

## ABSTRACT

Camping with Patients: How seeing patients outside of the clinical setting affects views on patient care

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This thesis focuses on the experiences of pediatric physicians and other medical professionals who serve campers with chronic illnesses and diagnoses through illness-specific partner camps associated with Camp For All in Burton, TX. Since literature on this topic is scarce, existing literature was supplemented with personal interviews. The object of these interviews was to evaluate the effects of patient interaction in a non-traditional setting on patient-campers, medical professionals, and the patient-doctor relationship. Our findings indicate that illness-specific camps benefit patient-campers by promoting self-empowerment, disease management, and normalization of the clinical experience. Medical professionals see many personal benefits of the camp environment, including personal rejuvenation, reinforcement of vocation, professional growth, strengthened patient-doctor relationships, and increased understanding of their patients' conditions. The patient-doctor relationship is ultimately strengthened by the illness-specific camp environment.

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CAMPING WITH PATIENTS: HOW SEEING PATIENTS OUTSIDE OF THE  
CLINICAL SETTING AFFECTS VIEWS ON PATIENT CARE

A Thesis Submitted to the Faculty of  
Baylor University  
In Partial Fulfillment of the Requirements for the  
Honors Program

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Waco, TX  
May 2020

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## ACKNOWLEDGEMENTS

I would like to extend my gratitude to the many people who made this work possible. I want to thank Dr. James Marcum, my thesis director, for supporting my vision and for giving me the space to make it come to light. Furthermore, I thank my thesis committee members, Dr. Lauren Barron and Dr. Carson Mencken, for their insightful teaching and their willingness to engage with my research during this time.

I am deeply grateful for the medical professionals who agreed to participate in this project; this thesis would not have been possible without their input. I truly believe that I will be a better physician by knowing these people. I also want to thank Kurt Podeszwa both for granting me the permission to do this project and for giving me a number of resources to be successful in doing so. Furthermore, I want to extend my gratitude to my Camp For All family at large for making Camp a home away from home.

Last, but certainly not least, I would like to thank my friends and family for trusting the process and for supporting me throughout my college journey.

## DEDICATION

*To the campers who will forever hold a piece of my heart and to the people who taught me the meaning of love, laughter, hope, and healing.*

## CHAPTER ONE

### Introduction

#### *Introduction of Purpose*

To become a doctor is to subject oneself to an occupation dedicated to the wellness and the health of others. It is a career of service and of good deeds; it is a career dedicated to healing others and alleviating bodily harm. While constant advances in science and technology threaten to dominate the medical profession, humanism continues to remain at the core of medical practice (Nelson, 1989). During my undergraduate years, I have spent time shadowing and observing physicians and I have seen many methods by which physicians work to preserve what I believe to be the most important aspect of medical care: the patient-doctor relationship.

In looking for a way to spend my summer, I sought out places where I could learn about the nature of patient-centered medicine and find ways to incorporate it into my career going forward. Through my search, I learned about Camp For All and was struck by its mission statement: *Camp For All is a unique, barrier-free camp working in partnership with other not-for-profit organizations to enrich the lives of children and adults with challenging illnesses or special needs and their families throughout the year* (Camp For All). The atmosphere at Camp For All was exactly what I was looking for to solidify my interest in medicine. After two full seasons of working as a member of the Program Staff at Camp For All, I am pleased and grateful to say that it has guided me towards becoming the physician I have always sought to be and has given me the resources and contacts to be able to do so.

### *Statement of Purpose*

This thesis focuses specifically on the role of pediatric physicians who serve campers with chronic illnesses and diagnoses by volunteering with partner camps associated with Camp For All. By interviewing these physicians, I am hoping to evaluate both their motivation to spend time with patients outside of the clinical environment and the impact that interacting with patients in a non-traditional setting has on their view of patient care. Since literature on this topic is not readily available, the introduction and literature review portion of this thesis will focus on the role and purpose of illness-specific camps, as well as the role of pediatric physicians in treating chronic illness in the traditional setting. The two domains will be combined through research conducted specifically for this thesis.

### *Role as a Program Staff Member*

Before further investigating the topic at hand, I will first describe my affiliation with Camp For All (henceforth referred to as Camp) and its partner groups. Beginning in May of 2018, I began working at Camp for All in Burton, Texas, as a Program Staff member. In this position, I worked alongside other staff members ranging in age from 18-24 years old. The summer season lasts from mid-May to mid-August, with programming beginning in early June. In addition to the summer seasons, Program Staff members are encouraged to work weekends during the fall and spring seasons as well.

As a Program Staff member, I was trained to facilitate various activities offered by Camp. Programming at Camp encompasses a wide variety of activities, including horseback riding, swimming, ropes challenge courses, climbing walls, archery, paintball, fishing, canoeing, etc. Our training for each activity was two-fold: traditional and adaptive. We were taught how to run activities for campers who could complete the task



without assistance and how to adapt the activities for campers who needed additional assistance to complete the activity. We constantly found creative solutions to help campers achieve their goals, while also promoting safety at all activities. In addition, Program Staff members have various other duties including set-up and tear-down of activities, refilling water jugs, serving food, cleaning dishes, and maintaining general camp facilities.

In terms of staff-camper interaction, my role as a Program Staff member was to engage and promote activities in a variety of capacities. On most days, I was assigned to lead a cabin of campers and facilitate all the activities that were scheduled for that cabin that day. Most cabins were divided by gender and consisted of about 8-10 campers and 3-5 counselors, with numbers contingent on the number of total campers and the nature of the diagnosis represented at Camp that week. A typical day as a cabin leader consists of breakfast, 3 morning activities (each about an hour in duration), lunch and cabin time, 3 afternoon activities and an all-camp swim (Table 1). After dinner, there are a variety of activities hosted by Program Staff, including talent shows, dances, and dive-in movie nights at the pool. In addition to being assigned to host a specific cabin, a Program Staff member may also be assigned to an activity that requires multiple staff members or staff with additional qualifications, such as lifeguards or ropes specialists.

