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Reframing Type One Diabetes Care: Everyday Rituals at Bearskin Meadow Camp

A Thesis Presented
by

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Submitted to Scripps College in Partial Fulfillment of the Degree of Bachelor of Arts

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Table of Contents

Introduction.....	3
Biomedical Care of Type One Diabetes.....	9
Staff Training and Counselor Conceptions of Care.....	14
Rituals of Care at Camp.....	22
Conclusion.....	29
Bibliography.....	31
Acknowledgements.....	34

Introduction

Mealtimes at Bearskin Meadow Diabetes Camp are known to be a bit hectic. With dozens of blood sugars to check, insulin injections to give, and carbs to count, the whole process can take about forty minutes. There's a lot to be discussed between the camper, counselor, and medical staff. Every meal, I observed and participated in "insu-line," which is what everyone at camp understands as the time before meals. This is a play on words combining dinner or lunch line with insulin, the drug that those with Type 1 Diabetes (T1D) need to survive. Every camper checks their blood sugar, counts their carbs, and decides how much insulin to take with their counselor and medical staff based on factors such as the upcoming activities. Usually, one counselor is in charge of recording blood sugars for each table. As one counselor told me, "I like to, as I'm going around collecting the campers' blood sugars before a meal, respond positively to every single one. 'What's your blood sugar? 350. Awesome. Let's do a correction. What's your blood sugar? 140. Great, I'll see you down at insu-line. What's your blood sugar? 40. Awesome, let's get you some juice.'" Some of the campers would resist this, she explained. Campers have been quick to reply with, "No, high blood sugars are bad. Low blood sugars are bad. What do you mean all numbers are good? That makes no sense." The ritual of "insu-line" happens at every meal, with the assigned roles and repetitive actions meant to transform how campers think about their T1D management. This model of care works against aspects of mainstream biomedical care that categorize certain blood sugars as successes or failures.

This thesis focuses on how counselors at Bearskin Meadow Camp approach care and teach campers about T1D management. Counselors and staff at Bearskin Meadow work as social and medical caregivers to their campers. The counselors, many of whom are past campers and live with T1D themselves, are personally invested in providing care and support to the campers.

Their personal motivations as well as the intentional approach to care of Bearskin Meadow shapes camp as a unique space of diabetes care. Counselors at Bearskin Meadow perform repetitive rituals that center around daily management of T1D and building community. Through these rituals, counselors work to change campers' moral and affective approaches to managing T1D. These rituals and the joyful, safe, and fun camp setting create a space where campers can practice real-world diabetes management skills. This approach to care begins during broad conversations in staff training and extends down to small individual interactions between campers and staff.

The care that counselors and staff perform at Bearskin Meadow centers on daily rituals such as “insu-line.” The framing of care as a ritual helps conceptualize the daily repetitive practices at Bearskin Meadow and how they work to transform how campers relate to their own T1D management. Felicity Aulino argues that a ritual framework enables an understanding of caregiving that focuses on the interpersonal and symbolic functions of repetitive rituals (Aulino 2016). She uses the phrase “rituals of care” to make space for the type of transformations that can occur through ritualized acts of caregiving. Adam Seligman claims that the framing of actions make them a ritual, not the actions themselves (Seligman 2008). Counselors frame rituals with the end goal of transforming how campers view their diabetes management. Counselors frame actions of caregiving in particular ways, such as reminding them that there are no “good” or “bad” blood sugars during “insu-line,” in order to intervene in how campers view and relate to their own bodies and diabetes management. This framework of a ritual of care (Aulino 2016) is useful to gain a deeper understanding of the care at Bearskin Meadow.

Two forms of ritual help campers reorient their approach to diabetes management. The first is the emphasis on daily routine, where campers mimic and practice real-world diabetes

management through rituals at camp. This consists of the daily routine at camp and all the activities of diabetes management such as checking blood sugars before meals or exercise. These tasks are done in a community setting such as “insu-line,” so care at camp transforms the individual activities of diabetes management into a shared ritual. The second aspect of care at Bearskin involves rituals of joy and celebration. Care is structured around fun activities such as soccer, hiking, and swimming, as well as celebrations like the list of “firsts.”

These rituals of care (Aulino 2016) are made possible by the specific setting of the summer camp. Many staff members explained that the beautiful environment of Sequoia and Kings Canyon National Park drew them back to camp each year. The weather allows for open-air decks, meaning that even younger kids sleep outside each night. Historian Leslie Paris describes the role of summer camp in American popular culture, explaining how they often function to help youth become more mature through energizing activities in nature (Paris 2008). Originally, the motivation for locating the camp in the wilderness was to give kids with diabetes a summer camp experience (Wolf 2005). The idea of the American summer camp shapes the perception of Bearskin Meadow as a fun getaway for youth. In addition, the outdoor space of camp allows for activities such as hiking, archery, swimming, and campfires at night. Many American summer camps involve rituals similar to those at Bearskin Meadow such as campfires, camp songs, and communal activities. The outdoor space of camp as well as the emphasis on routine and celebratory rituals allow for a type of care distinct from the care that might occur in a more formal biomedical setting such as a clinic.

Care at Bearskin Meadow intervenes in the medical and social aspects of the daily work involved in self-management of T1D. The daily work that patients engage in to live with and manage illness has been conceptualized as “patient work” (Strauss et al. 1982). While Strauss et

al developed the concept of “patient work” to describe care for hospitalized patients, I argue that the idea of “patient work” is also useful when talking about management of T1D due to the large amount of outpatient effort it requires. Previous scholarly work has investigated care of chronic illnesses as well as the experience of living with a chronic illness like diabetes. In H el ene Mialet’s “Bodies in Balance,” Mialet describes T1D as being characterized by a tension between body and mind due to the constant thinking that managing T1D requires (Mialet 2022). The body exists in metabolic imbalance, and the person dealing with the disease must constantly anticipate and calculate the body’s next move. Physiologically, diabetes management involves balancing insulin levels and blood sugar.

