Prospectus

Developing a Novel Solution for Esophageal Atresia
(Technical Topic)

Theory of User Configuration and the Impact of Chronic Care Management on Young Patients
(STS Topic)

By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Introduction

A common birth defect seen in many newborns in the United States is the condition known as esophageal atresia, which is a discontinuity in the esophagus (CDC, 2017). This condition can have drastic negative effects on a newborn because it can prevent them from feeding (CDC, 2017). The current method of treatment is a simple surgical procedure which connects the two ends of the discontinuous esophagus (Kunisaki & Foker, 2012). Despite the usually successful surgery, recurrent narrowing of the esophagus known as anastomotic strictures can occur and result in difficulty swallowing for patients (Kunisaki & Foker, 2012).

The technical solution for this problem is first determining the exact cause(s) for the anastomotic strictures and then developing a novel solution based on the cause. A novel solution would treat the esophageal atresia but not cause strictures and as a result prevent repeat hospitalizations for the patients. Regardless of the cause, a technical solution alone is not sufficient to completely solve this issue. Social aspects such as the physician's own ideas about the patients they are designing a treatment plan for play an integral role in it as well.

Chronic care management has become the most common method of treating most long-term illnesses and conditions (Sochalski et al., 2009). The treatments plans however are usually designed with adult patients in mind (Sochalski et al., 2009). To further analyze the social aspects of this issue I will examine a case study of a young girl with asthma who was treated using a chronic care treatment plan designed with adults in mind and use the theory of user configuration to gain insight into how the designers of chronic care treatment plans neglect to consider the needs of younger patients when developing said plans but instead have an idea of the user that does not actually reflect the actual users of their technology. A complete solution to

this issue will consider both the technical and social aspects. Such a solution will effectively treat esophageal atresia while also not ignoring the needs of a child.

Technical Problem

Esophageal atresia is a birth defect that effects about 2.8 per 10,000 births in the United States (Kuo & Urma, 2006). The condition comes about when the esophagus does not develop correctly and forms into two portions which are not connected (Kuo & Urma, 2006). This can cause various issues to the patient including the inability to eat food (Tambucci et al., 2017). The current approach of treating Esophageal atresia involves a corrective surgical procedure that aims to connect the two unattached ends of the esophagus (Tambucci et al., 2017). This step of treatment is usually successful with most patients able to eat properly soon after (Kuo & Urma, 2006).

In about 20%-50% patients with esophageal atresia, however, there exists a phenomenon called an anastomotic stricture formation (Raitio, Cresner, Smith, Jones, & Losty, 2016). An anastomotic stricture is a narrowing of the esophagus which can result in difficulty swallowing in the patient (Ridtitid, Siripun, & Rerknimitr, 2018). The most common treatment for these strictures is known as an endoscopic dilation which involves inserting a balloon into the esophagus and then inflating said balloon to expand the esophagus (Raitio et al., 2016). A series of medications is also required for the patient to take after each dilation to promote repair and prevent any serious infections (Goldthorn, Ball, Wilkinson, Seigel, & Kosloske, 1984). This solution however is not a permanent one as the strictures can occur again and thus require more dilations and repeat hospitalizations (Stenström, Anderberg, Börjesson, & Arnbjörnsson, 2017).

Due to the nature and severity of esophageal atresia, along with the fact that it impacts patients early in their lives (Stenström et al., 2017), it is imperative that a novel solution is

developed to aid in the treatment of the condition. Without the development of a more permanent novel solution to the condition physicians will be forced to continue using the current method of endoscopic dilation. The current method while effective in treating the short-term symptoms of the disease simply does not fix the underlying cause of the anastomotic strictures and thus results in patients needing to have multiple hospital visits and stays (Stenström et al., 2017). The current procedure is also highly invasive and possess a variety of dangers for younger patients such as infections of the esophagus (Raitio et al., 2016). Since the patients are young children and newborns, these repeat hospitalizations and procedures can be disruptive and have a negative effect on their early development and quality of life since the strictures can occur into adulthood (Raitio et al., 2016). Furthermore, a novel permanent solution would benefit the parents of the patients as the financial and psychological burden would be decreased from not having their child hospitalized frequently. Hospitals would also benefit from this novel solution as less resources would have to be expended frequently in the service of treating patients with the aforementioned affliction.