**Table 1: Typical Daily Schedule as a Program Staff Member**

Time	Activity
7:20-8:00 AM	Morning meeting and activity setup
8:00-9:00 AM	Breakfast and morning energizers
9:00-10:00 AM	Activity Block 1
10:00-11:00 AM	Activity Block 2
11:00-12:00 PM	Activity Block 3
12:00-1:00 PM	Lunch

**Table 1: Typical Daily Schedule as a Program Staff Member (continued)**

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1:00-2:00 PM	Cabin Time
2:00-3:00 PM	Activity Block 4
3:00-4:00 PM	Activity Block 5
4:00-5:00 PM	Activity Block 6
5:00-6:00 PM	Pool
6:00-7:00 PM	Dinner
7:00-10:00 PM	All Camp Night Activity

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Program Staff members have a unique role in the camper experience. Since we do not cohabitate with campers in the cabin, we do not see many of the behind-the-scenes experiences of campers in their respective cabins or in the medical center during their week at camp. And, except for in unique cases, Program Staff members have no affiliation with campers prior to engaging with them at Camp. However, we engage with campers in a way that is unique from their peers, parents, and physicians. We provide a welcoming and engaging environment in which a camper is encouraged to embrace possibility and to achieve new goals. When campers can do that in a judgement-free zone, they are more willing to share their experiences and joys with complete strangers. We see the strengths of campers and stand alongside them as they conquer lifelong fears, take steps towards achieving goals, and master new skills.

#### *Campers at Camp For All*

While Camp For All serves campers year-round, the groups represented in the data collected for this thesis are from the summer season, so this study will focus on the campers served during this time period. Camp For All operates in Burton, Texas, so many of the campers are recruited through hospitals in the greater Houston area.

A few of these hospitals include: MD Anderson Children’s Hospital, McLane Children’s Hospital, Texas Children’s Hospital, Children’s Memorial Herman Hospital, and the University of Texas Medical Branch Children’s Hospital. There are also several groups of campers who come with an organization related to their condition, such as the AIDS Foundation Houston, Muscular Dystrophy Association, and the Epilepsy Foundation of Texas.

**Table 2: Campers Served at Camp for All during Summer Season**

Partner Camp Name	Campers Served
Camp Janus	<i>Serving burn patients from Memorial Herman Hospital</i>
MDA Summer Camp	<i>Serving children with neuromuscular disease</i>
Camp Spike n Wave	<i>Serving children with epilepsy</i>
Camp Star Trails	<i>Serving children with cancer or blood disorders and their siblings</i>
Camp Rainbow Connection	<i>Serving campers with cancer or blood disorders and their siblings</i>
Camp Dreamcatcher	<i>Serving children with cancer and their siblings</i>
Camp that Love Built	<i>Serving children and adults with spina bifida</i>
Camp Smiles	<i>Serving children with cerebral palsy</i>
Camp X-Treme	<i>Serving children and young adults participating in wheelchair sports</i>
Camp PHEver	<i>Serving children and teens with phenylketonuria (PKU)</i>
Camp Social Superheroes	<i>Serving children with social and learning differences</i>
Camp Hope	<i>Serving children and teens with HIV/AIDS</i>
Camp Champions	<i>Serving teens and adults with intellectual challenges</i>
Camp Periwinkle	<i>Serving children with cancer or blood disorders and their siblings</i>
Camp Cell-a-Bration	<i>Serving children and teens with sickle cell disease</i>
Camp Discovery	<i>Serving children with a variety of skin disorders</i>
Camp Shining Stars	<i>Serving children and teens with kidney disease</i>

Source: American Camp Association

Since Camp For All and its partner groups operate on a partner model, campers are not recruited by Camp For All itself. Campers are brought to Camp by their respective partner groups (Table 2), and Camp For All provides the programming and facilities for the duration of the camp experience. Additionally, Camp For All provides the funds to cover half of the cost for each camper that comes to Camp to alleviate the financial burden on patients and their families (Camp For All).

As highlighted in Table 2 above, there are several partner camps that encourage the participation of siblings in addition to patients. Several studies note that chronic, long-term diseases and disabilities affect the family as a whole, so siblings of patient-campers are also invited to experience the recreational environment (Kyle J. Shelton & Peter A. Witt, 2009). The purpose of illness-specific camps, as well as their effects on patient-campers, will be discussed in a later chapter.

In order for a camper to be eligible to come to Camp, they must be of a certain level of health, as determined by their regular physician or other medical professional (Gillard et al., 2011). These criteria vary between partner camps depending on the nature of and potential risk factors associated with a camper's condition. Camp For All provides additional programming opportunities for patients who are unable to leave the hospital, but they are outside the realm of this project.

#### *Medical Staff at Camp For All*

Each partner group brings their own campers, counselors, and medical staff. As a result, the medical staff varies from week to week depending on the group of campers present during that time. Generally, partner groups bring medical personnel who are associated with both the hospital/organization present and the pediatric subspecialty represented by that group. For example, pediatric hematologist-oncologists typically accompany camps serving children with cancer and blood disorders, while pediatric nephrologists will accompany groups serving children with kidney disorders. Of course, this is at the discretion of the partner group.

Groups may bring other medical professionals, including nurses, social workers, medical students, and child life specialists in order to round out their staff. Traditionally, these roles are filled on a voluntary basis. These medical staff interact with campers in a

variety of capacities, as members of the medical center, in-cabin counselors, or camp directors. Medical staff serve as a healthcare liaison between a camper's home clinic and the medical care provided at Camp; they enforce medical adherence and ensure the general well-being and safety of campers in a foreign environment (Gillard & Watts, n.d.). A more in-depth evaluation of the various roles of certain physicians at Camp will be evaluated in the chapters focusing on personal interviews.

## CHAPTER TWO

### Literature Review

#### *Subjects for Review*

Since there is very little research done on the role and effects of physicians who volunteer at illness specific camps, this literature review will serve to provide background information in relevant areas. I will approach the role of pediatric physicians from both the angle of camp involvement, defining and investigating the purpose of illness-specific camps, and from the angle of physician duty, evaluating the patient-doctor relationship and the role of pediatric physicians in treating chronic illnesses. The two domains will be bridged in subsequent chapters through evaluation of research conducted specifically for this purpose.