This balance is difficult to achieve, especially due to the emotional labor required to continually manage blood sugar levels. Diabetes management is not made up of a series of neutral tasks, instead it is highly emotional and social. Dr. Justin Altschuler, the medical director of Bearskin Meadow, told me about some of the emotional consequences of the difficulty of blood sugar management:

No matter how hard you work at diabetes, there are still going to be highs and lows, so from a classic psychology operant conditioning perspective, intermittent negative reinforcement is kind of the worst kind. So, if you work at it really hard, you’re going to have highs and lows, and if you don’t work at it at all, you’re going to have highs and lows, so that really creates this sense of nihilism or defeatism.

Dr. Altschuler introduces the emotional impacts of the difficulties of control. The highs and lows refer to blood sugars as well as emotional highs and lows. This constant frustration, this difficulty of doing what is correct and still dealing with highs and lows, means that care must not only focus on control, but also work to intervene in how people with T1D relate to their daily management and blood sugars.

Caregiving has been described as a relational and embodied practice that is shaped by moral understandings of what “good care” means to the caregiver and care recipient (Aulino 2016; Buch 2013). What constitutes “good care” is constantly shaped and evolved through day-to-day embodied practices (Mol 2008). To frame my analysis of the care at Bearskin Meadow, I draw on multiple anthropological approaches to care as embodied, relational action. In her book, *The Logic of Care*, Annemarie Mol describes non-linear care that involves “tinkering” between the caregiver and patient where both parties play an active role (Mol 2008). At camp, this caregiver is the counselor who is a trained individual working with medical staff. They work together with the camper with T1D to tinker with insulin dosages, discuss how different activities impact their blood sugars, and learn new management skills. This “tinkering” occurs throughout the daily rituals of care at Bearskin Meadow. Taking the discussion of embodied practice in a slightly different direction, Aulino promotes an analysis of care that focuses on the ritualized dimensions of care and associated repetitive and scripted practices (Aulino 2016). These two frameworks are useful as staff at Bearskin Meadow work alongside medical professionals and campers to edit, redefine, and adjust the care of T1D in a nonclinical space.

This study, approved by the Scripps College Institutional Review Board, focuses on the staff members and counselors of Bearskin Meadow Camp and how they interact with and care for campers. Bearskin Meadow Camp, run by Diabetes Youth Families (DYF), first ran in the summer of 1938. Although Bearskin Meadow now runs in a new location (Sequoia and Kings Canyon National Parks), it is still owned and run by DYF. Camp runs every summer from June to August, and hundreds of campers with T1D attend. I observed and participated in staff training in order to understand how staff are trained and prepared for their roles. I gathered information regarding diabetes policies and attitudes surrounding care at Bearskin from the DYF

website. Some of my questions centered around the experiences that counselors had with their biomedical care and their understanding of certain limitations of mainstream biomedical care. I conducted one-on-one interviews as well as participant observation for three weeks in June 2022 at Bearskin Meadow Camp. In addition, I worked as a co-coordinator of counselor training at camp, so I interviewed many of my coworkers. Interview participation was voluntary and had no impact on the status of any staff members. Any staff members or counselors named in this thesis have been given a pseudonym. I also had the opportunity to interview Dr. Justin Altschuler, the medical director and a family medicine doctor who was also a camper at Bearskin when he was a child. As a staff member and researcher, I participated in all the daily activities and looked after campers. In addition, having spent ten summers at camp (as a camper, counselor, and researcher), many of the descriptions of camp in this thesis represent years of observations, although more formal participant-observation took place during my role as a researcher. This past summer, I spent time participating in and observing staff training, mealtimes, and various camp activities.

This thesis is informed by my experience as a type one diabetic for over ten years. I attended Bearskin Meadow as a camper for six summers and then began working as a counselor, which I did for four summers. Bearskin Meadow has been formative for my growth as a person with T1D, and I have many fond memories of engaging in camp every summer, forming relationships with friends and coworkers that I have kept in touch with for many years. I have worked alongside many of my informants in previous summers, so I had personal relationships with some of them. My lifelong goal is to become a physician, so my analysis of care at Bearskin is also influenced by the biomedical perspective I've gathered participating in settings such as clinics or hospitals. This thesis addresses some aspects of biomedical management of T1D and

how that interacts with the care at Bearskin Meadow. Throughout this research, I reflected on my own experiences in settings such as emergency rooms or clinics as a patient and employee. These perspectives helped me understand some of the limitations of mainstream biomedical approaches to diabetes care as well as conceptualize the care that counselors carry out at Bearskin Meadow.

Biomedical Care of Type One Diabetes

At Bearskin Meadow, counselors position their care as different from certain aspects of mainstream biomedical care of T1D. At camp, I listened as counselors discussed what they perceived as certain limitations of biomedical care, stemming from personal experiences and stories from their campers. Many of these limitations pertain to the emphasis on ideal or standard blood sugar values in biomedicine. Despite the day-to-day complexities of T1D management, mainstream biomedical management of the disease centers around helping patients meet certain “ideal” blood sugar values throughout their daily life. Biomedical management reflects the creation of the “normal body,” a statistical average which is meant to represent a standard body. With this, bodily variation came to be quantified in terms of deviation from the norm (Lock and Nguyen 2018). This construction of the “normal body” has impacts on the everyday disease management of those with chronic illness. Lock and Nguyen explain how the “normal body” is associated with moral valences surrounding blood sugars. For example, it can lead to people with T1D interpreting certain blood sugars as “good” or “bad,” and therefore an assessment of how well they are managing the disease. In this context, not meeting the “standard” blood sugar can represent a failure. This also extends for blood sugars within the “normal” range, which are often seen as a success of personal will. These standards and ideal ranges cause those with T1D to internalize certain feelings of failure or success associated with their blood sugars. The nature of

T1D as self-managed and self-regulated contributes to the idea that the ability to meet certain standards relates to one's effort or success.

