

**Wearable Medical Devices in Use:
A Study of Insulin Pump Adoption by
Young Diabetic Patients
In Saudi Arabia**

Abeer Ghazy A. Almakky

A thesis submitted in partial fulfilment of the requirements of De Montfort University
for the degree of Doctor of Philosophy

Software Technology Research Laboratory
De Montfort University



February 2017

DEDICATION

In The Name of Allah, the Most Beneficent, the Most Merciful

This thesis is dedicated to my Father Professor Ghazy Almakky, and my Mother Wafaa Daghurstani.

My husband Khaled Shaban, my darling children: Rayan and Omar, without whom nothing would have ever happened.

ABSTRACT

This research belongs to the multi-disciplinary research community concerned with wearable medical technology and branches of sociology and psychology that study its impact. It addresses a real-life problem of Insulin Pump (IP) adoption by Children. This is important for Saudi Arabia, since it is among the top five countries in the world with the highest rate of diabetes. Theories of reasoned action (TRA), technology acceptance model (TAM) and health belief models (HBM) for some of the cases predict that the perception of benefits is the main motivator for the proper use of the technology. This is often not realised in practice, because the main theoretical focus is on the benefits of IP, specifically in the pre-adoption phase. In contrast, this research project is focused on the reasons why some diabetic children patients misuse the IP in spite of the initial perception of its benefits. To find answers to this research question, an empirical study of adoption of IP by children and young adults in Saudi Arabia was carried out. A novel analytical framework was developed in this study in order to unify different perspectives and expectations of the benefits of the IP for a diabetic child and young adult. The analytic framework is applied using empirical study of diabetic children struggling with the IP in the course of the adoption process, with main emphasis on the post-adoption phase. Research methods were predominantly qualitative, involving in-depth interviews and case studies. In the discovery phase, data was collected through interviews of medical personnel and case studies with children and their parents. The analysis was focused on different interactions between medical personnel, patients and their caregivers, the discourses among them in order to explicate the contradictions between them. The main findings are that contradictions show different expectations between the different actors. The medical personnel used medical reasons, whereas the caregiver focus on emotional aspects. However, the diabetic child was concerned with the life-style changes that the use of the IP caused. The different motivations create misunderstandings and result in resistance towards the IP. Age-related and culture-specific factors were also considered, but further research is needed to ensure that the findings can be generalised to other devices, age-groups, cultures and different social contexts. Such studies would also refine

the analytical framework and enrich research methodology to make generalisations possible.

DECLARATION

I declare that the work described in this thesis is original work undertaken by me for the degree of Doctor of Philosophy, at the software Technology Research Laboratory (STRL), at De Montfort University, United Kingdom.

No part of the material described in this thesis has been submitted for any award of any other degree or qualification in this or any other university or college of advanced education.

Abeer Ghazy A. Almakky

ACKNOWLEDGMENT

I would like to express my appreciations and acknowledgements for those who have supported me through my PhD journey.

First and foremost, my deepest gratitude to **ALLAH** (SWT) the most Gracious and Merciful for His infinite blessings and guidance.

I owe sincere appreciation to my supervisor, Professor Duska Rosenberg, without her continuous support this thesis would not have been possible. I have benefited greatly from her experience, wisdom and knowledge. Special appreciation goes to Dr Antonio Cau for his technical suggestions and guidance through my PhD journey.

I would also like to express heartfelt appreciation to my family. To my parents, Professor Ghazy Almakky and my mother Mrs. Wafaa Daghostani, I am grateful to your constant, love and support - you both have made me the daughter, wife and mother I am today.

Special appreciation goes to my mother in-law Mrs. Shadaya Kurdi, for her continuous prayers and moral support

My biggest thanks to my husband and best friend Khaled Shaban, for his friendship and continuous support in our life together, and especially for the very useful debates we shared during our PhD studies; he was my trustworthy advisor during my PhD journey like he is in our daily lives.

Special thanks go to my children, Rayan and Omar, I love you so much, thank you for being patient with me and letting me work on my thesis. I have devoted so much time from you during this research, thank you my dears.

I would also like to thank my sisters Dr. Hana and Dr. Rawa, and my three brothers, Dr. Mohammed, Anas and Badr for their continuous and unremitting love and support.

Finally, I would like to thank all my friends for all the encouragement they gave me during my PhD journey.

Thank you all.

Table of Contents

DEDICATION	II
ABSTRACT	III
DECLARATION	III
ACKNOWLEDGMENT	IV
CHAPTER 1 INTRODUCTION.....	13
1.1 INTRODUCTION	13
1.2 RESEARCH PROBLEM.....	15
1.3 RESEARCH MOTIVATION.....	17
1.4 RESEARCH QUESTION	21
1.5 RESEARCH AIM	21
1.6 RESEARCH OBJECTIVES	21
1.7 KEY DELIVERABLES	22
1.8 THESIS STRUCTURE.....	23
CHAPTER 2 LITERATURE REVIEW	26
2.1 INTRODUCTION	26
2.2 WEARABLE DEVICES	26
2.3 INSULIN PUMPS	27
2.3.1 <i>Technical Specifications</i>	28
2.3.2 <i>How it works</i>	30
2.4 BENEFITS OF IP FOR CHILDREN.....	31
2.4.1 <i>Medical Benefits</i>	33
2.4.2 <i>Non-Medical benefits</i>	35
2.5 DRAWBACKS OF IP	37
2.6 READINESS TO RECEIVE THE IP	47
2.6.1 <i>Patient Readiness</i>	49
2.6.2 <i>Family Readiness</i>	52
2.6.3 <i>Readiness improvement and education before using the IP</i>	55
2.7 CHAPTER SUMMERY.....	56

CHAPTER 3	THEORIES IN ADOPTION OF IP IN CHILDREN	59
3.1	INTRODUCTION	59
3.2	THEORIES OF ACCEPTING NEW MEDICAL TECHNOLOGIES.....	60
3.2.1	<i>Wearable Devices in Technology Acceptance Models (TAM)</i>	63
3.2.2	<i>Technology Acceptance Framework in Medical Wearable Devices</i>	64
3.2.3	<i>Health Belief Model</i>	65
3.3	BEHAVIOURAL MODELS IN ACCEPTING AND REJECTING ENFORCED BEHAVIOUR	67
3.3.1	<i>Patient adherence to medication / patient compliance</i>	68
3.3.2	<i>Cognitive dissonance and Psychological Reactance behaviours</i>	70
3.4	SOCIAL THEORETICAL FOUNDATIONS	71
3.4.1	<i>Contradictions</i>	71
3.4.2	<i>Sociomateriality</i>	73
3.5	KNOWLEDGE GAP ANALYSIS.....	74
3.6	CHAPTER SUMMARY	77
CHAPTER 4	RESEARCH METHODOLOGY	80
4.1	INTRODUCTION	80
4.2	RESEARCH STRATEGY	81
4.2.1	<i>Phase 1: Interview Research</i>	82
4.2.2	<i>Phase 2: Case Study Research</i>	85
4.2.3	<i>Ethical Considerations</i>	87
4.3	RESEARCH QUALITY	87
4.3.1	<i>Reliability</i>	89
4.3.2	<i>Validity</i>	90
4.3.3	<i>Credibility</i>	90
4.3.4	<i>Reflexivity</i>	91
4.3.5	<i>Transferability</i>	95
4.4	CHAPTER SUMMARY	96
CHAPTER 5	TECHNOLOGY ADOPTION FRAMEWORK FOR IP (TAF IP FOR CHILDREN)	98
5.1	INTRODUCTION	98
5.2	DEVELOPING THE ANALYTIC FRAMEWORK	98
5.2.1	<i>Research Perspective</i>	99
5.2.2	<i>Level of Analysis</i>	100
5.2.3	<i>The Analytic Constructs</i>	102

5.3	SUMMARY OF THE (TAF IP FOR CHILDREN).....	103
5.4	APPROACH OF THE ANALYTICAL FRAMEWORK.....	104
5.5	RESEARCH MODEL	105
5.6	CHANGE AGENT PERSPECTIVE	108
5.6.1	<i>Change Agent Motivations to prescribe the IP.....</i>	<i>109</i>
5.6.2	<i>Using change agent power to avoid improper use of the IP.....</i>	<i>110</i>
5.6.3	<i>Reasons for improper use from change agent perspective.....</i>	<i>111</i>
5.7	BENEFICIARY PERSPECTIVE: DIABETIC CHILD AND FAMILY.....	115
5.7.1	<i>Change agent perceptions</i>	<i>118</i>
5.7.2	<i>Caregivers' perceptions, feelings, attitudes and behaviour</i>	<i>120</i>
5.7.3	<i>Patient self-perception</i>	<i>126</i>
5.8	INTERPRETATIONS: CONTRADICTIONS	133
5.8.1	<i>First contradiction: between change agent and the diabetic child.....</i>	<i>134</i>
5.8.2	<i>Second contradiction: between caregiver and change agent.....</i>	<i>135</i>
5.8.3	<i>Third contradiction: the relationship between patient and caregiver</i>	<i>137</i>
5.9	SUMMARY	141
CHAPTER 6	DISCUSSION	143
6.1	INTRODUCTION.....	143
6.2	LITERATURE REVIEW AND KNOWLEDGE GAP.....	144
6.3	THE RESEARCH ANALYTIC APPROACH: EVALUATING THE ANALYTIC APPROACH.....	145
6.3.1	<i>Summary of Analytic Framework.....</i>	<i>145</i>
6.3.2	<i>Analytic Framework Evaluation</i>	<i>147</i>
6.4	AREAS OF IMPROVEMENT IN USING THE ANALYTIC FRAMEWORK TO OTHER DOMAIN.....	150
6.4.1	<i>Sampling technique</i>	<i>150</i>
6.4.2	<i>Evolving the level of contradictions among different actors through time</i>	<i>150</i>
6.4.3	<i>Generalisability of the analytical framework.....</i>	<i>151</i>
6.5	THE RESEARCH FRAMEWORK	153
6.5.1	<i>Change agent perspectives towards the IP</i>	<i>154</i>
6.5.2	<i>Perceptions of the Caregivers towards IP</i>	<i>155</i>
6.5.3	<i>Child perception towards the IP</i>	<i>157</i>
6.5.4	<i>Contradictions between different agents (the definition of contradiction)</i>	<i>157</i>
6.6	CHAPTER SUMMARY.....	159
CHAPTER 7	CONCLUSION	161

7.1	PROBLEM DESCRIPTION	162
7.2	RESEARCH QUESTION: HOW CONTRADICTIONS BETWEEN THE DIFFERENT ACTORS IN DEFINING AND UNDERSTANDING THE IP AFFECT THE MAIN BENEFICIARY (CHILD) UNDERSTAND, DEFINE AND BE MOTIVATED TO USE THE IP?	163
7.3	UNIFORM ANALYTICAL FRAMEWORK.....	165
7.4	CONTRIBUTION TO KNOWLEDGE	165
7.5	RESEARCH METHODS	166
7.6	IMPLICATIONS FOR PRACTICE	167
7.7	RESEARCH LIMITATION	169
7.8	FUTURE RESEARCH	170
	REFERENCES.....	172
	APPENDIX.....	196

LIST OF FIGURES

FIGURE 1-1: RESEARCH MOTIVATION	20
FIGURE 1-2: CONTRIBUTION STRUCTURE.....	23
FIGURE 1-3: THESIS STRUCTURE	25
FIGURE 2-1: CHAPTER 2 STRUCTURE	26
FIGURE 2-2: SMART WEARABLE	27
FIGURE 2-3: IP DEVICE ATTACHED TO THE BODY (ADAPTED FROM HYDERABAD ENDOCRINOLOGY, 2016).....	29
FIGURE 2-4: INSULIN PUMP AND INFUSION SET (ADAPTED FROM REECE & WILLIAMS, 2014)	30
FIGURE 2-5: FACTORS AFFECTING THE ACCEPTANCE OF NEW TECHNOLOGY	31
FIGURE 2-6: BENEFITS OF IP	32
FIGURE 2-7: DRAWBACK OF INSULIN PUMP THERAPY	38
FIGURE 2-8: SCHEINER ET AL., (2009) FACTORS RELATED TO SUCCESSFUL INITIATION OF INSULIN PUMP THERAPY	48
FIGURE 2-9: READINESS ELEMENTS.....	49
FIGURE 2-10: FACTORS OF PATIENT TO BE ESSENTIAL FOR ACHIEVING SUCCESS IN USING THE IP.....	49
FIGURE 2-11: FACTORS OF FAMILY TO BE ESSENTIAL FOR ACHIEVING SUCCESS IN USING THE IP FOR CHILD	53
FIGURE 3-1: CHAPTER 3 STRUCTURE	60
FIGURE 4-1: CHAPTER 4 STRUCTURE	81
FIGURE 4-2: RESEARCH STRATEGY	82
FIGURE 4-3: REFLEXIVITY ELEMENTS	92
FIGURE 4-4: CHAPTER SUMMARY	97
FIGURE 5-1: CHAPTER 5 STRUCTURE	98
FIGURE 5-2: ANALYTIC FRAMEWORK ELEMENTS	99
FIGURE 5-3: LEVEL OF KNOWLEDGE	101
FIGURE 5-4: THE ANALYTICAL FRAMEWORK	103
FIGURE 5-5: MODEL TO UNDERSTAND DIABETIC CHILD BEHAVIOUR.....	107
FIGURE 5-6: CONTRADICTION FRAMEWORK.....	117

CHAPTER 1 Introduction

1.1 Introduction

Wearable devices are now being used by a significant proportion of people in their daily lives to manage their health and wellbeing (Giani et al., 2016). Wearable device releases, lower prices, and company rationalizations marked the first quarter of 2016 in the worldwide wearable market. According to data from the International Data Corporation Worldwide Quarterly Wearable Device Tracker, overall 19.7 million wearable device units have been sold in 2016, an increase of 67.2% from the 11.8 million components shipped in 2015 (Mass, 2016).

In this thesis, the research focus is on the adoption and use of the Insulin Pump (IP) as a medical wearable device. The first connected devices, which help the user to take their therapy through convenience and the use of apps, are already on the market and in development. For example, Insulet Corp. (Billerica, Mass.) market the stick-on OmniPod IP. However, rates of IP use appear to vary greatly world Wide (Maahs et al., 2010); (Beck et al., 2012). Moreover, Heinemann (2015) mentioned that the exact number of IP users worldwide is not known, because it is not reported by the manufacturers. However, it is estimated from financial reports, which suggest that the number may be between 0.75 to 1.0 million. A recent Medtronic Mini Med Paradigm and 530G pump recall included 444,374 units in the US and 293,000 patients elsewhere (close Concerns, 2014). Worldwide sales of medical devices are predicted to reach 27.8 billion Us dollars by 2022, as reported by Grand View Research, Inc. “Rising prevalence of conditions such as obesity and hypertension, as a result of sedentary lifestyle is anticipated to boost the demand for wearable medical devices”.

Wearable devices in general, such as fitness and wellness monitors, are used in

monitoring activity and emotions. Healthcare and medical devices are used in monitoring vital signs, such as blood pressure monitors and glucose monitoring defibrillator. Another type of medical device are drug delivery products such as, IP. Thus, the IP is considered to be a wearable -health management that is self-managed device that is prescribed to deal with diabetes and is overseen by medical professionals.

Diabetes is a global epidemic with 382 million people affected by the disease worldwide and with figures expected to rise to 582 million by 2035 (Guariguata et al., 2014). In Saudi Arabia, diabetes remains a major public health problem affecting 24% of the population. Furthermore, the number of children and adolescents with type 1 diabetes has more than doubled in the past decade with average incidence rates reported at 27.2/100,000 population (Al-Mendalawi and Al-Herbish, 2009; AlBuhairan et al., 2016).

The number of diabetic patients is increasing in numerous regions of the world (Association, 2012; Aanstoot et al., 2007). In many studies, it has been reported that the incidence of diabetes in Saudi Arabia are raised drastically over the last 25 years (Cherian et al., 2010). The rates of children and adolescents with diabetes in Saudi Arabia is almost 109.5 per 100,000, which is higher than many developed countries (Al-Hayek et al., 2014; Al-Herbish et al., 2008). Thus, the Saudi government subsidize the IP for those children who suffer from diabetes, as IP has several benefits for the children and many doctors advise it. However, as mentioned by Heinemann (2015) there are several reports of patients' and doctors' dissatisfaction with risks involved in misusing the IP and consequent withdrawal of the pump (de Vries et al., 2015, Hofer et al., 2010a) Hofer et al., 2010). As reported by Heinemann (2015), estimates of rates of IP discontinuation in children and adults range from 0–64%.

There are number of advanced medical technologies such as monitoring, and delivery of medication since 1922 have transformed the lives of millions. However, the fact that “sophisticated technology can be added to deliver devices and accessories, does not mean it is always the best thing for the patient” (Fry, 2012, p. 947). Therefore, it is important to understand why the IP or a similar medical device that is expected to help and improve

the condition of diabetic children is failing to do so. For this reason, this research investigates the reasons for adoption and discontinuation among Saudi nationals, evaluating the views and attitudes of users, families and the healthcare sector specialists. These may affect the children patients, and their families, and encourage them to use it properly. Indeed, the misuse of IP, as is the case with any technology, would cause harm and dissatisfaction or even unintended results which in turn may lead to the discontinuation of IP.

1.2 Research Problem

Diabetes is one of chronic diseases that cause biological (Nelson et al., 2012) psychological (Wong et al., 2010) cultural and social challenges and that have strong impacts on quality of life. These factors have been studied focusing on medical condition (Moyses et al., 2009), psychosocial condition of the patients, their family members and caregivers (French et al., 2010). The view of IP as a wearable device brings into focus the specific nature of the device as it becomes integrated with the patient's body (unlike more traditional wearable devices such as smart glasses, smart clothes, etc.) and this has consequences for the adoption, patients' attitudes, behaviour, in the way they respond to their condition in general and the IP. Thus, the study of IP adoption in this context requires a broader perspective on the people involved - not only the patient and the medical personnel, but also the patient's family, friends, social pressures. Thus, this research addresses a real-world problem - IP has the capability of improving the quality of life of diabetic patients, but its take-up is disappointing. In the literature, there is a research gap between the expectations of IP benefits that are based on the capability of the technology to maintain steady glucose levels and the reasons why these expectations are not met in the real-life practice.

The use of IPs in Saudi Arabia is currently somewhat low, and there is limited indication regarding their effect on glycaemic control and diabetes treatment satisfaction (Hayek et al., 2015; Sharef et al., 2015). Bin Abbas et al. (2005) mentioned that the number of IP

users among Saudi children is still small. As he stated, the lack of patient/family motivation, health care team enthusiasm and proper technical support are among the contributing factors for that” (Bin-Abbas et al., 2005) A partial explanation for this may be related to the usability of modern technologies, where interest levels may be transient and adverse experiences common, for example occurring in over 40 % of users per year, with a minority, particularly in children, requiring hospital management. This research thus aims to generate insight into the range of potential IP-associated adverse events and their impact on adoption and ongoing usage of the technology, including the incidence, features, impacts, and contributory factors such as skills and knowledge of the pump user, their supporters and healthcare professionals.

The use of IP by children presents unique issues and different problems not found in adult IP users and in older individuals (Giani et al., 2015). Furthermore, it was mentioned that there is no guarantee that patients will achieve improved diabetes control with IP. (Gonder-Frederick et al., 2011). Moreover, problems of discontinuation of IP has been noted widely in literature (de Vries et al., 2015; Hofer et al., 2010). Discontinued pump use has been, for variety of reasons noted, most commonly related to user comfort (Heinemann et al., 2015). The reasons can be attributed to the IP design factors or human factors (FDA, 2014). The problem is not with the design only, since pump failures can be caused by insulin infusion or blockage on the insulin infusion set, as well as the site where the insulin infusion is attached to the body, issues with the insulin stability, as well as user error and or any combination of these issues. (Regittnig et al., 2013). Self-management of the IP is essential (Educators, 2009, Comeaux and Jaser, 2010a, Tumminia et al., 2015). Thus, evidence from literature shows that the technology is not the main factor responsible for this discomfort with the IP; rather, the causes lie in people and technology. Thus, the research in this project is focused on their interaction with the IP.

Human interaction with technology can be understood using different theoretical lenses such as socio-technological approach and technology acceptance models. Indeed, human behaviour is mainly driven by psychological factors such as attitudes, motivations and

perceptions. Thus, understanding these psychological factors is expected to be useful for understanding the relationship between the patient and her/his family (i.e. socio perspective) and the technology (i.e. techno perspective). If factors affecting this psychological relationship are discovered, human behaviour can be adapted to the proper use of IP in particular circumstances.

Psychological factors are important, not only where there is psychopathology (pathological anxiety or fear, depression, eating disorder, and cognitive impairment) but more importantly as the factors that determine everyday “normal” behaviour (Harvey (2015)). Because of the perception of obligation to use the IP forever, a higher rate of complications might occur in patients who are poorly motivated or non-adherent (Pickup et al, 2014).

1.3 Research Motivation

The main motivation is to increase knowledge about assistive technology so that genuine people needs for assistance can lead a better and safer life. The research in this project was centred on medical devices for diabetic patients, since medical technology is advancing, and diabetes is increasing.

Understanding and minimising real life problems that arise when patients interact with a medical device is important. Technology has delivered great benefits, and it can continue to do so. For diabetes (and other chronic conditions), the delivery device is the drug-to-patient interface which is important. The ultimate objective is to help patients comply with their therapy and manage their condition (Fry et al., 2012).

The IP is a medical device that is integrated to the diabetic patient body to improve and or control the diabetes, “expected to improve long-time metabolic outcome in patients using this treatment” (Giani et al., 2015). Although Pańkowska et al., (2009) mentioned that the systematic reviews of children in using IP showed only modest benefits between 0% to 0.9% medical improvements compared with the normal insulin injections. (Giani et al., 2016). Indeed, this raises an interesting research question, why the IP does not have

a significant improvement on children health? The answer to this question can be sought in the improper use of the IP (Shulman et al., 2016).

That's why I am interested to see how technology can have an effect for patient health. I was motivated to go and investigate the use of technology in Saudi Arabia why the IP is not used in the proper way.

In this project, the effect of technology on patients' health and well-being was centred on the adoption of IP by diabetic children and adolescents, with special emphasis on the misuse of IP. There are different schools of thought interpreting improper use of the IP. These include cultural (Al-Hayek et al. 2014), family (Alsaleh et al., 2012) and psychological factors (Müller-Godeffroy et al., 2009). Culture is defined as the shared patterns of behaviours and interactions, cognitive constructs, and affective understanding that are learned through a process of socialization (Hofstede 1984). Culture has a significant effect on people's behaviour, beliefs, and decisions. Thus, it is not surprising that culture influences an individual's acceptance and use of wearable technology. Although there are studies in developed countries (Willi, et al., 2015) and developing countries (Daya et al, 2014), Arabic Gulf countries have a distinctive environment where the income is comparable to developed countries but the culture and behaviours are still, from technology adoption angle, in the range of developing countries. Furthermore, the Arabs have a distinct lifestyle and culture that does not always work to their advantage with regards to diabetes care (Beshyah & Deeb, 2012). In developing countries, a perception of being weak or disabled is a source of shame (Hofstede, 2010). This can expose the unique perspective in understanding the patient behaviour in a country such as Saudi Arabia, taking into consideration the cultural factors.

In particular, family members' and the surrounding' social group perceptions, attitudes and behaviours can be significant factors leading to discontinuation of the IP. Binek et al, (2016) mentioned that the caregiver's lack of engagement and therefore lack of management of IP is an issue. Indeed, it is not clear from their study what the reasons behind this disengagement in managing the IP for their children regardless the obvious benefits of it may be. Such lack of proper management of IP would cause discomfort to

the child, discourage the parents, and eventually lead to the discontinuation of the IP. At the same time, many families have a negative perception towards the IP. They perceive it as uncomfortable or are apprehensive of the daily use of newer IP technologies in younger children (Cope et al., 2012). As the contribution of the caregiver is significant in children and young adults, their attitude and perceptions toward the IP for children is a cornerstone in understanding the patient behaviour (Kesavadev et al., 2010).

Family members are not the only ones who can shape the diabetic children behaviour towards the IP, doctors and educators are also important. The ways the relationships between diabetic children and doctors and educators are developed are largely based on cultural factors. These relationships between the behaviour and culture in the adoption of medical devices have been discussed in different contexts. For instance, Compos (2007) mentioned that the Hispanic cultural values can affect the patient-provider relationship negatively, which can result in decreased satisfaction. Such behaviours include: Patients may be hesitant to ask questions because questioning an authority figure (e.g., a physician) is viewed as disrespectful. Patients may nod in response to physician's instructions as a sign of respect even when they do not understand the instructions. Indeed, this problem can be approached from another angle: the significance of doctors' role. If doctors and educators understand these cultural problems and appreciate how they might affect the patient behaviour, they can overcome potential misbehaviours.

Thus, in this research the interaction between patient behaviour and culture is explored from a user-centric perspective in order to see how the patient and his/her parents are perceiving themselves, perceiving others perceiving them and how they respond to these perceptions. In Information Systems literature, perception affects the attitude and attitude affects motivations and behaviours (Montano and Kasprzyk, 2015). Thus, by understanding the different perceptions and the interactions between them, a new framework can be developed for understanding behaviour.

Furthermore, from a psychological perspective, there are two main approaches to understanding behaviour. First, the acceptance of adherence to an "obligatory" device attached to the body in continuous use over a long period of time. In other words, long-

term commitment and integration of an external body to human body may be psychologically rejected from the patient perspective. The psychological factor of the patient having the pump being attached to the body and feeling discomfort, embarrassment (de Vries et al., 2010) can lead to difficulties controlling the diabetes (Morris, 2015). Meanwhile Binek et al., (2016 p.68) mentioned that “The individual psycho-emotional state of the child and appropriate education are important at the start and continuation of IP”. As Wood et al., (2006) mentioned, IP discontinuation in adult populations may not be applicable to youth with type 1 diabetes given the unique physiological and psychosocial characteristics of children and adolescents, such as pubertal growth and development, reliance on family members for assistance, and the challenges of increasing autonomy during adolescence (Moreland et al., 2004; Palmer et al., 2004).

Most of the studies regarding non-adherence to treatment were done in developed countries and with adults, where the culture from developing countries is different (Raza et al., 2014). It has not been studied how a different culture in a developing country with a different age group (i.e. children) can have different and unique results.