#### *Defining Illness-Specific Camps*

Illness-specific camps have seen increasing popularity in recent years as research in the area continues to grow and facilities to host such camps continue to be developed. In essence, illness-specific camps serve to replicate a classic childhood experience for children who may be unable to attend traditional summer camps due to their condition (Faith et al., 2019). Depending on their diagnosis or disability, campers may require assistance with mobility, daily tasks, or medical adherence; these personalized resources are not always available to campers in traditional camp settings. Additionally, illness-specific camps held at fully-accessible host sites provide a space where children who use mobility equipment can move about unhindered and access all facilities, an uncommon finding in everyday life (Kyle J. Shelton & Peter A. Witt, 2009). As a result,

these camps provide a unique and novel environment for campers who may have been previously limited from traveling due to cumbersome mobility equipment or dependence on extensive mobility assistance (wheelchair lifts, portable ramps, Hoyer lifts for bathing, etc.).

In addition to logistical assets, illness-specific camps serve other purposes, including socialization. Socializing patients in non-clinical settings has been proven to positively impact patients (especially pediatric patients) suffering from chronic illnesses (Gillard & Watts, n.d.). While there are several camps who cater to children of a wide variety of chronic illnesses with accessible programming and facilities, it is worth noting that camps who group camper populations by specific illnesses tend to yield better outcomes in terms of patient adjustment and benefit (Faith et al., 2019). This is due to a variety of reasons, but most noteworthy is the uniqueness of exposing patients to other children with similar experiences. By experiencing their illnesses outside of the confines of the hospital environment and away from school-age peers who do not fully understand their condition, patients are more likely to engage with their peers and elders (Gillard et al., 2011). Illness-specific camps expose camper-patients to peers who understand their conditions on a personal level, an understanding which lays a common ground from which to build and foster new relationships. This common ground, in addition to the relaxed nature of a recreational environment, allows campers to learn important inter- and intrapersonal skills such as anger management, conflict resolution, confidence, and positive self-concept by granting them a sense of belonging, inclusion, and freedom from judgement (Gillard & Watts, n.d.). Summer camps are an excellent source of socialization for all children, but they are incredibly beneficial for those who suffer from chronic illnesses. Pediatric patients suffering from chronic illnesses like cancer or

HIV/AIDS are at high risk for developing negative social behaviors due to increased levels of isolation, depression, and anxiety (Watts et al., 2009). Thus, the development of a caring and nurturing environment during childhood lessens the temptation to engage in more dangerous, risky behaviors as children mature (Gillard et al., 2011).

Other purposes of illness-specific camps include illness education and respite care. Illness-specific camps create an informal teaching setting through which children can compare and learn from the similar clinical experiences of others (Gillard & Watts, n.d.). Rather than learning how to manage their illness from a medical professional who has likely never personally experienced it, campers are able to discuss and share real-life tips or tricks that they have found helpful. Additionally, some camps offer more structured educational opportunities, like Teen Talk for discussing concepts like disclosure and medical adherence with teens living with HIV/AIDS, or Epilepsy Education for children living with a variety of seizure disorders (Gillard et al., 2011). In these settings, camps may use child-life specialists, survivors, or older campers as resources to teach younger or newer campers about important aspects of their diagnosis (Conrad & Altmaier, 2009). The educational and accessible aspects of illness-specific camps are but a few reasons why parents are comfortable sending their often dependent children away from home and surrendering them to the care of strangers (Kyle J. Shelton & Peter A. Witt, 2009). While this is a difficult task for many parents, parents who have children with chronic illnesses find it to be worthwhile. Parents are ultimately relieved and grateful for the time their children spend at camp because it not only gives their children a chance to be independent, but it also gives the family time to care for themselves and their other children (Kyle J. Shelton & Peter A. Witt, 2009). Oftentimes, parents are just as excited as their children when camp comes around.



### *The Effects of Illness-Specific Camps*

After evaluating the hypothesized benefits of illness-specific camps, I will now focus on the effects on campers following their camp experience. Existing literature has found that many of the purposes listed in the section above are true for campers following exposure to illness-specific camps. Previous studies show that the most prominent effects of the camp experience are developing a sense of agency and establishing a positive self-concept (Faith et al., 2019). By engaging in age-normative activities with their peers, campers are able to interact with others in a way that boosts morale, makes them feel connected, and improves their overall emotional wellbeing more than their typical social experiences (Conrad & Altmaier, 2009). Additionally, campers are more likely to experiment with new activities and explore new interests in this setting, developing a more defined sense of independence and self-confidence as a result (Gillard & Watts, n.d.). These increased feelings of confidence and ability are a result of overcoming social barriers such as hopelessness, exclusion, and loneliness. As part of a case study on Camp Periwinkle, a camp for children suffering from cancer or blood disorders, campers reported feeling decreased levels of hopelessness following their week at Camp as well as feeling more “normal” after interacting with campers who shared similar experiences (Watts et al., 2009). One camper reported the following: “[Counselors, staff, and peers] don’t look at you like you’re a cancer patient; they look at you like a person,” a testament to the empowerment of the judgment-free environment crafted by illness-specific camps. Another case study, this one focused on Camp Hope, a camp for children living with HIV/AIDS, found that campers experienced decreased feelings of loneliness following their time at camp (Watts et al., 2009). Campers made strong, lasting friendships after spending merely a week around one another.

In addition to fostering many positive social changes, the camp setting also provides campers with an environment where they can learn from their peers and combat illnesses together. In the case study focusing on campers with HIV/AIDS, Gillard et al. found that the camp environment was a strong agent in destigmatizing disclosure issues for teens with HIV/AIDS. Some of this was done through Teen Talk education, where campers were taught about HIV/AIDS in an open, conversational setting (Gillard et al., 2011). However, the informal learning environment mentioned in the section above contributed to the campers' understanding and promotion of medical adherence, especially since many of them took the same medications. During unstructured gatherings like meals or cabin time, campers gave each other tips and tricks for how to stave off undesirable side effects and how to take nasty pills (Gillard et al., 2011). Additionally, campers were more likely to comply with their medical regimen while surrounded by others doing the same.

### *Role of Pediatric Physicians in Chronic Illness*

Having discussed the effects of illness-specific camps on patient-campers, we will turn now to the role that pediatric physicians play in treating patients with chronic illnesses. Overall, trends in pediatric patient visits have changed over the years. In the present day, visits related to chronic illnesses predominate the total amount of patient visits for pediatric physicians (Wise, 2007). Treating patients with chronic illness tends to require more extensive resources, and for that reason the treatment of chronic illness is a difficult domain for general pediatricians to manage alone. As a result, the field of pediatrics is leaning towards a more community-based approach to patient care which includes the contributions of pediatric subspecialists, nurses, child-life specialists,

therapists, and the like (Wise, 2007). It takes a village to raise a child, but an entire army to raise one with a chronic illness.