Two key elements characterize living with T1D in the present: the disease is chronic and depends on self-management. T1D can be diagnosed at any age, although it most commonly develops in adolescents. Beginning from diagnosis, those with the disease are insulin dependent. Insulin does not represent a cure, but instead a way of staying alive. Those without T1D produce their own insulin, and their body releases the proper amount of the hormone throughout the day. Therefore, those with T1D are faced with a daunting task—to do what their body should do automatically—for the rest of their lives.

Strict self-regulation has been a characteristic of the illness since before it was treated. Before insulin was discovered, those with T1D lived for a few years at most. Many physicians promoted strict starvation diets where patients were held to less than 600 calories a day (Wolf 2005). Before the discovery of insulin, the treatment for T1D was to tightly control food intake, bringing patients to the brink of death for both lack of insulin and starvation (Wolf 2005). In 1922, a young boy was injected with insulin for the first time, which allowed him to live for thirteen more years using insulin therapy (Karamanou et al. 2016). Beginning from the successful application of insulin, the problem shifted to helping diabetics live with the disease. Austin Bunn wrote in *The New York Times*, “Insulin was a miracle drug, resurrecting diabetics from comas and putting flesh on skeletons, and since it needed to be administered at least twice daily, it was a miracle that would be performed over and over. The era of chronic medical care had begun” (Wolf 2005). This new era was shaped by constant monitoring of sugar levels and insulin dosing despite limited technology. Although insulin was a “miracle,” those with diabetes were still faced with time-consuming care, and by the 1940s, it was clear that those able to treat

the disease were still subject to dangerous and devastating complications later in life (Wolf 2005).

Living with T1D requires consistent self-regulation and effort from the person living with the illness (and/or their caregiver). The self-regulation involves measuring blood sugar values and giving insulin doses. These are the aspects of “patient work” that make up the day-to-day management of those with T1D. They rely on technology such as blood glucose meters and continuous glucose monitors to measure blood sugar, and insulin syringes, pens, or pumps to deliver insulin. This is made more complicated because the technology registering the blood sugar data has an active role in the management of the disease and is not just a passive tool (Mol 2000). Mol writes how usage of measurement devices such as glucose meters can impact how people view their own self-regulation. For instance, improved devices for blood sugar regulation have influenced the expectations for regulation; patients expect tighter control due to more convenient and more accurate measuring (Mol 2000). New technology centers around goals to create “closed-loop” or “artificial pancreas” systems, where glucose sensors and insulin pumps will work together to manage blood sugar and insulin dosing of a patient with T1D, just as a functioning pancreas would do (Hoskins 2022). While these new technologies have made it more feasible to manage the disease, they still require a significant amount of energy and focus to use on a day-to-day basis. Patients continue to engage in bodily self-regulation and control to manage the disease. In fact, this new technology can cause increased anxiety for some patients due to a larger amount of health information available (Mathieu-Fritz and Guillot 2017). New technology has only shaped the type of self-regulation involved with management of T1D, not eliminated the “patient work” of regulation altogether.

Devices and technology can also contradict how someone is feeling. In other words, the body may begin to feel low; shaky, sweaty, hungry, and weak, but the glucose meter might read a normal blood sugar. Or say a person with T1D orders a diet soda and doses insulin before their meal. The waiter accidentally brings a regular soda, and about thirty minutes after eating, their blood sugar has spiked significantly due to consuming far more carbohydrates than they gave insulin for. These scenarios are meant to show that a person with diabetes can in theory do everything correctly and still not have consistently “healthy” or “in range” blood sugars. Both did everything as they were taught; they checked when feeling low and gave the correct amount of insulin based on the drink they ordered. The self-regulation involved in T1D management is nuanced and complicated, changing each day and with every scenario.

However, the care in a diabetes clinic focuses on determining how “well” someone has performed this self-regulation. For instance, one of the first things that happens at a checkup with an endocrinologist (what many would call their “diabetes doctor”) is a blood draw to measure a hemoglobin A1C. This is a standard test that is meant to reflect someone’s blood sugars over an average of two or three months. The test is supposed to give a general idea on how “well” someone is managing their diabetes and if they are generally staying close to “normal” range, emphasizing the nature of diabetes management as a constant comparison to a “standard” value. The A1C will be discussed by the endocrinologist, and many doctor’s offices have charts showing certain A1C values as “high risk” or “low risk” for diabetes complications. It is difficult to avoid seeing where one’s A1C fits on this chart, leading to feelings of anxiety. Reminders of certain “ideal” blood sugars can lead to an understanding that a “good” blood sugar means the person has done something right, and a “bad” blood sugar means they have done something wrong. With this logic, blood sugars that are in range are “good,” and should be celebrated, but

blood sugars that are out of range and “bad” means the person failed. A “good” or “bad” blood sugar reflects the person with diabetes and the amount of effort they put in. This focus on target blood sugars places a moral duty on patients to meet those values. Language that healthcare providers use often rewards or punish patients based on if they meet certain standards of self-regulation (Ketchell 2016). In addition, notions of “compliance” or “noncompliance” used by medical providers define and simplify patient behaviors in terms of meeting certain standards (Hunt and Arar 2001). Overall, the need for self-regulation of T1D means that patients are held responsible for the outcome of their treatment.