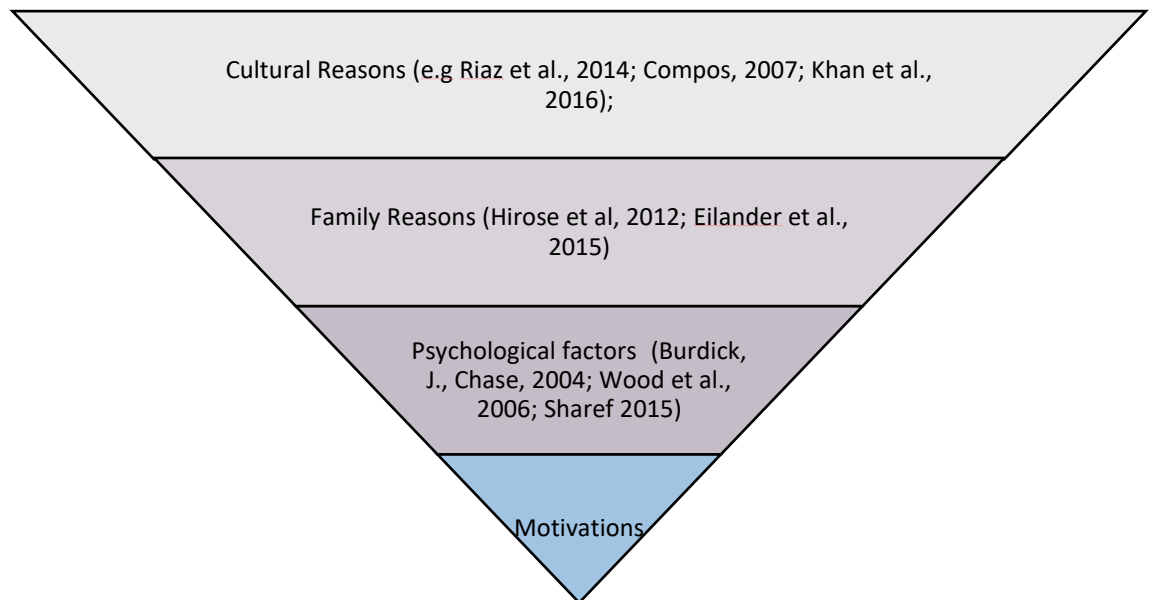


Figure 1-1: Research Motivation

1.4 Research Question

The main research question is “How contradictions between the different actors in defining and understanding the IP affect the main beneficiary (child) understand, define and be motivated to use the IP?”

The research sub questions are:

- Why some children use the IP improperly after its adoption?
- What is the role of the family in preventing or facilitating improper use?
- What are the motivations that lead to improper use?

1.5 Research Aim

By answering this research question, the research can achieve its aim which is

To develop an *analytic framework* for understanding the contradiction between different actors' definitions and motivations towards the IP that influences beneficiaries' motivation to use the IP.

1.6 Research Objectives

To fulfil this research, aim, this research has certain objectives. These objectives focus on understanding different perceptions: agent, parents, and child. By having such understandings, the contradictions between them can be shown and investigated in such a way the behaviour can be understood.

1. To identify and to understand the change agent perspective towards the IP
2. To understand the parents' perspective towards the IP
3. To understand the main beneficiary (child) towards the IP
4. To understand the interactions and contradictions between different actors
5. To understand how these interactions are affecting the child perception, attitude and motivations towards the IP.

1.7 Key Deliverables

There are two main key deliverables. First is the analytic framework to understand the reasons for improper use. The analytic framework serves to provide and derive an understanding of the facts, taking into consideration the various theories that can be partially or wholly utilised to explain those facts. As a consequence of this, the proposed analytic framework restricts the understanding into a limited number of main interpretations: understanding how different discourses and perceptions shape the perception of beneficiaries, using both contradictions and socio-materiality theory; and understanding how the produced perception creates a pattern of behaviour, using TRA (i.e. the belief that subjective norms affect attitude, which in turn affects behaviour).

The second deliverable is applying the analytic framework on two case studies to understand the child motivations to misuse the Insulin Pump. According to the analytic framework there are three level of analysis: facts, interpretations, and explanations. The facts are based on what the actor perceives while interpretation is how the researcher understands what is said based on the context and other actors' perceptions (List of perceptions are included in 5). The explanation is based on deriving from the different interpretations of different actors towards a single object, the IP. Explanations are focused on understanding how these facts are influencing the child attitude towards the IP, which in turn affects the behaviour. The main finding is the contradictions in defining the IP between actors creates a unique perception by the child which in turn led to un-intended behaviour.

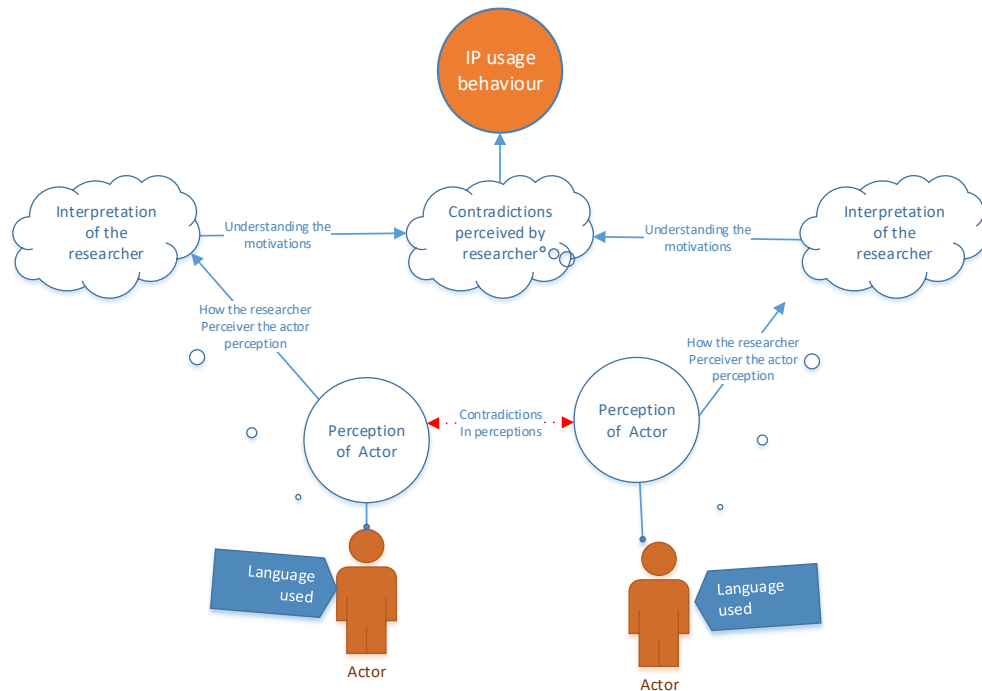


Figure 1-2: Contribution Structure

Symbol	Meaning
Clouds	Views toward the IP
Circle	Behaviours
Red dotted arrow	Relationship – Contradictions
Tag	Discourse used in understanding technology

1.8 Thesis Structure

The thesis is structured into 7 chapters Figure 1-3. The content of the 6 chapters is briefly outlined below:

Chapter Two is a review which provide a coherent theoretical background of the insulin pump (IP), specifically for readers who do not know about the benefits and drawbacks of this device. The defining the concept of wearable devices. This is followed by a discussion of the underlying concept of IPs, as well as their technical and operational specifications. Given that this thesis aims to understand the reasons for the improper use of IPs, a discussion is provided of their main motivators (benefits) and de-motivators (drawbacks). Finally, as the proper and improper use of IPs is generally thought to be

largely dependent on whether they are ready to use before and after adoption. The chapter concludes with an examination of patient's readiness to receive the IP.

Chapter Three provides further literature sources to discover how the person perceives and defines the technology affects the attitude toward it and therefore the use of the IP. Will first highlight and explain the theories in adapting the IP (TAM, TRA, TPB and HBM). Secondly the behavioural models in accepting and rejecting medication by the patient the perception of benefits will be discussed. Thirdly the sociological themes to develop the theoretical foundations for understanding how the child logics are formulated.

Chapter Four discusses the research approach and methods adopted and reflected in the way which data about the problem situation should be gathered. This research is an interpretive qualitative research. Its strategy is based on two phases; interview research and case study. Finally, the research issues are discussed.

Chapter Five aims to develop the technology adoption framework (TAF) for IP for children. It includes 2 main stages. The first stage is developing the analytic framework, through understanding the research perspective, level of analysis, analytic constructs and application of this analytic framework. The second stage is the implementation of the analytical framework. It is based on empirical investigation in Saudi Arabia using qualitative methods including interviews, observation and case studies. Representative sample of the informants were chosen from medical personal (change agent) and child and adolescent diabetic patients together with their families and caregivers (beneficiaries)

Chapter Six seeks to provide an explanation of the discovery results and the answer to the research question: How contradictions between the different actors in defining and understanding the IP affect the main beneficiary (child) understand, define and be motivated to use the IP)? In simple terms, the explanation seems to be found in the contradictions that exist between the differing expectations of the three types of agent involved in this context, namely the change agents, patients and caregivers

Chapter Seven summarises the problem description, research question, critical review of the contribution is given, research limitation and Future research.

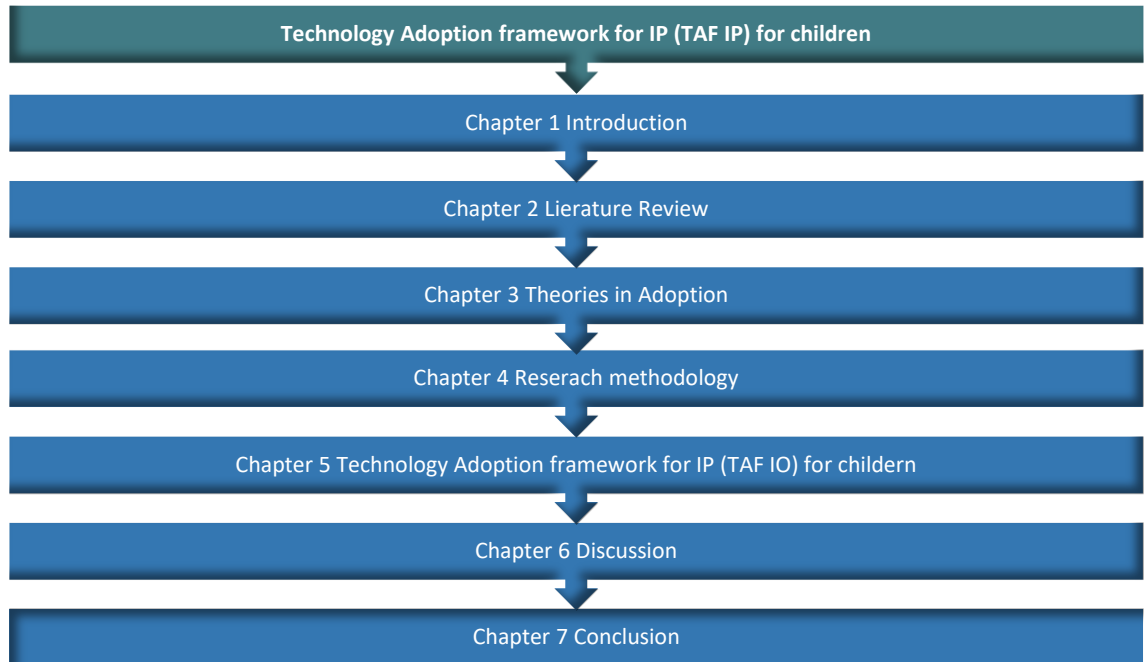


Figure 1-3: Thesis Structure

CHAPTER 2 Literature Review

2.1 Introduction

This chapter seeks to provide a coherent theoretical background of the insulin pump (IP), specifically for readers who do not know about the insulin pump specification, benefits, drawbacks and readiness of the device. The structure of the chapter can be found in Figure 2-1, and begins by defining the concept of wearable devices. This is followed by a discussion of the underlying concept of IPs, as well as their technical and operational specifications. A discussion is provided of their main motivators (benefits) and demotivators (drawbacks). It also provides the readiness to receive the IP, as the proper and improper use of IPs is generally thought to be largely dependent on whether they are ready to use before and after adoption (Cogen et al., 2002; Weissberg-Benchell et al., 2003; Grunberger et al., 2014). That will include the patient readiness, family readiness and role of education.

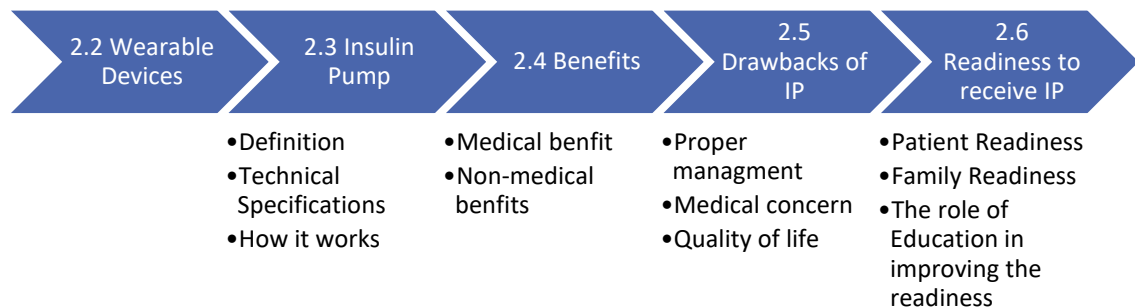


Figure 2-1: Chapter 2 Structure

2.2 Wearable Devices

The term ‘wearable technology’ is usually deemed to include a range of devices that are mounted on the bodies of users, “such as “wearable computers, smart clothing, and functional clothing” (Dunne, 2004). The term is used to describe devices that may or may

not “compute” and which have been constructed to perform set tasks, to fulfil the needs of a specific target group (Malmivaara, 2009; Dunne, 2004). In broad terms, wearable technology can be classified as smart, interactive or digital clothing, referring to devices that have been combined into garments to add new functionality, such as the ability for information to be processed (Dunne et al., 2005). These kinds of modifications impart the ability for ‘intelligent’ or ‘smart’ clothing to react to environmental circumstances by sensing and adapting to local stimuli (Baurley, 2004). These types of clothing therefore constitute the integration of science with fashion, with several computerised functions. This research focuses on one medical wearable device, namely, the Insulin Pump.

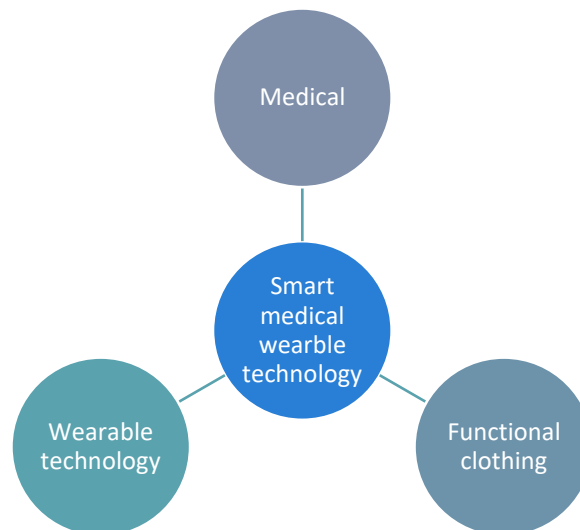


Figure 2-2: Smart wearable

2.3 Insulin Pumps

The first insulin pump (IP) was designed in the 1960s, by Arnold Kadish. While the first version was the size of a large backpack, these devices have become much smaller and more sophisticated in the years since, with many now being approximately the size of a small mobile phone. The improved development and design of these devices makes

insulin pump therapy, also known as continuous subcutaneous insulin infusion (CSII), a viable alternative to the use of multiple daily injections (MDIs) (Reece, 2014; Marcus and Fernandez, 1996) in the treatment of conditions such as insulin-dependent diabetes (Reece and Williams, 2014; Bray, 2012; Heinemann et al., 2015).

Modern IPs are small devices that generally weigh around 400 grams and are worn outside the body, such as on a belt. They contain insulin-filled cartridges that deliver insulin continuously through a thin tube is inserted internally (Duffy, 2015). Effectively, an insulin pump can be understood as, “an electro-mechanical device that mimics the body’s natural insulin secretion from pancreatic beta-cells by subcutaneously delivering rapid-acting insulin both at pre-set continuous basal rates and in extra bolus doses at mealtimes on demand” (Reece and Williams, 2014).

These devices are therefore used by people who require the regular delivery of insulin to their body, such as individuals with diabetes. Pumps are programmed to deliver or ejects insulin continuously through the day, as well as to release supplementary doses of insulin to handle rises in blood sugar (e.g. after eating) (Bruttomesso et al, 2009; Danne et al., 2008; Phillip et al., 2007). As is evident from this outline, the existing literature on IPs is technically oriented, describing the technological artefact without taking into consideration its human aspects. Therefore, this research defines an IP as a medical wearable device that shall be continuously attached to the body so as to, if properly used, improve the quality of life of diabetic persons.

2.3.1 Technical Specifications

The components of the insulin pump include a tank or called reservoir, a pump, and an infusion set (Schaepelynck et al., 2011, Reznik and Cohen, 2013). The reservoir functions in a manner like a syringe. It typically has the capacity to hold the supply of the insulin for 2-3-days, which functions with the battery-powered pump (Reece et al., 2014). The infusion set consists of tubing that connects the reservoir to a cannula (i.e. a tiny tube that delivers insulin subcutaneously); this delivers the insulin from pump to patient’s body

(Schaepelynck et al., 2011; Reznik and Cohen, 2013). The design of a representative IP can be seen below Figure 2-3.

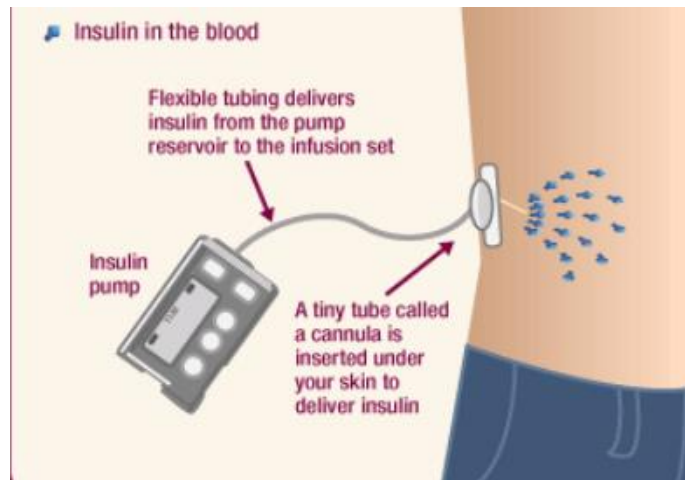


Figure 2-3: IP device attached to the body (adapted from HYDERABAD ENDOCRINOLOGY, 2016)

A small piece of adhesive holds the cannula in place at the insertion site (see Figure 2-4(Reece and Williams, 2014)), which is typically the upper arm, the upper thigh, or the abdomen. The infusion set is generally changed every 2-3 days, which also corresponds to the aforementioned capacity of the reservoir (Reece and Williams, 2014). Pumps deliver insulin through small tubing called a cannula into a catheter that is inserted into the skin. Insulin is then absorbed from the subcutaneous tissue (Heinemann et al., 2015).



Figure 2-4: Insulin pump and infusion set (adapted from Reece & Williams, 2014)

2.3.2 How it works

The insulin pump (IP) offers another way to provide intensive insulin therapy, as opposed to the more common approach of MDIs (multiple daily injections), either using insulin pens or syringes. As with these more traditional methods, IPs still require the patients to undertake certain manual tasks, like carb counting and blood glucose monitoring, refilling the insulin reservoir, changing the infusion sets etc. (Kamble et al., 2013).

Pumps deliver insulin in two ways. The first method involves the continuous delivery of basal rate insulin (Morrison and Weston, 2013). This describes small increments of rapid/short-acting insulin being delivered at specific intervals throughout the day in accordance with the baseline requirements of the patient (Sherr and Tamborlane, 2008; McAdams and Rizvi, 2016b). The specific dose is calculated to the needs of the individual and can be changed if necessary. The second mode of delivery is bolus insulin, which describes the insulin given with meals and snacks containing carbohydrates. This can also be used to correct high blood-glucose values (Everett, 2004; Bray, 2012; Błazik and Pańkowska, 2012).

The calculation of bolus doses requires the user to know the number of carbohydrates that will be consumed and their current blood glucose level, which is then used to calculate the dose based on a number of factors. These include: the insulin sensitivity factor of the user, meaning the expected effect that a single unit of insulin will have on their blood sugar; the specific insulin-to-carbohydrate ratio of the user; and the remaining insulin that is active from their last dose (Rubin and Peyrot, 2010). For the insulin pump to be effective, it must be used safely: carbohydrate consumption must be counted and tracked; the blood glucose of the user must be checked four or more times every day; and the insulin dosage must be continually adjusted in response to these values, plus overall level of physical activity (Pickup, 2012; Approaches to Glycaemic treatment, 2015). Pumps are also able to deliver boluses that provide additional insulin boosts to account for

ingested carbohydrates or hyperglycaemia (Boyd & Boyd, 2008), or deliver corrections to adjust pre-meal blood glucose values (Klobassa & Moreland, 2013).

Due to the fact that the IP is a relatively new technological improvement, patient readiness may be a critical factor in accepting this new technology (Heinemann et al., 2015), which may be exacerbated by the perception of benefits (e.g. theory of planned behaviour and theory of reasoned action) and drawbacks (Judith et al., 2012). In the following sections, these key factors are discussed in reference to the literature, as illustrated in Figure 2-5.

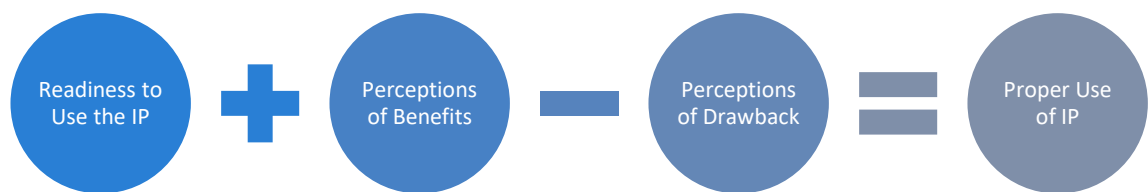


Figure 2-5: Factors affecting the acceptance of new technology

2.4 Benefits of IP for children

The insulin pump offers a number of benefits and drawback. This section will discuss the perception of the positive using IPs in the treatment of children. The following section will discuss the negatives of using the IP.

Insulin pumps can be perceived from the medical (i.e. physicians) angle and non-medical (i.e. patient) angle. In general terms, the medical benefits tend to be more concerned with the patient materialistic system, whereas non-medical benefits are individual or soft (psychological) benefits. However, the patient considers both the medical and non-medical benefit of the IP during the post transition. While often closely related, these two benefits can often be perceived differently, because the medical benefit provided by the IP will be perceived from the professional perspective of the patients having to control the diabetes. In other words, the outcome of diabetes technology management in children and families with type 1 diabetes is likely to be a clear impact on the quality of life and

glycaemic control (Hirose et al., 2012a). Having said this; the management of the insulin pump can impact the outcome medically and non-medically.

Having precise insulin dosages enables the IP to be programmed and administered (DeVries et al., 2002), giving the patient increased flexibility in daily living with regard to a range of activities, such as mealtimes, travel, or work schedule (Davidson et al., 2008). As quality of life measures have shown improvement with Insulin pump compared with traditional injection (Hoogma et al., 2006, McAdams and Rizvi, 2016a). In simple terms, the IP offers the benefit of glycaemic control, enabling a reduction to be made in the occurrence and severity of the difficulties of diabetes, as well as improving the flexibility of meal times, carbohydrate quantities, and physical activities (Cummins et al., 2010).

This section will highlight how the medical benefits and the procedures involved in using the insulin pump will also impact upon the non-medical benefits, as illustrated in Figure 2-6.

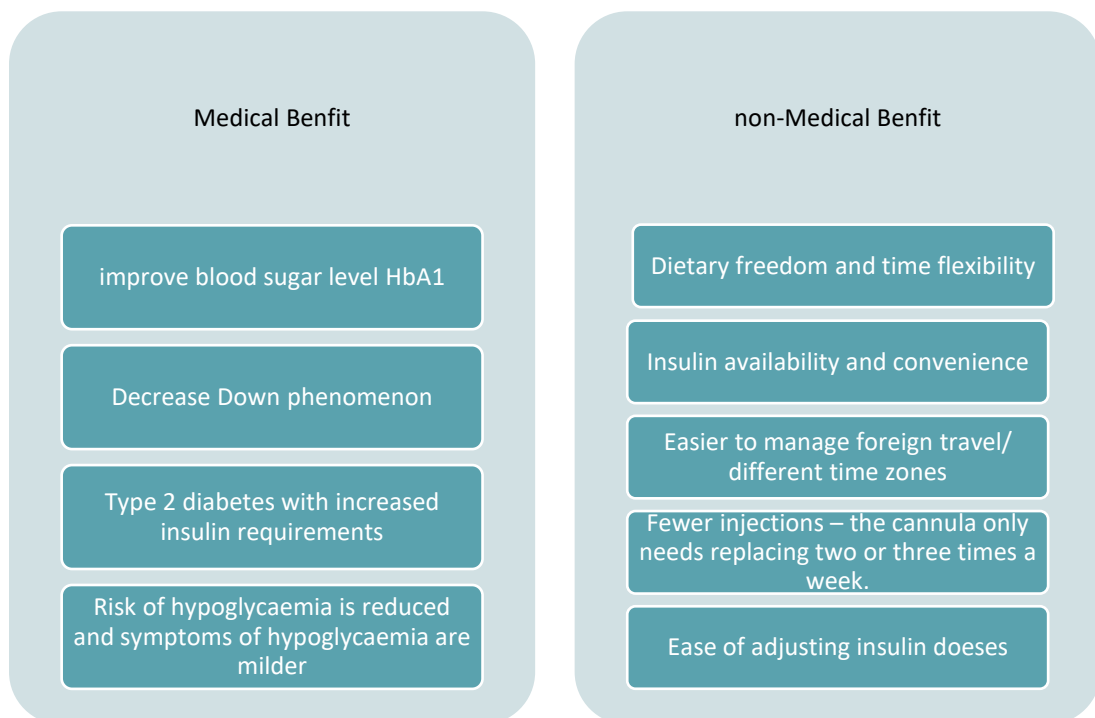


Figure 2-6: Benefits of IP

2.4.1 Medical Benefits

The main driver of medical benefits is mainly controlling the glycaemic level (American Diabetes Association; ADA, 2015). Glycaemic level is a medical term that describes the general levels of blood sugar (glucose) in an individual who is suffering from diabetes illness briefly explained by (Güemes et al., 2016),

The effective control of glycaemic levels has become a key aspect of diabetes treatment (Tarnow et al., 2008). The importance of this value has also been recognised in the management of the ongoing effects caused by the loss of pancreatic insulin-production capacity in type 1 diabetics (Adams, 2008). Studies have suggested that insulin pumps may improve glycaemic control for children and young people (Silverstein et al., 2005; Pańkowska et al., 2009; Pickup and Sutton, 2008; Phillip et al., 2007; Hirose et al., 2012a). Several studies have reported that IP therapy leads to improvements in glycaemic control in children with type 1 diabetes, with the controlled glycaemic level leading to improved cognition, behaviour and emotions (Grunberger et al., 2014).