Several barriers to treating children with chronic illnesses surround the transition to adulthood. Pediatric physicians are not equipped or trained to follow their patients throughout the lifespan and must teach their patients how to seek care and self-advocate as they become adults, a task which requires additional resources outside the realm of healthcare (Wise, 2007). Physicians can promote this transition towards independence by encouraging participation in activities like illness-specific camps or social groups and by enforcing certain behaviors and management strategies early in treatment. It is important that physicians are consistent in enforcing medial adherence strategies with their patients so that their patients can develop strong and healthy habits (Drotar, 2009). Other studies also suggest that physicians have even more duties to their patients outside of the clinic, including following up on phone calls received outside of work hours or providing adequate resources for their patients while being out of town (Nelson, 1989). This duty to serve patients outside of the clinic is one that will be touched on in more detail in a later section.

### *Importance of Strong Doctor-Patient Relationships*

The cornerstone of treating any patient, regardless of age, is a strong patient-doctor relationship. The ability to provide healthcare based on authentic human connection can make some doctors more effective than others (Goldberg, 2008). Doctors should, by craft, be able to empathize and care for their patients in order to promote the well-being of their patients (Peabody, 1927). The patient-doctor relationship is one that has been long affiliated with the medical profession and continues to be influential today, as noted by comparing the dates of the publications cited above.

In the famous speech by Dr. Peabody, we learn that patients are more than the sum of their symptoms and that illnesses do not exist in a vacuum. Patients have personal and emotional backgrounds and histories which influence their illnesses and affect their experiences and it is the duty of the physician to understand these confounding variables in order to deliver appropriate treatment (Peabody, 1927). In the case of patients suffering from chronic illnesses and frequenting hospitals, it is important not to lose sight of this. Oftentimes, patients in the hospital are treated for their illness and not as a whole person (Peabody, 1927). This not only impacts the quality of care the patient receives, but also their ability to form meaningful connections with their caretakers. For patients who spend a majority of their lives confined to these environments, they may fail to develop strong social skills and be at risk for developing negative emotions and coping mechanisms (Watts et al., 2009).

#### *Implications for Further Research on Physician Involvement in Illness-Specific Camps*

Having investigated the benefits of illness-specific camps for patients and the roles of pediatric physicians in treating chronic illness, the following chapters will focus on the benefits of linking the two together. Research shows that the use of non-clinical settings has a stronger impact on the effectiveness of therapeutic interventions for patients as compared to traditional clinical settings, and illness-specific camps are an excellent resource for facilitating and promoting healthy behaviors and illness-management strategies (Gillard & Watts, n.d.). While the camp environment itself is conducive to patient-camper health and wellness, the addition of pediatric physicians strengthens patient care both in and out of the clinic in a multitude of ways. First, it is traditionally the role of the physician to share awareness and promote the participation in illness-specific camps (Gillard & Watts, n.d.). Parents may be hesitant to send their sick

children to an unfamiliar place, but with physician approval they are more likely to do so (Kyle J. Shelton & Peter A. Witt, 2009). By means of social persuasion, a physician with personal experience working or volunteering with a certain camp would be better able to educate a parent or child who is interested in a camp experience. Additionally, the physician brings a unique perspective to the camp staff and volunteers since they know and understand the camper's life outside of camp (Gillard & Watts, n.d.). As noted previously, many camp volunteers and staff members have no association with campers prior to meeting them at camp. Having someone there who knows more about the camper makes campers more comfortable and allows counselors and staff to better interact with a camper, which contributes to a more positive camp experience.

#### *Study-Specific Research Goals*

The following chapters seek to further connect pediatric physicians and illness-specific camps and continue to fill the gaps between the two by addressing physician roles, attitudes, and takeaways from personal experience and involvement with illness-specific camps. The following excerpt is from a social worker interviewed in the Gillard et al. case study of Camp Hope and suggests that seeing patients in a non-traditional camp setting is beneficial to patient care:

*“[Camp] gives me the opportunity to see [my patients] outside of their clinical visit. It gives me the opportunity to learn about them on a more intimate level and have them see me as more than just the social worker in the clinic. They see me and they want to talk to me, and it’s more of a relaxed atmosphere.”*

## CHAPTER THREE

### Methods of Investigation

#### *Defining Topic of Interest*

The object of this thesis is to evaluate if and how interacting with patients in a non-traditional setting affects a physician's view on patient care and their motivations to seek out these non-traditional environments. This study focuses specifically on pediatric physicians who volunteer as doctors through partner camps associated with Camp For All, a camp serving campers with chronic illnesses and diagnoses. Since data on this topic is limited, personal interviews were conducted in order to gain the information necessary to make these conclusions.

#### *Personal Interview*

##### *Inclusion and Exclusion Criteria for Interview Candidates*

As stated above, the candidates eligible for this study were healthcare professionals associated with partner camps that come to Camp For All during the summer season (Table 2). While the primary focus was on pediatric physicians, candidates eligible for interview needed not to be physicians nor focused in pediatrics. Additionally, there was no role requirement for these candidates; they could have served the camps in an administrative role, medical staff role, or a more informal counselor role.

In order to be included in this study, the subject must have had experience with illness-specific camps prior to the interview. Since the camp experience is only one week in duration, it was important to select candidates who had prior experience with illness-specific camps and were not in their first week at camp. Additionally, subjects must have

had a background as a healthcare professional in order to qualify for this study. This study defines healthcare professionals as physicians, medical residents, child life specialists, and nurses.

Subjects who were not eligible for participation in this study were non-healthcare professionals and individuals who did not have a full weeklong experience with illness-specific camps prior to the time of the interview.

### *Self-Selection of Interviewees*

Subjects were chosen from a pool of individuals who had self-selected to participate in a weeklong illness-specific camp. If any recruitment occurred, it was done by the partner group prior to the beginning of the summer. This is an important point to note for this study because the self-selection bias could have an impact on the responses that were received in the study. Subjects could be more likely to think positively of the camp experience and may not reflect the view of other physicians.