The first phase to this technical solution will involve determining the actual cause for the repeated anastomotic strictures. Currently the cause for recurrent anastomotic strictures of the esophagus is unknown (Nguyen, Stevens, & Wolfe, 2003). In order to determine the cause of intermittent anastomotic strictures a computational model will be developed to observe whether the strictures are of a mechanical origin, biological origin or a combination of both. A novel solution will then be developed depending on the results of the computational model. First This solution, must be as effective as the current corrective surgical procedure for treating esophageal atresia. It must allow food to travel through the esophagus to the stomach efficiently, and it must be a safe solution to use in young children and newborns. Secondly, the solution must take into

consideration the cause(s) of reoccurring anastomotic strictures and avoid them. The core goal of the resulting solution will be to treat a severe and prevalent issue in newborns while also minimizing the amount of hospital visits and stays they will have to experience, post-operation.

STS Problem

In medicine, chronic care is care which is concerned in the management of pre-existing conditions or long-term illnesses as opposed to short-term care which deals with acute illnesses or conditions (Lubkin & Larsen, 2013). Repeat hospital visits and stays are a common experience for people with chronic medical conditions. People with asthma are admitted most frequently for repeat hospital stays in the United States (Adams, 2000). For the purpose of this analysis I will be discussing the case of a fifteen year old female patient born with asthma from Greece (Theodoratou-Bekou, Andreopoulou, Andriopoulou, & Wood, 2012). The patient was born with a severe form of asthma that was highly unstable and required frequent hospital visits for injections along with visits for any life-threatening asthma crises (Theodoratou-Bekou et al., 2012). The patient was also on a stringent treatment regimen of multiple medications in order to mitigate her severe symptoms (Theodoratou-Bekou et al., 2012). On a psychological level the patient was severely depressed due to frequent hospital visits caused by her asthma attacks, which caused her to feel ashamed and isolated from her friends and family (Theodoratou-Bekou et al., 2012). Academically, she had failing grades as a result of many lost school days, which in turn caused her parents to criticize her and furthered her depression and feelings of isolation (Theodoratou-Bekou et al., 2012).

The most unfortunate thing to occur with the patient was the severe burden her asthma and by extension the chronic disease management plan, placed on her already financially strained family. Both parents would have to miss some days of work in order to take care of the patient as

they could not afford a nurse and one was not provided to them (Theodoratou-Bekou et al., 2012). As a result, her father became emotionally distant from the patient and eventually the rest of the family (Theodoratou-Bekou et al., 2012). The rest of the family also grew quite anxious out of fear of losing the patient to a particular strong asthma attack (Theodoratou-Bekou et al., 2012).

The case study outlined here demonstrates an immense failure in the current method of managing chronic medical issues. Current methods lack intimate knowledge of the specific patient who is in need and instead follows a "one size fits all" methodology (Lubkin & Larsen, 2013) that fails to consider the unique circumstances that comes with each individual patient that can complicate treatments. While this method can work well for many adult patients it becomes especially likely to fail and create excess distress in young patients. Young patients have many more factors than adult patients which much be considered. Young patients risk social isolation due to frequent hospitalizations that separate them from their friends and family (Tsai et al., 2018). Their academics can suffer as well due to missing school days or simply from the stress brought about from their treatment regimens (Adams, 2000), and lastly there exists the psychological and financial burden chronic care can place on a whole family which in turn can negatively affect the child (Chen, Bloomberg, Fisher Jr., & Strunk, 20030108).

In order to further analyze the failings of the current chronic treatment model I will make use of the science, technology, and society (STS) framework of user configuration. User configuration is the concept that designers create technologies with their own ideas of who the users will be in mind; however, these "projected users" may not actually represent the actual users of said technology and as such may fail to successfully satisfy the actual users' needs (Oudshoorn & Pinch, 2003). In the case study of the fifteen-year-old asthma sufferer the

designers of her chronic disease management plan formed the plan with the assumption that the recipient would be a self-sustaining adult.

Conclusion

This paper will propose a solution to the problem of esophageal atresia that will be socio-technical in nature. The technical report will propose a permanent solution to esophageal atresia. The solution will be based on a computational model that determines the exact cause of recurrent anastomotic strictures. The resulting treatment will be effective and safe for newborns and children. The STS report will provide greater insight into the rigid ideas about the patients that govern many chronic illness management plans, such as those for asthma and thus makes them detrimental to the development of a child.

The resulting solution from the technical report combined with the insights from the STS paper will address not only the technical problem but also the social issues brought about by esophageal atresia and recurrent anastomotic strictures. The solution will consider the needs of a child and treat the condition in a way that does not lead to recurrent strictures. As a result, the solution will drastically minimize the amount of hospitalizations a young patient will receive. Since the amount of hospitalizations will be reduced, young patients will not have their early development disrupted and as such can lead healthier lives.

Word Count: 1800

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