of the presence of the COH program.

According to Kazak (2006), children with cancer move around and within subsystems that could be sources of both protective and risk factors. Psychological support should then extend to families of children with cancer. COH has also provided the patients' families to process their shared experiences. It seemed that through these relationships, the *Loob* and *Kapwa* were strengthened. Through mindfulness interventions, participants have become more mindful of ineffective communication patterns and approaches as well as their general disposition towards relationship. It has

enabled them to effectively regulate themselves by being able to manage stress. According to parent participants, they have become more open to developing relationships with others, being more “*masayahin*” and “*palangiti at tawa*” compared to before. It is also through nurturance of these relationships that participants come to have a model for their own relationships with their families. The COH staff have been pivotal in providing this model of relating and attachment.

Apart from considering the family subsystem, the socio-ecological framework also considers bigger systems such as the cultural context. The group therapy approach as well as the emphasis on the *loob* and *kapwa* seem to have contributed to achieving the desired outcomes of the program. There is decreased feelings of isolation, thereby also decreasing depressing and anxiety. More so, participants are now able to identify their stress management strategies such as mindful breathing. They have also turned to problem solving when faced with challenges within the family.

Through increased self-awareness and improved effectivity in relating, COH also encourages that participants become community leaders and embody “*Diwa*” which meaning a will to contribute to the community and to also be models of resilience as well as shifting dialogues from problem oriented to finding solutions.

LIMITATIONS

A quantitative method of evaluation would provide more insight regarding the effectivity of the model of care of the COH. Standardised tools on measuring desired outcomes such as decreased anxiety could be used to identify improvements in mental well being.

CONCLUSION

COH is based on the framework of *loob-kapwa-diwa* in the delivery of psychosocial services to teenagers with cancer and their families. These components have been translated to activities and psychotherapeutic approaches that emphasize effective interpersonal skills, collaborative helping, mindfulness, and improving relationships within and outside the support group. The socio-ecological framework supports the importance of considering these Filipino values in service delivery as well as shifting the approach towards relating to participants as “*kapwa*” rather than clients. Through these relationships formed within COH, participants have shared that they have decreased feelings of isolation and that their quality of relationships have improved, thereby deepening feelings of hope and meaning into their current life situation.

References:

- Brier, M. J., Schwartz, L. A., & Kazak, A. E. (2015). Psychosocial, health-promotion, and neurocognitive interventions for survivors of childhood cancer: A systematic review. *Health Psychology, 34*(2), 130-148. doi:10.1037/hea0000119
- Enriquez, V.G. (1975). Mga batayan ng Sikolohiyang Pilipino sa kultura at kasaysayan. *General Education Journal, 29*, 61-88.
- Harrington, A. D., Kimball, T. G., & Bean, R. A. (2009). Families and childhood cancer: An exploration of the observations of a pediatric oncology treatment team. *Families, Systems, & Health, 27*(1), 16-27. doi:10.1037/a0014909
- Kazak, A. E. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice, and collaboration in pediatric family systems medicine. *Families, Systems, & Health, 24*(4), 381-395. doi:10.1037/1091-7527.24.4.381
- Kazak, A. E., & Noll, R. B. (2015). The integration of psychology in pediatric oncology research and practice: Collaboration to improve care and outcomes for children and families. *American Psychologist, 70*(2), 146-158. doi:10.1037/a0035695
- Lee Mendoza, R. (2009). Is it really medicine? The traditional and alternative medicine act and informal health economy in the Philippines. *Asia Pacific Journal of Public Health, 21* (3), 333-345.
- Miranda, D. (1992). *Buting Pinoy: Probe Essays on Value as Filipino*. Manila: Divine Word Publications.
- Pe-Pua, R. & Protacio-Marcelino, E.A. (2000). Sikolohiyang Pilipino: A legacy of Virgilio G. Enriquez. *Asian Journal of Social Psychology, 3*, 49-71.
- Reyes, J. (2015). Loob and kapwa: An introduction to a Filipino virtue ethics. *An International Journal of the Philosophical Traditions of the East, 25*(2), 148-171.
- Tuliao, A.P. (2014). Mental health help seeking among Filipinos: A review of the literature. *Asia Pacific Journal of Counselling and Psychotherapy, 5*(2), 124-136.