The Journey Through Illness of the Type 1 Diabetes Caregiver, from Disruption to Positive Coping

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Abstract. Type 1 Diabetes is a chronic autoimmune disease that affects mainly children and teenagers. The life, feelings, thoughts and thinking patterns of their parental caregivers must be taken in consideration as they are severely affected by this illness. In the following qualitative study, we are drawing a timeline inspired by mythology aimed to locate the different phases in a universal narrative of the caregivers. Thus, this timeline is used to create a conceptual tool for understanding, forecasting, and designing technological devices for them.

Keywords: Human-Computer Interaction (HCI) · Type 1 Diabetes · Parental caregivers · Hero's journey

1 Introduction

The experience of the caregiver of a child with Type 1 Diabetes (T1D) is very close to a first-hand experience of the illness. Especially in the beginning, the parent totally identifies herself with the condition of her child and experiences disruptive feelings such as anxiety, distress, and they lose interest in many things they considered important before. They also have negative thoughts for the threat of the son's night hypoglycemia of the son that are affecting their sleeping pattern. Therefore, it is possible to draw a path across this chronic condition for the carer as well. This path that started with heartache ends with achieving a balance in the inner and outer world of the carer, an improvement in their daily life and a newly found openness toward the external environment. This considerable improvement in the life of the parents occurs at the same time with an improvement in the life of the cared, because of the tight relationship between hyperglycemia and mood. The rationale of our contribution lies in providing a temporal and causal sequence of what happens to the caregivers by following the sequence of myths [4]. Our research question is "How can the tool we create help the caregivers?". To support our reasoning, we will bring forth an analysis of a set of interviews with T1D caregivers.

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We organize the paper as follows. We begin with a brief definition and history of the illness followed by a literature review of the topic. Next, we expand on the methodology and data analysis. We then proceed with a discussion of the findings of our research and an answer to our research question. We conclude the paper with a short conclusion drawing a summry of the results of this research.

2 What T1D is

Diabetes is a metabolic disease characterized by the fact that the body either does not produce enough insulin or cannot use it efficiently [5, 22]. There are three different types of diabetes: Type 1, Type 2, and gestational diabetes [11]. Since 2019, 9.3% of the global population has been diagnosed with diabetes [13, 19]. In particular, Type 1 diabetes (T1D) is a complex chronic disease in which the body does not produce insulin or produces it in insufficient quantities [5]. Worryingly, rates of incidence of Type 1 diabetes are continuously rising around the world [17]. At the moment, there is no cure for T1D [5]. It is possible, however, to manage the disease by following healthy-living strategies like eating well-balanced meals, doing sport activities, checking blood sugar levels and balancing insulin doses [11, 12]. As documented in several studies, regularly keeping up with these daily routines is challenging for the T1D patients. This rigorous life-style is especially trying for young kids [19] and adolescents that have been diagnosed with T1D. Both patients and their families, may experience a great degree of difficulty in accepting and managing this condition. They go through different behavioral stages before being able to fully adopt, for the rest of their lives, these positive routines.

3 Related Work and Research Gap

Taking into account the existing literature and the analysis of the database we have collected, it emerged that, even with different research approaches to the question, to the transcripts and using a different qualitative analysis, the results tend to coincide. Therefore, we can affirm that the most relevant events of the life story of the caregivers have been triangulated, offering relevance to the study. From our own analysis and from the literature we reviewed, despite the social and geographical differences, the monologues of the T1D parents look very similar in content. Thus, they show a common thread that we would like to set as a narrative for this paper. This model is grounded in the collective unconscious, and, therefore, has properties of universality [4]. In the literature, there are reliable qualitative studies on the topic. For instance, [20] describes the emotional work of the T1D parental caregivers that is twofold: on the one hand, they need to embrace the complexity of their children's condition, continuously looking for patterns to rely on and forecast short term and long term consequences. On the other hand, they need to prevent their offspring from experiencing negative feelings related to their illness, preserve their positive attitude and progressively build "normal" family routines for all of them. Also, a consistent work on their emotions has a positive effect on their glycemic levels, due to the tight relationship between those emotions and the patients' mood. [9] explores the embodiment aspects of parental caregiving as it is assumed that "thoughts, feelings, and behaviors are grounded in bodily interaction with the environment" [16].

