



GIVING HOPE TO CHILDREN WITH CANCER THROUGH A HOSPITAL-BASED EDUCATION PROGRAM

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Abstract:

The hospital-based Education Program (HBEP) is a research and community extension program that eventually became Dumanlas Elementary School Annex (DES-SPMC Annex), a public elementary school in Davao, City Philippines. Evaluated in this study is the impact of HBEP from 2013 to 2018 utilizing qualitative research design particularly Applied Research approach involving a Case Study of three patients enrolled in HBEP alongside parents, the DES administrator/teachers, CED-USEP Extension Program Coordinator as well as Volunteer Teachers and other stakeholders. An interview protocol was used to obtain information of participants while secondary data which consist of school records and other pertinent records were also considered. Results revealed that a number of opportunities were enjoyed by participants which include flexible and free access to education using Alternative Delivery Mode; development of physical, cognitive, and socio-emotional domains through fun-filled class activities, and opportunity for continuing education. Consequently, benefits obtained include the development of socio-cognitive aspects, sustained peer support, strong student motivation, and growing self-confidence. Meanwhile, Challenges confronted by the participants were: physical effects after treatment, cognitive and emotional disturbances, and coordination issues on student whereabouts, financial constraints, and volunteer-teacher availability at the initial phase. Hence, this study recommends sustaining HBEP in support of EFA goals of UNESCO and of inclusive education. Furthermore, it recommends expanding community extension activities to assist DES in the development of student Individual Education Plan (IEP) and other services for better delivery of education.

Introduction

Unarguably, education has always been considered as a potent tool for children to acquire a bright future. It equips children with the necessary knowledge and skills to be able to live a better life in the future. As a matter of fact, UNESCO (2018) stresses the right of children to education which is a fundamental human right. Furthermore, UNESCO highlights that every individual, irrespective of race, gender, nationality, ethnic or social origin,

religion or political preference, age or disability, is entitled to a free elementary education.

Cancer which has been recorded as the second leading cause of death worldwide has affected a number of children. In fact, World Health Organization (WHO, 2020) statistics shows that 9.6 million deaths; or one in six deaths is caused by cancer. It is a large group of diseases that can possibly start in almost any important organ or

tissue of the human body with the irrepressible abnormal growth of cells. Consequently, survivors of the illness can get deprived of the opportunities to live a happy and normal life with others; which was found out to have adverse effects of cancer treatments on children and in helping children fight and cope with this killer disease.

In the Philippines, the Department of Education (DepEd) advocates the fundamental principle of inclusive school where all children at different aspects of life learn together wherever possible, notwithstanding any difficulties or differences they may have [1]. This urgent mandate from the DepEd especially identifies children who are sick and chronically ill must be included in the implementation of this inclusive education. This has been evident in Article 6, Section 1.2.8 of Policies and Guidelines in Special Education DepEd Order 72 Series of 2009. Obviously, Inclusive Education is used as a strategy for increasing Participation Rate of Children especially for children with special needs. Also in 2019, RA 11215 known as the National Cancer Integrated Act was promulgated to endeavor in preventing cancer and improve cancer survivorship by augmenting vital programs, including education.

With this premise, Southern Philippine Medical Center (SPMC) in Davao City Philippines through the initiative of the University of Southeastern Philippines (USEP), a Hospital-Based Education Program (HBEP) was established to provide access and opportunity to children with cancer.

Hence, this study aimed to evaluate of HBEP for children with cancer at the House of Hope (HoH) in SPMC. Furthermore, this paper intended to capture the different views and perspectives of the patients, parents, staff, and other stakeholders involved in terms of the effectiveness and significance of the program. Their voices were noteworthy to be heard of by the world as their accounts are authentic and empirical; which can certainly contribute to the development and enhancement of a hospital-based education program in the Philippines and elsewhere.

METHOD

This study utilized applied research design to improve understanding about hospital-based

education program and to contribute improve ways in delivering the program. Evaluation is a research process where a researcher conducts a study to determine the effect of a particular given intervention. Furthermore, it means that it is conducted to identify if there are certain success indicators where intervention is administered and therefore decides whether a program or policy can possibly be expanded within the setting.

Howard & Raitzer (2017) stressed that the purpose of evaluation is to ensure that development actions lead to development outcomes and learning which is to contribute to the body of academic knowledge on the basis of the employed techniques and the conclusion drawn from the research. The convergence of rising need for evaluation evidence among development practitioners and increased interest among academics present a unique opportunity for intersecting research and practice at the same time [2].

