# GAME REQUIREMENTS GATHERING AMONG HOSPITALISED PAEDIATRIC CANCER PATIENTS: A THEMATIC ANALYSIS

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DOI: https://doi.org/10.22452/mjcs.sp2019no1.6

***ABSTRACT***

*This paper presents a study that analyzes hospitalized pediatric cancer patients' routines and activities to inform the game design to be used for the development of a digital game to empower them. This study focuses on discovering patients' experiences while being hospitalized. The patients' activities throughout their hospital stay are recorded through non-participatory observations strategy and their experiences inward are gathered through interview sessions with their parents or guardians who have been nursing them during their entire stay in the hospital. The findings suggest that the patients' experiences are divided into two main themes, namely positive and negative affect. These two themes are depending on the patients' treatment phases: before, during and after receiving medical treatments. These findings are crucial to being translated into design principles to inform game design. It is important to ensure that the digital game for pediatric cancer patients is designed properly to ensure its suitability to be played by them. The ability to understand the actual routines and experiences in the hospital would help designers and developers of digital games to develop a digital intervention to empower pediatric cancer patients while being hospitalized.*

***Keywords: Thematic Analysis, Pediatric Cancer Patients, Children Actions, Positive Affect, Negative Affect, Game Design.***

## 1.0 INTRODUCTION

The diagnosis of cancer among children causes an elevated level of stress for both children and their parents or guardians. The experiences of young patients diagnosed with cancer can be tough, confusing, and shocking. There are too much to be processed, including their treatment protocols, medications, and side effects among others. Indeed, living with cancer can be challenging for young patients, especially when they have no other options but to deal with this chronic illness.

According to the American Cancer Society, there is an estimate of 1,688,780 new cancer cases reported for the year 2017 [1]. In Malaysia, according to the Malaysian National Cancer Registry Report 2007-2011, a total number of 103,507 new cancer cases were diagnosed from 2007 to 2011 [2]. The same report publishes that childhood cancer in Malaysia ages from 0 to 18 years old comprised of 3,829 cases where 2,131 (55.7%) cases were males and 1,698 (44.3%) cases were females. Type of cancers in children below the age of 14 years is leukemia followed by the brain, nervous system and lymphoma. These numbers are expected to increase, however, the latest report on the current statistics is still not publicly available.

Cancer is a set of more than 100 diseases that have several factors in common [3]. It is argued as the second leading cause of death following heart disease in the United States and most developed countries (https://www.cancer.org). A study conducted by [3] suggests that cancer is a top cause of death in the world and the number of death cases raises together with the rise of the world population. They also describe cancer as an imbalance of cell reproduction which means that an individual who suffers from cancer will experience abnormal growth of cells or tumor in the body [4].

Lymphocytic leukemia, brain tumors, and neuroblastoma are the usual type of cancers among children below 14 years. Several other types of cancers among children include lymphoma, rhabdomyosarcoma, and retinoblastoma [5]. Cancer treatments for children include surgery, chemotherapy, radiation therapy, and immunotherapy amongst others [6]. Today, the advancement of cancer treatments and care have significantly improved the overall outlook for children diagnosed with cancer. This contributes to the increment of survival rates of pediatric cancer patients.

However, being diagnosed and experiencing the side effects of the treatments of cancer remain extremely stressful and challenging for the patients and their families [7] [8]. These treatments, all of which may severely affect children's physical and psychological well-being [9] [10]. One example of the challenges is that these procedures could consume a lot of time and require patients to be hospitalized during the entire treatment session [11]. The reactions that can be seen among the children are for instance, they may experience medication, psychological, and cognitive and neuropsychological side effects. These factors can impact how the children view themselves and eventually become obstacles in the transition process back into the lives and routines they had before they were diagnosed with cancers. Previous studies reported that children with cancer are at a substantial risk of depression [12] [13].

The experience of being hospitalized, especially for a long period is argued to be a problem for pediatric cancer patients. Hospitalization itself is a stressful situation, and a patient's stress level could increase significantly as the length of hospitalization increases. Most pediatric cancer patients have to be absent from school each time they went to the hospital to complete their treatment cycle. The patient would feel stress, bored and lonely in the hospital because they have no friends to play with during the treatments since most of their friends are at home [14]. Being hospitalized is an experience that can cause stress in patients. The stress influences their feelings toward the treatments given. Some of them would even feel that the treatments provided are not working, experience feelings of a loss of control, bitterness, and anger [15].