The following section will discuss the outcomes of the management of glycaemic control by IP therapy.

- *Improves HbA1c levels*

The main medical benefit offered by IP therapy is the improvement of glycated haemoglobin (HbA1c) levels (Hofer et al., 2010; Moser et al., 2015; Cummins et al., 2010; Olsen et al., 2015; Shalitin et al., 2008; Kesavadev et al., 2010). HbA1c testing shows the amount of glucose that sticks to the red blood cells, which is proportional to the amount of glucose in the blood (ADA, 2015). ADA (2015) states that when the HbA1c level of a person is higher than 7%, they experience what is known as the dawn phenomenon [early-morning increase in blood glucose] and marked variability in glucose from day to day (Scheiner et al., 2009); hypoglycaemic episodes requiring assistance or a lack of awareness about hypoglycaemia (Reece and Williams, 2014; Bode et al., 2002a; Scheiner et al., 2009). Importantly, intensive IP therapy has been shown to lower HbA1c if managed correctly (Alsaleh et al., 2013; Pickup et al., 2002).

- *Reduces risk of hypoglycaemia and lessens symptoms of hyperglycaemia*

Hypoglycaemia and hyperglycaemia are terms that describe the problematic and even dangerous situation in which glucose levels are either significantly below (hypo-) or above (hyper-) normal levels. “Low blood sugar is described as a glucose level of <3.8 mmol/L (<70 mg/dL), whereas high blood sugar refers to levels of >6.1 mmol/L (>100 mg/dL) (Diabetes Management, 2016)”. Patients who are hyperglycaemic (high glucose) can also become momentarily hypoglycaemic, under certain conditions, such as not eating frequently or after energetic exercise. However, correct use of IPs can improve glucose levels and prevent anticipated hypoglycaemia from exercise or fasting. This ability to set basal profiles is considered to be a main benefit of IP therapy (Schade and Valentine, 2002).

However, it should be noted that utilising intensive approaches to normalising blood sugar levels can increase the risk of the most dangerous version of hypoglycaemia by as much as three times. In this form of glycaemia, patients are unable to manage the episode alone and generally require aid from other individuals (Hilliard et al., 2016). Clinical studies have suggested associations between IP therapy and the reduced risk of severe hypoglycaemia, as well as the requirement for associated medical care (Sulli and Shashaj, 2003, McAdams and Rizvi, 2016b; Al Hayek et al., 2015; Bruttomesso et al., 2009). Overall, these studies indicate that diabetes can be manageable with balanced medication via IP therapy.

- *Manages the “dawn phenomenon”*

The dawn phenomenon refers to the occurrence of particular high levels of blood glucose in the early morning, which is attributed to the release of specific hormones during the night (Bouchonville et al., 2014). This can be partially addressed by IP therapy, which enables the user to set basal profiles, effectively enabling insulin dosage to be prepared in order to meet anticipated changes in need, such as occurs during the dawn phenomenon (Schade and Valentine, 2002).

- *Manages the insulin resistance of Type 2 diabetes*

IP therapy is well established in the treatment of type 1 diabetes, but its application in the management of type 2 diabetes is still under debate. For this reason, the health authorities of many countries still do not reimburse the costs associated with IP use in the treatment of type 2 diabetes (Reznik and Cohen, 2013). The IP therapy has been recognised in cases of extreme insulin resistance and poor glycaemic control among some patients with type 2 diabetes (Garvey et al., 1985). It was found that while these patients received 40% less insulin than they had previously required, they were able to reach a lower mean glucose level overall. This was accomplished through the delivery of insulin “transiently by intravenous insulin infusion” (Reznik, 2013, s219). Heinemann et al., (2015) suggest that intermittent use of IP may be especially beneficial for use with type 2 diabetic patients who do not respond well to oral measures. This is predicated upon the idea that insulin resistance will be lowered in response to better control of blood glucose levels (Reznik and Cohen, 2013)

2.4.2 Non-Medical benefits

Although medical benefits are always perceived and noted by physicians, the non-medical benefits are often focused on the patients. However medical and non-medical benefits are somewhat connected. Because of the IP medical benefits as well as the technological capabilities (e.g. programmable and easy to use technology), the literature widely supports the position that IPs improve the Quality of life of patients (Reece and Williams, 2014; Bode et al., 2002a; Scheiner et al., 2009).

Insulin pumps are able to closely mimic normal pancreatic physiology by means of a number of advanced features, such as bolus calculators, extended and dual wave bolusing, and temporary basal rates (Nicholls and Partridge, 2015; Plotnick et al., 2003). These functions can offer young people and their families a greater sense of control over diabetes, more independence, fewer physical complaints, and more flexibility with diet and schedules, enabling IPs to offer greater Quality of life improvements than injections (National Institute for clinical excellence technology appraisal guidance, 2008; Hoogma et al., 2006); Walsh & Roberts, 2006; Barnard et al., 2007; Barnard et al., 2016; Brottomesso et al., 2009; Hanas, 2010; Hirose et al., 2012; Chase, 2010). Some studies

have also reported specific QoL improvements for parents, especially in terms of reduced stress and fewer worries about hypoglycaemia, coupled with high levels of satisfaction when their child successfully adapts to IP therapy (Mednick et al., 2004, Müller-Godeffroy et al., 2009).

- *Procedures benefits*

IP therapy offers flexibility and the benefits of controlling the amount of insulin delivered to the patient body (Bolderman, 2002; Walsh and Roberts, 2006; Hanas, 2010; Chase, 2010; Morrison and Weston, 2012). As the patient needs to manually start the process, they are able to improve their glycaemic control by taking the opportunity to pre-bolus, which refers to a bolus of insulin given before it is actually needed to cover the quantity of carbohydrates eaten. This can affect the quality of life by basically pressing a button on the pump to adjust the insulin doses to match the desired levels of food intake and physical activity at a particular time (Chase, 2010). In this way, by informing the pump of the required quantity of insulin to inject, IP users are able to replicate the release of insulin that occurs during normal function of the pancreas. As mentioned earlier (section 2.3.2), this normal pancreatic function is mimicked in two ways: the continuous, slow release of insulin (basal rate) between eating episodes; and a higher release of insulin taken to pre-empt food intake (bolus rate) (Steineck et al., 2015).

- *Dietary freedom and meal time flexibility*

IP users can have dietary freedom and meal time flexibility by eating when and what they want (Bolderman, 2002; Walsh and Roberts, 2006; Hanas and Adolfsson, 2006). This often means that they feel less guilty about sweet foods and skipping meals (Shulman et al., 2016), which may be because basal rates are determined by health care providers in collaboration with patients themselves, with the rate set at a level that meets the ongoing daily requirements of the patient (Cope et al., 2012). Furthermore, as the majority of pumps on the market are able to store more than one pre-set basal profile, patients are able to create contingencies that enable them to react to disruptive events more effectively and with less risk of under- or overdosing (Scheiner et al., 2009).

- *Flexibility and freedom/ Insulin availability and convenience*

As outlined above, IP therapy often improves QoL by reducing the impact of diabetes through greater flexibility and freedom to use the desired insulin medication (Walsh & Roberts, 2006; Chase, 2010). IP therapy also avoids the side effects of multiple daily injections, which can be uncomfortable and can cause insulin resistance in some areas of the body (Krzymien et al., 2016). In contrast, the IP requires a single needle stick every 2-3 days, after which the device is attached to the body, meaning that the insulin will be with the patient all the time (Nishio and Chujo, 2015). In addition, IPs can be programmed to deliver insulin as desired for the individual patient, enabling them to choose when they sleep, exercise and eat, which makes activities like travel or work more straightforward (Hirose et al., 2012). IP therapy has also been credited for the improved socialisation of diabetic children, with parents, school staff and the children themselves recognising the improvements that the greater flexibility affords to their lifestyles and development (Shulman et al., 2016)

Diabetic patients on a programme of multiple daily insulin doses may take as many as 1,460 injections of insulin per year. In contrast, pump sets are only changed every 2 or 3 days, creating less pain and increase lifestyle flexibility (Golden and Sapir, 2012). This helps patients to feel better, have more energy and feel more in control of their diabetes (Bruttomesso et al., 2002).

2.5 Drawbacks of IP

The introduction of IP technologies into the daily routine care of a user imposes both psychological and ‘time-effort’ burdens that many patients and their families will find demanding (Acerini, 2016). IP therapy requires more work than multiple daily injections (Shulman et al., 2016; Alsaleh et al., 2012; Darby, 2006; Rankin et al., 2015; Sullivan-Bolyai, 2004). Despite the evidence which is currently available of the potential benefits of using advanced technologies in diabetes management from the perspective of patients and physician, there are some limitations noted in the literature (Giani et al., 2015; Shah et al., 2016). Figure 2-7 outlines a synthesis of the literature on the drawbacks of insulin

pump therapy. Examples of these include: the higher cost compared with multiple daily injections; the increased risk for subcutaneous infections; the inconvenience of being attached to a device; and a theoretical higher risk for diabetic ketoacidosis (Moser et al., 2015); Shetty & Wolpert, 2010; Saarinen, 2014). The drawbacks have been organised into the following categories: medical, management, quality of life, and psychological. These factors will be discussed in greater depth in the following sections.

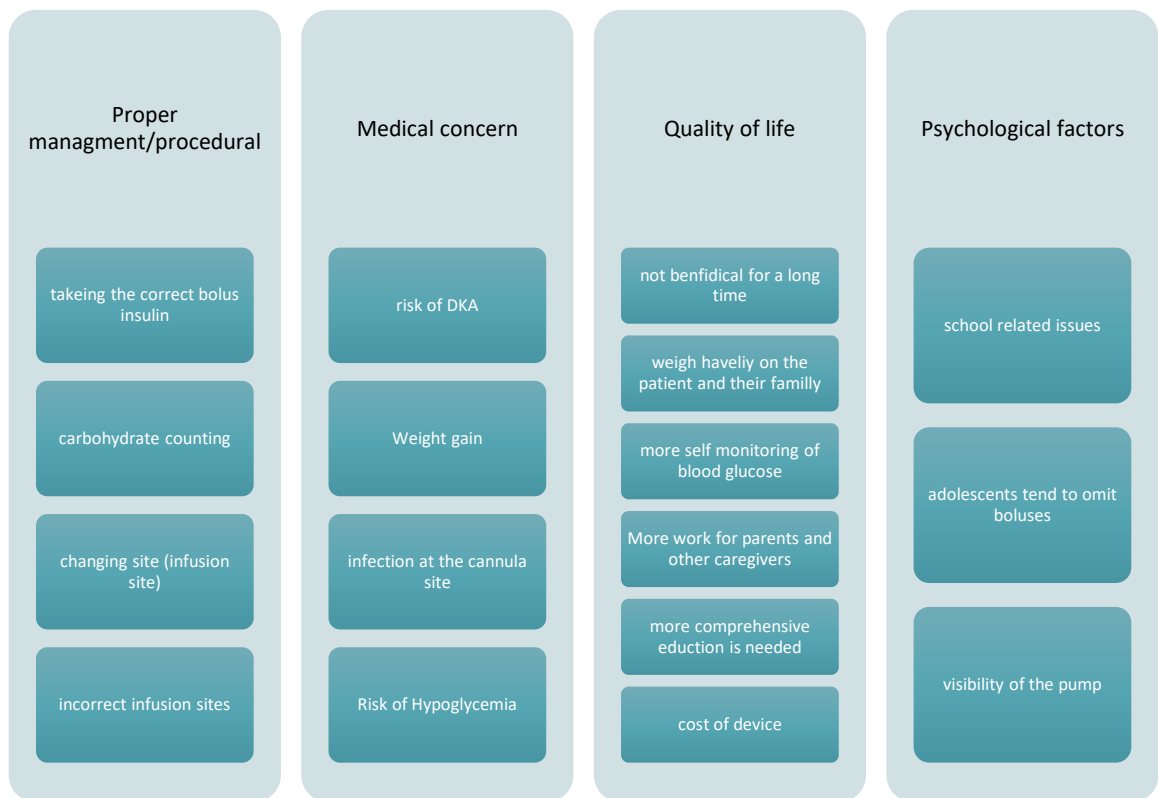


Figure 2-7: Drawback of Insulin Pump Therapy

i Proper management / procedural is essential

As an inherently complicated health intervention, IP therapy necessitates proper training to be given to the user and/or the parent or caregiver. This training must provide adequate competence in multiple tasks, including the delivery of insulin, actions to be taken in the case of pump failure, effective estimation of carbohydrate intake, the management of blood sugar, and the possible repercussions of strenuous physical activity or illness on

pump efficacy (Shulman et al., 2016). In the case of younger patients, all individuals who interact with the child must be able to offer support across a range of settings, including the home and at school (Phillip et al., 2007, Borus and Laffel, 2010; Shalitin and Phillip, 2008; Alsaleh et al., 2012, Darby, 2006).

In order to enable users to participate in certain events, the flow of insulin may be intentionally interrupted. Alternatively, the interruption may be unintentional, such as in the case of depletion of the insulin reservoir or battery failure (Wolfsdorf et al., 2006). The IP currently on the market do not warn against dislodgment or certain other types of failure, such as leakage (Phillip et al., 2007), meaning that a certain amount of manual blood glucose monitoring is recommended. Should the levels be outside accepted parameters, or when the users are feeling unwell, other tests should also be performed, such as the checking of urine or serum ketones. In this way, it should be possible to respond quickly enough to avoid Diabetic Keto Acidosis (DKA) (Bolderman, 2002; Walsh and Roberts, 2006; Bruttomesso et al, 2009; Hanas, 2010). DKA is most common when users are insufficiently prepared to deal with hyperglycaemia, with emotional issues being the most common reason for the failure to administer insulin appropriately (Pańkowska et al., 2005). Therefore, patients should be comprehensively trained in all IP functions, so they are able to react calmly and effectively (Shalitin et al., 2010). This is a major reason why IP initiation in young children requires testing to ensure that adequate supervision is available for important tasks, like blood glucose monitoring (Weinzimer et al., 2004).

Additional training and the reliance on a new device can place a heavy burden on families during the initial training and adjustment period (Malik and Taplin, 2014). Therefore, the following section will discuss a number of procedural factors that can affect the proper use of the IP: taking the correct bolus of insulin, changing the site on time, carbohydrate counting, and ensuring the correct infusion site location (Pickup et al., 2014).

- *Taking the correct bolus insulin*

The most common non-mechanical issue with regards to IP usage among younger users is forgetting to administer bolus insulin doses (Hanas & Adolfsson, 2010). This task is

comparatively simple, particularly since all correctly programmed pumps have the ability to determine the right bolus dose of insulin (Heinemann et al., 2005; Morrison & Weston, 2013; David & Curtis, 2013), as long as the user enters their current blood glucose level and the number of grams of carbohydrate to be eaten. However, children may intentionally or unintentionally neglect to administer their dose (Liberatore et al., 2004), leading children to have unnecessary episodes of elevated blood glucose. For this reason, most current IPs are able to display the history of the bolus insulin delivery time. This can be complicated by the potentially large degree of variability in terms of the basal insulin and total daily requirement for young users, due to variations in physical exertion, sleep or hormones (Holterhus et al., 2007). Adolescence age are particularly have difficult time, includes suboptimal adherence to diabetes routines as a result of developmental behaviours, change in family dynamics, and with social pressures (Shulman et al., 2016). Children behaviour can affect the correct use of the IP, such as the patient choosing to avoid using the device at a social event (Comeaux and Jaser, 2010a). In literature, it was already mentioned that the caregiver responsibility in the management of the IP and need to take proper actions, for example setting reminder alarms on the pump doing the correct boluses measuring the carbohydrate etc. (Comeaux & Jaser, 2010; Compas et al., 2012). As also mentioned by Shulman et al., 2016, “Pump therapy is thus a complex health intervention that requires the user or caregiver to be appropriately trained in the estimation of dietary intake, how insulin is delivered, pump failure, management of blood sugar levels, the effects of activity, and sick day management.” (Shulman et al., 2016 p.65).

- *Changing site on time*

It is important for the IP to be changed and kept clean in order to ensure that the device is working properly. For this reason, the cannula, tubing and reservoir should be changed every 2-3 days (see section 2.3.1) and the cannula should be inserted into a different area of skin. Users may not make the required change to the sites, for reasons like forgetting, not wanting to reinsert a needle into their skin, or a desire to save unused insulin (Heinemann et al., 2015). However, if the length of time between changes of the infusion set gets too long, or if the skin is not adequately prepared for insertion, then this may

increase the chance of skin infection (Heinemann and Krinelke, 2012) or high blood glucose (Taylor et al., 2014; Roemer, 2012; Pickup et al., 2014). Reasons for this include (Roamer, 2015):

- Degradation of the tubing and reservoir insulin due to high temperatures;
 - Saturation of the tissue at the cannula site is saturated, preventing further insulin absorption;
 - Insufficient pressure in the reservoir to deliver the remaining insulin;
 - Insufficient insulin in the reservoir.
- *Carbohydrate counting*

When patients are on IP therapy, they must still calculate and monitor the precise level of carbohydrates present in any of the foods that they consume. These values must then be used to deliver the correct doses of insulin to match the spikes in blood sugar. These values must also be tallied against variations in meal size, exercise, and other insulin doses (Kesavadev et al., 2010) in order to ensure the delivery of accurate quantities of bolus insulin. If required, the patient is also able to pause or suspend the delivery of insulin by the pump, for a variety of medical reasons (McAdans & Rizvi, 2016) as this is outside the scope of this research.

- *Correct infusion sites*

The greatest common mechanical issues that happens with pump use is an incorrect or bad infusion site (Bolderman, 2002). The infusion site is the location of the insulin insertion. Which is the thin Teflon or stainless steel cannula that delivers the insulin to the tissue under the skin. Most cannulas are inserted manually, while others are inserted with a 'spring-loaded' insertion device (Taylor et al., 2014; Roemer, 2012). The problems that occur in this regard tend to occur when the cannula becomes uneven or crumpled when inserted, other occasion when the tip of the cannula is pressed against muscle or other tissue that does not absorb insulin as its best. Even when the precise cause of the problem is unclear, the fact that an issue exists will be signalled by a rise (sharp or steady) in blood glucose. Importantly, the 'no delivery' alarm built into all IPs will only trigger

when the tubing or cannula is blocked, which means that there is no discernible difference in terms of whether the insulin is being delivered correctly or being wasted (Roemer, 2012).

ii Medical concern

Technologies for diabetes management, such as IP therapy, are designed to help patients to achieve the recommended levels of haemoglobin HbA1c, as well as to assist in the prevention of diabetes complications like the progression of micro- and macro vascular complications⁴ (Giani et al., 2015). However, it should be noted that IP may not be the right management option for all individuals with insulin-requiring diabetes and should therefore only be considered as “one of a range of options” (Morrison and Weston, 2013). Even when IP therapy is the most appropriate course of treatment, it is not necessarily without complications. Close monitoring should therefore be maintained to guard against outcomes that include infusion site issues, user error, pump failure, or blockages with any part of the infusion set (Heinemann et al., 2015; Suh et al., 2015). In this way, users can therefore be visible to major and potentially serious hazards: interruption of insulin infusion can result in hyperglycaemia and DKA, as well as delivery of excessive insulin which can cause severe hypoglycaemia. On the other hand, the available evidence on the safety and efficacy of IP remains limited (Heinemann et al., 2015).

- *Risk of Hypoglycaemia*

It is mentioned in the literature that inappropriate insulin administration, whether intentional or otherwise, can result in IP therapy causing hypoglycaemia (Shalitin and Phillip, 2008) Hanas & Adolfsson, 2006). Therefore, effective adjustment of the insulin dosage in the IP is essential, with viable strategies including the consumption of

⁴ “Diabetes is associated with both microvascular and macrovascular diseases affecting several organs, including muscle, skin, heart, brain, and kidneys”Cade, W. T. (2008) 'Diabetes-Related Microvascular and Macrovascular Diseases in the Physical Therapy Setting', *Physical Therapy*, 88(11), pp. 1322-1335..

carbohydrates immediately prior to exercise, consciously delivering a smaller bolus for the meal before exercise, or reducing the basal rate before exercise (Scheiner et al., 2009).

- *Infusion site reactions*

Users of the Insulin pump may experience allergic reactions to the skin and other skin irritation from the adhesive on the back of an infusion set. The precise type of reaction can differ according to the type of infusion set, the manufacturer, or the characteristics of the individual user (Bolderman, 2002; Walsh and Roberts, 2006; Bruttomesso et al, 2009; Hanas, 2010). Additionally, “skin irritation, lipohypertrophy, scarring and infusion site infections” (Shalitin and Phillip, 2008) have been recorded (Heinemann et al., 2015; Hammond et al., 2007).

- *Weight gain*

Previous studies have demonstrated that one of the unforeseen outcomes resulting from the higher level of flexibility afforded by IPs is the possibility of greater weight gain than experienced by patients using other therapies (Shalitin and Phillip, 2008, Plotnick et al., 2003; Weintrob et al., 2003; Hanas and Adolfsson, 2006). This has been observed among users with a poor control over their diabetes (HbA1c 8%), who may experience weight gain after a few months of transitioning from multiple daily injections to IP therapy (Scheiner et al., 2009). Long-term pump use may cause side-effect of weight gain (Gender-Frederick et al., 2011; Weissberg-Benchell et al., 2003)

- *Risk of diabetic ketoacidosis (DKA)*

An important risk associated with IP therapy can be attributed to the “lack of a subcutaneous depot of intermediate- or long-acting insulin and the short half-life of serum insulin” (Shalitin and Phillip, 2008), which has the effect of increasing the susceptibility of patients to “ketonemia and DKA secondary to dislodgment or occlusion of the infusion set or pump failure” (Shalitin and Phillip, 2008). This is important because of the serious repercussions of untreated DKA and the rapid onset time should a malfunction occur with the infusion set or insulin delivery. Unlike multiple daily injections, which creates a safety

net of long acting insulin, patients on IP therapy can experience ketoacidosis (DKA) within as little as 7-8 hrs (Bode et al., 2002b) (Cryer, 2012).

iii Quality of life

Numerous factors associated with insulin pump use may negatively impact QoL (Rankin et al., 2015). These factors include: the weight of obligations on the patient and their family (Phillip et al., 2007); more work for parents and other caregivers (Rankin et al., 2015) (Lange et al., 2014); the need for comprehensive education (Lange et al., 2014); the fact that the device is not beneficial for long term use (Heinemann et al., 2015); the importance of proper management and procedures (Weinzimer et al., 2004, Shalitin et al., 2010); school related issues (Hirose et al., 2012a) ; and the cost of the IP and its infusion sets (White et al., 2014; Cummins et al., 2010).

- *Weigh heavily on the patient and their family:*

The decision to participate in IP therapy can be significant for a patient and their family, with requirements for additional training and supervision placing a strain on the relationship between young patients and their parents or their caregivers at school (Phillip et al., 2007). For this reason, in order for the diabetes treatment to be successful, a heavy burden is placed on children to ensure self-management, meaning that younger users will generally require external assistance to ensure the effectiveness of their treatment (Hirose, 2012). Overall, parental support is related with good glycaemic control in children (Hirose et al., 2012; Neylon et al., 2013; Hilliard et al., 2013; Hilliard et al., 2016) and this is subsequently linked with better life satisfaction in parents (Nylon et al., 2013; Hood et al., 2013).

It have been said that there is more work for parents and/or the caregiver in taking on responsibilities for which they may not have been initially aware or prepared (Rankin et al., 2015). Alsaleh et al. (2012) argue that IP therapy actual entails more work than MDIs. This is sometimes exacerbated by difficulties that parents experience in involvement responsibility for their child's diabetes with others. For example, some parents reported difficulties getting schools to assist in pump management (Shulman et al., 2016, Low et

al., 2005); others perceived the complex pump management as a barrier to their ability to leave their child with outsiders (Duffey, 2015).

This illustrates that pump initiation may be stressful for parents because of the demands of learning a new technology and because of frequent blood sugar testing. Further, unrealistic expectations regarding the potential benefits of the pump may be counterproductive and may in fact lead to disappointment.

- *Risks associated with prolonged usage:*

From a clinical perspective, the daily use of devices including automated parts in wide range of conditions poses considerable challenges to performance. This is important, as the consequence of this complexity and the intended duration of use means that “the precision of insulin infusion rates over the life span of a pump might be acceptable at the time of manufacture but may not be as precise following several years of real-world use” (Heinemann et al., 2015). Given that the pump will be worn for long periods and during everyday activities that can potentially damage it, such as sports, both the design of the device and strategies for its effective use need proper consideration (Potti and Haines, 2009).

However, this issue is complicated by the fact that some users may find that it uncomfortable or unwieldy to continually wear the pump and infusion set tubing, even when it has not been designed to be especially sturdy (Bächle et al., 2013, Bolderman, 2002; Walsh & Roberts, 2006; Hanas, 2010). However, the pump must be worn while the user sleeps, works and plays, in order to ensure the delivery of a continuous flow of insulin (Millstein et al., 2015).

- *Cost of IP*

Generally speaking, in most countries, traditional insulin injections are the cheapest and most cost effective option for insulin treatment (Cummins et al., 2010). Pumps cost around £2500–3000 each, plus an additional annual fee for the various consumables required to operate the device, which can constitute a significant additional expense.

These consumables, including tubing, cannulas, batteries and reservoirs, typically cost £1,000–2,000 per year extra. It is also important to factor in the costs involved in the cost of providing education in the use of the device for caregivers as well as the patients themselves, including both the initial training and ongoing support, where required (White et al., 2014).

As Insulin pump is more high-priced than MDI, few health care and insurance systems will only repay the supplementary costs when they judge the health of the patient show evidence of significant benefit (Heinemann et al., 2015). Despite all of these considerations and especially the significant financial investment involved, it is important to note that a percentage of those who ask for IP therapy fail to meaningfully improve their HbA1c (Schade and Valentine, 2006).

iv Psychological stress

Although clinical factors were mentioned. The social and psychological factors were obvious reasons for both the reluctance to try the pump therapy and the decision to discontinue therapy (Seereiner et al., 2010). The dependency on an external mechanical device can also have a number of physical or emotional side effects for some users, which may be exacerbated by the fact that the patient is connected more or less 24 hours per day. Unlike more traditional injection therapy, the presence of the IP device clearly indicates to others that the individual suffers from diabetes (Nicolucci et al., 2008), as well as continuously reminding the patient of the presence of the disease (Torrance et al., 2003; Pickup et al., 2014; Cope et al., 2012; Forlenza et al., 2016). Hiding the device from others may even reinforce these negative emotions, potentially contributing to a growing sense of alienation, a poor self-image, and even cause lack of confidence or fear (Gonder-Frederick et al., 2010).