The key approaches for evaluation of Owen are objectives-based, needs-based, goal-free, process-outcome studies, realistic evaluation and performance audit. Specifically, this study utilized the Goal-Free approach to Evaluation (GFE) wherein the evaluator conducts the evaluation without particular knowledge or reference to the stated or predetermined goals and objectives of the program. In GFE the evaluator attempts to observe and measure all the actual outcomes, effects, or impacts, intended or unintended, all without being cued to the program's intentions.

This study involved three (3) sets of participants who were deemed necessary in evaluating the impact of the interventions; these are: the evaluand, the evaluation users, and the evaluators [2]. The selection of the participants was based on the inclusion criteria that covered only participants who had cancer and were currently enrolled in Dumanlas Elementary School Annex-SPMC Campus (DES-SPMC), Davao City, Philippines. They also served as the pioneering recipients of the HBEP.

The evaluand, is referred to here as the Hospital-based Education Program (HBEP) aimed to determine its impact on children with cancer.

The evaluation users were the participants of the study, the three children with cancer who were with the HBEP since it started in 2013 and were currently enrolled in the program. The evaluators were coming from University of Southeastern Philippines and their task was to facilitate the implementation of the program.

Participants involved which served as evaluation users is composed of Grade four students; all nine (9) years of age and diagnosed with leukemia and leukemia with tuberculosis of the spine respectively. All three are undergoing treatment during the conduct of the study.

A validated researcher-made interview protocol guide was used to obtain detailed information or stories pertaining to participants' exposure to HBEP. While, the secondary data were obtained from the school records and other pertinent records as tools to assess the impact of HBEP to the learners with cancer.

Thematic analysis in the context of the study, was conducted by the researcher particularly closely examining the data to identify common themes—topics, ideas and patterns of meaning that came up repeatedly until deemed useful and accurate representations of data. Writing up the thematic analysis followed.

RESEARCH RESULTS

Results are presented according to opportunities afforded by HBEP to children with cancer and other stakeholders, benefits brought to them, challenges met in its implementation and an incidental finding of the study.

Opportunities

Results revealed that the opportunities enjoyed by the participants consist of free access to education, development of physical, cognitive and socio-emotional domains through fun-filled activities initiated by CED-USeP volunteer-teachers.

Flexible and Free Access to Education (Using Alternative Delivery Mode (ADM))

One significant opportunity afforded to children with cancer is that they were able to avail of a highly accessible education, free and flexible at

that. These children have been given the chance to enroll and participate in the class brought right to the facility by quality teachers coming from a leading teacher education institution by way of their laudable extension program dubbed Hospital-Based Education Program (HBEP) to which at a later part have been formally endorsed to Dumanlas Elementary School (DES) to make their classes officially enrolled with DepEd which have formally become into an Annex school of DES.

As regards flexibility, children with cancer-learners find it appropriate for their case as they are taught with the use of modules as an Alternative Delivery Mode (ADM). The distribution of learning materials (modules) to students while they are confined in HoH and even upon discharge has allowed them to learn at their own pace which is highly significant since their current health cannot warrant their success in the regular class. Modules serve them well as these are handy which means they can bring it with them whether they are in the hospital beds undergoing medication or resting at the HoH facility waiting for scheduled treatment.

Responses of the participants on the opportunities they enjoyed in the Hospital-Based Education Program, particularly on accessing free education, were captured from students as: *“The program... Sometimes Science, Math, spelling, etc. ...we were taught how to read and write and have play and fun.”* Stakeholders also claim that *“We teach them, we give them worksheets. Though, they are under medication in the hospital, they brought with them the worksheets as our basis for attendance in a day.” While they undergo chemotherapy, if they want to go to school they won't beg anymore to sit in; here, education is free. Children have big improvements because they were given encouragement”*

Development of Physical, Cognitive, and Socio-emotional Domains

The education children-with-cancer receive from HBEP has developed them not only academically but has transported them way beyond classroom learning particularly citing their physical, cognitive and socio-emotional domains. Not to be left out are the socio-emotional domains developed via the HBEP. It can be observed that

participants acknowledged how they have improved socially and emotionally. Putting into consideration their health status, these children are expected to sulk and wallow in self-pity if not given proper care and attention.

Claims made by research participants revealed how HBEP has developed them not only cognitively but physically too as well as their socio-emotional aspect. Students highlighted the fact that they are learning much and it gives them the excitement as any normal student in school. The lessons learned are taken seriously and put to heart by the learners despite their situations. They engage in class activities willingly and communicate their thoughts and feelings openly. The program indeed has allowed them to experience real school experience in a hospital-based context.