Research shows that, even though T1D patients do not show visible specific physical changes, they can still experience social stigma and exclusion. That happens because the child does not completely understand his condition, which requires the parent to exhibit constant vigilance and struggle to protect the child. [I5] is a phenomenological analysis touching the main points of the life story of parental caregiving. This contribute focuses on the life and feelings that parents live, like the constant alertness that leaves no room for relaxation, the isolation from the external world that cannot understand the never ending battle they are fighting, loss of spontaneity, freedom, and interest for life. [8] reviews the existing literature, up to 2019, on the consequence of T1D on family life. It draws a picture of the parental stress following the diagnosis, the partial adjustment of routines, perspectives and mood, and finally the long term work towards the independence of the young T1D patient across adolescence and finally, maturity. [9] makes use of inductive qualitative content analysis and provides a rich explanation of the topic, in particular the work of parents and children on learning to cope with this lifelong illness, from the struggle to understand the condition to the organization of daily life, from the difficulty to manage work to the collaboration with the school staff. [15] focuses on the concept of burnout in order to model the events occurring when parental caregiving, therefore applying already existing paradigms coming from the work environment. At the forefront of this prosperous qualitative literature on parenting a T1D child, there is a lack of a unifying paradigm that can allow meanings to be organized across a temporal full-fledged, coherent and explicit model, that can be used for forecasting, explaining, or providing ICT support. Therefore, we propose our qualitative analysis contextualizing it in existing narratives in order to draw a path from diagnosis of the T1D child toward positive coping. This paper fills this gap and offers a temporal, logical and causal sequence, by following the steps of the hero's journey [4].

4 Method

We interviewed 9 caregivers (8 mothers and 1 father; 1 in person and 8 over the phone [10]) of teenagers and young adults with T1D and tried to understand how their daily life and their feelings towards the events related to the illness unfold. The interviewees were recruited, on a voluntary basis, from a Facebook page dedicated to T1D and come from all over Italy. We interviewed all the people who answered to our request and the interviews were anonymized. The interviews were semi-structured allowing the respondents to reveal their personal narrative by answering our open-ended questions [1]. The interviews were transcribed, analyzed, and coded by the authors, using Grounded Theory [6]. After reading and re-reading the transcripts, the authors understood that there was a lot that was left unsaid by the interviewees. It was up to the researchers making sense of the narratives [3]. In the search of a Gestalt inside the transcripts we reviewed the related literature in order to find a pattern to organize the transcripts. This was found in [4]'s and in [14]'s modelling of collective unconscious.

5 The Hero's Journey in Mythology

We made use of mythology to map out our study. Mythology is a privileged way to get in contact with one's own psyche in a poetic and transcendent way, as it condenses human imagination and concretize it into the collective unconscious. Mythologies are canvases that define strategies and provide meanings to human experiences; in this sense, they look like a cognitive device [21]. For example, in his extensive work, Campbell analyzed, the worldwide similarities based on the hero's journey, the "monomyth" that is pervasive across many cultures of the humankind. Just like Campbell's hero's adventure, the journey of the caregiver begins in the ordinary world. He must depart from the ordinary world, when he receives a call to commence his adventure. The adventure of the hero starts with a request to leave his community (the "departure"); although reluctant at first, he starts a lonely travel across an enchanted and sinister region in which he will be guided by a mentor, who will guide him across "a guarded threshold, leading him to a supernatural world, where familiar laws and order do not apply". The mentor gives him advice and supernatural powers. After a long search, and an encounter with allies that will help him, and enemies he will defeat (the "Initiation"), he returns from this challenging venture to his community and is rewarded (the "return"). This monomyth used for reading the transcripts gives access to a narrative grounding in the collective unconscious as it was described by the classic psychologist Gustav Jung [14]. It also adds an advantaged access to consciousness, agency, and a spiritual dimension that were noticed in the story of the interviewed people. The monomyth allows to map their thoughts, actions, and events into a narrative that empowers and provides meanings to their life story.

6 The Journey

In the following sub-chapters we draw a comparison between The Campbell monomyth and the results of the qualitative studies. From the Hero's journey we isolated 4 phases: the departure, the road of trials, the victory and the acquisition of new powers. In Fact, the Campbell framework can be applied by recognizing even few phases from the original sequence.

6.1 The Departure

T1D enters in the life of a family often abruptly, with the child having a few symptoms revealed by blood tests, whose results often come as a shock to the parents. This is a traumatic experience and one of the worst memories in the life of a caregiver. Often, during the interview, after this question, the tone of the voice becomes sadder and the speaking is decelerated. There is a sharp line dividing life before – without the diabetes - and after the illness -with diabetes. This bleak revelation spurs negative feelings such as disruption, guilt, and fear inside the parent. Disruption comes from not knowing what the illness entails, thus, ignoring the impact it will have upon their lives. The guilt, however, originates from the thought of having an ill child, the fear is caused by a sinister and subtle, yet constant threat to the child's life. This is the beginning of the journey through the illness. The transformation from parent to parent-caregiver begins here.