There are a substantial number of studies to investigate coping strategies to support pediatric cancer patients. The results of these studies suggest that either counseling, physical therapy or pharmacological therapy can be applied to help the patients [15]. Other research in different fields have also been conducted to find the best support systems and practices to support hospitalized pediatric cancer patients. One of the ways is the use of digital games [16]. Research conducted by [15] shows that digital games can be used during the treatment session to reduce depressive symptoms. It is argued that digital games can be applied to pain management for patients while receiving treatment [15]. Furthermore, research on digital games for cancer patients have revealed that playing digital games during a chemotherapy session can reduce nausea after receiving the treatment [17].

However, little has been done to record the actual pediatric cancer patients' routines and behavior while being hospitalized during their treatment. In this paper, we argue that it is important for the designers and developers of digital games to understand thoroughly how pediatric cancer patients' behavior and routines in the ward to be used in the design phase. Thus, through a non-participatory observation strategy and thematic analysis, we attempt to gather user requirements to be used in the design stage of the development of digital games to be played by hospitalized pediatric cancer patients.

## 2.0 RELATED WORK

### 2.1 Pediatric Cancer Patients

It is argued that medical providers find it challenging to design specific video games for cancer children [18]. Pediatric cancer patients experience anxiety attacks from medical procedures namely surgery, chemotherapy, and radiation therapy. Cancer children and their family's early reactions after they received the diagnosis include denial, anxiety and depression which consist of non-acceptance of the reality [18]. The patient's reaction becomes bigger in the second stage as they feel a loss of perception, separation and death thoughts, and disaffection with the body which defines the elements of anxiety [19].

There are consequences of cancer treatments for patients. A few mutual side effects, namely appetite loss, constipation, tiredness, hair loss, nausea, vomiting, and some patients might experience a concentration issue [4]. Additional cancer treatment effects are low platelet, red blood cell, and white blood cell amount. The risk of infections and bruises will rise due to these side effects and the patient could simply bleed [11].

Chemotherapy can be defined as the use of a chemical substance to kill the cancer cells from spreading [20]. Chemotherapy procedures consist of several unpleasant side effects such as mouth and throat sores, mucositis, fatigue, diarrhea, pain, nausea and vomiting, constipation, hair loss, nervous system effects, changes in memory and thinking, appetite loss, radiation recall, and long-term side effects [21]. Chemotherapy treatments are the treatment that uses blends of several common drugs such as Vincristine, Daunorubicin, Doxorubicin, Cytarabine, L-asparaginase, 6-mercaptopurine, Methotrexate, Cyclophosphamide, and Dexamethasone [11].

### 2.2 Available Video Games for Cancer Patients

It is argued that video games could impact cancer patients positively. In the United States, 97% of children playing video games and these kids spend nearly one hour every day playing video games. Several studies have identified that video games are very useful and suitable to be used for the advantage of cancer patients. It is also argued that video games have histrionic, complex, various and realistic changes that allow child interactions [22]. Video games can be used to motivate them, to be used as a tool to encourage positive communication between medical providers, parents and patients and to allow patients to distract themselves during hospitalization.

Video games that are precisely designed for patients can change the patients' behavior. Video games designed for health can distract their attention. Behavioral moralities can lead to the development of a video game that precisely emphasise on the changes in the numerous health behaviors of each patient. The study planned a procedure for emerging video games that offer a compact foundation for behavioral change by highlighting the improvement of the player’s knowledge and skills. The study also proposes that to encourage learning, the video game atmosphere generates personal mastery by using game characters and avatars [23].

The study led by the Department of Radiation Oncology at the University Hospital in Halle (Saale) in Germany suggests that computer-generated games can help in lessening the patients' negative feelings and strengthen their self-esteem. Throughout a treatment meeting, adult cancer patients are driven to be physically active by playing a Nintendo Wii game console. The study includes physical training for five days for each patient. Patients were required to play the Nintendo Wii for 30 minutes each day [24].

The outcome from this study [24] proposes a raised level of acceptance by patients to play video games to surge their physical activity. Patients were inspired to become physically active once admitted to the hospital by discovering the Nintendo Wii console game. They were preoccupied entirely with the normal routine of the hospital when they were playing the console game. They also expressed that they feel better after game gatherings. The outcome suggests that patients feel relaxed while playing video games [24].