Continuing Education

One dreaded effect of getting the disease is that children stricken with cancer would not be able to proceed with their studies; that they will be forced to cease from enlisting themselves in the conventional school and would be required to focus on medication which normally takes a long process. And for those who live far from SPMC would need to leave their provinces to undergo treatment, leaving their families, school, and all in their normal lives prior to the ailment. They would need to stay in the city, away from home and school, and for some, with very limited resources. They would need to leave school.

Children in HoH generally look forward to attending scheduled classes and seem appreciate the experience knowing its 'real' school they are engaged with, not merely a remediation class to while away time.

This finds support in the study of Sullivan et al. (2001), who found out that going back to school is one of the biggest steps for a young survivor since it is the primary tasks of children. Returning to school, for children with illness, may be a road towards psychosocial cure. As she added, school serves as an avenue for children with chronic illness to approach the process of living each day and begin to regain control of their lives and

resume to pre-illness activities that foster normalization process.

Benefits

As with any other thing on earth there will always be something good, something positive, something beneficial that lurks somewhere. The education received by children with cancer through HBEP has surely paved for a way bringing in more benefits than previously intended.

In fact, four themes pertaining to benefits gained from the HBEP emerged out of the study namely: Development of Socio-cognitive Aspects, Sustained Peer Support, Strong Student Motivation, and Growing Self-Confidence.

Development of Socio-cognitive Aspects

Considering the very nature of children with cancer who most often than not are the types who would choose to stop learning, stop mingling with others whether peer or family, stop all activities engaged with prior to their illness, HBEP has created a way to assist these children into becoming dynamic the way they used to, into allowing them to focus on other fruitful endeavors other than their medication. They have gained access to develop socio-cognitive skills needed when they go back to the mainstream society hopefully after the successful fight with the disease.

The opportunity to learn with others of their kind have been considered beneficial as they would not fear of being deviant in the group. This has helped them to not focus on their limitations but rather encourage them to try to learn as they see others struggling with the disease also learning.

This finds support in the study of Chen et al. [2] that Hospital-Based School is considered to have a student-centered service with customized programs to tailor-fit the unique needs of the sick children. It was further emphasized that children confined at hospitals must not be deprived of their right to pursue happiness through education. The Arkansas Children's Hospital believed that school is a normal activity for children and adolescents. Further, when a child is in the hospital, it can interrupt the normal pattern of schooling

Sustained Peer Support

Children are children. There is genuineness in everything they do whether it shows pain or pleasure. Such is what helps children with cancer survive the rigors of intensive medication and hospital-based education. They seemed to enjoy the camaraderie with other tenants in the facility and are actually banking on their support. They have created friendships as they learn and it has immensely helped each one of them. The friendships they have formed and the things which they commonly share (medication and education) have become a very strong support. This could have given them a feeling of togetherness during those difficult times. They could also serve as a source of strength and inspiration one to each other.

In fact, Gravestock et al. found in his study that a number of parents reported that their children experienced bullying and teasing from peers after the diagnosis and during the treatment, resulting to being distant from peers. Hence, HBEP paved the way on connecting children with their peers [4].

Strong Student Motivation

Nothing can be more inspiring than knowing children with cancer having a strong motivation towards learning. It came out in this study that students engaged in HBEP rely on no one other than themselves. Except for really impossible times for them to join the class (like a recent chemotherapy/radiotherapy performed for the patient), students generally show enthusiasm in learning just like any normal learner despite their situations.

This positive attitude has contributed a lot to the success of HBEP implementation considering that the primary clientele's response to the offered extension program is crucial. Any extension program are crafted with the 'good end' in mind nevertheless its success also lie in how its target clientele take the offered service.

Hence, the warm response of students particularly made up of children sick with cancer, benefits firstly themselves and in effect all stakeholders running the program. The volunteer-teachers from CED-USEP and DES find it inspiring to come to the facility and conduct classes to

enthusiastic learners which kept them coming back. They felt welcomed by eager learners in spite of their health conditions.