The daily labor of managing T1D can result in anxiety, stress, and other negative emotions. A study from the *Journal of Clinical Nursing* looked at some of the emotional impacts that diabetes can have on adolescents. It detailed how many adolescents might avoid doing tasks of diabetes management, such as checking blood sugars or giving insulin, so that they can feel “normal” (Castensøe-Seidenfaden et al. 2017). Counselors often told me that they felt their doctors did not check in on their emotional well-being. David Goldberg, a child psychiatrist, observed the care performed in a biomedical setting, a juvenile diabetes clinic. He explains that there was a large emphasis on the concept of biochemical balance, or “aiming for balance” through managing insulin, food, and exercise (Goldberg 2006). The balance he describes does not involve the important aspect of emotional well-being.

Counselors often told me that the mainstream biomedical care they receive seemed to take their management out of context or separate it from their overall personhood. To contextualize a biomedical approach to diabetes care, Annemarie Mol and John Law’s “Embodied Action, Enacted Bodies: The Example of Hypoglycaemia,” discusses how biomedical approaches to chronic conditions such as diabetes often introduce new tensions to

those living with the disease. (Mol and Law 2004). This is rooted in the biomedical understanding that the body with disease is separate and controllable (Mol and Law 2004). They write that those with diabetes are not only “people with diabetes,” but also people who live in their bodies and experience life in ways that are not directly related to diabetes. Mol and Law write how biomedical care often assumes that disease management is separate from the day-to-day context and tensions that a patient faces.

In contrast to these dominant forms of biomedical diabetes management, the care at Bearskin Meadow actively tries to separate value judgments from blood sugar readings and pay attention to the day-to-day context of the person managing T1D. Counselors often explained their care at camp in terms of how it is different from certain mainstream biomedical approaches to care. Counselors do not use explicit language to reference biomedical care and how it is different from the care at camp. However, they do make a distinction between the care at camp and the care they receive from biomedical providers.

With this context in mind, in the following sections I analyze how Bearskin Meadow shifts the way campers relate to their diabetes management and the associated daily “patient work.” To do this, I discuss the staff training that counselors and staff are required to attend. In addition, I will explain how counselors and staff create a form of care that challenges some of these limitations. The fun and enjoyable community setting of Bearskin Meadow shapes the type of care they practice.

Staff Training and Counselor Conceptions of Care

The goal of the care at Bearskin Meadow is to change how campers relate to their diabetes management. At staff training, counselors learn the goals of camp through broad

discussions about diabetes care and the emotional struggles associated with daily management. Specifically, the counselors seek to intervene in how campers affectively relate to blood sugars and overall diabetes management. Counselors focus on the emotional labor associated with managing T1D as well as learning the importance of the daily routine and rituals at camp.

One of the first activities regarding diabetes care that everyone participates in during staff training is making a list. Dr. Justin Altschuler, who the staff call “Dr. Justin,” or “Dr. J,” draws a line down the center of a whiteboard. On the left he writes “increases blood sugar,” and on the right he writes “decreases blood sugar.” Everyone then compiles a list of different activities, hormones, and emotions that can increase or decrease blood sugar. It takes about 5-10 minutes of brainstorming to come up with a non-exhaustive list. Other than a few straightforward ones, like insulin decreasing blood sugar and carbohydrates raising blood sugar, there aren’t really any correct or incorrect answers. It depends on the person and about fifteen other factors. Each year, the staff come to the same conclusion: there are a lot of factors that impact blood sugar and diabetes management. Staff begin their training with a few simple facts in mind: controlling T1D is hard, unpredictable, inconsistent, and blood sugar fluctuations will happen.

Staff training is mandatory for all staff members, even those who have worked at camp before. It takes place over a week before the first camp session of the summer. Some parts of training involve all staff (including kitchen team, maintenance, and management), while some sessions focus on counselors. Broadly, I see staff training as divided into two distinct but overlapping categories. The first is teaching staff skills about how to manage social aspects of camp. This involves showing staff strategies of helping campers with homesickness, managing bullying or exclusion in groups of campers, and going over general camp rules, activities, and rituals. The second focuses more directly on management of diabetes and the daily routine of

camp. There are lectures that focus directly on managing diabetes at camp, such as checking blood sugars to make sure campers are at a safe glucose level before going to sleep or before vigorous activity. My analysis focuses on the counselor-specific aspects of staff training, including how counselors are taught about care and how they understand their roles as caregivers at camp. Grounded in their personal experiences, counselors approach diabetes care with an understanding of emotional aspects of daily management of T1D. Counselors engage with the everyday life situation of the campers to intervene in the “patient work” (Strauss et al. 1982) of the campers.

The DYF website states that more than 70% of the staff have T1D themselves, and those that don't are often partnered with more experienced counselors so that they are better able to learn camp's approach to diabetes care (“Diabetes and Healthcare at Camp DYF” 2019). The connection many counselors have with T1D and camp creates a more personal type of care between counselors and campers. When interviewing staff members, I noticed that there was a common theme of “giving back” to the camp as a motivation to come work as a counselor. One told me about their motivation to be a counselor for the second year in a row:

Camp was just really important to me since I was little. The first year I got diagnosed I was too scared to go to sleepaway camp by myself, so me and my mom went to family camp, and it was like my whole family and I fell in love, I made so many friends, I tried my first site, I tried a pump for the first time, and this was like three months after my diagnosis so I was very early to it, and since then, the impact camp has had on me made me want to work at camp and do that for other people.