Constant reminder

One of the most important negative aspects to IP therapy is the presence of the device itself and the fact that this serves as a reminder of the disease being treated (Ramchandani and Heptulla, 2012). Although few patients discontinue insulin pump therapy because of the constant reminder (Hofer et al., 2010a, de Vries et al., 2011), it is important to note

that this weakness is not found in treatments like multiple injections, which allow patients to forget about diabetes after having the needle injection by the traditional insulin pen and afterward hides it in the bag (Raphael, 1999).

Wearing a pump, despite it being about the size of a cell phone, can be difficult for some people, with a level of disruptiveness that has led some patients to state that its use is “like getting diabetes all over again” (Chase et al., 2007, p. 13). Adolescents report numerous practical challenges in wearing the pump unobtrusively (Alsaleh et al., 2012, Ritholz et al., 2007). This may explain the higher rates of pump discontinuation amongst adolescent patients (Hofer et al., 2010b), because teenagers are extremely image conscious (Alsaleh et al., 2012; Forlenza et al., 2016). This is particularly exacerbated among female patients, who are perceived to have greater risk of body image issues (De Wit & Snoek, cited in Mameli et al., 2014), which has been suggested as a risk factor for pump discontinuation (De Vries et al., 2011; Babar et al., 2009; Alsaleh et al., 2012, Ritholz et al., 2007) Bolderman et al., 2016; Hanas, 2010; Chase et al., 2007).

2.6 Readiness to receive the IP

The first stage in adopting the IP is the screening process, during which physicians recommend the patients to use the IP. This is because the particular characteristics of a patient are integral to the successful use of the device (McAdams and Rizvi, 2016b), meaning that this decision those who may be noncompliant on insulin injection regimens or who do not meet certain requirements, as discussed below, are more likely to do badly on IP therapy and are generally therefore not selected (Grunberger et al., 2014; Pickup & Keen, 2002).

The main challenge inherent in adopting any new technology as a medical solution is how much the patient and his family are ready to use it. The concept of technology readiness, meaning the “propensity to embrace... new technologies for accomplishing goals in home life and work” (Parasuraman, 2000), is typically used in conjunction with general use technologies in home and work. However, it can be a useful theoretical lens for understanding the adoption of new medical wearable devices, with a positive relationship

to optimism and innovativeness and a corresponding negative relationship to discomfort and insecurity. When this theory is applied to the adoption of the IP among young patients, the optimism and positivity towards innovativeness that is common among children does not necessarily guarantee success (Godoe and Johansen, 2012) . Indeed, children may look at this wearable device as a new version of traditional approaches using needles. This area has not been adequately explored in terms of the use of medical wearable devices.

Another framework can be used for understanding the level of readiness among patients is the actors network theory, which shows that the interaction of beliefs, attitudes and behaviours of different actors shape the belief of the main actor (Pollack et al., 2013) (i.e. the patient in the current research) and therefore behaviour toward a certain object (Latour, 2005). Therefore, this study only investigates the patient and his surrounding circle (physicians and his family) actors, rather than focusing on the other two actors (the healthcare and dedicated follow up team) Figure 2-8.

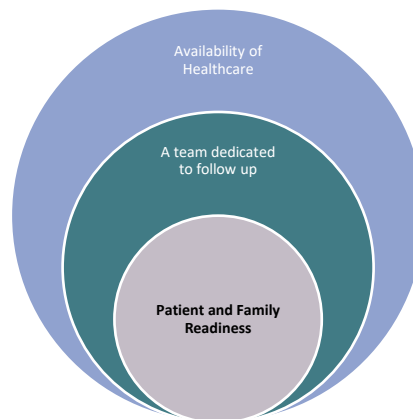


Figure 2-8: Scheiner et al., (2009) factors related to successful initiation of Insulin Pump therapy

Therefore, this section will discuss the readiness towards adopting the IP to understand the different perspectives of the readiness's of different actors, which is the patient readiness and family readiness, and readiness on the education readiness Figure 2-9.



Figure 2-9: Readiness elements

2.6.1 Patient Readiness

The assessment of the readiness of patients to receive IP therapy requires the consideration of several factors (Grunberger et al., 2014; Phillip et al., 2007; Liberman et al., 2014; ADA, 2004). Individuals are recommended for IP therapy based on their personal and psychological suitability, or in other words their physical and mental capacity to manage full adherence to IP protocols over a protracted period of time (Lawton et al., 2016). The literature describes several factors as being essential in achieving success in the use of IPs (see Figure 2-10), namely: background and knowledge of the patient; the psychological readiness of the patient; and their physical readiness to receive the IP.

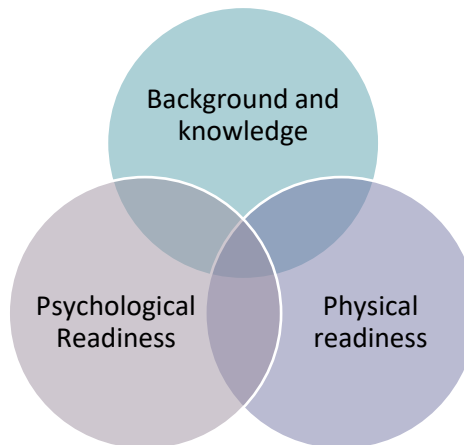


Figure 2-10: Factors of patient to be essential for achieving success in using the IP

i Background and knowledge readiness

Grunberger et al. (2014) argue that successful implementation of IP is largely dependent on the skills, knowledge and resources to utilise this form of insulin therapy in a manner that is both effective and does not bring undue risk to participants. This means that the careful selection of both clinicians and patients is essential.

IP therapy can normally be initiated when the diabetic patient is familiar with management of the device and associated tasks, such as carbohydrate counting (McAdams and Rizvi, 2016b). With regards to the minimum age of patients, some argue that the IP should be limited to adults, with the cognitive and emotional development of children requiring patients to be at least 15 years old before commencing therapy (Cogen et al., 2002). However, Fuld et al. (2010) argue that patients of 15 and under should be considered, although the selection process should be conducted on an individual basis. The age at which the child will have the capacity to administer the functions of an IP independently is likely determined by numerous factors, but especially their maturity and physical aptitude (Klingensmith et al., 2001). As a consequence of this, there are no universal guidelines for the acceptable age to begin IP therapy (Cogen et al., 2002), although there is broad agreement that patient age and period of diabetes should not be main causes in determining when patients transition from injections to IP (Grunberger et al., 2014). It should be noted that the achievement of target HbA1c requiring greater efforts from the patient in the management of the IP (Olsen et al., 2015).

In summary, patients who are 15 years old or younger can use IPs, taking into consideration various psychological and knowledge factors. The focus of this research is therefore to identify and analyse these psychological and knowledge factors with respect to the ages of patients.

ii Psychological Readiness (motivation)

According to scientific and professional literature, candidates for IP should satisfy the prerequisites of wanting to undergo IP therapy and being willing to perform the required procedures (Heinemann et al., 2015), like carbohydrate counting, frequent blood glucose

monitoring (typically 4-6 times per day) and participating in ongoing clinical support (Reece and Williams, 2014, Scheiner et al., 2009), as well as following manufacturer guidelines about how often IP components like the infusion set are changed.

Willingness means the desire and motivation to do as well as the ability to perform. This means that the ideal candidate IP therapy is an individual who wants better glycaemic control, is well-informed about the various aspects of diabetes self-care, and who is motivated to take the steps to ensure their own health (Scheiner et al., 2009). Second, the motivations should be managed through the IP lifecycle. This argument is supported by studies of emerging technologies which recommend the incorporation of standardised psychosocial measures in the evaluation of QOL and treatment satisfaction in addition to glycaemic control (Franklin, 2016). Research suggests that the greater flexibility afforded by IP therapy, and the corresponding benefits to independence and social life, makes this approach to insulin management particularly valued by young adolescents (Shulman et al., 2016).

iii Physical readiness

Success with IP therapy requires a thorough assessment of the physical and psychological readiness of a prospective candidate to meet the particular challenges involved in living with the device. Using the IP is not easy for a patient of any age or abilities, as it is a highly specialized gadget that requires developed self-management activities (Tobergate et al., 2013) which needs physical abilities for effective operation (Alvarado-Martel et al., 2015). In other words, the patient needs to press a button on the insulin pump and choose the appropriate dose. Injecting the appropriate insulin dose requires skill: “the intake of carbohydrates, the actual blood glucose level, physical activity, infection and stress are examples of variables that must be considered before the injection” (Sjöblad 2008; Bangstad et al. 2009).

Furthermore, the device requires programming and constant interaction from the wearer (Lieberman et al., 2014). The consequence of this is that the long-term success of IP therapy is largely dependent on regular, accurate self-monitoring of blood glucose levels, supplemented by a readiness and ability to stay in contact with the professional team

associated with the device (Lieberman et al., 2014). Bolderman (2013) adds that physical readiness to be a candidate (and/or parent(s) of a pump candidate) for IP therapy include a range of factors: the physical ability to view the pump screen and hear the alarms; sufficient dexterity to insert or charge the pump battery, and fill and replace the insulin cartridge/reservoir in the pump; the capability to insert an infusion set; a willingness to wear the pump; and the capacity to perform any other technical functions (Grunberger et al., 2014).

2.6.2 Family Readiness

Because the scope of this research is to investigate the use of IP in adolescence (age<15), the role of family is discussed thoroughly because it has an immense impact as illustrated in literature. Successful IP therapy in young children requires parents or caregivers to monitor, adjust and even ensure the delivery of insulin (Klingensmith et al., 2001, Cope et al., 2012), as well as to enter temporary basal rates (Forlenza et al., 2016), and to increase or decrease bolus doses for food consumed (Alsaleh et al., 2013). The children's primary caregivers therefore need to be readily available to the children (Franklin, 2016). The consequence of this is that the possible effects on parents should be investigated, because parental involvement is inversely correlated with HbA1c in children treated with IP (Phillip et al., 2007).

In effect, when the patient is a child of preschool or elementary school age, the actual user of the IP becomes the parent or caregiver. The result of this is that pump initiation is a more complicated process for young children (Klingensmith et al., 2001). The ADA emphasises that adult supervision remains important for older children and adolescents, and therefore full independence in the management of insulin should be attained gradually, with adult supervision being available until complete competence is assured (Silverstein, 2005). After careful analysis of literature, family readiness can be classified into psychological and knowledge readiness, which are discussed in greater detail below.

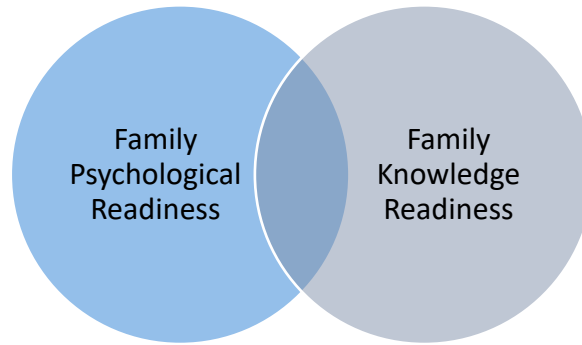


Figure 2-11: Factors of family to be essential for achieving success in using the IP for child

i Family Psychological Readiness

The ideal diabetic candidate for insulin pump therapy should have a motivated family who are committed in monitoring the blood glucose as a minimum four times per day and who have a working understanding of fundamental diabetes management, mainly carbohydrate counting, blood glucose measuring, and insulin sensitivity (Grunberger et al., 2014). The family or the caregiver should be motivated to encourage patients and to follow up with their children, as:

“Encouraging parents to remain involved in monitoring the blood glucose and interpretation and reducing family conflict during adolescence may prevent deterioration of glycaemic control common in this age group” (Laffel et al., 2003)

This is supported by other studies, which have found that parental involvement is associated with better glycaemic control in children (Neylon et al., 2013; Wu et al., 2014). This relationship between parents and their children is an important element in the success of IP therapy (Williams et al., 2004), with some suggesting that parents should assume over-arching responsibility for the management tasks related to their child’s diabetes (Silverstein et al., 2005). In this way, adolescents and older children could also be encouraged and empowered to use the pump appropriately with continued support from parents.

Many parents of children with type 1 diabetes fear that hypoglycaemia may have implications for diabetes management and glycaemic control (Hirose et al., 2012b). For

this reason, they are typically concerned with the complications of diabetes and therefore want to ensure continued control over their child's glycaemic level (Hirose et al., 2012, Faulkner and Clark, 1998). It is common for parents to expect that achieving better glycaemic control through correct IP usage will result in fewer and less serious complications (Sullivan-Bolyai et al., 2004, Low et al., 2005). These fears and expectations may influence on parenting styles and the child's corresponding physical and psychological health (Weinger et al., 2001; Anderson et al, 1991).

ii Family knowledge readiness

Before young children adopt the use of IP, an examination must be conducted into the readiness of caregivers to take responsibility for important tasks, like the monitoring of blood glucose levels (Phillip et al., 2007). Another important factor is parental knowledge of pump functions, which is strongly correlated with better outcomes. In contrast, parents who are less skilled with pumps are more likely to transfer responsibility for diabetes self-management to their children, with measurably worse glycaemic outcomes (Mitchell et al., 2013). Indeed, diabetes technologies can inhibit parental involvement by exposing the 'digital gap' that may exist between young people, who have grown up in the digital generation, and their parents, who often find technology less intuitive (Lieberman et al., 2014).

Given the widespread agreement about the importance of the assessment of caregivers (Weinzimer et al., 2004), health care providers should therefore encourage pump competency among parents and a willingness to work with their child and healthcare professionals in order to ensure they can optimally support their children (Ritholz et al., 2007; Hirose et al., 2012). Lieberman et al. (2014) explain that when patients change to intense insulin regimens, such as the use of insulin pumps, this typically requires more education for parents or caregivers, such as in dealing with unexpected eating patterns, extreme glucose variability, and inconsistencies in insulin sensitivity. This means that parents must be willing to learn new but potentially challenging skills, such as the adjustment of doses, the insertion of infusion sets, or the operation of insulin pumps. The majority of parents become competent at these tasks within 1.5 to 9 months after therapy

begins (Sullivan-Bolyai et al., 2004). There may also be worries for parents, such as whether the children is receiving an incorrect dose of insulin, whether the button might be pressed accidentally to deliver insulin when it is not needed, or whether there may be problems with the technology, such as malfunctions (Hirose et al., 2012b). Although these worries are legitimate, effective preparation and education should help to ensure correct management of the IP.

In summary, the role of family knowledge is immersing in the children proper IP use. This shall be reflected in assessing the family knowledge to have a confident supervision on their children in using the IP.

2.6.3 Readiness improvement and education before using the IP

The selection of candidates for pump therapy is necessary (Scheiner et al., 2009). The patient should be well educated on the management of the insulin pump, with the training having been based on a full assessment of the person's attitudes, beliefs, learning style, ability and readiness to learn, existing knowledge, and goals (Lange et al., 2014). The patient education should also include the principles of basal-bolus insulin therapy and sick day management (Saboo & Talaviya, 2012; Reece and Williams, 2014). Perhaps the most important factors for patient success, and therefore the focus of the training, is the willingness and ability to conduct frequent blood glucose monitoring, coupled with realistic expectations of the benefits of IP therapy. Overall, this approach has been said to require, "an above- average level of diabetes management, more intensive patient education and training, and close follow-up" (Carrhill et al., 2013 cited in Amod et al., 2013). Therefore, before transiting to the actual use of the insulin pump, education should be provided for insulin adjustment for exercise, prevention and treatment of hypo- and hyperglycaemia, carbohydrate counting, and important procedures like site preparation and infection obstacle (Saboo and Talaviya, 2012).

Well-educated patients can affect the success of IP therapy (Grunberger et al., 2014), with sufficient knowledge of IP use to manage insulin helping to prevent complications, ensure better adherence to therapy and leading to better overall glycaemic control (Jasper, et al., 2014). Thus, the family still require adequate education and support on IP use, especially

for young infants (Wilson, 2002, Brink et al., 2009, Doyle et al., 2004, Phillip et al., 2007). The education for IP therapy is provided to the child with their parents and caregiver by a diabetic educator (Bolderman, 2013), and should be delivered in a structured, curriculum-based programme that prepares the individual to deal with the worst-case scenario (Bolderman, 2002 cited in Morrison & Weston, 2013). Each individualised education plan normally spreads learning over several weeks, with at least three 1-3 hour visits by the diabetic educator. The plan requires a thorough understanding of the knowledge that the patient has of diabetes, their personal learning style, and any knowledge defects they may have (Bolderman, 2014). These programmes seek to reduce the resistance or fear of the patient and their family with regards to the IP, thereby improving the ease and effectiveness of the adoption process.

2.7 Chapter summery

The IP as a wearable device that is programmed to maintain the steady level of insulin in the blood and is thus expected to improve patients' medical condition as well as quality of life. In this chapter a theoretical background of the insulin pump (IP) was discussed with reference to the literature of different disciplines relevant to the research question – what are the reasons for the improper use of IP? In order to set this theoretical background, this chapter assumed that the main reason for the improper use is the perception of benefits, drawbacks and readiness to use the IP as shown in Table 2-1. Benefits found in literature were medical benefits and non-medical benefits (i.e. diabetic patient quality of life). The drawback of IP in both respects is well documented in the literature, covering several aspects, namely, medical, management, quality of life and psychological. Lastly, the readiness towards adopting the IP has been discussed and consolidated from the literature to understand the different perspectives of the readiness's of different actors, which is the patient readiness and family readiness, and readiness on the education. Therefore, these elements were discussed in order to bring together multi-disciplinary literature sources on the medical, technological and psychological factors that influence the use of IP as a wearable device.

The main point of this chapter is Thus; it is not clear why do some patients misuse the IP. The IP benefits seem to be much higher than the drawbacks and also the readiness is not the only major determinant of the quality of use of the IP. Therefore, the next chapter is to address different psychological, behavioural and social literature papers are consulted to develop a theoretical foundation for doing the understandings of this phenomenon

Table 2-1: Summary of IP for children

Benefit of IP	Medical benefit	Improves HbA1c level Reduces risk of hypoglycemia and lessens symptoms Manages the “dawn phenomenon” Manages the insulin resistance of type 2 diabetes	Hofer et al., 2010; Moser et al., 2015; Cummins et al., 2010; Olsen et al., 2015; Shalitin et al., 2008; Kesavadev et al., 2010 Al Hayek et al., 2015; McAdams & Rizvi, 2016; Sulli & Shashaj, 2003 Bouchonville, Jaghab, Duran-Valdez, Schrader, & Schade, 2014 Heinemann et al., 2015; Reznik & Cohen, 2013)
	Non-medical benefit	Procedure benefits Dietary freedom and meal time flexibility Flexibility, freedom of insulin availability and convenience	Steineck et al., 2015; Hanas, 2010; Chase, 2010; Morrison and Weston, 2012 Shulman et al., 2016; Cope, Samuels-Reid, & Morrison, 2012) Krzymien et al., 2016; Nishio & Chujo, 2015
Drawback of IP		Require Proper management Medical concern Quality of life	Malik & Taplin, 2014; Borus & Laffel, 2010; Shalitin et al., 2010 David & Curtis, 2013; Pickup et al., 2014; Suh et al., 2015 Rankin et al., 2015; White et al., 2014; Lange et al., 2014
Readiness to receive the IP	Patient Readiness	Background and knowledge readiness Psychological Readiness Physical readiness	Grunberger et al. 2014; Olsen et al., 2015 Heinemann et al., 2015; Reece and Williams, 2014, Scheiner et al., 2009 Lieberman et al., 2014; Bolderman et al., 2013
	Family Readiness	Family psychological readiness Family knowledge readiness	Wu et al., 2014; Grunberger et al., 2014; (Hirose et al., 2012b) (Mitchell et al., 2013; Hirose et al., 2012b; Mitchell et al., 2013

	Readiness improvement and education	Lange et al., 2014; Saboo & Talaviya, 2012; Reece and Williams, 2014;
--	-------------------------------------	---

CHAPTER 3 Theories in Adoption of IP in Children

3.1 Introduction

The aims of this chapter are twofold. The first is to try to answer the research question (why some children use the IP improperly after its adoption) building on the research findings from literature. However, an investigation of the extant literature on the use of IP has not provided clear identification of the causes of misuse, therefore the main research question of this study remains unanswered. The second aim of this chapter is to develop theoretical foundations that can be used later in the following chapter for building the analytic framework that will provide the answers sought.

According to the literature covered in the previous chapter, IP has several benefits for the patient and his/her family. Therefore, according to the Technology Acceptance Model and the Theory of Reasoned Action, perfect use of the IP can be expected because of the perceptions that these patients have of its benefits. Despite these benefits, there are some cases of patients who struggle and misuse the IP, or the IP is not seen to be improving their diabetes, as already discussed in chapter 2. Therefore, different psychological, behavioural and social literature papers are consulted here in order to develop a theoretical foundation for improving our understanding of this phenomenon. This chapter, as illustrated in Figure 3-1, will therefore first highlight and explain the theories in adapting the IP (TAM, TRA, TPB and HBM). Secondly, the behavioural models in accepting and rejecting medication by the patient the perception of benefits will be discussed. Thirdly, the sociological themes to develop the theoretical foundations for understanding how the child reasoning, attitude and perception are formulated.

This will address the knowledge gap identified in the approaches to technology adoption and the actual practices of IP use in particular circumstances (in this study, the misuse of IP by children and adolescents where the role of caregiver is important). The key objective of this research is to consider how the person perceives and defines the technology and how their perceptions affect their attitude toward it and therefore the use

of it in everyday life. The adopted framework for understanding how perceptions are formulated is based on socio-materiality theory and is focused on the contradictions between different actors in the understanding of the technology.

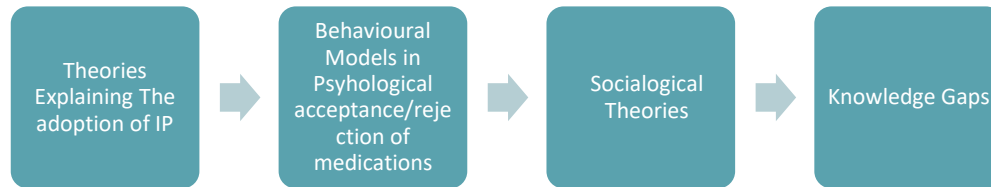


Figure 3-1: Chapter 3 Structure

3.2 Theories of Accepting New Medical Technologies

Since medical wearable devices have certain unique challenges, a range of new frameworks have been developed to better understand these technologies. One of the most important of these, Ajzen and Fishbein's theory of reasoned action (TRA) (Ajzen, 1991), which is of fundamental importance in the technology acceptance research discipline. This framework has been customized in the IT context into the theory of planned behaviour (TPB) and the technology acceptance model (TAM). These are paralleled with and supported by several technology readiness models and innovation diffusion models. Finally, attempts have been made to develop a unified model that integrates all of these concepts into one cohesive whole, the best known of which is the Unified Theory of Adoption and Use of Technology (UTAUT) developed by Venkatesh et al. (2003).

The TRA suggests that stronger intentions lead to increased effort to perform the behaviour, which also increases the likelihood for the behaviour to be performed (Ajzen and Fishbein, 1975). They suggest that two main factors, attitudes and subjective norms, determine the intention (ibid). Downs and Hausenblas (2005) added that "people's intention, or motivation, is the main determinant of their behaviour" (p.4). Intention is influenced by people's attitude (e.g., positive/negative evaluations developed from behavioural beliefs) and subjective norm (e.g., perceived social pressure to comply with

important others' wishes formed from normative beliefs). The surrounding environment also plays an important role in determining behaviour. Badewi et al. (2013) explain that subjective norms (i.e. how others perceive what you do) and one's attitude (i.e. how one feels toward the technology) drive behaviour in particular ways. However, this argument can be criticized in the context of the insulin pump (IP), as the friends of a patient may not be using the IP, which makes the person stand out in the crowd, potentially making the user more noticeable or uncomfortable. This incidence of shyness in this context is more pronounced in developing countries than the advanced countries (Hofstede, 2010), therefore extra care should be taken to foster adoption in these environments.

In the 1970, the Theory of Planned Behaviour (TPB) was proposed by Ajzen in an attempt improve the predictive power of the TRA, by taking into consideration perceived behavioural control (Ajzen, 1991). The TPB states that there are three kinds of categories of behaviour to consider (Ajzen et al., 2011): behavioural beliefs, which describe the understanding and evaluation of the most probably outcomes of particular actions; normative beliefs, which are concerned with the expectations of others and the corresponding motivation to modify behaviour to ensure compliance with these ideas; and control beliefs, which are concerned with the power of certain factors to either support or hinder the actualisation of certain behaviours. In a similar vein to the concepts in TRA outlined above, attitude in TPB refers to how one generally feels towards the object of the study (i.e. the IP in this research) (Fishbein and Ajzen, 1975). Perceived control can include both obligatory and voluntary usage (Fishbein and Ajzen, 1975; 2010). Subjective norms, which are defined as norms of attitude and behaviour that are considered normal, typical or average, are used to describe whether or not others approve of a given behaviour (Armitage et al., 2001).

The TRA has been further developed in many important directions, perhaps the most influential of which is the technology acceptance model (TAM) (Delone and McLean, 2011). Davis's TAM (Davis, 1989) is one of the most commonly used theories within the field of technology adoption (Şener et al., 2015). In its original context, the TAM provided a way in which to understand the degree to which there was acceptance among consumers with regards to the technologies used in wearable devices (Holden and Karsh,

2009; Ayyagari et al., 2011). However, understanding how theorists developed and utilised the theory in different context may offer a better understanding of the adoption process of wearable devices in general and medical ones in particular. According to the TAM, there are a number of key considerations in determining the level of technology acceptance (Venkatesh and Davis, 2000). One of the most common and significant of these is the perceived usefulness of a device, which describes how significant a user feels that the technology will be in improving their job performance (Davis, 1989). Another important factor in technology acceptance is the perception of ease of use, which means the belief that a given device will be simple and stress free. These two determinants were added to the TAM to improve its predictive power (van Bon et al., 2010), in recognition of their role in influencing the attitude of users towards a given technology and their likelihood to use it (Davis, Bagozzi, and Warshaw, 1989).

Venkatesh et al. (2003) formulated a new technology acceptance model which they called UTAUT, or the unified theory of acceptance and use of technology. Many predictive studies into the adoption of new technologies have subsequently utilised the UTAUT model (Morris, Davis and Davis, 2003), which is generally viewed as a more robust model than other similar frameworks, as it explains 70% of the variance in the usage intention. The UTAUT consists of (Venkatesh et al., 2003): expectancy of effort; social influence; performance expectancy, which is the combination of the perceived usefulness of a particular construct (Davis, 1989), the relative advantage that the technology offers (Moore and Benbasat, 1991), the degree to which it fits its intended usage or job (Thompson et al., 1991), the specific expectations that a user has about outcomes (Compeau and Higgins, 1995; Compeau et al., 1999), and any motivation from external rewards (Davis et al., 1992); and finally, all other facilitating conditions (Venkatesh et al., 2003). Also, Chen and Shih (2014) have used the UTAUT model to evaluate model of acceptance of a product with wearable technology. These studies demonstrated that adoption will usually be low when technical difficulties occur or when patients already have good control.