Video games are beneficial for special health care purposes by capturing the players' attention. The research proposes that video games could support patients to overcome their anxiety by increasing the patient's psychological state of mind. The key outcome of this research demonstrates that video games such as remission could generate the patients' alertness. There are several types of video games that could expand the patients' motor function, namely the Wii Virtual Reality [25].

It is argued that technology has helped children with cancer by facilitating a better environment during their challenging times battling with chronic illnesses. Patients are lonely without friends because they often miss out on school as they have to complete their treatment at the hospital. The study also proposes that video games could support the patients to feel included in their society as they feel connected again each time they play online video games with their friends [26].

Video games also allow social interactions and play a big role to make pediatric patients feel other healthy children. The study [26] suggests several social media platform such as Facebook has video game on the platform for patients to stay connected with their friends using social media such as Facebook and Instagram. Patients can use the platform to play with their contacts and they can communicate with their friends, although they are in the hospital. The research also proposes that patients can feel present with their networks without physically being present through technology. For example, a patient can make a video call with their family, Face Time with friends and play

online games like Mine Craft. The research recommends that it is essential for patients to get used to their new form of regularity after they have been diagnosed with a chronic illness. Social media can support patients to feel normal again [26].

Based on the literature, this research aims to investigate the experience of children after the cancer treatment session and analyze how they cope with the painful experience. The researchers have also considered the following research questions:

1. What are the activities performed by pediatric cancer patients during their stay in the ward?
2. What would be the most preferred activity among patients in the ward?
3. Why would the patients react in a certain way during the treatment?
4. What would be a suitable intervention for the patients?
5. How would children cope with the treatment?

### 2.3 Negative and Positive Affect as a Hospitalized Patient

In general, hospitalization is a stressful experience for children, and it brings a negative effect on patients. A study that was carried out emphasizes that hospitalized children are very concerned about pain, mutilation, immobility, separation from significant others, loss of control and the disruption on their daily routine are potentially stressful [27]. Cancer treatment may also cause financial stress for pediatric oncology patients and their families [28]. Surgery and hospitalization have always been measured by negative experiences that affect health in adults and children [29].

Social interaction with family members and visitors is essential for the patient who is being hospitalized as it conveys a positive effect on the patient. A study is conducted to observe pediatric Hospitalist rounding practices and characteristics [30]. The study suggests that positive affect could arise from a program called Family-Centered Rounds (FCRs) which involves patient and family member's perspectives and preferences in clinical decision-making that occur inside the patients' rooms [30]. FCR's positive outcome includes increased family involvement and understanding, trainee role modeling and effective team communication.

## 3.0 METHODOLOGY

In this study, we conducted non-participatory observations and unstructured interviews, targeting parents or guardians of the patients to investigate the experience of children after cancer treatment sessions and how they cope with that painful experience. We collected data from 10 parents and guardians from March to April of 2017. The ethnographic study did not consist of any communication and contact with patients during the observations [18]. Therefore, only parents or guardians of the pediatric cancer patients were asked about their children's affective states of mind and behaviors.

### 3.1 Participants

The interviews included 10 parents and guardians of pediatric cancer patients. The age of the parents and guardians was between 35 years old to 52 years old. They have been nursing their child throughout the hospital stay.

### 3.2 Procedure

The researchers performed observation and interviews at the pediatric oncology ward, Faculty of Medicine, The National University of Malaysia (UKM). The observations were conducted to observe pediatric cancer patient's routines in the ward and the objective of the interviews is to confirm with the guardians about the routines of pediatric cancer patients in the ward. The interviews were conducted individually at several distinct times. The interview for each meeting acquired around thirty minutes and sometimes up to one hour. A voice recorder was used to record the responses from the informants. Before the interview began, each informant was given a consent form to confirm that they agreed to be interviewed. To start the interview, each parent and guardian was asked to describe his or her child's emotions and behavior. They were asked the following:

1. What is your child's current treatment protocol?
2. Is there anything that your children like to do whilst warded in the hospital?
3. Any particular emotions that you realize after your child received treatment?
4. What is the type of activities that help to motivate your child whilst warded in the hospital?

After the interview ended, the data from the voice recorder was transferred into a text transcript. The text transcript was used in preparing the question for the next interview ahead. This process was applied in all interviews. After that all the data that was collected from the interviews were then extracted and categorized into different themes based on thematic analysis strategy.

### 3.3 Ethical Clearance

In undertaking this research, this study considered the ethics of conducting observations and interviews of the pediatric cancer patient's emotions and behavior. Approval was sought from the Ethics Committee of the National University of Malaysia. The ethical clearance number is UKM PPI/111/8/JEP-2016-145 dated 21 April 2016.