Staff members' motivations are often personal and based on their own experiences at camp. Many campers become counselors and feel motivated to create the type of environment that their counselors created for them as youth. This results in an intentional approach to care, guided by the counselors' personal understandings of what camp did for them, whether it helped them

make friends or use a pump for the first time, as the counselor explained above. The counselors' connections to camp also work to foster an environment that is joyful, positive, and productive in terms of practicing diabetes skills in a safe setting.

I observed the emotional connection many staff have with T1D during staff training. One conversation stuck with me. Dr. Justin talked about complications arising from diabetes and how fear of developing those complications can impact mental health. He explained that new technologies and medications have made many complications treatable and manageable early on. I looked around at my fellow staff, and many were visibly tearful. Some heaviness had lifted. Staff typically have a personal understanding of the difficulty of living with diabetes, and camp is a space where those feelings are welcome. This personal connection and understanding of the difficulty of managing T1D allows for the counselors and staff to empathize with campers in a way that clinicians likely cannot. As discussed earlier, many counselors felt that their biomedical care outside of camp lacked an understanding of the stresses and anxieties associated with diabetes management. To me, it was visible that there was no lack of empathy or understanding in the room. The deep insight of the counselors extends to how the counselors understand the day-to-day tensions of diabetes management.

Counselors try to communicate an approach that focuses on the tensions of life outside of diabetes, and also how the tensions of diabetes interact with the tensions of life. Staff at Bearskin understand diabetes as social, psychological, and physical all at the same time. A counselor explained what she learned from camp's approach: "I learned that you manage yourself and then you manage your diabetes. And at home it was manage your diabetes and then yourself." This contrasts with Mol and Law's explanation of biomedical care that treats the person with the disease as separate from the disease itself (Mol and Law 2004). The counselor indicates that care

at Bearskin Meadow prioritizes the person managing their diabetes and does not separate them from their diabetes management. The daily “patient work” (Strauss et al. 1982) of someone with diabetes includes the context of their day-to-day life. The emphasis on context extends to specific facets of management and how they differ from mainstream biomedical approaches. Counselors working at Bearskin Meadow understand that no matter how hard one tries, an “ideal” blood sugar value might not be possible due to many different factors. Taylor, a counselor, walked me through an example of the difference between what might happen in a biomedical context versus at camp:

I think at camp, what the kids learn about diabetes, I feel like it comes more from a place of seeing diabetes as a part of a whole person, rather than just like a series of metrics to either accomplish or fail. I know that for me, at least, I would go to the endo growing up, and the conversation would pretty much be “you’re not bolusing at your meals, you should be. You need to be.” And not even, “why aren’t you doing that?” No one ever asked me “why aren’t you doing that?” Because I think in that context it’s sort of assumed that it’s a lack of technical knowledge, rather than an emotional or psychological or social issue, and here we recognize that all of those factors are a part of how a person takes care of their diabetes and that we can empower them by giving them some of those technical skills. More importantly, we can support them in figuring out how to live with it in a way that fits with where they’re at emotionally and socially in terms of maturity.

First, Taylor sees diabetes care at camp as acknowledging that diabetes is part of a whole person, differing from what a mainstream biomedical approach might suggest. The mainstream biomedical context, as Taylor understands it, takes a technical approach to the issue of the person not taking insulin before meals. At camp, counselors learn that it is important to understand why someone might not be performing certain tasks of their diabetes management in order to find an approach that might work for them. Therefore, part of diabetes care at camp is understanding each camper’s individual circumstances and working with them to care for their diabetes. The biomedical understanding of the counselor not bolusing before meals also assumes that they

knew they were supposed to give insulin and chose the alternative. This is viewed as a simple choice to bolus before meals, which leads to the physician critiquing the counselor for their incorrect choice. The counselor describes this as insufficient care because it lacks an understanding of context and reduces diabetes management to a choice.

In “Living with diabetes: care beyond choice and control,” Annemarie Mol, after observing care in a Dutch diabetes clinic, explains that the framework of “choice” is insufficient in terms of disease management. She detailed that the reason a patient was not measuring his blood sugar was due to his work schedule, not because he was choosing to avoid it (Mol 2009). Similarly, the idea that it was a choice for the counselor to not take insulin before meals ignores all the aspects of life that interact with diabetes. The counselor explains that in their opinion, care at camp asks the question of why they weren’t bolusing at meals, not assuming that they made a simple choice against their doctor’s advice. Good care, as conceptualized at camp, means asking why, it means understanding why their management looks a certain way, not reducing it to a single choice. By putting “patient work” (Strauss et al. 1982) in context, the counselors model an approach that considers the day-to-day life of campers. This approach is a rejection of a model of diabetes care that sees management as separate from the personhood of the person with T1D. In a way, this approach rejects understandings of diabetes management that see diabetes as separate from the person with the illness (Mol and Law 2004).

This approach to care comes through as counselors interact with campers. For instance, in terms of blood sugar management, counselors acknowledge that campers might have certain expectations regarding blood sugars based on their experience with physicians. Physicians recommend a range of blood sugars for their patients. The “standard” blood sugar of someone without diabetes ranges from 70-120 mg/dl, and people with diabetes are told to aim to keep

their blood sugars as close to that range as possible. From a treatment perspective, this makes sense, as there needs to be a number to adjust to, but this can lead to people viewing their blood sugars as “right” or “wrong.” Kevin, a counselor, told me how counselors work to change how campers assign moral judgments to blood sugar values:

In front of the campers, and I remember this when I was a camper, it’s a lot of “this is just what it is, it’s not your fault,” we don’t test blood sugars, you aren’t being graded, this isn’t a test, we’re going to check your blood sugar, we’re just checking to see what it is, there’s no right or wrong number, it’s just a number, we’re not testing, we’re checking, we’re not gonna get angry at different numbers. You might be frustrated with it, of course that comes with being diabetic, because you’re going to be frustrated, but it’s not getting angry at that, it’s being like okay, what can I do from here? And especially with the younger kids, making it feel like it’s not their fault, they didn’t choose to have diabetes, so why would they choose to feel bad with high blood sugars? Of course they wouldn’t do that, so making it feel like it isn’t their fault. That is the main thing that I, when I was a camper, pulled out, and I try as a counselor to let them know.