Indeed, the majority of UTAUT literature focus on voluntary and/or work contexts, rather than obligatory and individual use contexts. This suggests the importance of determining

whether this framework is fit to explain the adoption process. Furthermore, the surrounding context is widely recognised in the literature as the key reason for the use of IP, yet this theory fails to explain the impact of social influence on the use in the post adoption phase. This has led some academics, such as Alagöz et al. (2011), to argue that traditional acceptance models like the TAM and the UTAUT are not simply translatable and adoptable in the context of health-related technologies.

3.2.1 Wearable Devices in Technology Acceptance Models (TAM)

In research conducted in the field of wearable technology, the issue of perceived usefulness is of paramount importance. In this context, it describes the ability of users to integrate the given technological device into their everyday life, which means that this factor is potentially one of the most significant in determining the adoption of a device. Şener et al. (2015) support this assertion, explaining that perceived usefulness has an indirect influence on purchase intention through its effect on attitude. With higher levels of perceived usefulness, consumers adopt a more positive attitude towards using and wearing the technology, effectively reinforcing the likelihood that they use it positively (Park and Chen, 2007).

Hwang (2014) extended the TAM to examine the effects of consumer-oriented variables on the attitudes of consumers, looking at purchase intentions for solar-powered clothing. Similarly, Chae (2009) utilised the extended TAM to examine acceptance models of smart clothing and differences with regards to clothing acceptance through the classification of consumers depending on the level of technology innovation and fashion innovation. The variable of perceived usefulness has been argued to be the most influential in determining the attitude of users towards new technologies (Chae, 2009), with models like TPB and TAM having been used effectively in studies of wearable devices like smart bras or smart t-shirts (Turhan, 2013). Although these models can fit with these wearable technologies, there are certain challenges with regards to their use for medical wearable technologies that can affect the understanding of patient behaviour. For example, unlike something voluntary like sports wearable technologies, medical wearable technology is obligatory (Gonder-Frederick, 2011, Chiauzzi et al., 2015). Furthermore, these devices offer no clear tangible improvement in lifestyle compared to other

wearable technologies (Gao et al., 2015). The consequence of this is that investigations into patient responses to wearable devices cannot be based on the same assumptions, meaning that it is necessary to go more in-depth into the literature conducted into medical wearable devices.

3.2.2 Technology Acceptance Framework in Medical Wearable Devices

Technology acceptance models are rarely used in the context of medical wearable devices, particularly in explaining the proper use of the IP. However, the TAM was used by van Bon (2010) to investigate the future acceptance of the artificial pancreas (AP) and its possible determinates. The AP will consist of a “subcutaneous glucose sensor, a continuous subcutaneous insulin pump, and a mathematical model that regulates the amount of insulin based on the glucose levels” (van Bon, 2010, p.597). The study found that the initiation to use the AP was highly dependent on trust, which was related to the quality of glucose control provided by the combined wearable technology. The definition of perceived usefulness in this context was the ability of the device to ensure improved glucose control and to thereby lower the impact that diabetes would typically exert over the daily lives of patients, leading to correspond improvements in overall quality of life (van Bon, Verbitskiy, von Basum, Hoekstra, and DeVries, 2011, Barnard et al., 2014). Previous healthcare literature supports this, demonstrating that “integration into existing health and psychosocial support infrastructure of the patient is a trigger for perceived usefulness” (Winkelman et al., 2005)

Attempts to increase the predictive value of TAM have been based upon extending the variables of its perceived usefulness and ease of use (Bevier et al., 2014, van Bon et al., 2011). In this context, the determinants of perceived usefulness are social influences, including peer pressure, conformity and persuasion, and cognitive instrumental processes, which refers to judgments and evaluation. Perceived ease of use was also improved with: perceptions of internal control (self-efficacy to perform a task), perceptions of external control (facilitating conditions such as specific training), intrinsic motivation (openness to process) and emotion (computer anxiety) (ibid). This framework enabled the identification of the major barriers to adoption, namely specific concerns regarding the number of obligatory components to be worn and issues of trust regarding

the degree to which the Artificial Pancreas would be technically accurate, especially in exercise situations (ibid).

The TPB emphasises the role of social support systems to bring about changes in behaviour or to help maintain existing behaviours (Shepard et al., 2012, Gonder-Frederick, 2011). The study by Shorer et al. (2011) used the TPB to assess the role of parenting style in helping adolescents with type 1 diabetes to achieve metabolic control. “In a study of 100 adolescents and their parents, an authoritative nonhelpless parenting style was found to be associated with better adherence to treatment” (Shorer et al., 2011, p.1735). Omondi, et al. (2009) also applied the TPB model to understand physical activity behaviour among a group of type 2 diabetes patients in Kenya, enabling the prediction of diabetes management behaviour in much the same way as the other behaviour change models.

This discussion has shown that technology acceptance models, including TPB and TRA, can be employed to successfully understand the adoption of IP. This is important because despite the existence of positive perceptions towards the IP, with subjective norms to use and to believe in the IP, some children are not using it appropriately. Nevertheless, the previous literature fails to explain, understand or to investigate this phenomenon. However, the next theory is the health belief model, which may explain parts of the problem.

3.2.3 Health Belief Model

Technology acceptance models have been adopted, refined and extended by researchers in the field of human computer interaction (HCI) in the area of medical devices. This new framework is known as the health belief model (HBM). The HBM was first described in the 1950s by a group of social psychologists who sought to understand why people rejected to take screening tests for the early discovery of asymptomatic diseases (Janz and Becker, 1984). Although the original function of this model was to anticipate the course of health behaviours performed by healthy people to reduce their chance of becoming ill (Becker, 1974; Becker and Maiman, 1975), later versions have also been successfully utilised in conjunction with those individuals suffering from chronic diseases

and conditions. The health care behaviour and decision making processes informed by this model stress the importance of the attitudes, beliefs and perceptions of those who are involved, namely the patients (Janz and Becker, 1984, Rosenstock et al., 1988).

The most important patient constructs in this context include the seriousness of the particular health problem and the perceptions of each individual with regards to their personal susceptibility to harm. These factors in the HBM are supplemented by environmental conditions; individual coping styles; any obstacles to the attainment of goals that are perceived to exist (Rosenstock et al., 1988); as well as the perception that a patient has regarding their ability to successfully manage challenging situations, the benefit-to-cost ratio of the condition and its treatment, and the (Gao et al., 2015). In the context of diabetes, the likelihood of using diabetes technology can be influenced by condition-specific factors like negative emotional reactions to glucose readings, or the fear of hypoglycaemia and hyperglycaemia (Gonder-Frederick et al., 2011, Hood et al., 2004, de Zoysa et al., 2014).

Numerous studies support the relationship between the HBM and a wide range of diabetes self-care behaviours in adolescents, including insulin, diet, and exercise (Bond et al., 1992, Cerkoney and Hart, 1980, Rosenstock et al., 1988). The HBM is a psychosocial model and as such “is limited to accounting for as much of the variance in individuals' health-related behaviour as can be explained by their attitudes and beliefs” (Janz and Becker, 1984). With regards to health-related matters, Lewis (1994) argues that the value-expectancy approach can be explained as meaning: (a) the belief that illness can be prevented or improved by following certain types of behaviour; and (b) the wish to either recover from ill health or to avoid it altogether. The consequence of this is that a person becomes more likely to adopt certain health behaviours if they perceive themselves as being more vulnerable to a particular health risk, as well as the potential repercussions of the given illness (Barnard et al., 2015). The seriousness of the risk creates a proportional incentive for people to act. The HBM has therefore been widely used to investigate adherence behaviour with self-applied treatment (Conner and Norman, 1996); those based upon behaviour observations (Baum and Creer, 1986, Greca et al., 2003); and those that utilise physiological measurements, like blood glucose levels (Dolgin et al., 1986, La

Greca et al., 1990). However, self-reported health behaviour suffers from an unwillingness for patients to report non-adherence to the recommended form of treatment, which can result in the measures being deemed invalid or at least unreliable (Carpenter, 2010).

In summary, the HBM fails to explain why some children are continuing to misuse the IP, regardless of the benefits that this technology offers, or the high level of trust and belief that exists in the IP. However, acceptance model theories, including the TAM, the TPB, and the HBM may be able to explain parts of the story. These frameworks all attempt to address the relationship between technology and the beneficiary, as if the patients are living in isolation, without communication, with the result that the situation and user behaviour may be misunderstood. For this reason, going deeper into the behavioural and psychological aspects antecedent to the proper use of the IP may enable the phenomenon of the misuse of devices in the post-adoption phase to be understood more thoroughly

3.3 Behavioural models in accepting and rejecting enforced behaviour

Doctors who are treating diabetic youngsters need to be aware that both diabetes and adolescence are challenging states for any individual, so having one process can make the other more complicated (Comeaux and Jaser, 2010b) (Davidson et al., 2008). Hamburg (1998) notes that adolescents meet different challenges, such as recurring themes of identity, achievement, autonomy, and intimacy. They also face numerous complex and important choices, such as those involving issues of self-worth, sexuality, attitudes to health, and decisions about their future (Hamburg, 1998). Given the need to be aware of the specific responsibilities associated with their disease, these challenges are likely to be exacerbated for young people who have chronic diseases like diabetes (Hamburg, 1998). For this reason, there are clear associations between the presence of chronic illnesses and increased absence from school, greater levels of pain and fatigue, and higher levels of parental involvement, all of which can complicate the normal processes of developing during adolescence (Seiffge-Krenke, 1998).

Psychosocial factors can influence both technology provision and clinical outcome, with technology also having a measurable impact on psychological outcomes, underlining the position that the “optimal use of the various diabetes self-management technologies is influenced by previous self-care behaviours, demographic and psychological factors” (Franklin, 2016). In one year, long event, more than half (56%) of the adverse events that patients reported in children could be attributed to pump malfunction, either transient or permanent (Wheeler et al., 2014). This may be exacerbated by the difficulty that many young patients report in keeping to their self-care regimen, with dietary adherence and correct blood glucose testing being particularly problematic (Wysocki and Wayne, 1992; Franklin, 2016; (Cogen et al., 2002). In essence, this shows that psychological factors play a crucial role in the proper use of the IP (Ratheau et al., 2011). In this context, psychological factors do not refer to the motivation to use as acceptance models, but rather they describe self-perception. Therefore, the following sections focus on the factors affecting adherence to medication and cognitive dissonance. This discussion of the factors begins with the question of why patients might resist or accept being forced to adopt certain medications, after which this chapter will proceed on to a discussion of how resistance can be reflected in the behaviour of patients.

3.3.1 Patient adherence to medication / patient compliance

Extensive research has demonstrated that a significant proportion of patients (as many as 40% for the most complex regimens) fail to maintain good levels of adherence to the treatment recommendations for their condition (DiMatteo 2004c; Dunbar-Jacob et al. 2000; Laederach-Hofmann; Bunzel 2000; Haddad et al. 2004; Haynes et al. 2004). For the most intrusive and complicated regimes that involve significant modification of lifestyle or habits, the level of non-adherence can reach 70% (Dishman 1982, 1994; Brownell and Cohen 1995; Katz et al. 1998; Chesney 2000; Li et al. 2000). In Saudi Arabia, a very significant majority (79%) of patients have been shown to be non-compliant to their insulin regimen (Khan et al., 2012).

Although the dictionary definition of compliance describes the behaviour of obeying the rules given by those in authority, the healthcare definition is when “patient’s behaviours (in terms of taking medication, following diets, or executing life style changes) coincide

with healthcare providers' recommendations for health and medical advice" (Sackett 1976, p.60). Although alternative terminology is occasionally used, the intended meaning describes the same meeting of patient behaviour with official healthcare advice (Jin et al., 2008). For example, the term adherence is often used interchangeably with compliance. Adherence is defined as the ability and willingness to abide by a prescribed therapeutic regimen (Inkster 2006).

The problem of non-adherence is not confined to the lack of effective treatment for a diagnosed condition. By failing to follow medication advice, such as regarding dosage quantity or frequency, patients may potentially even be harmed (Joshi and Milfred 1995; Salzman 1995; Bedell et al. 2000). For example, the mistaken belief that a patient has taken their prescribed medication may result in a doctor making changes to medication or dosage that can have adverse repercussions, leading to less than ideal health and harmful complications (Matin et al., 2005). Indeed, the issue of medical non-compliance is a recognised and significant public health problem that places high pressure upon health care systems, both in terms of cost and the pressure on medical staff (Donovan, 1995).

The factors most commonly associated with non-compliance in the context of diabetes patients are: the duration of diabetes, their knowledge about the disease, the frequency of their visits to the diabetic clinic, the patient's family history of diabetes, a lack of support by their family, the occupation and educational of the patient's parents, and whether they have a fear of hypoglycaemia (Riaz et al., 2014). More factors affecting the ability of a patient to adhere to medical devices are the characteristics of the child and family, the characteristics of the health care system in which they live, and the characteristics of the patient's disease or regimen (La Greca et al., 2003).

Because of the interconnectedness of many of these factors, it is difficult to deduce an accurate estimate of the levels of patient adherence. The particular reasons that a particular individual is able to adhere to a treatment regimen, or for being unable to do so, can be difficult to determine. Nevertheless, this evaluation plays an important role in choosing or designing effective therapeutic approaches to maximise adherence and thereby optimise the chance for successful treatment. When collaboration is effective and

appropriate, this can lead to greater levels of patient satisfaction, lowering their nonadherence and ultimately improving healthcare outcomes. For this reason, the next section provides a more in-depth discussion of these topics in an attempt to enable clearer understanding of the potential reasons for non-adherence of a patient with regards to an enforced medical device.

3.3.2 Cognitive dissonance and Psychological Reactance behaviours

Cognitive dissonance is a term used in “psychology and social psychology to designate feelings that are professed as disagreeable and which are prompted by cognitions (meaning perceptions, thoughts, opinion, attitudes, desires, or intentions) that are incompatible with his freedom”. (Jarcho et al., 2011). New restrictions are rejected because of active reactance to the limitation (Brehm, 1966), which happens in response to the feeling that an individual is being deprived of options to which they feel entitled. In its purest terms, people need freedom (Brehm, 1966), so they react to any restriction to their choices or actions, typically by resisting any behaviour they perceive to be inhibiting their freedom. Brehm (1989) describes the term ‘psychological reactance’ as this strong response to attempt to reduce the freedom of a person in response to either direct orders or being denied permission to undertake a particular activity. Typically, when denied an option, people will often want it more (ibid). Having said this, the patient can follow under the psychological reactance toward using the insulin pump, coming to manage it correctly.

As stated by Pickup et al., (2014) patient of insulin pump should be adequately psychologically stable. There has also been a growing interest in the range of psychological problems associated with insulin pumps (Aberle et al., 2009), indicating that it would be more “appropriate to use specific, validated psychological instruments pertaining to, among other factors, coping, self- efficacy, depressive symptoms, quality of life, and treatment satisfaction for surveying these issues in pump patients“ (Pickup et al., 2014, p.148).

To sum up, cognitive dissonance theory is arguably one of the main theoretical angles from which to better understand the behaviour of patients towards compliance with

certain wearable technologies. This may be more important in the context of working with children, due to their inability to understand the rationale for using medical devices. This inability to comprehend their physical need to use the IP could be a main cause of their cognitive dissonance. The capacity to understand the need for use may in fact be a developmental process based on the age of a patient, their interactions with others, and the way that surrounding environment knowledge feeds into their minds. Therefore, the next section examines the ways in which understanding of the IP is formulated. This may comprise another building block to greater adoption, supplementing the understanding offering by TRA, TAM and HBM. In other words, learning how patients perceive and believe in the IP, may provide better and more functional understanding of their consequent behaviour.

3.4 Social Theoretical Foundations

The aim of this section is to develop the theoretical foundations for understanding the formulation of child logics. Logic means the values, definitions, perceptions and discourse that direct behaviour (Thornton, 2015). Once a certain logic is created in the mind of a child, this will inform his behaviour, so understand this development can provide useful insights into their interactions with the IP. Because some children are too young to create their own logic, they are extremely vulnerable to adopting logics of their parents and the surrounding environment. Indeed, it is intuitive that if the parents and doctors have aligned logics, the child may follow this logic, leading to successful use of the IP. However, it is somewhat unclear what occurs when the logics of parents contradicts the logics of medical personal. It is also unclear how the way in which a child interacts with the IP can create their own logic, or how different logics can interact to create a new logic, which is called the Socratic approach to building knowledge and ideas (Bereiter and Scardamalia, 2014). Therefore, the next two sections seek to build a theoretical foundation to enable these knowledge gaps to be bridged.

3.4.1 Contradictions

Contradictions is a concept used in literature to show a conflict between two perspectives, discourses, logics, ideas, or mentalities (Ford and Ford, 1994, Scott, 2013, Leonardi, 2013

; Van Parijs et al., 1982). Contradiction is defined as “contradiction refers to these various ruptures and inconsistencies both among and within the established social arrangements.” (Seo and Creed, 2002) Another definition by Greenwood et al, (2011) “Contradictions and complementarities between logics potentially provide divergent bases of valuation and critique, categorization of the real, and alternative modalities of action”. In terms of logics, contradiction has been recognised as being important in the medical sector and has been studied in this context. For example, Kristiansen et al. (2015) demonstrated how different assumptions by different roles in the hospital create contradicting logics, with a new a way of management being created.

Logics can be an effective way of explaining how people behave (Kim and Park, 2011), as they influence people’s practice and “shape their assumptions and values, influencing how they perceive, pay attention to, evaluate, and respond to environmental stimuli”(Ocasio, 1997; Pache and Santos, 2010). However, although studies have not examined how contradictions in the logics of patients and doctors with regards to medical wearable devices, research has endeavoured to shed light on the conflicts between medical staff and admin staff, as well as between different medical institutions. Indeed, the perspective of institutional logic offers a meta-theoretical framework that enables the effective analysis of the interrelationships that can exist between individuals, institutions, and organisations (Thornton et al., 2012). This is important within the context of healthcare organisations, where the existence of competing and contradicting logics has been shown to be commonplace. Through understanding the way in which institutional logics and healthcare practice are connected, it is necessary to properly study the way in which individuals relate to one another socially (Thornton et al., 2012). In other words, medical personal is controlling their behaviours and practices, which may or may not fit with the discourse and logics of their patients.

Logics and the contradictions between logics create a unique form of sensemaking to different actors (Kristiansen et al., 2015). The term ‘sensemaking’ refers to a social process and describes the way in which people process information or events that defy their normal expectations, perhaps because they are new or ambiguous (Maitlis and Christianson, 2014) Sensemaking is the key mechanism in social interaction that

positions the identities and practices of actors within the broader cultural edifice (Thornton et al., 2012, Thornton, 2015); (Weber and Glynn, 2006). For this reason, sensemaking is an instrumental part of social interaction and enables logics to be linked to the complex interrelated practices that can exist across different groups of actors in many contexts, such as healthcare (Thornton et al., 2012). In other words, doctors can make decisions based on sensemaking that mainly are derived from their professional world view, rather than from patient psychological needs perspectives. The patient is also assumed to take actions and form behaviours to the IP based on their view towards their own interactions with the IP and what shall be (i.e. subjective norms). The main thing here is that the communicative and sensemaking process between different parties should be aligned and consistent, otherwise it can be expected to result in the creation of a new form of unintended behaviour. Here, the aim of this research is to find out why some diabetic children are misusing the IP even when the benefits are clear to their doctors. This misuse may occur due to the differences in understandings, which create competing logics.

3.4.2 Sociomateriality

The proposed theory to understand the evolution of differences in logics is the sociomateriality theory. In the context of this research, the IP is a technical solution from the medical personal perspective, whereas for the patients it is a long life tool integrated in a human body (i.e. their own) (Krzymien et al., 2016). Different perceptions regarding the same technology can create different understandings and different definitions. Here, the aim of sociomateriality is therefore to explain the way in which different relationships with technology and people can lead to the creation of such a wide range of different views, opinions and logics (Hultin and Mähring, 2014). Sociomateriality is a theory originally built upon the intersection of technology, work and organization (Mueller et al., 2016) in an attempt to understand “the constitutive entanglement of the social and the material in everyday organizational life which creates a certain way to define technology” (Orlikowski, 2010, p.1437). Sociomateriality makes a philosophical statement about the relationship between the social and the material that begins, quite overtly, with the name ‘sociomaterial’, a deliberate fusion of the words ‘social’ and ‘material’ in which “the

social and the material are considered to be inextricably related — there is no social that is not also material, and no material that is not also social” (Orlikowski, 2007, p.1437).

Sociomaterial perspectives have been adopted by researchers who are most interested in the intersections that can exist between digital self-tracking devices and human actors (Pantzar and Ruckenstein, 2015).

One promising area of research is that of ‘sociomateriality’, which seeks to challenge the deeply rooted belief that it is necessary to investigate work, organisational structures, and technology as separate areas of research, rather than an intimately interconnected whole (Orlikowski et al., 2008). This approach holds that technical and social matters are inherently connected, so the traditional views of technology should be challenged and reframed, to allow the many new, complex and vibrant sociomaterial configurations inherent to modern organisational practices to be studied more effectively (ibid). This approach creates a unique way of understanding technology, life, and how we understand our positions in the life (Orlikowski and Scott, 2008). It should be noted that most sociomaterial research is currently being developed in information systems in organisations (Fuenfschilling and Truffer, 2014). Therefore, this research constitutes a novel approach to understanding patient perceptions and views with regards to a certain wearable medical technology, in this case IP.

3.5 Knowledge Gap Analysis

i A new holistic approach for understanding children reasons for improper use of IP Technology acceptance models like TPB, TRA and UTAUT are useful to understand the process by which new technologies are adopted in business, the behaviours of employees towards technology, and the attitude and behaviour of patients towards technology (Mathieson, 1991; Ajzen and Fishbein 1980). However, the ability of this theory to understand wearable technologies has been questioned. Relatively few studies have been conducted to understand this theory in the context of wearable technologies. The general evidence shows that if the patient perceives there to be benefits to a given piece of wearable technology, s/he will adopt it appropriately. However, the subjective norms of

TRA, which are used to measure the frequency and means of technology adoption, hold that few people are diabetic and need to use the IP. Therefore, this research aims to develop a novel holistic approach for better enabling a comprehensive understanding of the adoption process of the IP, taking into consideration the users in isolation, without peers.

Existing theories do provide the use of perceptions of ease of use and usefulness as a driver for the utilisation of technology. However, as these theories are used to understand behaviour of children in the pre-adoption phase (Davis et al., 1989), it is insufficient to rely on only these perceptions in examining the proper use, after integrating the IP into a patient's body (Ajzen, 1985; Godin et al., 1996). The literature review failed to show compelling research into the factors affecting the proper use of devices in post-adoption behaviour in the IP context. Thus, this research seeks to address this gap, by providing better understanding of the factors affecting post-adoption behaviour.

Because a patient uses the IP alone in his environment, often feeling obligated to use it, he/she may be more inclined to react against the IP. Particularly given the assumption that many children may not be able to comprehend the rationale for using the IP. As comprehension comes from the understanding that the child derives from the surrounding environment, an inconsistent message from the parents or physician may affect the perceptions and logics of a diabetic child with regards to the use of the IP. This can lead to improper or discontinued use of the IP. This analytic approach has not been used before to understand the problem of why some children are not using the IP properly, even though they presumably know about its benefits.

ii The role of family in the improper use of the IP

The family or the caregiver affects the degree to which children use the insulin pump properly (Mitchell et al., 2013; Liberman et al., 2014). The main determinants of how a family can facilitate or hinder a child's proper use of the IP is their readiness to the IP (Maahs, 2010). The readiness of a family can be understood in terms of their psychological and knowledge readiness. Regarding the psychological readiness, parents should be motivated for their child to use the IP in order to improve their diabetes (Laffel,

2003, Grunberger et al., 2014). The knowledge factor of parents on how to use the insulin pump is critical in the case of children below 18 years (Lieberman et al., 2014; Mitchell et al., 2013). The primary role of family knowledge and motivation is to instil proper IP use in their diabetic children, which is reflected in assessing the family knowledge to ensure confident supervision in the use of the device.

The motivations of parents toward engagement and involvement with helping their children is not necessarily fixed through the time, often having been shown to decrease after their child receives a pump (Mitchell et al., 2013). Having a depressed parent will double the risk for children, and in cases where both parents are depressed, children are four times more likely to have mood disorder than youngsters with healthy parents (Talakoub, 2012). This can often be reflected in the level of HbA1c, which can indicate improper use of the IP. In this way, decreased levels of family involvement with their children in using the IP is highly correlated with the level of HbA1c (Lieberman et al, 2014; Franklin, 2016). More national studies are needed to assess control of diabetes among diabetic patients in Saudi Arabia (Aljabri et al., 2013), especially because the psychological factors pertaining to families have not investigated in many eastern cultures, such as Saudi Arabia, which possesses different cultural values and principles in the relationship between parents and family (Georgas, 2003); (Almutairi, 2015). This focus on the family role in an Arabic country is another knowledge gap that shall be spotlighted in the current study, with regards to the improper use of the insulin pump.

iii Parents, Diabetic child and Doctors' perceptions, views and definitions towards the IP

In both Arabic and western culture, illness is often a matter of a shame (Hofstede, 2010). Patients in Saudi Arabia are psychologically disadvantaged by the way in which society looks at them (Almutairi and McCarthy, 2012). It is therefore expected for children using the IP to experience some of this stigma. However, relatively literature has been undertaken to investigate how society, including family, perceive diabetic children who use the IP. In the context of the current study, the more important point is how the child perceives the society looking at him and the effect that this prejudice might have on

behaviour. There is no any evidence in literature to show or explain how the diabetic child perceives himself, according to other perceptions, using the IP in the public.

Parents are often the key factors affecting the way in which diabetic children perceive themselves. However, it is not clear from literature how these parents perceive their children and the consequences of these perceptions. Moreover although the IP has been shown to be inherently appealing to patients and families (Shulman et al., 2016), it is less clear whether doctors and the use of complex technical language affects the diabetic child or their family (Elzubier, 2002). It also remains unclear whether the conflict in logics between the medical perspective of doctors rather than the lifestyle perspective of the diabetic child could affect the use of the IP. These knowledge gaps have not been answered in the literature on the use of medical wearable technologies and especially in the context of obligatory use among diabetic children.

3.6 Chapter Summary

Few literature sources have sought to understand why some diabetic children are misusing the IP, despite the benefits having been recognized in literature and in medical practice. Therefore, throughout this chapter, different theories have been critically evaluated to understand why classic theories (e.g. TRA, Health Belief Model and TAM) that seek to understand technology usage may not function well in this context, as summarised in Table 3-1 . Based on these understandings a new theoretical angle has been introduced. This new theoretical angle is based on sociological, psychological and behavioural research in an attempt to unify their findings.