Participants were recruited from this pool by word of mouth and peer nomination. As a Camp For All employee, I was able to interact with only a handful of these physicians and relied on camp directors to provide contact information for those I could not introduce the project to firsthand. Subjects then voluntarily chose to participate in the study if they were interested and time permitted.

### *Composition of Questions*

In order to best identify the attitudes and effects of illness-specific camping from a healthcare professional's point of view, open-ended questioning, rather than survey-like questioning with an arbitrary rating schedule, was used to gain the most information. In

addition to larger, umbrella-like questions, further probing questions were included to steer the conversation towards relevant information.

Furthermore, questions on the background of subjects were included to understand who was choosing to be a part of the study. These questions asked about the camp that the subjects were involved in, their previous involvement, and their role at that specific camp. Additionally, questions related to the research outlined in Chapter 2 were included to connect this study with those previously conducted on the benefits of illness-specific camps for the patient-camper. Questions concerning the effect of illness-specific camps on physician attitudes and behaviors were also included.

### *Interview Methods*

#### *Composition of Final Group*

The final group of subjects who qualified for and participated in the study included males, females, doctors, nurses, and represented five different camps (Table 3). There were equal numbers of male and female subjects, for a total of twelve participants. Many subjects were pediatric physicians, so the term physician may be used interchangeably with medical professional to describe the participants.

The camps represented in this study are Camp PHEver (serving campers with PKU), Camp Discovery Texas (serving campers with skin disorders), Camp Periwinkle (serving children with cancer and their siblings), Camp Dreamcatcher (serving children with cancer and blood disorders and their siblings), and Camp Shining Stars (serving children and teens with kidney disease) [Table 2]. While not all camps for the summer season are included, those involved represent a diverse group of camper-patients.



**Table 3: Interview Subject Composition**

Gender		Occupation		Camp	
Male	6	RN	2	Camp PHEver	1
		MD	9	Camp Periwinkle	5
Female	6	Medical Resident	1	Camp Discovery Texas	1
				Camp Dreamcatcher	4
				Camp Shining Stars	1
Total	12		12		12

*Interview Process*

Originally, subjects were going to be interviewed in-person and on-site during their time serving at camp for easy accessibility and for emotional priming. However, due to the busyness of the daily camp schedule and the variety of different roles that each of these individuals served, it was difficult to coordinate these times.

As a result, contact information was gathered during the week of camp and follow-up information was sent after the camp had concluded. In some instances, individuals were contacted and invited to the study without having heard of it during their time at Camp depending on when their contact information was acquired. Subjects were then prompted for their interest and were given a consent form to introduce the study and the option to do either an electronic interview or a phone interview, depending on their preference and schedule. Electronic interviews were sent via email and collected after the participant had completed them. Phone interviews were scheduled and conducted between the subject and the principal investigator. The same questions were asked in both instances.

### *Questions Asked*

The drafted questions resulted in a list of six open-ended response questions detailed in Table 4. These questions ask about subject background, motivations for engaging in illness-specific camping, benefits for the camper-patient, and effects on their attitudes and behaviors as physicians.

The bolded questions were considered the main idea questions and were asked of all participants. The sub-questions found in italics were considered probing questions and were only used if a participant did not have many ideas or did not answer sufficiently. Those who elected to participate in the electronic interview had access to both the bolded and italicized questions, while those in oral interviews may not have heard the italicized questions if they answered the italicized portion in their response to the main question.

**Table 4: *Questions for Conducting Personal Interviews***

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Questions

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- 1. How are you affiliated with [insert camp name here]?**
  - a. What is your role at this camp?*
- 2. How long have you been associated with [insert camp name here]?**
  - a. What motivated you to get involved with illness-specific camps?*
- 3. Have you seen any benefits for patient-campers with regards to managing their illness/engaging in social activities?**
- 4. Are there any benefits you have found to being a [insert health care profession here] at Camp?**
- 5. What is the impact of seeing patients outside of a clinical setting?**
  - a. Are there any instances where seeing a patient outside of the clinic caused you to change the course of or your attitude towards a treatment plan?*
- 6. Would you recommend this experience to colleagues or students pursuing medicine?**
  - a. Why?*
  - b. Anyone else?*

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### *Recording of Responses*

All responses were recorded and stored electronically on word-editing software. They were kept in original form and consolidated into their respective questions.

Electronic interviews were received in written form and were kept as such. Oral interviews were transcribed by the interviewer and saved. While the original responses identify the individual, the results and discussion portion of this study will not identify any subject by name or other identifying information, including a combination of any of the characteristics listed above. The only identifiers used will be the occupation and the associated camp to protect the identity of the subjects.

## CHAPTER FOUR

### Results

#### *Results of the Interview*

In order to best describe the results of the personal interviews conducted for this project, the responses have been separated by question. This way, they can be evaluated by content and compared across different camps, doctors, and experiences. Responses will be summarized, with quotes integrated throughout.

#### *Questions 1 and 2: Nature and Duration of Camp Affiliation*

The pool of subjects who qualified for and participated in the study included twelve participants ranging in age, medical profession, and gender. The subjects represented five different camps and served their camps in varying capacities and for varying lengths of time.

Many of the participants served as in-cabin counselors and were thereby responsible for overseeing the safety and wellbeing of their group of patient-campers throughout the week. Some of the duties required of individuals in this position included facilitation of camper interactions, resolution of camper conflicts, organization of camper items, and assistance in medical regimens, if applicable. These individuals had the most interaction with campers while at Camp, since they were with campers 24 hours a day for the duration of the camp. Other participants in the study interacted with patient-campers in other roles, including camp leadership and medical staff roles. Individuals involved in camp leadership were primarily responsible for recruiting campers and volunteers, planning camp programming and activities, managing camper diets, and overseeing other

logistical aspects of camp like cost, fundraising, and the like. Those who participated as part of the medical staff oversaw the medical needs of campers and delivered and administered medical regimens at mealtimes. They were the primary liaisons between the patient-camper and their primary physicians during the time patients were at Camp. In some instances, the doctors on the medical staff were the primary physicians of some of the campers present, but this was not always the case.