Here, Kevin explained how blood sugars are talked about once they are checked. Some people use the phrase “testing” blood sugars, but counselors are encouraged to intentionally use the word “check” to avoid the connotation associated with the word “test.” The word “check” represents more of a glimpse into a single moment of their overall care and management. As Kevin explained, frustration comes with being diabetic, but the key point is to make the next decision in terms of management. Due to the number of blood sugar checks throughout the day, there would be tests constantly and therefore many opportunities to “fail” these tests. Counselors attempt to decrease some of the emotional anxiety involved in the interpretation stage of diabetes management. Counselors understand that assigning blood sugars a moral judgment results in anxiety and can lead to burnout, which is the state of stopping all or most aspects of diabetes management (Abdoli et al. 2019). This connects to the idea of the “normal body” in mainstream biomedicine (Lock and Nguyen 2018). Here, Kevin rejects categorizing a “bad” blood sugar as a failure. This rejection happens throughout small activities associated with diabetes management.

Throughout the day, as campers check their blood sugars, Kevin reminds them that they are “checking,” not “testing,” and that they cannot fail a check. A blood sugar is not a failure or success, instead it is just a way to see how everything is going.

Counselors also acknowledge that blood sugars may be out of range, and that it is not the fault of the person with the disease. High or low blood sugars often cause physiological symptoms that can be uncomfortable. The counselor makes sure to take the blame away from the camper, as they may be feeling physically unwell due to their blood sugar. Kevin states that the camper would likely never choose to feel unwell and implies that the camper may be feeling like the blood sugar is their fault. The counselor emphasizes the next step in management to help the camper learn how to deal with their high blood sugar. In addition, Kevin emphasized that there is no “right” or “wrong” number. The assertion that there is no correct number contradicts the message from the biomedical clinician, which emphasizes the placement of a blood sugar into the “normal” or “abnormal” category.

After observing care in outpatient diabetes clinics, Annemarie Mol explains that diabetes patients who engage in the self-regulation of their disease are often blamed for times when they are not able to effectively perform that self-regulation (Mol 2000). In other words, the responsibility of self-regulation comes with the risk of being blamed for that regulation. Those with T1D can face blame from their doctors, their parents or family members, and can blame themselves.

The goals of care at camp and how they are different from certain aspects of mainstream biomedical care are explained at staff training. Counselors learn how to interact with campers in certain ways, highlighting the daily context of the camper with T1D. Certain language is emphasized as a way to help campers remove value judgments from their blood sugars. In

addition, counselors learn about the everyday rituals of diabetes management at camp. These rituals become a way for them to achieve the objective of shifting the mindset of campers away from self-blame.

Rituals of Care at Camp

I followed a group of campers to the field after breakfast. One camper was walking next to me carrying a large bright blue backpack with green flowers. “Do you like carrying the low bag?” I asked. “No, but everyone has to take a turn,” he answered. Every deck of campers had a brightly colored backpack, known as a “low bag,” filled with various supplies. It contains the binder where blood sugars are recorded, lancets, glucometers and test strips, sugar cubes, glucose tablets, and glucagon in case of emergency. As our group arrived at the field, everyone gathered around the low bag. The counselor instructed campers to check their blood sugars and show a counselor. Everyone had to have a blood sugar over 100 before they could play games on the field. All the campers sat down on the field to check their blood sugars with a meter or lined up to show a counselor what their blood glucose sensor said.

This is one example of the collective, ritualized care practices that occur throughout the day at Bearskin Meadow. Rituals are common in American summer camps, but many of the rituals at Bearskin Meadow center around care of T1D. There are also celebratory and fun rituals at Bearskin Meadow. The rituals at camp are repetitive, such as the practice to check blood sugars before any physical activity or having one camper carry the low bag. There are scripted components, such as making sure each camper shows their blood sugar to a counselor. Through these care practices, counselors at Bearskin work to both increase knowledge surrounding diabetes management and provide a supportive and fun space where campers feel comfortable. A

large part of the ritualized care at camp centers around the knowledge component of diabetes management. Counselors translate this knowledge through everyday activities, such as having campers check blood sugars before activities or count carbohydrates together before meals. While there are some specific diabetes education sessions for the campers (where they are encouraged to ask the diabetes educator questions), most of the knowledge comes through practice in the context of typical camp activities. These activities include archery, hiking, field games, and community gatherings such as campfire, so that campers can gather knowledge through fun activities. The ritualized nature of the diabetes care at Bearskin creates a comfortable space for campers to experiment with their management and allows for increased transfer of knowledge surrounding diabetes management practices. In addition, the collective and ritualized nature mimics a daily routine with T1D, helping campers think about their own routines.

Rituals of the Daily Routine

Developing a routine is a key component of T1D management. Many of the rituals of care (Aulino 2016) at camp are typical everyday activities such as waking up and eating meals. The care practices mirror the everyday management of T1D, which takes place throughout one's daily routine. The context of camp as a diabetes camp means many of these everyday rituals focus on components of diabetes management.