The proposed theoretical perspective to understand the phenomenon is mainly focused on how a diabetic patient perceives the technology, how he/she perceives himself/herself living with the technology, and how other people perceive him/her as the user of the technology. All of these perceptions are developed from studying the interactions of patients with doctors and caregivers. If the diabetic child receives an inconsistent message from his parents and physicians, this may affect his perceptions and motivation to use the IP. All of that (i.e. patient understanding of the reasons for using IP and his/her

interactions with parents and doctors) can lead to the improper use of the IP. Thus, the new analytic approach will be developed in the next chapter to consider patient behaviour, not only in pre-adoption, but also in post-adoption phases.

Table 3-1: Summary of theories

Theories of accepting new medical devices	Known	Unknown
Theory of reasoned action (TRA)	<p>Stronger intentions lead to increase effort to perform the behaviour, which will increase the likelihood for the behaviour to performed. (Ajzen and Fishbein, 1975)</p> <p>Theories are used to understand behaviour of children in the pre-adoption phase (Davis et al., 1989), Intention is influenced by people’s attitude, which is the main determinant of their behaviour (Downs and Hausenbles, 2005)</p> <p>Provide way in which to understand the degree to which there was acceptance among consumers with regards to the technologies used in wearable technologies (Holden and Karsh, 2009; Ayyagari et al, 2011).</p>	<p>The impact of social influence on the use in the post adoption phase.</p> <p>factors affecting the proper use of devices in post-adoption Behaviour in the IP context</p> <p>How the intention to use is affected with an obligatory technology.</p>
<p>Technology acceptance model (TAM),</p> <p>Theory of planned behaviour (TPB)</p> <p>Unified Theory of Adoption and Use of Technology (UTAUT)</p>	<p>The use of perceptions of ease of use and usefulness as a driver for the utilization of technology</p> <p>Technology acceptance models like TPB, and UTAUT are useful to understand the process by which new technologies are adopted in business, the behaviours of employees towards technology, and the attitude and behaviour of patients towards technology (Mathieson, 1991; Ajzen and Fishbein 1980).</p>	<p>Few studies have been conducted in an attempt to understand this theory in the context of wearable technologies</p> <p>No any evidence in literature to show or explain how the diabetic child perceives himself, according to other perceptions, using the IP in the public.</p>
Health belief model (HBM)	The belief that illness can be prevented or improved by following certain types of behaviour; and (b) the	HBM fails to explain why some children are continuing to misuse the IP, regardless of the

	wish to either recover from ill health or to avoid it altogether	benefits that this technology offers.
--	---	--

CHAPTER 4 **Research Methodology**

4.1 Introduction

This research seeks to investigate the adoption of Insulin Pump (IP) in Saudi Arabia, with focus on the barriers to successful adoption. IP adoption in this context requires a broader context, including all the factors that may be involved – not only the patient and the medical personnel, but also the patient's family, friends, social pressures, etc. Therefore, it requires an inter-disciplinary analytical framework that, in this study, captures the distinct perspectives of change agents (medical personnel) from Saudi Arabia, diabetic patients and their care-givers from Saudi Arabia (but can be in future extended to capture other significant factors in other cultures, countries, or age groups).

Thus, for the purposes of this study, the main aim is to understand why diabetic children are misusing the IP. The objectives are focused on understanding the different discourses among different actors, looking at how the contradictions affect the use of the IP and may lead to its misuse. The problem is not only in the interaction between patient and the wearable device from the technical perspectives (Patel et al., 2012; Regittnig et al., 2013), but also from the attitudinal and psychological perspectives (de Vries et al., 2010; Binek et al., 2016) of the diverse agents involved (medical personnel, patients, caregivers).

This chapter will discuss the research strategy and research quality. The research method is detailed and structured on two main phases Figure 4-1. The first phase is to understand the reality from the doctors' perspective through interviews. The second phased is for understanding the patient and his/her family perspective through case study research. The research quality will include the reliability, validity, credibility, reflexivity and transferability.

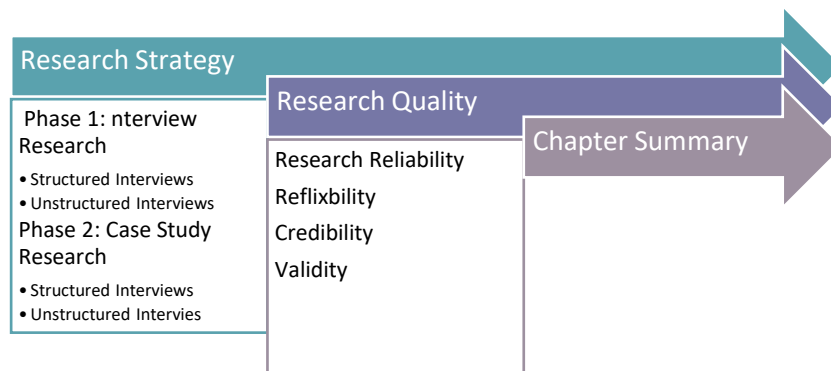


Figure 4-1: Chapter 4 Structure

4.2 Research Strategy

The main motivation for the selection of a qualitative approach for this research is its suitability for the study of people in their natural settings and its ability to enable a deeper understanding of phenomena in terms of the meanings people bring to them (Atkinson and Hammersley, 1994). The methodological focus of this approach is on the narrative analysis, reports, personal experiences, and observations, in an attempt to provide new insights to often familiar situations (Cohen et al., 2013). As per the maxims of qualitative research, the truth is based upon the idea that individuals develop within social settings (Creswell, 2013). Qualitative research is therefore more substantial to the researcher than others because of the likelihood of different outcomes (Guba and Lincoln, 1981; Creswell 1998). The qualitative approach relies upon analysis of the content, the discourse, and the context of each story, focusing on insights and understandings. In the current research, the aims of the discovery stage were to discover what the informants say and do, in order to capture their viewpoints, perspectives and attitudes from their personal perspectives, then to use this data to address the research questions.

The research strategy for this research has two main components: interviews conducted with medical personnel in Saudi Arabia, who are the change agents; and case studies conducted with Saudi patients and their families. Both studies were carried out in Saudi Arabia. The first discovery stage is to understand the change agent (doctor and educator) practices adopted. The goal of comprehending the reality from the perspective of the

change agents (medical personnel). The use of interview research (13 unstructured and 22 structured interviews) is intended to provide understanding of their views, definitions and discourse in terms of the IP (detailed description is provided in section 4.2.1). The second phase is to capture the perspective of the patients and their parents regarding their views, definitions and discourse on the IP using case study research.

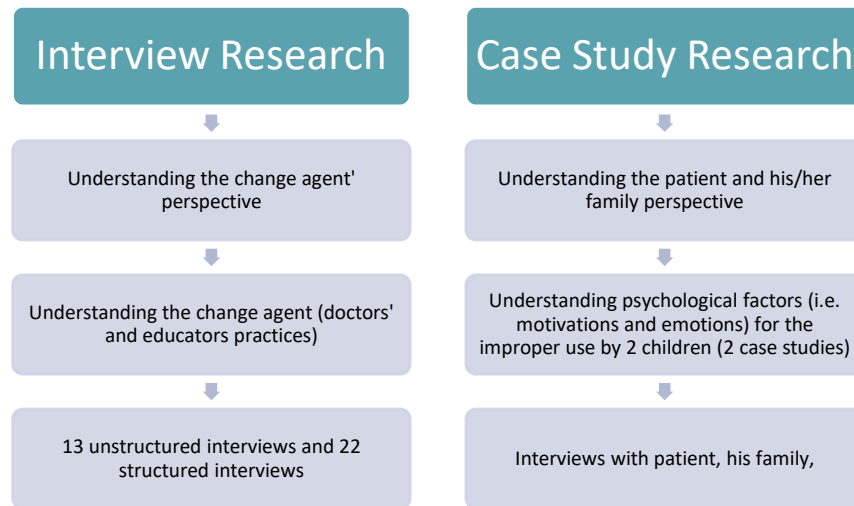


Figure 4-2: Research Strategy

4.2.1 Phase 1: Interview Research

In order to establish the broad context in which new technology is being adopted into the daily lives of patients in particular communities, as well as to provide some insights into how these are controlled by the doctors and educators, I used a set of establishing questions with the doctors and the diabetic educators. These questions are: when does the doctor recommend the IP, when does doctor choose not to recommend the IP, and when does the doctor withdraw the IP. These were intended to provide information on the three key strategies used by doctors and educators in managing the adoption of new technology and its integration into the daily life of the patient.

The significance of in-depth interviews in this context is that they help to elicit the perspectives, definition and narratives of each interviewee, enabling effective documentation of the pre-defined issues. These interviews also enable both the interviewer and the participant to include or elaborate upon any ambiguity that may

emerge during the interview. Nevertheless, it ought to be borne as the main priority that once answers are repeated and no extra knowledge gained in an unstructured interview, the participants can be guided by a more structured interview structure to provide more responses, thus ensuring more reliable results and findings. The interviews should then be ended once the picture obtained is sufficiently clear (i.e. saturation level is reached) (Glasser and Strauss, 1991; Charmaz, 2012). This section will explain the rationale for performing the unstructured interview and the structured interview.

i Unstructured interview

The unstructured interview is an examination process that enables an exploration of issues and collection of rich data on the contexts being researched, as it permits the participants to recount their stories in detail (Denzin and Lincoln, 2000, Tod, 2006). This approach is most commonly employed when there is minimal to zero learning or data on the research question (Legard et al., 2003). The researcher typically listens to the interviewees and assists them, by addressing the discussion to topics that they consider to be significant and essential. These interviews are usually recorded, as well as being annotated by field notes. I believe that this type of interview offers the potential for valuable insights into the underlying reasons for the improper use of the IP by children. This understanding can be facilitated by the arrangement of a schedule in which there is a discussion with the interviewer that is more likely to make interviewees more explicit about more issues. These interviews also have a tendency to empower the social qualities, attitudes and standards of participants, enabling them to be more effectively investigated by an interviewer (Mason, 2002; Tod, 2006). Although unstructured, as a rule, the interviewer uses pre-structure interview questions and probes during in-depth interviews to start the conversation, as well as to explain or to elicit additional data from participants.

Qualitative research, which stresses the in-depth investigation of a small number of communities, often utilises snowball sampling (Biernacki and Waldorf, 1981) rather than random sampling. That was also the approach adopted in the current study, with the doctors referring me to other quality doctors and educators who might be willing to take part in my research. The number of respondents was based on theoretical sampling

(Charmaz, 2012), which mainly focuses on the saturation level of the findings and results. As the emphasis in the current study is on quality rather than quantity (qualitative rather than quantitative data), interviews were held face-to-face and, with the addition of following up sessions, took an average of 1 to 2 hours per participant. Appointments were made in person, at the reception of each clinic, with some interviewees being met face to face beforehand, to deliver the consent form and arrange the appointment for a time and location most suitable for them.

The interviews were held in the doctors' clinics, after I had made an appointment and described the reason for the interview. A consent form was presented (Appendix A) and explicit consent obtained from each participant to be interviewed. During each unstructured interview, it was important for the participants to feel unstrained, with plenty of time available for them to discuss how they understood and described their experience. As a consequence, the interviews took about an hour to an hour and forty-five minutes, using questions that were designed to identify patterns and common themes in the accounts given by each participant.

ii Structured Interview

Before finishing the analysis of the unstructured interviews, another wave of structured interviews was launched to extend and validate the findings, using a structured interview approach following a well determined interview guide. The interview guide was developed based on the findings of the unstructured interviews. The structured interview guide was administered over the phone, because most the medical personnel were too busy to schedule a face-to-face interview. Phone interviews also made it easier for the researcher and to organise and schedule the data collection. As with the previous data collection stage, the sample size was defined by saturation level. In other words, once the results were perceived to be repetitious, it was determined that there was no need to increase the sample size and the recruiting process was halted. A total of 22 respondents was deemed sufficient, as the latest 8 respondents did not add anything in terms of understanding the behaviours, motivations and attitudes of patients, with regards to either the IP or its improper usage.

4.2.2 Phase 2: Case Study Research

The second phase was the case study with the beneficiary (i.e. the patient and their family). These case studies comprised “an empirical inquiry that investigates a contemporary phenomenon within its real life context” (Yin, 2003, p.13). However, it should also be noted that this research took the stance that a “...case study is defined by interest in individual cases, not by the methods of inquiry used” (Stake, 2003, p.134). The purpose of the second phase of this research was to obtain a different perspective than that of the change agent perspective (i.e. doctors and educators). Instead, the case studies sought to examine the problem from the perspective of the patient and their families, rather than the doctor. (Gummesson, 1991) stresses that while case studies vary in character according to the phenomenon studied, there are two types of particular interest: the type that attempts to derive general conclusions from a limited number of cases; and the type that strives to reach specific conclusions regarding a single case, because the specific ‘case history’ is of particular interest. This research took the latter approach, which was deemed to have the characteristics required to ensure the provision of different perspectives in the development of the framework.

Criteria were used to select sites for the study (patients and family using the insulin pump), which included consideration of manageability, diversity in family conditions, ages and gender, and the willingness of respondents to speak freely with the interviewer. In addition, informal networks were used to identify the most appropriate cases, because of the unavailability of the patients’ information in the public domain (e.g. websites or public directories) and the limitation that medical personnel are not allowed to declare names of the patients. For this reason, I approached my informal networks to find children with diabetes who were struggling or frustrated with the IP. I found four viable children and selected two of these to participate. These two selected children are different gender (one male and one female) and different age groups (8 years and 15 years). The aim is not to contrast the participants, but to find evidence for supporting and extending results of the interview research with respect to different ages and genders.

i Interviews

Each case involves an interviews with different actors, which were held face-to-face, at the house of the participating families. Meeting the patient and his/her family in their own house makes the interview more natural, helping them to talk more freely and for the patient and their behaviour to be observed. This also enabled the researcher to observe how the diabetic children viewed and interacted with the IP and how the family interacted with him/her regarding the IP. This opportunity to observe the patient and his family behaviour is more useful and valuable than only conducting interviews.

ii Observation

Observations comprise the informal observation and recording of materials, situation, occasions, narratives and practices as they happen in an individual's environment. This is an adaptable data collection process that does not restrict what the spectator ought to watch and note, instead holding that everything is potentially valid and useful for the purposes of recording and checking (Holloway and Todres, 2007, Parahoo, 2006). Nevertheless, an unstructured observation can become more particular in terms of when and where observations are conducted, the most important parts of the setting or behaviour to monitor, and how to effectively document observation. The objective of an unstructured observation includes the collection of subtle elements, practices and associations in all of the specific settings that as could be expected under the particular study circumstances. Then, without filtering it through any interpretive process, to depict the important conduct and attitude with regards to the IP that can properly explain the motivations to misuse the technology. Unstructured observation effectively serves the function of enabling in-depth comprehension around an undefined subject (Bowling, 2014, 2002). This method therefore appears to be highly appropriate to the objectives of this research, the overarching aim of which is to search for knowledge, to investigate and increase understanding about the misuse of the insulin pump among children.

Hence, it is believed that looking into the subject, not confining the view by adopting an unequivocal theory or agendas, and maintaining flexibility in the observation of the

contexts associated with the research question may be facilitated by viewing the setting normally as it happens.

4.2.3 Ethical Considerations

Because the study involved human participants it was necessary to consider ethics and gain ethical approval from the researcher's university. Ethical approval was granted. Towards this informed consent was conducted whereby participants were informed about the purpose of the study and their consent was gained. The participants were also informed about their right to withdraw from the study at any time.

4.3 Research Quality

Research quality describes the process of ensuring that the output of this research is trustworthy and captures reality, in addition to providing the data required to address the research question. There are different research quality criteria. This section outlines the five research quality aspects used in this study, the first four of which pertain to trustworthiness and the final aspect being concerned with the applicability of this research in different places (i.e. 'generalisability'). Given that data are collected from people and understood by people, and in recognition of the fact that human nature is inherently subjective in understanding and presenting ideas, the four aspects are reliability, validity, credibility and reflexivity. Reliability describes the degree to which participants can be relied upon to be truthful in telling facts and giving their perspective (Rossman and Rallis, 2003). This is important, because participants may give false information misrepresent what believe in because they may feel threatened, under observation, or shy about expressing their ideas frankly (Kirk and Miller, 1986). Because of this, I adopted different measures, as discussed later, to ensure the integrity of the interview and the ability of participants to speak freely.

The second issue, validity, concerns whether I understand what the participant wants to say correctly (Arksey and Knight, 1999, King and Horrocks, 2010). Therefore, during the interviews, I occasionally paraphrased the answers given by respondents to check that my

comprehended meaning matched the content that they had intended to convey. In addition, with the medical personal. I sent the interviewees e-mails to summarise the main points we had addressed in their interviews. While with the parents I phoned them.

Credibility is the third issue and refers to the degree to which the written records of findings are correct and trustworthy, with no mistakes having been made in reporting observations or scripts (Lincoln and Guba, 1985). Therefore, all interviews were recorded (except where specifically forbidden by participants), transcribed and translated to ensure the integrity of reporting my findings.

The final consideration is reflexivity, which can be explained as the trustworthiness in deriving my framework and that the rationale for my interpretations of the data are the best fit for the intended purpose. Thus, using literature, I evaluated different potential understandings of the salient facts, and derived from these the most meaningful interpretations of the improper behaviour of children in dealing with the IP.

Research Quality	Definition	Measure used
Reliability	Participants are telling the truth and their discourse is constant over time.	<p>Asking the same question in different ways at different times.</p> <p>Allowing doctors who refused to be recorded the chance to talk without recording.</p> <p>Showing a consent form to confirm that all data gathered are confidential and will not be shared with anyone.</p> <p>Trying to help them be relaxed</p>

Validity	Ensure that the understanding of the researcher matches that of participants.	Paraphrasing the answers and ensuring similar results. Emails were sent to give confirmation of the interviews.
Credibility	Ensuring that everything written is correct, truthful and trustworthy.	Consistency of the report with few contradictions between findings by using a recorder and recording interviews, then checking transcripts.
Reflexivity	Ensuring that the researcher's understanding is correct and her interpretations are the most suitable in the context.	Evaluating different possible understandings of the facts using literature review and different rationales.

4.3.1 Reliability

In the context of academic research, 'reliability' is traditionally understood as being a measurement of the consistency, stability and reputability of the responses of study participants, considering if the same questions were asked at different times (Stenbacka, 2001). Reliability is problematic and even practically impossible because human behaviour is not static, is highly contextual and changes continuously depending on the influence of numerous factors. This dynamic nature of human behaviours can make it more difficult to achieve consistency in qualitative studies (Cohenetal, 2007).

However, in qualitative research, reliability can be seen as being highly influenced by whether the participants are telling the truth and saying what they want to say. In other words, it was essential that my participants would not face any pressures to tell me false information, especially what they thought I wanted to hear, and that they would have the freedom to talk. I attempted to remove bias from the discourse of interviewees, as well as to ensure that participants felt unthreatened and comfortable that they would not be misrepresented, or under psychological disadvantage due to his illness. I also rephrased questions in different ways at different times, to facilitate understanding and improve the chance for good data to be gathered. Participants were assured that the data gathered

would be confidential and used only for research purposes. As permission was required for the interview recorded, some medical personnel refused to allow this during their interviews.

I followed recommendations from Arksey and Knight (1999) regarding the importance of building rapport in my interviews. Participants were given the scope to express their personal perspective of things, inviting their trust and openness. In the first child case study, I used different measurements reassure the boy, encouraging him to talk freely without shyness, manipulation of his opinions, or making him feel that he needed to present a different image. In addition, I invited the family with the young diabetic child to visit a family entertainment restaurant with my own family, to allow the participating family to relax, to build rapport, and to better observe the child and his mother in a public place. I tried to be open with the child and talk about different subjects in open conversation, like studying in UK and my long-term aims. I also brought a gift for the other child and his family to help them to relax and not worry about our conversation. Therefore, despite the boy in the first study being very young and shy about his IP, I was able to obtain useful information about his true feelings.

4.3.2 Validity

In the current research, 'validity' is deemed to measure the degree of matching that exists between what a researcher understands from the participant and what the participant intends to convey (Patton, 2001, Seale, 1999). This definition is not necessarily similar in other research, especially that which is quantitative positivistic in nature (King and Horrocks, 2010). Therefore, to ensure the researcher understanding matches the participant understanding. In an attempt to ensure that the participants conveyed their intended meanings, the researcher paraphrased their answers and sometimes repeated key comments back to them. In addition, I summarised the dialogue of the doctors and asked them to check that I had understand them correctly.

4.3.3 Credibility

In qualitative research, credibility is regarded as the degree to which the research data are conceivable and reliable (Lincoln and Guba, 1994). Credibility describes the research

findings matching reality and is therefore somewhat similar to internal validity. It is dependent on a researcher to evaluate the degree of validity in their own study, given their personal comprehension of the research topic. The majority of positivists recommend that no separate reality exists to be found, arguing instead that all individuals develop their own picture and perceptions (Smith and Ragan, 2005). This means that, from an interpretive point of view, comprehension is co-constructed and that there is therefore no objective truth or reality to which the outcomes of a research study can be referred.

To ensure the credibility of this research, I did my best in capturing and archiving all interviews correctly. I followed two techniques in an attempt to avoid incompleteness of the data gathered, by recording the interview when accepted by the informant and extensive note-taking in all of the interviews (Robson, 2002). In this way, as well as creating good records for later analysis, I tried to address the validity of the collected data through avoidance of potential distortion or misrepresentation from remembered comments (Cohen et al, 2007). Therefore, credibility was ensured by carefully checking the correctness of what was written, matching the truth and maintaining trustworthiness. This was checked by measuring the consistency of the report with the few contradictions between findings

4.3.4 Reflexivity

Reflexivity is usually a component of qualitative research, as it is a particularly viable strategy to enable qualitative researchers to approve their practices (Cutcliffe and McKenna, 2002, Pillow, 2003, Kingdon, 2005). This useful evaluative process involves the interviewer consistently monitoring and assessing how their behaviours, beliefs and attitudes influence the setting of the research, especially the fieldwork engagement and data analysis (Gerrish and Lacey, 2006). In the specific context of case study approach and interviews, there are various issues related to, which ought to be considered.

One of these problems is objectivity, given that reflexivity is so dependent on the individual experience of the interviewer issue. (Savage, 2006). They contend that the outcomes created from utilising this technique are not legitimate, as a result of the chances

that could occur due to the ‘reactivity and subjectivity’ of the specialist (Spenziiale and Carpenter, 2003).

Alternately, it can be argued that the cooperation that exists between interviewees and an interviewer is a potentially useful tool for the effective construction of “interview questions and comprehending the answers during the data collection” (Berkwits and Aronowitz, 1995, p. 410). Lietz et al. (2006) underscore the significance of reducing the effects of the interviewer within an interpretive research by suggesting that the researcher organises the attitudes, emotions and encounters of the interviewers and gives them precedence over that of their own.

Regardless, reflexivity is generally perceived to be rooted in the position a researcher takes in the research in terms of their understanding and selection of cases. Ultimately, the most important outcome to stress is the importance of striving to attain objectivity in selecting cases and interpreting the facts (e.g. transcripts and interviews).

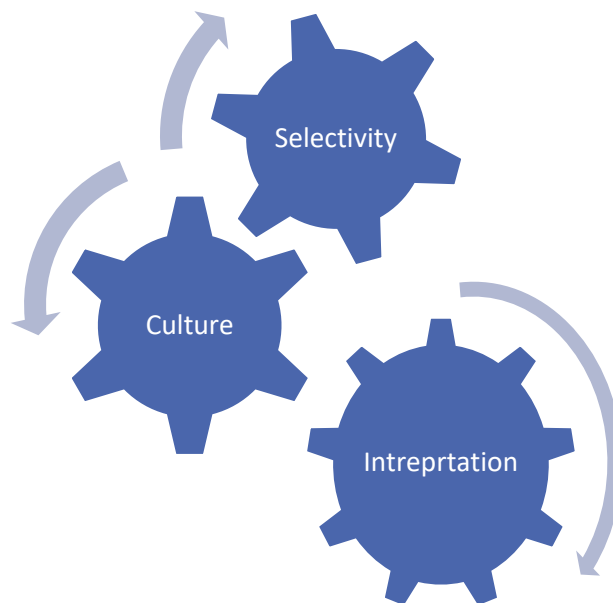


Figure 4-3: Reflexivity elements

i Reflexivity of my Cultural: Position of the researcher

My position in the case studies also afforded me permission to enter the home of participants and be honoured to speak to the members of the family as a guest, in contrast to many others (such as researchers who are male or foreign), who would have been denied access or placed under different, more onerous restrictions. This advantage has been acknowledged in the literature, as in “the investigation of national associations in Arab society, these paradigms are the outcomes of the constrained access of the male interviewer to collect useful evidence. I trust that under these conditions, just female scientists can easily access the information required” (Soraya, 1994).

As a component of culture, I may have overlooked some points of interest that I may have learned to underestimate but which an outsider may have taken consideration. I also actively confronted the expectation of interviewees that I would intrinsically comprehend their experience or the importance of their words without clarification. For instance, on a few occasions, they asked me, "you realise what I signify" or "you know", anticipating that I should reply "yes" without further elucidation. In such circumstances, I requested them to clarify, by saying: "what do you mean by that", " or by offering a clarification that would show that I concurred or could not help contradicting their message.

I would also contend that originating from the same culture, and in addition being of a similar gender of the mother, is likewise critical where a shared comprehension of general social standards and conventions affords valuable knowledge of guidelines, limits, and desires. However, I understood that I ought to be clear about these negative perspectives and issues which I have made an effort not to put my research data for fear of bias. Therefore, I attempted to separate myself as an insider with the end goal of analysis and in concentrating on the investigation. I purposefully endeavoured to position myself as an outsider in discussions, especially those about a participant's way of life, society, or social standards, which I achieved by alluding to these perspectives as "their" way of life, "their" social rules or "their" nation. By utilising "they", "them", and "their" rather than "we", "us" or "our", I sought to demonstrate that I recognised my position as being distinct from that the interviewees and abstained from giving the impression of complete

comprehension regarding their way of life and experience with society. I supplemented my management of this issue by offering explanations to those interviewees who continued to expect my comprehension.

ii Reflexivity in analysis and interpretations

A researcher's awareness of their own experiences, bias, attitudes and beliefs creates the risk of influencing their data interpretation (Reid et al, 2005). As noted above, this is referred to as reflexivity and it is important to acknowledge these influences within this study. I am not a diabetic and I do not have any member of my family who uses a medical device. The function of the case study with the children was observe how the patient and their family view of the IP. However, considerations of reflexivity allow a researcher to write about their beliefs, biases, orientation, and past experiences that can affect their interpretation of the data, and approach to the study (Creswell, 2013). Reflexivity is also considered in developing cohesive interpretations of different facts. Therefore, for virtually every interpretation I performed, I used comparative and contrasting theories in order to understand the facts, then noted the reason for my selection of a specific interpretation.

iii Selectivity and bias

In the case of the case study component of this research, the selection was based on a rationale that a family perceives that doctors believe that their child is failing to use the IP correctly. For this reason, an 8 year-old male child was chosen for the first case study, with his selection being based on references from his relatives. To be precise, his family is the neighbour of one of my relatives. Permission was sought from the parent and after consent was obtained from his mother, I interviewed and observed the diabetic child, his mother, sister, and their servant. He comes from a relatively large family: he has a sister 'Mariam', aged 15, and two brothers, who are aged 6 and 4. The child's mother is a 46 year old high school teacher in a public school. His father is a pilot who travel extensively. Finally, they have a servant in the house who joined the family one year ago. The child suffers from Type 1 diabetes, which was first diagnosed when he was 6 years old. He has

been on insulin injections since that time, until he turned 7 years old. The child was interviewed indirectly and observed. A series of semi-structured questions were directed to him. He is a sociable person so he can talk very well and explain, although he did not want to show or discuss his pump initially. However, once I had explained to him that my son wears a hearing aid because he has problem listening, the boy became willing to show me the pump.