Growing Self-Confidence

Adults and children alike are often robbed of self-confidence when stricken with dreadful diseases. And once their health deteriorates, they have the tendency to stop living the life they used to possess. As if, the world stands still for them. They lose the zest for life. Let alone education. Every day becomes a journey to uncertainty

It is, therefore, taken as one great benefit children with cancer has regained while undergoing medication and receiving education via HBEP. It has afforded them the chance to go on with their studies and focus their attention to it to while away time in between treatments which usually takes months. This, at least allows them to show to the world that they are still capable of doing some things done prior to the disease like schooling. That after the chemotherapy / radiotherapy and if blessed to recover may proceed with what life offers them. That they are not altogether useless and helpless in the society. Those things greatly contribute for children to grow self-confidence and press on against the odds. They regained reasons for waking up day after day as they wait for their teachers.

The opportunity to engage in schoolwork has elevated their sense of worth; that they too at their present health status can continue the lives they live prior to the disease without being laughed at. They usually experience bullying outside especially when their hairs start to fall off due to the therapy. Children being vulnerable to harsh and destructive words get much affected with the reactions of the people outside more so if these come from peers. In the contrary, they have started getting back the feel of being students in the middle of treatment. The program has rekindled their self-confidence in the sense that they get a taste of schooling and hence does not require them to go to the regular school and risk both physical health and emotional health.

Challenges

The challenges confronted by the participants included physical effects after treatment, cognitive and emotional disturbances due to death of friends

in class, post-medication monitoring of students enrolled, parent support, financial constraints and volunteer-teacher availability.

After-Treatment Physical Effects

It cannot be denied that cancer-patients undergoing chemotherapy/radiotherapy suffer adverse after-effect syndromes immediately after schedule of treatment. Gathered responses imply that children with cancer undergoing intensive treatment indeed suffer adverse after-effects of the chemotherapy/radiotherapy. This does not even have to be the same for each of them. One may have body malaise, the other may have extreme headache while some would throw up almost all their stomach can hold. Hence, at times these children get hampered by the physical reactions brought about by the treatment which makes it impossible for them to participate in the class. This downtime lasts a few days after treatment and should the class fall on the same schedule tendency is, they could skip the class no matter how interested they may be in learning. Medication sometimes takes its toll on their frail bodies preventing them from joining the class.

Cognitive and Emotional Disturbances

Undergoing intensive medication is no joke. The bodies react to the medicine so much so that they get to experience cognitive and emotional disturbances. Chemo patients have been observed to display lower cognitive functions and different negative emotions. Some may not be able to easily get a good grasp of the lessons and eventually feel inadequate to cope with the demands of schooling even right before their faces. There are also times they get disturbed with the passing of a co-patient. This brings them down and feel fear of their own fate. They get emotional knowing they are in a similar situation and may or may not recover. There is always this 'downtime' every after chemo/radiation therapy and when they lose somebody in the facility. Staying together in the same place has created in them a special bond that makes it more difficult for them to let go of anybody.

Teachers for their part also gets affected as they have not received a specialized training of coping stresses of this kind. One thing more, once the

student is discharged and heading towards recovery, they may find it difficult to proceed with schooling in the mainstream. Teachers are finding difficulty in persuading them to go back to mainstream school as they are not anymore staying in the HoH. There are obviously a number of things they are grappling with while engaged with HBEP.

Other Findings

Coordination issues

Another struggle in the implementation of HBEP pointed towards the issue of having a coordinated class schedule. The responses from most research participants revealed a common struggle everybody has gone through that which refers to coordination between teachers and students' schedule. At times, students are available but teachers cannot come. Meanwhile, there are also instances when the teachers report to class as scheduled but are met with the message that some students cannot make it to class for this reason and that reason. Everything seems unpredictable. And it is not in the hands of the teacher nor on the students that determine their absence or presence in each class. The HoH staff for their part cannot also predict who gets sick today and gets better the next day.

Financial Constraints

Though their education in HBEP is free, the struggle of children with cancer is the will to continue when they return homes. Some of those who have been discharged and are residing around Davao City would even want to go back to HoH just so they could participate in the class. This then entails extra expense for the family. Should the learner insist on going to HoH, they would need to bring him/her on the scheduled classes? Unfortunately, not all can afford the expenses incurred by bringing their children to and from the facility. Often, they are forced to drop schooling particularly for those who live outside of Davao City and lack the resources to bring them regularly to HoH. This could actually be an added burden for the family aside from the take-home medicines they need to purchase. It can be noted that those who cannot really support for transporting their children

to and from HoH would resign to the fact that they are forced to discontinue schooling as they are also not physically prepared to go mainstream.