In terms of longevity, many participants had been involved with their respective camps for a multitude of years. In this study, the duration of involvement ranged from 2-30 years, with the average being 11 years. This number varies from one illness-specific camp to another, depending on the recruitment technique of the partner camp and the degree to which the position is sought after. Additionally, no first-year camp physicians were eligible for participation in the study, though there were many who were involved throughout the course of the summer.

### *Question 3: Benefits for Patient Campers*

Chapter 2 of this work examined the purpose and benefits of illness-specific camps for patient-campers. Now, these benefits will be examined from perspective of our subjects, many of whom interact directly with campers both in the clinic and at Camp. A few of the benefits for patient-campers cited by subjects in this study included normalization of experience, self-empowerment, and disease management.

One of the biggest takeaways for patient-campers is the realization that they are not alone. Depending on the nature of their diagnosis, some campers have likely never met anyone who shares their condition; others may only know of other children who share their diagnosis through interactions at the hospital. At Camp, patients are surrounded by people who understand their experience, likely for the first time since they

were diagnosed. Physicians spoke of this aspect of Camp as being one of the most important aspects of illness-specific camps. According to one participant, “sometimes what [patients] need even more than what traditional medical treatments offer (if there even is a treatment for their condition) is social and emotional support.” At Camp, patients find comfort in the company of their peers. Physicians and health care professionals who took part in this study found that after attending Camp, campers exhibit a more normalized understanding of their condition. By recognizing that they are not alone in their diagnosis, camper-patients are able to realize that their condition does not define them as “different” or as “other,” but rather as individuals with unique experiences.

After a patient-camper understands that their diagnosis does not limit or define them, they are able to grow in other important ways. At Camp, campers are given the chance to step out of their comfort zone and challenge themselves to overcome their fears and doubts. Upon completion of a difficult task or acquisition of a new skill, campers feel more confident and more willing to take on future challenges. This confidence empowers them to live more independently and to advocate for themselves in other areas of their lives. Subjects who have served as camp directors remark, “we have received so many letters from parents saying that their child left for camp as one person, usually shy and quiet and unsure of themselves, and came back stronger, more hopeful about the future, and simply happy to be who they are.” This change can be seen by parents and physicians alike. Some physicians in this study stated that they have seen an increase in camper confidence as early as the first or second day of camp. While some campers may take longer to fully take ownership of their diagnosis, they continue to show positive improvement in mood and attitude throughout the week. Furthermore, several physicians

commented that the empowerment that a child receives from understanding and embracing their diagnosis spreads outside their own lives. Children who overcome the limitations of their diagnosis are more empathetic, kind, and compassionate towards the needs and suffering of others.

Finally, the last major benefit for patient-campers is improved disease management. One of the largest contributing factors to this improvement is the presence of older campers and counselors who have undergone similar experiences, as well as fellow campers in different stages of the disease process. Campers can learn things like how to explain their condition appropriately and effectively, how to respond to discriminatory inquiries or commentary, and how to comply with difficult or unpleasant medical regimens. In addition, the sense of empowerment that they gain from going to Camp grants them the ability to advocate for themselves and for their conditions, resulting in more direct and personal conversations with their primary physicians upon returning from Camp. Patients who embrace ownership of their condition, rather than feeling limited by it, are more compliant with their medical regimens, according to the physicians in the study. This is likely due to their ability to normalize their experience. For these reasons and the ones stated above, one physician sums up the Camp experience in the following way: “I often tell people that camp is the most powerful and empowering medicine I can prescribe my patients.”

#### *Question 4: Benefits for Camp Doctors*

When asked their motivation to serve at an illness-specific camp, many of the subjects expressed similar motivating factors. For the subjects who began early in their medical career (during medical school or residency), they were encouraged by their superiors and by the prospect of a relaxing yet fulfilling way to spend their limited time

off. For more established physicians, the driving factor was being able to interact with and understand their patients on a more intimate level and to reignite the spark with which they began their medical career. After spending time at Camp, physicians cited other benefits in addition to these, ranging from personal rejuvenation to professional edge.

By interacting with children in a recreational camp environment, physicians are immersed in childlike joy and excitement for an entire week. While their duties include monitoring the safety and wellbeing of campers, physician volunteers spend much of their time engaging with their campers as they participate in camp activities. They can unplug from their work environment and engage in a more social environment. As a result, physicians reported feeling both rejuvenated and recharged after their week at camp. Being a volunteer at Camp is a very time-intensive commitment and several physicians did recall their week as being physically exhausting, but each of them said that the exhaustion was worth being able to emotionally “reset” during the week.

Another common benefit reported by physicians was the sense of purpose instilled in them by spending a week at their respective camps. Many of the physicians in our study reflected on how spending a week at Camp reinforces and solidifies their desire to be a pediatric physician. They leave Camp with a renewed spirit and newfound energy and bring these feelings back with them to work. With physician burnout being such a large crisis in the medical community, being able to refocus on the purpose that drives them to medicine is something that these doctors found crucial to being successful in their careers (Ruzycki & Lemaire, 2018). In addition to finding a sense of purpose, physicians were also reminded of important aspects of their patients’ lives, namely what it is like to be a child living with a chronic illness. Camp gives physicians the opportunity



to get a behind-the-scenes look at the patient perspective and an opportunity to learn from their patients about what is important to them. As a result, these physicians feel more compassionate empathetic towards their patients (even those who do not attend Camp) and can treat them on a more holistic level.

In addition to the personal benefits, the camp experience also provides physicians with opportunities for professional growth as well. Depending on the partner camp they are associated with, physicians may be able to network with other physicians and healthcare professionals present from other hospitals or other departments. Several physicians reported that they have been invited to speak or attend conferences and other professional events as a result of the networking they did at Camp. Doctors even spoke of receiving nominations for prestigious awards or recognitions in their communities through opportunities presented to them at Camp. Awards and recognitions aside, physicians are also able to teach and learn from one another as they spend time together.

#### *Question 5: Impact of Seeing Patients Outside of a Clinical Setting*

The traditional patient-doctor relationship hardly expands past the examination room, so it should be no surprise that first-year campers are as shocked to see the familiar faces of their doctors when they arrive at Camp as they are to see their teachers at the grocery store. However, the initial uncertainty of the situation quickly fades as campers realize that their physicians are there to help them have fun, rather than to give them a medical examination. After camp is over, physicians report remarkable differences in their relationships with their patients.