### 3.4 Coding and Analysis

Using a grounded theory approach, this study iteratively reviewed and coded field notes and interview transcripts for themes as described by Ryan and Bernard (2003) and Jones et al. (2016). This study used thematic analysis to recognize, examine and describe themes from the data. This study develops a list of provisional codes based on an initial reading of ten randomly selected interviews and observations. The list of provisional codes then was checked by the principal investigator and other members of the research team and reached an agreement on the application of these codes for the interviews. The main theme revolved around affective states of mind and behavior. This study started by reading through several transcripts, looking for subthemes. This is a process of constant comparison, in which the investigators move back and forth in the data and gradually advanced from coding to main themes and subthemes. Finally, the discrete codes are grouped accordingly into themes and subthemes that reflect commonalities among codes. New codes were added as themes emerged. A different group of questions has been prepared for each interview. The response from the interview was brought up as a guideline to prepare a new question for the following interview.

## 4.0 RESULTS

### 4.1 Positive and negative affectivity before, during and after treatment

Most parents or guardians (n=10/10) reported that their children showed positive affectivity before, during and after treatment (Table 1). Two positives affect were described as active and energetic. For instance, one parent stated her son was very active before being diagnosed, but her son was very lonely during treatment. Other parents reported that their sons were active athletes at school before diagnosed with cancer.
However, no report was found during and after treatment on Positive and Negative Affect.

The fewest number of parents or guardians described their children's Positive Affect as the likes (n=3), love (n=4), interest (n=3), and passion (n=2) during treatment while two parents or guardians described their children's Positive Affect as happiness and comfort after treatment.

Interestingly, most parents or guardians only described Negative Affect experienced by their children during treatment. For example, one parent described that her son keeps complaining that he was very bored because the treatment process was too lengthy. Other parents stated that their sons were stressed (parent 5) and scared (parent 4).

Table 1: Main themes and sub-themes of pediatric cancer patients' experience of positive and negative affect during their admission into the pediatric oncology ward.

| **Theme** | **Sub Theme** | **Sub-Sub Theme** | **Code** | **Narrative** | **Number of informants (parents/guardians)** |
|---|---|---|---|---|---|
| *Positive Affect* | Before Treatment | active | The patient was very active before being diagnosed | "My son was very active before being diagnosed" - *Parent 1*. | Parent 1, parent 1, parent 3, parent 4 |
| | | energetic | The patient was very energetic before being diagnosed | "My son was an active athlete in his school" - *Parent 6*. "My son loves to play sports, play ball and run. He was an active person" - *Parent 10*. | Parent 6, parent 10 |
| | During Treatment | likes | The patient likes to play video games | "My son likes to play video games like football and zombies" - *Parent 5*. "My son likes to play video games and surf YouTube to watch cartoons" - *Parent 8*. "My daughter likes to watch television" - *Parent 7*. | Parent 5, parent 8, parent 7 |
| | | love | The patient loves to play Lego | "My son loves to play Lego, it is his favorite activity" - *Parent 1*. "My son loves to play sports in school" - *Parent 9*. "He loves downloading video games from the internet" - *Parent 8*. "He loves car racing video games on the computer at the mini-library"- *Parent 6* | Parent 1, parent 9, parent 8, parent 7 |

| | | | | | |
|---|---|---|---|---|---|
| | | interest | The patient is interested in mathematic exercises | "My child shows interest in mathematics since kindergarten, at the age of five years" - *Parent 2*. "He played football as a show of interest since he was seven"- *Parent 5*. "Based on my observations, my child is interested in the video game" - Parent 8. | Parent 2, parent 5, parent 8 |
| | | passion | The patient is passionate about drawing and mathematics | "My daughter was passionate in sketching" - *Parent 3*. "In the ward, my child makes math exercise, watch TV and play games. Because of her passion" - *Parent 2*. | Parent 3, parent 2 |
| | After Treatment | happy | The patient feels happy each time doctors discharge them from the ward. | "My son was happy when he was allowed to go home because he has friends to play with at home" - *Parent 10*. "The patient feels happy when allowed to go home because he can play video games online"- *Parent 4* | Parent 10, parent 4, |
| | | comfort | The patient feels comfortable at home | "At least he will feel more comfortable at home because he can meet his siblings" - *Parent 5*. ″patient also feel comfortable being at home″- *Parent 4*. ″My daughter was happy when she was allowed to go home because she felt more comfortable at home as she can lay down while watching television″ - *Parent 2*. | Parent 5, parent 4, parent 2, |