In the second case study, a 15 year-old female was selected. Explicit consent was obtained from the adolescent and her family to conduct an interview and observation of the girl. The selection of this participant was because her failure to correctly use the IP had resulted in her being admitted to hospital. It was therefore deemed interesting and valuable to investigate the kind of perception that could lead to profoundly improper use of the IP. The female girl was seen in a small gathering, during which I introduced myself to her. I was then invited to their house for a dinner. The adolescent was interviewed indirectly and observed. A series of semi-structured questions were directed to her, with a smaller number of supplementary questions being asked of her mother. The girl was initially diagnosed with diabetes when she was 8 years old, however she has only been on the insulin pump for 18 months. She comes from a well-known family in Jeddah, whose family bought her the insulin pump to improve her diabetes, and because she always forgets to take her insulin injections when she visits friends, which happens regularly. The parents therefore felt that the IP was a better choice, enabling their child more freedom and a better life style once it was connected to her body.

The adolescent is a very sociable girl who likes to be involved in events and social activities. She spends a lot of time visiting or hosting social events, with most of her time outside school being spent at events, at homes, or in restaurants. Her image is important to her and she likes fashion, so is reluctant to show her insulin pump to other people, even to her friends. She feels shy about telling her friends that she is diabetic.

4.3.5 Transferability

The data are transferable or generalizable if they fit into new settings outside the specific research environment. Transferability is undifferentiated from outside legitimacy, that is,

the degree to which discoveries can be summed up. Generalisability alludes to the extent to which one can expand the record of a specific circumstance or populace to different people, periods or setting than those specifically studied (Maxwell, 2002). Transferability presents a risk to substantial inductions in the common understanding of information and is a particularly important issue in qualitative research due to the inherent subjectivity that arises from the role of the interviewer as an important instrument. A qualitative researcher can improve transferability by enumerating the examination techniques, settings, and generalisations associated with the study (Thomas, 2010). Seale (1999) asserts that transferability is accomplished by offering a rich depiction of the settings to furnish participants with adequate data to ensure that they have the capacity to judge findings and then to apply them in different settings with which they are familiar (p. 45).

4.4 Chapter Summary

This chapter had discussed the research approach and methods adopted and reflected in the way which data about the problem situation should be gathered Figure 4-4.

This research is an interpretive qualitative research. Its strategy is based on two phases: the first is understanding the perspective of medical personnel (change agents), through interview research and the second is understanding the patient in his context with his/her interactions with others in a case study. Finally, research issues such as the credibility, objectivity and reflexivity of the research method were discussed with reference to both the studies reported in the literature and the study carried out in this project.

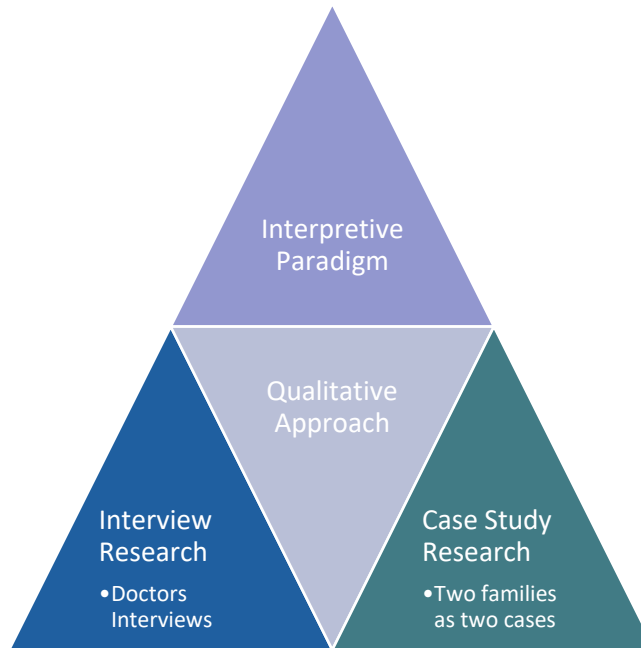


Figure 4-4: Chapter Summary

CHAPTER 5 Technology Adoption framework for IP (TAF IP for children)

5.1 Introduction

This chapter aims to develop the technology adoption framework (TAF) for IP for children. The chapter is divided into two stages Figure 5-1. The first stage is developing the analytic framework to understand the causes of IP misuse based on the perceptions and interactions of the three kinds of agent. This framework consists of several levels of analysis and presents novel analytical constructs. The second part of this chapter is describing how the approach undertaken and applied in the problem situation practice, which consists of the research model, change agent perspective, beneficiary perspectives, and lastly the interpretations. The chapter will conclude with the summary.

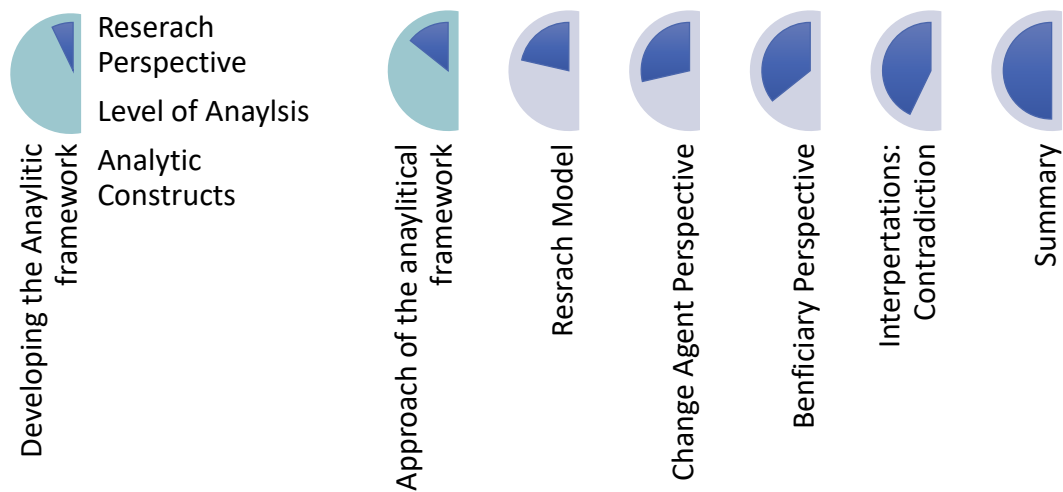


Figure 5-1: Chapter 5 Structure

5.2 Developing the Analytic Framework

The analytic framework consists of three main elements shown in Figure 5-2. The research perspective is to detail the philosophical stances underpinning the framework. Next is the level of analysis, which comprises facts data collection, classification and segmentation; interpretation of classified data and of the relationships between those

involved; and the explanation of the causes, reasons, motivations, attitudes underlying the informants observed behaviour. The final level is that of the analytic constructs, which are the actors and technology.

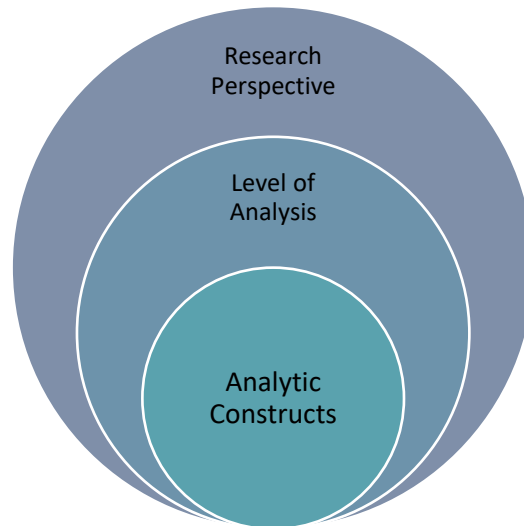


Figure 5-2: Analytic Framework Elements

5.2.1 Research Perspective

This section will discuss the understanding of the analytic framework in terms of the way in which the knowledge is gained and defined (Galliers, 1991). After comprehensive analysis and critique of the current literature, no framework or theory has been identified that is able to comprehensively address the complexity underlying these research questions. The analytic framework is therefore predicated upon the assumption that no single clear conceptual framework can be deduced from literature. The research gap is that no current research has investigated the reasons for the improper use of the IP by children in Saudi Arabia from the sociomateriality perspective. This research adopts an interpretivist epistemology that is primarily based on the interaction of the researcher with the lived experience, based on the beliefs of those involved. This epistemology has been selected in an attempt to better obtain a new and in-depth perspective on the patients' and their families' drivers to misuse the IP.

5.2.2 Level of Analysis

The main aim of this research is to gain a better understanding of why some patients are misusing the IP. The analytic framework will combine three approaches. The first, used to understand the differences in discourses, dialectics and contradictions between different actors, is the contradiction approach (Seo and Creed, 2002; Van Parijs et al., 1982). The second is sociomateriality (Leonardi, 2013), an analytic approach that can be used to understand how interactions between the individuals, technology and society are able to shape views, understanding and behaviour. Different actors often have different perceptions, which can result in the creation of a new perception with regards to the focal agent (users' perception) (Van Parijs et al., 1982). For this reason, the third is the theory of reasoned action (TRA), because new perceptions towards technology are generally assumed to affect the attitude and the way the technology is utilised, as illustrated by frameworks like TAM, TRA, HBM (Ajzen, 1994; Mathieson, 1991, Montano and Kasprzyk, 2015, Gao et al., 2015). In simpler terms, the interactions, and presumably contradictions, between different actors having different discourses to understand and to define a particular technology mean that the focal user can generally be assumed to have a new consolidated view towards that technology. This will typically be reflected in his/her attitude and behaviour towards the technology.

The analytic framework will be based on three levels of investigation. The first level is based on the facts, narratives and discourse of the diverse agents involved in this context, in an attempt to properly comprehend the perspective of each agent. This level utilises three main categories to make sense the facts: the discourse perceptions (including opinions and subjective norms) towards the IP; discourse is "defined as the symbols, idioms, metaphors and adjourns" (Johnson-Laird 1983, p.377); and the perceptions as mental models of each, looking at how each party perceives the other and the object (i.e. technology) (Johnson-Laird, 1983).

The second level seeks to understand why parties say and do particular actions (i.e. the interpretation of classified data and of the relationships between those involved). This level seeks to go more in-depth by associating different perceptions together to construct appropriate mental models in order to uncover how the various interactions and

contradictions shape the perceptions (Van Parijs et al., 1982). This is important, since different kind of contradictions creates different kinds of behaviours (ibid)(Leonardi, 2009). Here the analytic framework serves to provide and derive an understanding of the facts, taking into consideration the various theories that can be partially or wholly utilised to explain those facts. As a consequence of this, the proposed analytic framework restricts the understanding into a limited number of main interpretations: understanding how different discourses and perceptions shape the perception of beneficiaries, using both contradictions and socio-materiality theory; and understanding how the produced perception creates a pattern of behaviour, using TRA (i.e. the belief that subjective norms affect attitude, which in turn affects behaviour).

The third level is what I propose based on my understanding of the data and my interpretation of those findings in the research context (i.e. an explanation of the causes, reasons, motivations, attitudes underlying the informants observed behaviour). This level is provided in the discussion as future research.

These three levels of knowledge were formulated as a pyramid, illustrated below in Figure 5-3, to highlight findings from the preliminary evaluation that have been synthesised, combined in this research. Then, through the use of the different interpretations I developed my explanation. To validate my explanation and ensure that it is based on strong evidence, the explanations are contrasted and supported with literature in order to evaluate their external validity (i.e. applicability and generalizability

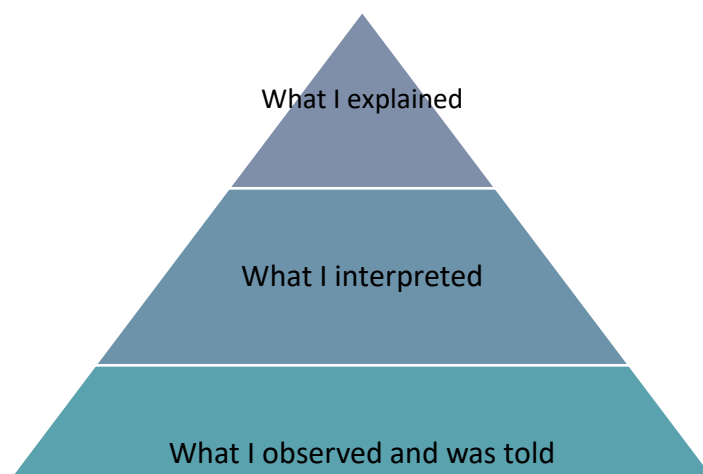


Figure 5-3: Level of knowledge

of these propositions in different contexts). Finally, I propose an analytic framework that can be utilised by other researchers operating in different contexts to support them in facilitating their acquisition of interesting results and findings based on the three level of analysis described above.

5.2.3 The Analytic Constructs

The concept of the adoption process was originally borrowed from the organisational transformational process (Venkatesh et al., 2012, Thong et al., 2006, Lee et al., 2015). The transformation of organisations is usually undertaken by external persons, otherwise known as change agents, to the people who will be changed and who shall therefore benefit from the change, because of which they are called beneficiaries. This process is typically championed, managed and followed up by the sponsors in order to ensure the quality of the change. This is also true in the medical context, when a doctor and educator introduces the IP to a diabetic child and their family. Here, the main beneficiary is the diabetic child, who can be expected to be the one who is most affected and whose lifestyle is directly changed. The supervision, controlling and following up is carried out by the sponsor, who in this case is the parents.

The main reason for the adoption of this framework in this research is that it offers an understanding of the practices, discourse and perception of each actor. As with the literature on transformational changes (Badewi et al, 2013), every stakeholder may have a different, specific agenda of benefits from the change. For this reason, each stakeholder is likely to be acting and defining the change based on their personal perception of the benefits and problems associated with the change. This recognition of individual agendas may be a reason why this framework has been shown to have significant success in information technology adoption (Karahanna et al., 1998). It is for this reason that the idea of different actors is used to investigate the different perceptions and motivations

(i.e. perceptions of benefits and dis-benefits) that arise from the change in the lives of diabetic children due to the existence of the IP.

To understand the facts, I interviewed the main actors: namely, the change agents (doctors and medical personnel) and the beneficiaries (diabetic children, who are the users of the IP, and their care givers). Working from ‘what I was told’, I identified the discourse utilised by each participant, the main ideas that each individual has focused on and the ways in which they define and approach the technology differently. In this way, I ‘interpreted’ the main clashes in their understandings and identify how these are reflected in their behaviour (i.e. to discern why they do what they do). From that, I drew my conclusions and endeavoured to form a cohesive explanation.

		Analytical Constructs	
		Technology	Actor
Level of Analysis	Facts	The definition of the IP for different actors. (How they view the IP, benefits and drawbacks? In addition, attempt to capture the discourse used to express their views.)	
	Interpretations/ Understanding	Understanding the misunderstandings and contradictions that exist between actors in understanding technology functions	
	Explanations/ propose	How the interactions and contradictions are to shape the attitude, motivation and behaviours of the diabetic child towards the IP?	

Figure 5-4: The analytical framework

5.3 Summary of the (TAF IP for children)

The framework is built on two main theoretical ideas. First, the contradictions in understanding a single object can lead to a new understanding and definition of this object. This is because the definition of the object, such as an IP, can lead to a particular attitude towards it, which in turn results in particular behaviour and patterns of use.

Second, theoretical foundation is provided by the sociomateriality approach, which considers how technology affects us and how we affect the technology. In other words, different ways of perceiving the technology can lead to different uses of the technology, which leads to different outcomes. These outcomes and this way of using the technology affects our life and our perception towards life. By combining both theoretical foundations which are the contradictions and sociomateriality, the assumption is that the different actors (doctor, caregivers, patients, their family members) have different perspectives, definitions, attitudes and motivations that determine their views on why IP should be used). Special attention will be given to the contradictions among them in understanding and motivations towards the IP. The interactions between these contradictions may lead to a unique perspective of the child towards the IP and therefore unusual behaviour (i.e. misusing) towards the IP. Based on these assumptions, the research question, aim and objectives were addressed.

The analytic framework was developed through explicating the research issues that arose when technical and psychological perspectives were brought together in a unified framework. These issues influenced the choice of levels of analysis, analytic constructs and finally the application of this analytic framework to a real-life problem situation that led to the scientific explanation

5.4 Approach of the analytical framework

This section describes how the approach undertaken in this research was applied in the problem situation in practice. The focus here is to better understand the relationship between the change agent (doctors and educators) and the beneficiary (the diabetic child who benefits from the IP and his/her family), as well as the ways in which this relationship may affect the perspective, attitude and behaviour of the beneficiaries toward the IP. The implementation of the analytical framework and research methodology has two discovery stages that target the change agents and beneficiaries. Because the focus is on the perceptions of change agents and beneficiaries of the technology, the research method is empirical – the discovery stage is based on unstructured and semi-structured interviews in phase one and case studies in phase two.

The first discovery stage is to understand the perspective of change agents toward the IP. In this case, the change agent is the person(s) who introduces and follows up the IP device with the patient. As described in the previous chapter, a change agent is expected to have effects on the perception, attitude and behaviour of the diabetic child and his family towards the IP. Therefore, their practices and the reasons behind these practices are crucial in encouraging the patient child to avoid improper use of the IP. The discovery of these was conducted by means of unstructured and semi-structured interviews. Furthermore, how change agents act in the relation to other actors (e.g. family and friends) is also considered, in order to investigate what makes it possible for them to change patients' perspectives. The aim of the second discovery stage, carried out by means of case studies, is understanding the differences between beneficiaries (i.e. the diabetic child and his/her family) and change agents, with particular emphasis on studying how the interactions between them develop and influence the beneficiary perspective, attitude and behaviour toward the IP.

In this chapter the application of the analytic framework, developed in section 5.2, is centred on the change agent perspective in the first part of the chapter (section 5.6). The second discovery stage takes two case studies centred on the perspective of the patient and the family towards the IP, the interaction with change agents, and how all of them perceive technology (section 5.7).

5.5 Research Model

Previous research into the understanding and improvement of technology usage behaviour has developed four main theories. First, technology acceptance models (TAM), which claim that the main drivers of behaviour are motivations to use and that these are informed by the perception ease of use and usefulness (Şener et al., 2015). Second, theories that seek to explain the relationship between change agents and beneficiaries, as well as the ways in which the characteristics of change agents can affect the perceptions, attitudes and behaviours of beneficiaries (Venkatesh et al., 2012, Thong et al., 2006). Third, the contradiction perspective, which shows how discrepancies and conflicts in the discourse can result in unintended consequences (Schultze and Stabell, 2004). Fourth, the

sociomateriality approach, which holds that perception towards a given technology is built by the interactions between that technology and its users.

Drawing from each of these theoretical frameworks, the three main elements of the research are:

- How the change agents (i.e. doctors and educators) perceive the IP and persuade the patient to adopt its use, which influences their interaction with the beneficiaries;
- How the caregivers (i.e. parents) perceive relationship between their diabetic child and the IP;
- How the diabetic child perceives the IP and himself with the IP, and the influence of their belief in the ways that others see them, looking at the way that these perceptions impact upon behaviour.

In order to understand these relationships, two research stages have been designed. The first stage is based on the interviews with the doctors and educators (Change Agent). The interviewees were asked to discuss how they perceive and define the IP, their motivations to prescribe it, convincing tools and mechanisms, how they manage poor IP behaviours with patients, and the most likely reasons for this improper use from their perspective. The aim of this phase is to better understand how change agents perceive the IP, which can in turn influence the perspective of their patients towards the IP.

The second stage is based on two case studies with two diabetic children (Beneficiaries Diabetic child) and their families (Beneficiaries). This area of study aimed to understand the relationships between the patients and the IP, as well as how this understanding is formulated through the use of narrative analysis (patient stories with the IP, with parental opinions of the IP, and both good and bad stories with the doctors). As shown in the Figure 5-5, this procedure seeks to provide an understanding of the misunderstandings or contradictions between all actors, which can build unintended perceptions towards the technology that formulates unintended attitudes and therefore behaviours towards the IP.

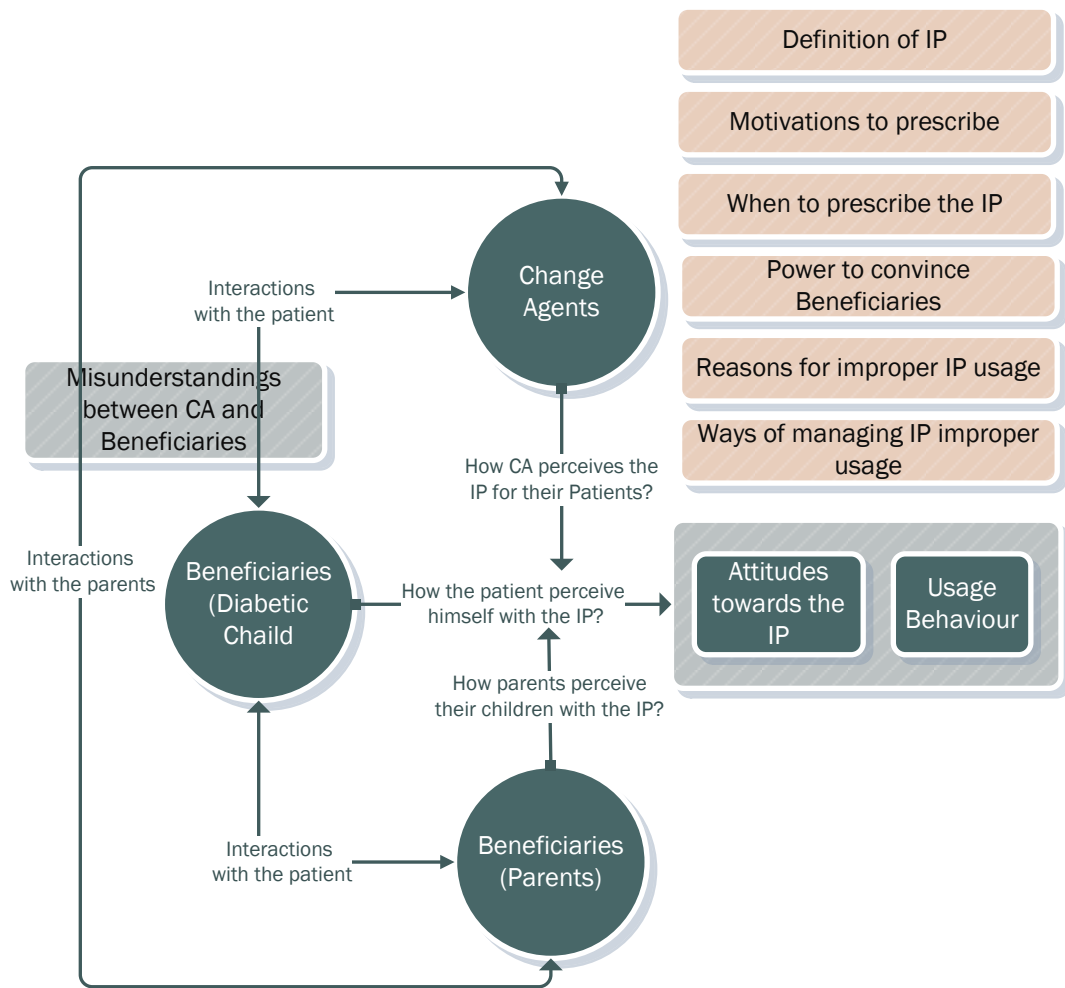


Figure 5-5: Model to understand diabetic child behaviour

A wide range of research strategies and approaches are available for this investigation. A good example of these possible options is ethnography, which is a potentially helpful way to understand the beneficiary’s perspective. Ethnography would require me to follow and observe the patient and his family from pre-transition to post-transition, however it is not necessarily the case that the patient would be engaged in improper behaviour with the IP. Indeed, by default it is assumed that most of users are properly using it due to its obvious benefits. There is also the risk that the presence of the researcher would influence beneficiary behaviour, adversely affecting understanding of potential problems. This is especially problematic given that the aim is to highlight the situation of beneficiaries who are engaged with improper behaviours and who struggle with the IP.

Therefore, the adopted approach in this research is the inversed method. In other words, I searched for families who are struggling with the IP due to non-medical reasons. Through the use of my informal networks, I was able to find two families who have diabetic children that use the IP and who are struggling with its use, leading them to feel at least partially dissatisfied with it. I approached these families and started narrative research to capture their discourse. In other words, the interviews and observations are led by the stories about and from the patient, his/her family, his/her doctors, and his/her educators. Questions were developed from the analytic framework in the previous chapter. To avoid any subjectivity in the interviewees, I met doctors and educators alone and then met the diabetic child with his/her family alone.

Because the study is focused on children who cannot express themselves entirely, meaning that the observation of their interactions with their parent and other family members is especially important. Both case studies were carried out in Saudi Arabia, in two different locations, which means that it took a few weeks to look for suitable, willing participants.

5.6 Change Agent Perspective

This section aims to define and to thereby better understand the roles and powers of the change agents, which allow them to affect the perceptions of patients. An attempt was also made to learn how they act in the context of those roles and how this makes it possible for them to change patients' perspectives. Therefore, the first point is to understand why change agents are prescribing the IP. The answer to this question should help in understanding how the IP is defined and justified by the change agent. The second point is the power used by change agent to push patients to adopt the IP. The aim of this question is primarily to understand how the relationship is established between beneficiary and change agent, as well as to clarify the communication sent to the beneficiaries to motivate them to use the IP. Finally, the study sought to identify the discourse used by the change agent in describing the reasons for improper use in order to facilitate understanding regarding the perception and definition of the problems facing the IP.

5.6.1 Change Agent Motivations to prescribe the IP

There are different motivations for prescribing the IP to diabetic patients. In order to learn some of these from practising medical personnel, I asked each change agent why they prescribe the IP.