The wake-up bell signifies the beginning of the day at camp. This bell is typically followed by wake-up music, which can range from Disney's greatest hits to The Grateful Dead, depending on picked the songs that morning. You can hear counselors shouting, "good morning, Meadowlark!" or "good morning, Granite!" greeting the decks they sleep on, attempting to wake up a sleepy group of kids. After waking up all the campers, the first step is typically to check

blood sugars. This might happen on the way to the bathroom before campers brush their teeth or right before everyone heads to morning announcements. Counselors record each camper's blood sugar and follow up with any treatment needed before breakfast. The day begins with blood sugar checks and ends with blood sugar checks at evening snack.

Throughout the day, a camper checks their blood sugar anywhere from six to twelve (and often more) times. Campers check before every meal and snack, before any physical activity, before bed, and anytime they feel like their blood sugar is “low” or “high.” In addition, many continuous glucose monitors offer a blood sugar reading every five minutes, leading to a constant flow of data. Living with T1D has been described as involving a “practice of attunement” (Kingod and Cleal 2019). Attunement involves receiving signals from one's body and being aware of technology used to manage diabetes. This constant need for attunement, both to the body and technology, can be overwhelming, as T1D patients must act on the feedback to stay alive. A low blood sugar, for instance, can be interpreted by technology or by a bodily sensation. A glucose sensor might ring with a low notification, alerting the person to the low blood sugar, or the person may begin to feel shaky, sweaty, and weak, which the person uses to regulate their blood sugar. As blood sugars are read throughout the day, whether at camp or not, there is a constant need for attunement. This attunement is the first step of a management decision, and the next step involves an interpretation. After a blood sugar is recognized, it must be interpreted. Living with the disease means gathering data, interpreting the data, and making a decision based on that interpretation. This means interpreting the blood sugar as compared to some “ideal” blood sugar and doing what's necessary to bring it closer to that value. Large influxes of data mean more interpretations and decisions must be made, which can be exhausting mentally.

As these rituals of checking and insulin dosing occur throughout the day, counselors and staff try to intervene in the dynamics of attunement by reframing the connections campers make with “good” or “bad” blood sugars. They do this by modeling their own practices of attunement and conceptualizing T1D management by focusing on learning new care practices and paying attention to how their bodies are feeling. Rituals can signal a transformation or serve a function for a group of people. In this instance, the repetitive rituals at camp are meant to transform how campers feel about their blood sugars.

The dining hall is a space where ritualized and practice-based care occurs throughout the day. During breakfast, lunch, dinner, and evening snack, each deck or group of campers sit together at one or two tables with their counselors. There are whiteboards evenly spread out across the dining area. Listed on the whiteboards is the menu for the meal with the associated carbohydrate counts. For instance, if lunch is hamburgers, the menu might say: “Hamburger bun 24g, tater tots (1 serving) 19g, ketchup packet 4g” (“Diabetes and Healthcare at Camp DYF” 2019). The counselors pass out paper plates and pens to every camper, and the campers all write down what they plan to eat and add up the carbohydrates (depending on their age). You can hear them ask their friends: “how many carbs is a bun?” Or “Is anyone else planning to have 12 grams of ketchup packets?” These little comments normalize aspects of diabetes management. Many counselors told me that some campers come from places where they don’t know anyone else with diabetes and express shame around performing their care in front of others. The day-to-day management is made into a ritual where all campers and many staff participate. This ritual is repetitive as it takes place before every meal as part of “insu-line.” There are scripted roles; for instance, one counselor sits with the medical staff and helps decide with each camper how much insulin to give for the meal. Another counselor sits with the campers to help them count

carbohydrates and keep them entertained. In staff training, the counselors are told to participate in this routine to model these daily rituals for their campers. If campers see their favorite counselor adding up their carbohydrates, they will be more likely to participate and even come to enjoy the activity.

The ritualized care is meant to help campers create a routine that mimics daily life with T1D. Many parts of the day at camp are repetitive. For instance, checking blood sugars happens before any physical activity. Everyone counts their carbohydrates together before a meal. Everyone gets their blood sugar checked at midnight. This modeling of a routine is meant to help campers after their time at camp. Staff are encouraged to make these routines consistent and mimic everyday life for someone with T1D. The mimicking of everyday life leads to everyday tinkering. For example, at each meal, campers bring their plate to the end of the table where the medical staff and a counselor sit. They go over the carbs they plan to eat, the activities they have coming up, and their blood sugars so far during the session. This is where campers work with medical staff and counselors to manage their diabetes on a day-to-day scale. These frequent check-ins during meals allow for this type of personalized “tinkering.” For instance, it was common for a camper to have frequent low or high blood sugars for the first day or two as the medical staff and counselors continued to make small adjustments. If the camper took all their insulin for the bedtime snack on the first night, and then had a low blood sugar at midnight, the next night they might try giving 80% of their insulin bolus for the food. If they were still low, then the next step might be to decrease it further until that camper had a safe blood sugar at night. The camper would typically be involved in these conversations, being made aware of the adjustments that were being made. This continual tweaking of insulin and glucose is “persistent tinkering” (Mol, Moser, and Pols 2010). It can be thought of as experimentation, where

something is continually tweaked until the desired result is reached. The environment of camp mimics daily life with T1D, which will inevitably involve constant adjustment and readjustment.

The set-up of camp means that campers can learn how to manage diabetes throughout their daily life. At the clinic, they are not able to practice how to manage diabetes while playing soccer. Instead, they are more likely to be subject to a lecture on how they must reduce the amount of insulin before and after they play. At camp, they play soccer and practice reducing their insulin along with their friends who are doing their own experimentation. Community oriented care can produce a type of “know-how,” which is a type of practical knowledge in terms of illness management (Pols 2013). The embodied knowledge of those living with T1D produces this “know-how,” and can be translated in a community setting. This “know-how” is shaped through practice, and the activities and rituals at camp create a space where this can be built and fostered.