| | | | | | |
|---|---|---|---|---|---|
| *Negative Affect* | During Treatment | bored | The patient feels bored in the ward | "Due to the lengthy procedure, the patient feels bored" - P*arent 10*. "Every day he complained to me that he was bored"- *Parent 9.* ″The patient plays video games because he feels bored″ - *Parent 4.* ″He was completely bored when he was in the hospital″ - *Parent 6.* | Parent 10, parent 9, parent 4, parent 6 |
| | | lonely | The patient was lonely in the ward | "He said that he felt lonely here because he has no friends" - Parent 1 | Parent 1, parent 6 |
| | | stress | The patient was stressed with the treatment | "My son was depressed because he could no longer go to school" - *Parent 5*. "Patients who received chemotherapy have unstable emotions and he will get angry easily"-*Parent 6*. "My son was stressed during the treatment. He complained of pain and did not want to undergo treatment due to his illness" - *Parent 9.* | Parent 5, parent 6, parent 9 |
| | | scared | The patient was scared when received treatment | "My child was scared of the treatment. He also thinks negatively" - *Parent 4*. "My child will begin to feel fear every time doctors told him that tomorrow they will take a blood sample from his body" - *Parent 8*. | Parent 4, parent 8 |

| | | | | | |
|---|---|---|---|---|---|
| | | sad | The patient was sad in the ward | "My son was crying when he was bored" - *Parent 9*. "My daughter cried when she felt ill"-*Parent 3*. *"My son* held my face and he was crying because he was thinking he could not see me if he had died″ - *Parent 1*. "Patients only survive in one and two needles. Patients started crying when injected for the third time due to illness and when pushed into injection" - *Parent 2*. | Parent 9, parent 3, parent 1, parent 2 |

Further analysis was carried out to see if these children were playing video games before and after treatment. Results showed that as many as 80% of the pediatric cancer patients were playing video games before treatment and 100% after treatment.

Table 2 Number of patients playing video games before and after treatment

| **Number of patients** | **Video games** | |
|---|---|---|
| | **Yes (n)** | **No (n)** |
| Before treatment | 8 | 2 |
| After treatment | 10 | 0 |

Based on the result of the study, Figure 1 below represents the themes of the pediatric cancer patients' experiences of positive and negative affect during their admission into the pediatric oncology ward. The blue color quarter is defined as Positive Affectivity and the red color quarter is defined as Negative Affectivity. The result showed that most of the Positive Affect occur during a treatment session where the patient plays video games. The Negative Affect such as being, bored, stress, lonely, scared and sad occur during the treatment procedure.

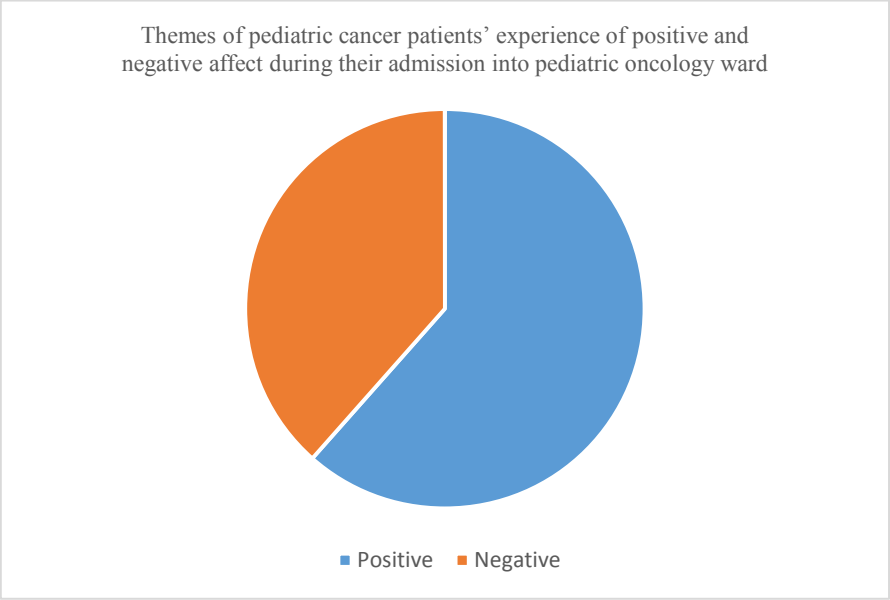


Figure 1: Themes of pediatric cancer patients' experience of positive and negative affect during their admissions into the pediatric oncology ward.