When physicians and campers spend time together outside of the clinic, they can overcome boundaries that previously strained their relationship. For patients, the hospital setting is characterized by rules and regulations that may prevent them from being

themselves. Oftentimes, patients are spoken over by their parents and cannot have direct conversations with their physicians. Additionally, some patients only see their physicians when they are sick or when they need treatment, both of which are typically uncomfortable and negative memories. These factors tend to strain the relationship that physicians have with their pediatric patients in the traditional setting. At Camp, these factors disappear (for the most part, depending on the nature of a camper's illness and treatment) and patients and physicians can interact on a more personal level. As a result, the patient-doctor relationship becomes more of a partnership and patients tend to be more comfortable holding direct conversations with their physicians during subsequent visits. These direct conversations allow physicians to better direct and manage patient care, personalize treatment plans, and make patients more compliant with their care as well. In the words of one physician in the study, "It is only one week a year, but the other 51 weeks are fundamentally changed by the week we spend together at Camp." Some physicians have also noted that patients and their families may decide to transfer their care to a doctor that they had favorable interactions with at Camp.

In addition to improving the relationship between doctors and patients, Camp also gives physicians the ability to understand their patients' conditions on a deeper level. Many of the physicians in this study interact with campers as in-cabin counselors, effectively being their parent for a week. This interaction adds a new dimension to the patient-doctor relationship and gives physicians a unique perspective on the reality of living with a chronic illness or diagnosis; it allows doctors to see the real side effects of illnesses and how variable the effects of treatments are on different patients. For some patients, treatments can be more difficult to manage than the condition itself, and physicians may not be aware of just how much more difficult. Each patient reacts to their

condition differently and a physician in the study noted the following: “we spend all day every day seeing children with similar ailments and can forget how intimate and personal each diagnosis is to a patient or family.” These individual adaptations to life with a chronic illness provide a physician with an array of tools they can use in patient treatment going forward, including valuable information on what patients do and do not like and their tips for taking unpleasant medications or remembering regimens, information that can be passed on to others. At Camp, a physician may also notice important characteristics about their patients that they may not have otherwise. For example, some physicians said that they were able to notice slight delays in social development when patient-campers were grouped in a cabin with their same-age peers. This, in addition to a camper’s social preferences, could make physicians better equipped to speak to their patients on a more appropriate level.

*Question 6: Recommendations*

When asked to whom they would recommend the camp experience, subjects responded in a variety of ways. Some subjects felt as though everyone should have this experience, especially those involved in the medical profession. Other subjects would direct their recommendations only to those who fit certain criteria that would enrich the lives of campers.

Many of the physicians in the study agree that Camp grants them an opportunity to learn invaluable information about their patients firsthand. It is a chance to get to know patients on a more holistic level and to understand what a patient’s experience is like outside of the walls of the clinic, something that is difficult to do through the traditional doctor-patient interaction. In the words of one physician, “you can’t learn from a textbook how someone lives with a disease—their emotional and physical struggles, their

hopes, their fears.” Since this aspect of the patient experience cannot easily be taught, many physicians extended their recommendation to members of the healthcare field, especially those pursuing pediatrics, child life, social work, physical and occupational therapy, and disciplines relating to the special needs population. New employees in these disciplines are strongly encouraged to attend as well. Subjects who strongly recommend participating in the camp experience believe that it is a positive experience in which physicians can reconnect with their love of medicine and better understand the intricacies of the human connection that drives medicine. They believe that people who have experienced Camp become better *people* and, as a result, better doctors.

Other physicians in the study recognize that people are drawn to their careers for a wide variety of reasons and that they recharge in vastly different ways. These physicians do not believe that just anyone will benefit from a week spent at Camp, and as a result, they direct their recommendation only to those who they believe would benefit from the experience. Many physicians who attend Camp are self-selected and have sought out the experience because they want to know their patients better and interact with them more. These physicians are energized by the relationships they build with their patients and will gladly relinquish their vacation time to spend time with their patients outside of the clinic. According to the subjects of this study, successful camp volunteers are responsible, fun, positive, and outgoing. Additionally, they are willing to sacrifice their vacation time and have a sense of adventure and a willingness to embrace new experiences.

## CHAPTER FIVE

### Discussion and Conclusion

#### *Discussion*

This thesis served to introduce a topic that had not been previously explored in the literature. By collecting data from those who have had first-hand experience as healthcare professionals at illness-specific camps, I was able to study how this experience shapes medical practice. This study serves as both a testament to the benefits of illness-specific camps for children, as discussed in previous research, and as an introduction to the unique role of a physician in this environment. There is plenty of room for new research to expand on the experiences discussed here.

#### *Major Findings*

Findings from the personal interviews in this study suggest that while the physician experience varies depending on the partner camp structure and camper population, the overall benefits and takeaways are very similar. This was overall a very positive experience for all parties involved. Responses were uniform across gender, occupation, length of involvement, role during camp, and camp affiliation. All twelve participants agreed to participate in full, gave natural responses, and were excited to speak about their experiences.

This study supported the conclusions drawn by studies discussed in the literature review. The physicians in this study cited Camp as providing the following benefits for patient-campers: normalization of clinical experience, self-empowerment,

and disease management. These three benefits were some of the most cited benefits in the literature reviewed in Chapter 2.

Additionally, this study found that physicians and medical professionals who volunteer at illness-specific camps in partnership with Camp For All experience personal benefits such as personal rejuvenation, reinforcement of vocation, professional growth, strengthened patient-doctor relationships, and increased understanding of their patients' conditions. While there were more individual benefits cited by participants, these were grouped by popularity and general concept.

Lastly, the Camp experience had a large impact on the relationship between patients and doctors in addition to benefitting both groups individually. The interaction of patients and doctors outside of the traditional clinical setting allows both parties to establish a more human-like connection. The resulting partnership allows for more open and direct communication during clinic visits and a more individualized treatment experience. Many of the doctors in the study give a testament to the effects of Camp by extending their recommendation to colleagues and students in medicine.