C09: […] *Therefore, I measured his glycemic level and it was more than 300…I don't remember exactly how much because I blocked out most of that night…*

The departure of the caregiver-hero, starts from the exordium of the condition, when the physician discovers the illness of the young one. This is a negative event that the parent tends to go through with great heart-ship. This is the call for the departure: abrupt, shocking, unpleasant, throwing the hero in an unknown and hostile world, and leaving him in confusion and chaos [18]. The hero, then, lives a separation from his previous life that does not interest him anymore. The work life of the caregiver is affected as well. Their work efficiency is lowered, some caregivers quit their occupation, some others go back to work, but perform it without motivation or energy.

C09: […] *In the beginning, I never went out of the house without my son, […] I went back to work, unwillingly, I forced myself to do it, because it was the right thing to do, wasn't it?….*

This is one of the most relevant effects of the initial life of the caregiver, losing interest for the outside world and totally devoting themselves to the ill child. The decrement of passion for the working life is only one of the signs of depression of the caregiver in the beginning, and in a certain sense his/her previous life will never return to normal.

6.2 The Road of Trials

After the initial shock, the path continues with the caregiver looking for information about the illness, in order to understand what it means and what it implies in term of self-management. The moment the caregiver starts gathering information, balancing doses of insulin while counting carbohydrates, is the moment when he slowly starts making sense of this new aspect of his family life. Thus, the caregiver begins to create his own strategies of self-management on behalf of his son, who is obviously too young to manage T1D on his own.

CO3: *[…] I had to do a lot of studying, [there were] a lot of notions that I had to learn, a lot of conferences to go to, travels to take […] in order to perfectly know this pathology, the progress the scientific research was making, to personally know the researchers, the doctors… I immersed myself into this world…*

The world of the carer is populated by a lot of learning about the condition, in the beginning, and the continuous trials aimed to balance the blood levels of their child, later on. In this setting, the healthcare staff, offering information and support, has the role of mentors in the monomyth. There is a lot of inferential reasoning starting from several elements involved in the illness (food, physical activity, mood, etc.) and suffering from negative emotions, like the threat of night hypoglycemia (that can kill the young patient). After each trial, the hero starts being more and more confident in doing what he considered impossible in the life before diabetes [20].

The inner life of the caregiver is turned upside down. His/her cognitive load is seriously affected by the anxiety related to the illness and the modification of the routines. Everything looks new and potentially harmful, the caregiver is overwhelmed by this new, unexpected, and unknown thing related to his son, therefore, affecting also parental identity and their self-confidence. They never know if what they are doing is right or wrong; from the doses of insulin to inject, to the food to administer, or the physical activity to advise there is a lot of unknown territory. Above all, however, he has to learn how to correctly relate with the young patient regarding issues about the illness. Also, the fear of a son's nightly hypoglycemia affects their sleep, and they start living only for the ill child.

C08: *[Often] I didn't know how many units [of insulin] I had to give him, because it is obvious that you have anxieties, if it is too early, if it is too late, if everything went well. It is a job you have to learn how to do, how to manage your anxieties […] the job of the parent is huge, because, it is obvious, the more you do, the more the child is relieved [of the burden]…*

This is the new environment of the hero-caregiver, a world populated by risks, hazards, and pitfalls; in this phase, there is the need to both practice inferential reasoning (from the health parameters, the carbohydrates intake, the physical activity and the way to guess the doses of insulin to inject) and manage distress and negative thoughts, while not forgetting to reassure and tranquillize the ill child. There is a detachment from the world in the sense that the majority of people do not understand the struggle and often criticize the parents for being too dedicated and fail to comprehend the real problem this condition represents.

6.3 The Victory

Then routines begin settle in, and there is a growing, yet unstable and dynamic balance in the daily life of the patient and of the carer. The cognitive burden, the worries, and a pervasive feeling of sadness still mark their life; anyway, there is a slight but constantly ascending positive mood.

C07: *[…] it has been a change, but not a total change, if I think about it… if before we could wait till the last minute to prepare lunch…now I always try to have some pasta in the fridge, so, if he has an episode of a low glycemic level, he can find it ready… medical visits are every 3 months [..], then, of course, you have always the telephone close by […] but I have to say, recently I feel quite calm, I don't live with the fear that he calls me anymore. Of course, there is always the state of alert in the background…*

Self-management becomes a bond between the patient and the carer. This newly formed bond increases s their feeling of belonging together. This newly formed facet of their relationship is marked by ties of companionship and alliance to the extent that they share an important parts of their life much more than an average parent shares with their son. This is one of the most important life skills that the caregiver acquires across this path.