Rituals of Fun and Celebration

In addition to the rituals of a daily routine, camp also has rituals that center around fun and enjoyment, as is the case at most American summer camps. These celebratory rituals are less focused on mimicking and practicing diabetes management and instead on developing a community and creating a comfortable setting for campers. The camp rituals, often celebratory, are designed to cultivate joy, pleasure, and “collective effervescence,” a phrase coined by Émile Durkheim (Durkheim 1915). Serving a unifying purpose, “collective effervescence” refers to the energy and “electricity” individuals feel when coming together to perform the same action as a group. Individuals doing the same activities throughout the day creates a sense of community.

In staff training, counselors are reminded that camp is meant to be fun. Camp is meant to feel completely different than a visit to the endocrinologist. Celebrating acts of diabetes care makes campers feel better about the daily tasks of management and “patient work” (Strauss et al. 1982). Staff motivate campers to take “healthy risks” and try new ways of caring for themselves. These actions, known as “diabetes firsts,” often make their way onto the “First List,” a camp tradition at Bearskin Meadow. After a camper does something for the first time, which can vary from giving themselves their first shot to going on a hike for the first time, they are encouraged to put it on “First List.” Every morning before breakfast, the “First List” gets read to everyone at camp and all the campers on the list run through a human-made tunnel and are celebrated with a song or cheer. The “First List” takes something like an insulin injection and transforms it into something the campers get to celebrate. This is an example of how a ritual can serve the purpose of transforming how campers affectively relate to tasks of their diabetes management. Pleasure and fun are not often associated with medical care. However, as Amy Cooper writes, people can take pleasure in certain activities related to their health (Cooper 2019). For instance, in the context of Venezuela health care, Cooper discusses how dance classes were a fun activity many adults participated in to maintain their fitness. This is similar to how the “First List” transforms daily diabetes tasks into a fun camp-wide activity. Bearskin Meadow is a summer camp as well as a diabetes camp, and counselors work to create a space where campers feel that way.

Similarly, many counselors claimed that their favorite camp activity is opening or closing campfire. Opening campfire takes place the first night of camp, and closing campfire happens on the last night. There is typically an obvious difference in the community cohesion when comparing opening and closing campfire. For opening campfire, campers are shy, have just left their families, and are just getting to know the kids in their group. Some campers may even

appear angry or distant. By closing campfire, the campers look like they've known each other for years. Both campfires end with the same song every single time. The song starts like this: "No one is an island. No one stands alone." Everyone crosses arms and holds hands gathered around the campfire. I was told it can feel awkward at first, but by closing campfire, the community spirit is undeniable.

These enjoyable rituals at camp are intended to build the community at Bearskin Meadow as well as provide a fun summer camp experience. The goal of campfire, evening activities, and arts and crafts are to cultivate pleasure for the campers. Through this pleasure, counselors hope that campers can learn to think differently about their diabetes management in a way that decreases shame or isolation. Through repeated diabetes practices, daily rituals, and fun activities, campers learn about diabetes and enjoy a fun summer camp experience. Some of the rituals are meant to impact how campers understand their bodies and T1D management, whereas some are meant to build community. The rituals are not distinctly labeled, however. Community can be built in "insu-line," where two campers bond over being diagnosed with T1D at the same age, just as it is built as campers run through the tunnel as the "First List" is read.

Conclusion

Many of the rituals at Bearskin Meadow focus on daily management of T1D, helping campers to build a routine that will be useful for them once they leave camp. The counselors seek to change how campers assign value judgments to their T1D management. Counselors shift the blame away from the camper, telling them that high and low blood sugars or other struggles with management are not their fault. Tessa, a counselor, told me how she conceptualizes this shift:

Sort of the message I always got is it's like a puzzle that you're trying to solve, and you have different pieces of the puzzle—exercise, diet, insulin doses—and you kind of have to figure out where all these puzzle pieces fit in. And it's not a reflection on you if you're having a hard time solving the puzzle, it's just a hard puzzle.

Tessa describes the message she gathered as a camper about how managing T1D can be compared to solving a puzzle. There are many factors, or “puzzle pieces” that can impact self-regulation and management, and solving the puzzle can be difficult at times. Camp tries to shift the blame away from the person and to the disease. While paying attention to the complexity of the factors that can affect blood sugars, counselors try to take the blame away from campers. This approach acknowledges the difficulties of self-regulation without blaming the person in charge of the regulation. At camp, the puzzle of diabetes management is blamed for being complicated, not the solver. This can be life-changing for many campers who blame themselves when they struggle with their blood sugars.

Diabetes care at Bearskin Meadow is not about improving glycemic control or other quantitative biomedical parameters. In fact, most studies have found that attendance at diabetes camps has limited impact on overall glycemic control (Fegan-Bohm et al. 2016). Instead, the care at Bearskin Meadow focuses on shifting how campers view the puzzle that is their diabetes management. The rituals of everyday routine and celebration at camp are repetitive, often containing scripted roles. They have the purpose of altering how campers view their diabetes management, shifting from a mindset with self-blame to a neutral or even positive outlook. Through rituals that center on dealing with puzzle pieces such as managing blood sugars during exercise or counting carbohydrates before meals, Bearskin Meadow shapes how campers view their puzzle. This change occurs during “insu-line” when a counselor responds positively regardless of a blood sugar, or when a camper injects their own insulin for the first time and is

celebrated on the “First List.” Through these everyday rituals, campers come to view their blood sugars and diabetes management in a way that minimizes shame and empowers them in their own management.

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