Volunteer-Teacher Availability at the Initial Phase

HBEP being an Extension Program of CED-USEP started in 2013 and basically was implemented with the concerted effort of the faculty and students of the college. They are referred to as volunteer-teachers considering that they are doing the activity outside of their regular tasks in the university and with no additional remuneration whatsoever except for the love and commitment of teaching children with cancer whose education has been put on hold due to long term treatment sought at SPMC.

It is worth noting that attendance of teacher-volunteers has affected the children. They get disappointed when they learn that the teacher is not around for the scheduled class though they are aware that teachers could have other matters to attend to over the HBEP. Some even pointed out that teachers may not be forced to report religiously as their presence is purely voluntary in nature.

CONCLUSION

Based on the results of the study it can be concluded that free access to education, development of physical, cognitive and socio-emotional domains through fun-filled activities are accounted as opportunities brought about in the Hospital-Based Education Program (HBEP). Moreover, spiritual enrichment, development of socio-cognitive aspects, sustained peer support, strong student motivation and self-confidence, collaboration with stakeholders and quality education are considered benefits brought by the Hospital-Based Education Program (HBEP). In addition, the after-treatment physical effects, cognitive and emotional disturbances, post-medication monitoring of students, parent support, financial constraints and volunteer-teacher availability posted as great challenges in the implementation of the Hospital-Based Education Program (HBEP).

RECOMMENDATIONS

Based on the conclusions of this study, it is recommended that Hospital-Based Education Programs be sustained for critically-ill children as an implementing arm of Inclusive Education in accordance to UNESCO's Education for All (EFA) policy. Additionally, other health facilities like the orthopedic or pedia-cardio department may be explored for another possible Community Extension project similar to children with cancer. Also, a multi-disciplinary team composed of a social worker, physical therapist, occupational therapist, psychologist, etc. may be involved in the preparation of Individualized Education Program (IEP) to improve delivery of lessons for children with cancer.

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MANG LẠI HY VỌNG CHO TRẺ MẮC BỆNH UNG THƯ THÔNG QUA CHƯƠNG TRÌNH GIÁO DỤC TẠI BỆNH VIỆN

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Tóm tắt

Chương trình Giáo dục dựa vào bệnh viện (HBEP) là một chương trình nghiên cứu và mở rộng cộng đồng, cuối cùng đã trở thành Phụ lục của Trường Tiểu học Dumanlas (DES-SPMC Annex), một trường tiểu học công lập ở Davao, Thành phố Philippines. Được đánh giá trong nghiên cứu này là tác động của HBEP từ năm 2013 đến năm 2018 sử dụng thiết kế nghiên cứu định tính, đặc biệt là phương pháp Nghiên cứu Ứng dụng liên quan đến một Nghiên cứu điển hình về ba bệnh nhân đăng ký HBEP cùng với cha mẹ, quản trị viên / giáo viên DES, Điều phối viên Chương trình Mở rộng CED-USeP cũng như Tình nguyện viên Giáo viên và các bên liên quan khác. Một giao thức phỏng vấn được sử dụng để thu thập thông tin của những người tham gia trong khi dữ liệu thứ cấp bao gồm học bạ và các hồ sơ liên quan khác cũng được xem xét. Kết quả cho thấy những người tham gia được hưởng một số cơ hội bao gồm quyền tiếp cận giáo dục linh hoạt và miễn phí bằng Phương thức Phân phối Thay thế; phát triển các lĩnh vực thể chất, nhận thức và cảm xúc xã hội thông qua các hoạt động vui chơi trong lớp và cơ hội để được giáo dục thường xuyên. Do đó, những lợi ích thu được bao gồm sự phát triển của các khía cạnh nhận thức xã hội, sự hỗ trợ bền vững của bạn bè, động lực mạnh mẽ của học sinh và sự tự tin ngày càng tăng. Trong khi đó. Những thách thức mà những người tham gia phải đối mặt là: ảnh hưởng về thể chất sau khi điều trị, rối loạn nhận thức và cảm xúc, và các vấn đề phối hợp về nơi ở của học sinh, hạn chế tài chính và sự sẵn có của giáo viên tình nguyện ở giai đoạn đầu. Do đó, nghiên cứu này khuyến nghị duy trì HBEP để hỗ trợ các mục tiêu EFA của UNESCO và giáo dục hòa nhập. Hơn nữa, nó khuyến nghị mở rộng các hoạt động mở rộng cộng đồng để hỗ trợ DES trong việc phát triển Kế hoạch Giáo dục Cá nhân cho học sinh (IEP) và các dịch vụ khác để cung cấp giáo dục tốt hơn.