#### *Analysis of Literature Review*

As noted previously, the existing literature surrounding illness-specific camps focuses on the effects on patient-campers and their families, rather than on the medical professionals and other volunteers who take part in this experience. This emphasizes the sort of camper-centered environment that these camps seek to produce. To align the results of this project with results with previously conducted studies, the following question was incorporated into personal interviews: *Have you seen any benefits for patient-campers with regards to managing their illness/engaging in social activities?* (Table 4). Many of the answers reflected the conclusions and hypotheses of previously

conducted studies on the benefits of illness-specific camps and the role of pediatric physicians in treating chronic illness.

The participants in this study confirm that the propositions of the illness-specific camp model are actualized by Camp For All and its partner camps. The physicians spoke of the classic summer camp experience that their campers were able to have, one of the main pillars in the initial development of these camps (Faith et al., 2019). While no physicians spoke directly on the accessibility of the Camp facility, it is worth noting that the facilities at Camp For All are fully accessible to all individuals by design, with eight-foot sidewalks for side-by-side wheelchairs, a sloping entrance into the pool, pool wheelchairs and lift, paved ramps, specialized horse saddles, low beds, and large accessible bathrooms and showers (Camp For All). Additionally, many of the physicians agreed that illness-specific camps provide age-normative socialization for campers. Physicians noted that their campers showed increased confidence and interpersonal skills, agreeing with the findings in a previous study on campers from Camp Hope, another partner of Camp For All (Gillard & Watts, n.d.). Socialization is one of the main purposes of all summer camps, but it is incredibly important for children who do not have other traditional socialization experiences due to extended hospital visits or who face social stigmas related to their condition (Watts et al., 2009). Lastly, illness education is one of the main benefits that was noted by the physicians in the study. Campers do, in fact, share tips and tricks on how to manage and take difficult medications with their peers and, by extension, share this information with medical professionals who are around as well (Gillard & Watts, n.d.).

I will return briefly to the literature on the role of pediatric physicians in chronic illness to determine how the Camp environment supplements this role. The literature

suggests that even though patient-doctor visits are limited to the clinical office, there are a number of duties that a physician has towards their patient outside of the clinic (Nelson, 1989). The literature suggests that these duties include simple tasks like answering missed calls and providing resources when the physician is not accessible, but the medical professionals in this particular study seem to take this a step further by adopting a duty to know their patients on a more personal level outside of the clinic. While many of these practices are voluntary and outside the professional practice of medicine, it was a common thread for the physicians who volunteered at Camp. Camp gives patients and doctors an opportunity to interact on a more casual level, which then allows them to have a more comfortable relationship later in the clinic.

### *Implications of Study*

This study serves several purposes. Not only does it affirm the previous research on the benefits of illness-specific camps for patient-campers, but it provides information on a group of medical professionals who have the unique experience of interacting with patients outside of the clinical setting. This information was used to introduce the benefits of illness-specific camps for volunteers and staff, as well as the effects on the patient-doctor relationship and physician perception of childhood illness, into the literature.

Looking forward, the major implications of this study arise from the following question asked of interviewees: *Would you recommend this experience to colleagues or students pursuing medicine?* (Table 4). Based on their personal experiences, all twelve participants said that they would recommend this experience to others and further defined who they thought would benefit from the experience. They cited young medical professionals as being some of the best candidates for this experience due to their high energy and need for meaningful clinical experiences. Some went on to say that any



medical professional, regardless of age or of discipline, should consider this experience; those nominated should note, however, that it is a time-consuming and physically demanding commitment and one should only participate if they can maintain a level of excitement appropriate for a positive childhood experience. The idea behind these recommendations is the fact that Camp teaches invaluable and irreplicable lessons to medical professionals about their patients and reminds medical professionals that patients are at the core of treatment. Furthermore, recall that the average length of camp involvement among participants was eleven years. This continuity of service and retention rate speaks volumes to the nature of Camp. The physicians I spoke to here, as many others I have spoken to in passing, keep coming back to Camp because they believe in its mission and purpose and have seen its effects firsthand.

From this information, I believe that there are a multitude of ways that young and aspiring medical professionals can connect with their patients outside of the clinic. It would be discrediting to institutions like illness-specific camps to make these opportunities mandatory in medical education, but I do think that they should be promoted and made available for young physicians to participate in if they feel so inclined. The effects of seeing patients in a non-traditional setting, like a recreational camp, reconnect doctors to the core of medicine and could be a way to combat the burn-out that they may experience along the way to becoming a physician (Ruzycki & Lemaire, 2018). The Camp environment gives them both a chance to rejuvenate themselves and to connect with and learn from patient-campers about the intricacies of living with chronic illness.

## *Conclusion*

This study focused on the role of pediatric physicians in illness-specific camps, namely those who partner with Camp For All during the summer season. Twelve physicians and medical professionals were interviewed about their experiences at Camp, the effects of the illness-specific camp environment on both themselves and patient-campers, the effects of these experiences on their views towards medical practice, and their recommendations for others. These participants spoke to the nature of the illness-specific camp in a way that confirmed and added to the existing literature on the topic. They spoke of the many benefits that they saw for patient-campers, including normalization of clinical experience, self-empowerment, and disease management. Additionally, the physicians found that Camp gave them an opportunity to reconnect to their vocation, build relationships with patient-campers, and network with other medical professionals. The benefits for both parties are also noted in the strengthened doctor-patient relationship that occurs following time at Camp. Patients see increased autonomy and agency in the management of their disease, while doctors have an increased understanding of the personal implications of living with a chronic illness.

The interaction of patients and doctors in a non-clinical setting has important implications on the practice of pediatrics, as it brings patients and doctors into a partnership that builds agency and self-sufficiency for patients as they age out of pediatric medicine. While there is still more research to be done on the topic and how to incorporate non-traditional clinical experiences into the lives of current and aspiring medical professionals, the participants in this study serve as a testament of the strength of this experience. One physician noted this experience is so powerful and that the illness-specific camp model should be a nationwide staple. Personally, I am grateful for the

chance to have spent time in this environment prior to entering the medical profession. I have learned invaluable lessons about the realities of living with chronic illness from the patient perspective, and these are lessons I will carry forward with me as I begin my medical training. I am reminded that the practice of medicine is centered on the patient and relies on human connection and partnership to be successful, and I am further humbled by the chance to interact and engage with patients on such a human level.

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