## 5.0 DISCUSSION

Based on the observations and interviews conducted, the aim of this study is to describe the voice and behavior of pediatric cancer patients via their parents or guardian's description to cope with the painful experiences of the cancer treatment process. The study demonstrates the variety of parent or guardian descriptions of their children's affective state of mind and behavior. Our findings indicate that, for most of our informants, pediatric cancer patients, the treatment produces more Positive Affect than that of Negative Affect. These findings are parallel with the results of a cognitive distraction by Vasterling et al. (1993), which found that those distraction patients reported less nausea prior to chemotherapy and lower systolic blood pressures after chemotherapy than controls [31]. Our finding can be explained in terms of positive changes due to satisfying events, namely, video games, Lego, sketching, enjoying television, and watching YouTube. Another possible reason is that video games may reduce anxiety before treatment [32] as well as to play a role as destructors of managing pain [33]. Redd et al. (1987) explained that distraction can be established because it may require an individual's ability to use cognitive and motor activity as well as encourage him or her to the sustained achievement of the level of difficulty (i.e. Challenge) of that particular game [17]. Therefore, video games can be considered as part of cognitive-behavioral therapy for pediatric cancer patients. The results support previous findings that video games have a potential in modifying affective states of mind and perhaps have a positive effect on brain activities. The findings also indicate that video games may be an effective tool in helping the healing procedure associated with cancer by reducing any negative affect.

This study also reported that most of the pediatric cancer patients have shown negative affect during treatment. The illness itself can be seen as a source of stress, which may produce a specific emotional outcome, such as sadness, boredom, loneliness, depression, and fear. In addition to individual differences in affective responses, this study suggests that the severity of the cancer (the stages), prognosis and length of time should be taken into account when designers and developers of games design the game. Since diagnosis may play an important role to produce negative affect. Relating the finding to the hospital environment, it seems that that the experience of loneliness resulting from a lack of social interaction with other people in the ward. Lack of social interaction may exacerbate stress and another negative affect. The findings were also in line with other views that non-pharmacological symptoms represent the negative affect that the pediatric cancer patients harbor toward their chemotherapy treatment.

However, this study offers several limitations. Although the researchers have obtained some relevant findings that suggest the benefits of using video games, the findings were restricted to our understanding of pediatric cancer patients experiencing the treatment. It is also important to note that a qualitative study such as this, with a small sample size, cannot be generalized to all cancer patients and should not be over-interpreted. The design used in this study was also unable to establish causal relationships between the variables. Another limitation was there were

several issues not explored in this study. For instance, there were no detailed questions to explore social support from family members and relatives.

Some clinical implications can be drawn from this study. The findings confirm the need for video games as a tool for managing the emotional state of mind and behavior in pediatric cancer patients who are undergoing active cancer treatment. The video game program intervention is suggested to specifically offer pediatric cancer patients who are being treated at different stages of treatment. Previous studies showed that playing video games offer an abundance of positive benefits, particularly to improve emotional health [33] [34] [35]. Moreover, this study suggests that the whole family needs to be targeted in order to improve the emotional state of mind and behavior of children with cancer.
The study also suggests that video games may offer a great positive therapeutic potential in addition to the pediatric cancer patients' entertainment value in helping them to reduce their painful experiences of treatment.

## 6.0 CONCLUSION

This study provides evidence that video games should be encouraged in children with cancer since it has been shown to produce Positive Affect and reduce Negative Affect. This study also suggests that video games could support children with serious health issues such as cancer. The designers and developers of video games should consider the patients' readiness to use this technology in the psychotherapy intervention program and the willingness of health care providers to support and engage in the intervention program. The outcome of the study has discovered that video games have captured the attention of children and adults. For future work, the researchers will call professionals from diverse backgrounds such as game designers, psychologists and also medical officers to test the result from the study. The findings of the study will be helpful for game designers to develop a game framework for pediatric cancer patients.

## ACKNOWLEDGEMENT

We would like to take this chance to thank all the people involved in the study who were willing to contribute their understanding. This work was reinforced in part by the Ministry of Higher Education of Malaysia under the Fundamental Research Grant Scheme (FRGS/1/2016/ICT04/UKM/02/3)

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