CO3: […] *The dialogues have changed during our daily life, because you enter in a different world, and your dialogues are now: how much is it?, is it high?, is it low?, did you get your insulin shot?, did you eat anything strange?…*

In time, living with T1D becomes a routine, and a new balance is gradually settled. It takes some time to make sense of the condition, accepting it and incorporate it in the daily life, in few words reducing it to just one more thing to think about. The illness becomes like an additional member of the family to take into consideration. There is a struggle in the family to seek normality, to reduce the burden of the condition as much as possible in order to consider itself as normal. This joint effort increases the components' synchronization and reinforces bonds. In particular, the special relationship between the parent caregiver and the ill child is tightened.

C08: *[…] Diabetes actually becomes a part of your routine, it is not difficult to have a routine, it becomes part of your life, you stick it into your own routine: When they are young, you wake up and measure their the glycemic level, you prepare lunch with the right food, you check the glycemic level again, if it is high, you take a walk…in the end, it becomes your own routine…*

M08: *[…] When he was younger, we always tried to make him understand that he was normal, that he did some things that were different from what the other children were doing, but normal nevertheless […], we tried to make him consider diabetes a normal thing, and, if managed in a certain way, his life could be like everyone else's…*

6.4 The Acquisition of New Powers

This phase of positive coping and the mastering of T1D brings some constructive consequences in the lives of caregivers, like appreciating good moments more intensely, searching and valuing authentic relationships, opening themselves to the world, optimizing time and being selective towards people and experiences. Life can never be like before the initial episode, but there are specific improvements that can make their life not so different from that of a non-caregiver.

M08: *[…] This illness, like any other illness, or like difficulties, strengthens you, in the sense that it gives you the capacity, that everybody has without knowing, of interacting with other people in order to survive…*

C09: *One thing that [S09]'s diabetes has taught me […] is to keep it simple and cut unnecessary relationships out of my life. It is useless to waste so many words: you either understand that I need you or you go away, if you are here only to cause troubles, you'd better go. I do not need you. This was our life change, even with family, once diabetes entered this house.*

The hero demonstrates he can master novel competences. Based on our data, we can affirm that the caregiver is able to manage not only the illness, but also all the negative feelings it brings along with it. Therefore, rationality and inferential reasoning as well as unconscious emotions like fear, anguish, guilt, or anxiety become more manageable for them. As a consequence, they regain interest for life. There is also a component of self-realization, the hero discovery of his unrealized, unused potential and his self-actualization [21], this, in turn, provides a new level of understanding about how the relationship with life could be.

7 Discussion

From the qualitative analysis, we learnt that caregivers gained, after much pain and trials, a privileged access to their irrational feelings that they have to accept, discipline, and turn into assets for caregiving. Caregivers fight against sugar fluctuations, and, in order to do this, they need to master both the unconscious and the rationality. These elements need to be managed, accepted and employed continuously. The work of Campbell [4] can be considered a canvas to make sense of parental carers' life stories and provides an interpreting tool that paints the whole picture of the story of parental caregivers. These men and women find understanding, inspiration, prediction and consciousness, intended as a deep sense of being present in one's own time and space, when facing a life-altering situation. In this sense, the mythology put forth by [4] is an organized narrative giving a meaningful structure to a set of symbols meant to organize a human experience. In fact, heroism is an approach to read intelligence as it is unfolding in daily life. The carer faces their problems in a transformative way that changes one's view on life, environment, and inner consciousness in the direction of an expansion, that is deeply restorative and generative. Accordingly, heroic behavior can be seen as a form of intelligent behavior that is embodied in everyday life, and proposes a reading of those "heroes". Thus, they are capable of heightened cognitive, psychological, and "transcendent" actions exhibiting increased awareness, the use of the body to modify the external world, and the acceptance of death [7]. Finally, as a possible future direction of this contribute, the Hero's journey in [4] can be considered in Healthcare HCI in terms of providing a broad and detailed canvas for the modelling of users and stakeholders in the phase of User Studies in the User-Centered Design process.

8 Conclusion

In this paper, we describe the strenuous journey of parental caregivers of T1D children and teenagers towards a complete management of the illness. We conducted a qualitative study based on narrative interviews that were analyzed and interpreted in the respective parts of the study. We used mythology [4] as a model for our narrative. In particular, we took inspiration from the journey of the hero that can be retrieved in numerous folk tales and myths and whose framework belongs to the collective imagination of most of the worldwide cultures and in the end to individual unconscious. Hence, we draw a path starting from a negative event, that is the kick-off point of a journey full of adventures due to which the hero learns and becomes stronger. From the qualitative analysis, some other minor steps of the Campbell paradigm emerged, like the help of the healthcare staff, that in the myth give the hero the instruments to win the battles, and the return to the original community with additional skills available for his members. The voyage ends with the hero having gained a novel balance in his life, as his travel through the illness has helped him to achieve novel levels of wisdom and understanding.

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