The first motivation is the real need for the patient to use the IP, from either a medical or social perspective. These can be seen in the following:

"I prescribe the IP because it has several benefits to patients... All diabetic patients want to have a like normal life, without worrying about diabetes. This is why I prescribe the IP – to make the patient's life better." DP.B

"Some patients are facing issues with needles and do not want to have many injections. So the IP is better alternative to the needles injections, they will have it attached for 3 days and must be replace after 3 day with a new infusion set." DP.As

Thus, the insulin pump is prescribed by doctors to control diabetes and to achieve the target HbA1c level. Indeed, over 60% of the change agents that interviewed are strongly arguing for the IP for those in type 1 diabetes, whereas none of them are strongly recommending it for type 2 diabetes. This may be an indicator that it is not possible to verify that the first cause of the decision among many doctors is monetary motivation, however the motivation for doctors to advise the use of the IP for the sake of patient health and wellbeing can be verified. Doctors were found to only advise IP for type 2 diabetes in special cases.

"If the patient is insured, it is better, because the treatment is expensive. I simply need to write a good report to the insurance company recommending that he needs the IP. The same is true with the diabetic organizations that we have ... they will only reduce the price of the device..." DP.AI

There also seems to be a common belief that prescribing the IP can make medical personnel more famous in children diabetic clinics.

"I was told that the more the doctor prescribes insulin pumps, the more popular he will get." E.MP

For this reason, prescribing an IP can be seen as a mechanism to attract more patients, because Saudi Arabia has few doctors in this sector and who are therefore capable of prescribing it. One of the supporting evidence for this assertion is the following quote:

"I have patients who come from different cities to me treat their diabetes with the IP" DP.Ab

Theme	Sub-theme
Non-patient motivations	Profit. Be famous. Attract patients
Patient related motivations	Improving quality of life Patient medical reasons

5.6.2 Using change agent power to avoid improper use of the IP

There are numerous different motivations for change agents to prescribe the IP, so they use a range of mechanisms and powers to convince patients and their families to use it. In this respect, a number of questions were asked to participants, including: "How do you motivate and encourage your patients to use the IP?", which is addressing non-medical superiority authority motivational techniques; and "What if the patient and their families are not interested in the IP, but you see necessity?", which is investigating medical superiority authority motivational techniques.

One mechanism cited by interviewees is by influencing the perceptions of the patients and their families.

"The patient wants to have a better lifestyle and to avoid injecting lots of insulin to the body. If we address these points to them, I believe that they will use the IP in the right way." DP.M

The first technique, which adopts the medical superiority power, is to show potential beneficiaries the future state their life will be in should the illness, arguing that the IP has

the potentially to prevent this. The second strategy is to show them their current state of health, explain how it is miserable and to persuade them that their situation would improve through use of the IP. This can be seen in the following comment:

Some of my patients are experiencing troubles with the having a better control of diabetes because of the life style they have, they are always out with friends and don't take the normal insulin pens, so I am telling them that the IP will be better for them so they can have the insulin at any time without it, they can suffer a lot"

D.H

Both techniques come from the knowledge power of the change agents, which enables them to affect the beneficiary's perceptions and attitudes toward their current and future health situation. Change agents use their medical knowledge power to convince the patients that they should use the IP by showing that it is necessary to their health. Doctors believe that before the transition patients are more likely to listen carefully and believe everything:

"Most of my patients were my clients. Once I referred them to use the IP, they trusted me and they did that."

Manipulating realities	Theme	Sub Theme
Using medical superiority power	Showing that their future health will suffer if IP is not used	Focus on medical reasons. Focus on deteriorations in patients' health without the IP.
Using knowledge power	Showing that the current state is miserable and that IP will improve quality of life	Focusing on social and psychological benefits of the IP.

5.6.3 Reasons for improper use from change agent perspective

Understanding patients' demotivation factors from the perspective of the change agent could be challenging. However, the aim here is not to claim these factors are final results. Instead, differences and similarities could match the gap between the assertions of change agents and the human and social beneficiary actors. From the perspective of change

agents, the post-transition phase motivation of patients starts to decrease. After the first four interviews, the reasons for this became clear and were integrated into the interviews that followed. Indeed, although they are known to the change agents, they have found only two clear strategies to deal with these issues: threatening the patient and their family about health risks; and telling the patient and their family to switch back to needle injections. Analysis of the interviews suggests that these strategies are only effective in the short term and that once patients fall in the motivational trap of not being interested in using the IP, these strategies become ineffective. Indeed, according to the change agents, literally all cases fall in the motivational trap and are therefore not able to use the IP in a proper way. According to the analysis of those interviewees who use enforcing motivations, their patients either quit, move to using a different change agent, or use the IP with enduring and continuous problems and disputes.

Nevertheless, it is interesting to learn how the change agents' perceptions of the impacts of the IP on the lives of beneficiaries are true from the perspective of those patients. This issue is dealt with in greater depth in the next section.

Because of the adverse relationship between the change agent and beneficiaries, 90% of the doctors perceive the main reasons for the misuse of the IP to be attributable to patient carelessness.

“The most important thing determining the proper use of the insulin pump is the carelessness of the adolescent diabetic patients.” DP.An

“Once, I had a patient who admitted that he does not want to take responsibility, even though he was motivated. He always forgot to count carbohydrates or to measure his blood glucose.” DP.A

“Some patients do not care about the consequences of not following the proper monitoring and counting carbohydrates. They come to the clinic with a high HbA1c level, because they have not entered the carbohydrate that they ate.” DPN

Their perspective may or may not be correct. However, according to the health belief model (HBM), if the patient believes and sees the value of the medical device, he can be

expected to be significantly more likely to use it. The issue here is the inability of the change agents to properly understand the psychological motivation and de-motivation for using the IP. This can be understood in reference to a critical factor like ‘feeling being enforced’, where only few of doctors agree that this may be an important factor. This position is also contrary to theory. For example, the psychological reactance theory states that once a person loses his freedom due to any decision or technology, s/he will reject it.⁵ This may partially explain the misuse of the IP, however very few of the doctors interviewed believe that the main reason for misusing the IP is the ‘feeling being enforced’ and those that believe this only use psychological indicators to assess IP performance in a very small number of cases. Only one of the change agents recognised that psychological reactance toward obligation to use the IP is a strong factor in its misuse, noting that this reaction becomes more common if the patient begins using the IP after childhood.

“Adolescent age is the most difficult age to treat diabetes. A 4 year old patient is easier than a 12 year old. The older the age, the higher the perception of seizing freedom due to the IP.” DP.B.

This psychological reactance is clearly illustrated in this anecdote:

“This adolescent has something called disobedience. He might not want to do something because he does not feel like doing it, even though he knows the proper way, but he does not want to do it... He said to me ‘I didn’t feel like entering the carbohydrate and measuring my BG. I feel that I am being restricted by a certain boring daily routine’.” DP.An

Another factor for misuse from the change agent perspective is too much confidence in the technology. The literature states that the greater the trust a person has in technology, the more they will use it. However, change agents in this research, too much confidence can lead some patients to believe that the IP is infallible. The result of this is that they do

⁵ This is a realistic interpretation, but it may be revised in light of additional data. Different kinds of patient will then be able to modify or refine that interpretation.

not follow procedures carefully, believing that no ill effects can occur, and therefore experience problems from the IP usage.

“Some patients, especially adolescents, think if they get the pump they are controlling their diabetes without the proper bolus correction, healthy diet and exercise. I believe here is the problem and the mother of all devils.” DP.B

“I have a few patients who do not come for the follow up diabetes routine check-up, maybe because they think the pump is working fine and it is safe enough, thus they do not need to come back to follow up.” DP.B

“Where is the parent? she have to look at her child, and remember why at the first she had it for her child. This is a much known case. They are irresponsible”.

Dada

Change agents cite other problems, like social issues (being shy about using the device in public) and human factors (the IP routine adversely affecting lifestyle). Nevertheless, although many change agents claimed that the behaviour of beneficiaries potentially hinders the proper use of the IP, they do not have any clear strategy to deal with these issues. Design issues were cited as one problem, as the IP is big enough to be visible under clothing, which is particular problematic for girls who wear light clothes in social gatherings. This was noted by E.RS:

“I have a few girls who eat and do not enter the carbohydrate and measure her blood glucose if she was with her friends, she does not want to show that she is wearing a medical device. So she eats without pumping, this affects her BG a lot, and I had gave her several warnings.” E.RS

Another change agent also said,

“Children who play a lot and do not record their blood glucose before and after the meal can have a problem, and that why we try to tell the parents to tell the school to monitor the child’s activity. That’s why it’s important to have a family who understands.” E.M

“The most problems we face is that parents don’t measure the blood glucose of the child to be entered, they are not accurate enough.... It is very important that they do that, because the insulin pump is programed to eject the insulin desired” EP.AS

“They had seen it before I prescribe it, and know that it will be connected to them and must take the responsibility, especially the parent, they are the responsible for their children, they would know how their child will use it.... if they can’t use it in the correct way, then it’s not for them, simple” DP.An

“Measure issue is the carbohydrate count. . . I am not sure how much I want to emphasize about that. Patents and patient don’t count the carbohydrate, even though they had attended the education on diet, and they know how to do it,, I have several times asked the patient, and the mother, they know how, but are too lazy to think harder and take it seriously” EP.E

However, this does not absolve change agents of their inability to handle patients who are sensitive to this unintended consequence of the ‘poor’ design of the IP. However, sensitivity to these issues can be proposed as being a likely reason for some degree of improper use of the IP.

For this reason, claiming that carelessness is the main reason for the improper use of the IP strongly suggests that miscommunication exists between the two actors and is therefore one of the factors in the misuse of the IP.

Having discussed the perspectives of change agents, the next section will now examine those of diabetic patients.

5.7 Beneficiary Perspective: Diabetic Child and family

The three main actors are change agents (i.e. doctors and educators) and beneficiaries (i.e. patient and caregivers). In the diagram below (Figure 5-6), the orange character depicts the main user beneficiary, i.e. diabetic child; the blue character on the left denotes other actors (change agents); and the character on the right represents the beneficiary as a

caregiver. Each actor has their own views, perceptions and language used with the regards to the IP. The relationships and interactions between these different actors combines to formulate the patients' specific perceptions towards the IP.

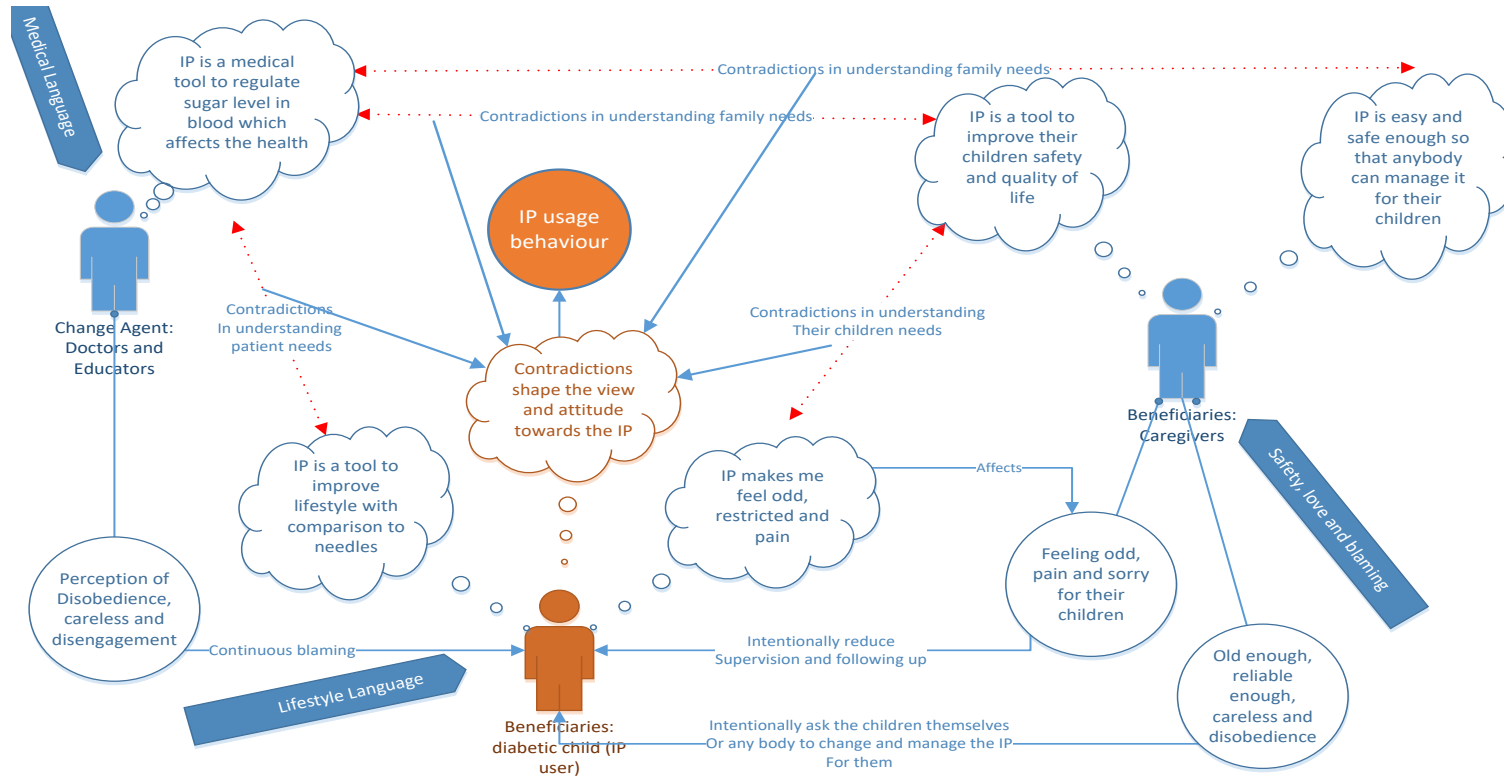


Figure 5-6: Contradiction Framework

Symbol	Meaning
Clouds	Views toward the IP
Circle	Behaviours
Red dotted arrow	Relationship – Contradictions
Tag	Discourse used in understanding technology

5.7.1 Change agent perceptions

i Discourse used in defining the IP

Doctors always explain the IP using medical language and metaphors. As illustrated in Figure 5-6, change agents simply view the IP as a medical tool that enables the regulation of the sugar level in blood, where improper use adversely affects the patient health.

“The IP will control the diabetes of the diabetic patient by having it programmed with basal and bolus... but the patient needs to record BG and enter the carb of all food consumption.” DP.A.

Other studies have shown that doctors focus more on the medical aspects of the IP than the social aspects (Lawton et al., 2015). In other words, the discourse of change agents is largely characterised by the use of technical and hard language. The following quotation is an example of density of technical medical words in defining the medical device.

“We want to achieve the HbA1c level of the patient reaching normal levels. If it is used correctly, this is the main point: to control the diabetes and achieve the target HbA1c level... the Basal is programmed to produce insulin during the day and the bolus when the child eats... so he needs to enter the BG and the carbohydrate count to produce the correct amount of insulin...” DP. E.

“The patient will need to understand the basal and bolus and when to use it, because the purpose is to prevent hypoglycaemia, hyperglycaemia and DKA from happening.” DP.A

This is supported by institutional logic literature, which shows that medical staff almost always prefer hard, deterministic and technical language (Witman et al., 2011).

ii Discourse used in understanding patient behaviour

To understand the interactions between change agent and beneficiaries, the change agent were asked questions that sought to uncover their perceptions of the technology, how they

deal with it, and their beliefs in the value of the technology for their beneficiaries. The summary of the findings of these questions are illustrated in Table 5-1. It is evident from the analysis that change agents favour technical and medical language, with the view of the IP almost solely as a technical device rather than one that is connected to a human body forever.

Question	Answer	Evidence	Reflections
How they define the IP, and when do they recommend it?	It is a technical device to improve patient health	<p><i>“She is not counting the carbohydrate properly. She is also not monitoring her blood glucose.” F.Ch-Agent</i></p> <p><i>“The routine check-up on the HbA1c is an important appointment for diabetic patients.” M.Ch-Agent</i></p>	Technical and medical language
How they deal with it?	Convincing the patients to use it for their health	<p><i>“I told her several times, if she is not using the IP as it should be, we will need to switch.” F.Ch-Agent</i></p> <p><i>“The problem with Mustafa is his family does not care about how to use the IP. This is not good for their son’s health issue.” M.Ch-Agent</i></p>	
How they believe in it for their beneficiary?	It is necessary to help them overcome their medical issues	<i>“IP is critical for Nora, as she may fall into DKA without it.” F.Ch-Agent</i>	Reactive strategy in handling improper use. A1 c level poor

<p>How the patient uses the IP and the proper use of the IP?</p>	<p>Careless and disengaged</p>	<p><i>“She is not coming to the 3 month check-up. I had to call her several times to come. She has become so careless about showing up for appointments.”</i> F.Ch-Agent</p> <p><i>“Mustafa’s family do not care enough about the use of the IP. They do not have sufficient time to manage their son’s IP properly.”</i> M.Ch-Agent</p>	<p>after misusing the IP.</p> <p>Continuously blaming the family and the patients, putting the responsibility for correct use on them.</p>
--	--------------------------------	--	--

Table 5-1: The interaction between change agents and beneficiaries

It should also be noted that change agents tend to use a reactive strategy in following up the patient use. They focus on the measurement of HbA1c level to determine the quality of IP use, despite the fact that HbA1c is a lagging indicator not a leading one, meaning that it is primarily useful in detecting abnormality after extensive misuse of the IP. However, if the change agent understands the attitude, motivations and demotivation for beneficiaries to use the IP, these can be a leading indicator for improper use.

5.7.2 Caregivers’ perceptions, feelings, attitudes and behaviour

i Discourse used in defining the IP

Parents do not perceive this technology (IP) as a source of pain and control imposed on their children. Instead, they view it as safe and easy enough even to delegate the

supervision of the device to others who may not be sufficiently qualified to perform the tasks.

“The insulin will be attached to my child, and it will be much safer for him to eat, as well as at night time.... the insulin will be ejected to him according to the settings. And if he needs more, it will be extending a bolus.” M.Mtr

As the other mother said,

“I feel more confident about my daughter wearing the IP. It is going to be with her all the time and control her diabetes” F.Mthr

In both case studies, parental confidence has led to delegation of following up whereas different in who will take the power. For young children (M.Pai), the power is instead given to uneducated servants and siblings, whereas in the case of older children (F.Pai) the power is given to the patient him/her self. In the female case, the mother had sufficient confidence to delegate the full power to the 15-year-old diabetic child, who is arguably too immature to fully undertake this responsibility.

Perception towards Technology	Evidence	Reflections
Safe to use	<p><i>“The IP is really safe to use. I never ever thought it can harm my son.” M.Mthr</i></p> <p><i>“Do not worry, the IP is really safe enough for my daughter. She knows how to use that very well.” F.Mthr</i></p>	Delegation of usage to other members of the family

Easy enough to be used by other members	<p><i>“My daughter is old enough to take responsibility. She is 15, so she can take care and monitor her diabetic young brother.”</i> <i>M.Mthr</i></p> <p><i>“I told Maria (servant) whenever she puts the food on Mustafa’s plate, she should know the carb count and enter it into his IP, or tell him to enter it. Sometimes Maria does not obey my orders and does not know what he has eaten.”</i> <i>M.Mthr</i></p>	
---	--	--

ii *Discourse used with the child*

The role of the caregiver is crucial because children are connected psychologically with their parents as well as because mother’s are closer to their children; because mother’s typically look after health roles in Arab culture (Al-Ayed, 2010). Thus, by understanding how parents perceives the technology, as well as how they think their child and friends perceive the technology, the reasons for any positive or negative attitude towards it can be better understood. Therefore, the parents were asked a number of questions on the topic:

- “Are you happy with IP used by your son/daughter?”
- “How do you feel your son/daughter feelings towards the IP?”
- “Do you think your son is happy with it?”
- “Do you think the doctor is happy with the way your son using the IP?”
- “How does he/she use the IP in public (e.g. friends, relatives) perceive the IP?”
- “How does he/she react when manage their IP, or when you manage the IP?”

The potential misuse of the IP should not necessarily be attributed to the diabetic child. The perceptions of their parents toward dis benefits, which are then perceived by child, have been reflected in the post transition phase. The parent’s perceptions may also vary towards different age groups. In addition, the potential use or misuse of the IP could be

affected by the child’s emotions, which influences the behaviour and attitude of parents towards the technology.

a. Perception towards the child

The older the child is, the lower the feeling of pity and the greater likelihood of delegation and forwarding of responsibility to them. However, in situations when the child is not sufficiently mature to take the responsibility, the reaction might be disobedience or psychologically reacting against this technology. The mother insisted that her child knows how to use the pump and manage her diabetes very well, but the adolescent takes sole responsibility, noting that:

"I do not know how to count her carbs and measure her blood glucose better. She knows more than her mother." F.Mthr

Answer	Evidence	Reflection
Old enough	<i>"She is old enough to do it. We have spent enough time with the educator to teach her and she knows what is good for her health." F.Mthr</i>	The problem occurs because of the misunderstanding between mother and the child. The mother believes that the daughter is old enough to carry out all of the responsibilities. However, the daughter is careless about accomplishing the tasks. This leads the mother to see her daughter as disobedient. In response, the mother becomes disinterested and disengaged in following up.
Reliable enough	<i>"Nora knows more than me, so I feel confident that she knows how to use the insulin pump and when to eject and when to correct the bolos." F.Mthr</i>	
Careless	<i>"She knows what is good for herself. She keep copying her friends and showing off with her friends. What can I do for her? I can't help much" F.Mthr</i> <i>"I told her father about her actions... maybe he can do something" F.Mthr</i>	

Disobedience	<p><i>“I told her to buy dresses that can open from the front, so that she can eject insulin when she goes to the party, but A.P does not listen to me.” F.Mthr</i></p> <p><i>“Nora tells me that it’s her choice and she can wear what she wants.” F.Mthr</i></p> <p><i>“She wants us to realise that we are the issues for her diabetes.” F.Mthr</i></p>	
--------------	--	--

b. Feelings and behaviours towards the diabetic child using the IP

The younger the child the more the emotions and behaviour of the parents are affected by the feelings of the child (Morris et al., 2007). For the first case study with the young diabetic child, the mother reported being affected by her son feeling odd, in pain, or being controlled. This resulted in her showing extra sensitivity and pity towards him, which affected her emotions and may have led to misuse the IP as accepted. This results in the mother not cooperating in proper use of the device. In fact (M.Mthr) is intentionally (from interviews) and unintentionally (I saw from observations) reacting negatively against the proper use of the IP by giving her son more freedom, less pain, less control, and more sweets. As an example of this, during observed case study I intentionally was talking about something outside the scope so that I can observe how the mother is treating her child (in both meetings and interviews), I saw her son incredible amount of sweet. It was also interesting that she did not offer his siblings the same quantity of sweets or told him to stop or even. This is an indication of the psychological reactance behaviour (Lauren, 2012), which states that the more one feels restricted in the use or consumption of a certain product, the greater the motivation to consume it. In this case, the same behaviour was noticed for the son (M.Pai). During the observation, I looked at her son while he was eating lots of chocolates and his mother told me:

“It’s ok, I will record the carb count. I do not want Mustafa to feel different or restricted because he has diabetes... and that is the feature of the IP, that it gives flexibility in eating.” M.Mthr.

In addition to this, the mother knows that her son is eating chocolates extensively in school, which is contrary to the correct management of diabetes and use of the IP. However, she does not want to ask him about his consumption levels, as she wishes to prevent him from feeling guilty about the quantity of sweet that he consumes.

“I am not sure what he eats in school. I will try to ask later what food they serve, but I have not yet, because B does not tell me what he has eaten.” M.Mthr

The sweet diet is even reflected in the body weight of the child. His doctor perceives that the mother is careless and may withdraw the IP because of that view:

“Mustafa is getting overweight. If his mother does not improve his diet, we need him to go back to the insulin injections. This is the problem of the mother’s responsibility towards her child.” M. Ch. Agent

Furthermore, regarding her son’s feelings of pain, I noted that she admitted to sometimes forgetting to replace the IP. This kind of behaviour was used as an example of carelessness by change agent.

“Ahh sadly, sometimes I forget to change the IP every 3 days. I know it should be changed regularly, but I forget!” M.Mthr

Table 5-2: to the mother of the young boy: How do you feel your son/daughter feelings towards the IP?

Answer	Evidence
Feeling odd	<i>“Wallah! My dear I want him to feel like his brother and sister, that he is not sick.” M.Mthr</i>

	<i>“I do not want him to feel that he has restrictions. It’s enough that he is already diabetic, and a medical device is connected to him.” M.Mthr</i>
Feeling of pain	<i>“He always panics when I change his syringe because it hurts him a little bit. That’s why I try to change it for him every 4 days and when I do, I try to make sure it is clean around it... but if Mustafa is getting itchy, I change it right away.” M.Mthr</i>
Being banned from sweets	<i>“I do not want Mustafa to feel that he is a special person who cannot eat what he wants, and be left out, or feel different from the others.” M.Mthr</i>
Feeling of pity	<i>“Poor boy, alhamdulillah, he is in a good health but I still feel sorry for him.” M.Mthr</i>

5.7.3 Patient self-perception

Observations and questions have been used in this research to understand how the interactions between different actors can shape meaning and opinion of technology. Observations were used to understand the interactions between the patient and their family regarding the IP, as well as the relationship between the patient and the IP. In order to obtain an insight into the way that patients perceive themselves in the context of the IP, as well as their perception of the IP and their understanding of the perceptions have of them, the following questions were asked:

- “Are you happy that you are using the insulin pump now?”
- “Do you use it when you go with your friends or in public?”
- “Is it ok if they see that you are wearing the IP?”
- “Have your friends commented about you if you are wearing an IP?”
- “What is your thoughts about wearing the IP in public?”

The aim of these questions was not only to understand the attitude of the patients toward the technology but also to understand how they view the perceptions of others towards him/her and the specific technology. This is informed by the belief that these views shape the understanding, perception and attitude of diabetic youngsters toward the IP.

i Discourse used in defining the IP

Children, because they are young, have a more limited understandings of the world than adults. They talk about the IP as a device to replace needles, or for the older child, a way for her to administer insulin and improve her lifestyle. Investigating the discourse of the two diabetic children shows that patient feelings towards technology are strongly influenced by their belief about how others perceive them and how they perceive the technology. The resultant perceptions are affecting the motivation of patients, leading them to avoid using the IP in certain environments and contexts. This improper use of the IP eventually weakens HbA1c levels, as noticed by change agents.

The main three observations in both cases are the perception of feeling odd or standing out in society, feeling restricted by the technology, and feeling pain. These emotional responses result in psychological reactance, leading to the avoidance of IP use and for the younger child to attempt to make his device more attractive, by playing with it. These situations both lead to misuse of the IP and consequently less control of the patient diabetes.

Feelings	Behaviour
Feeling odd	Playing with the IP to show friends he is unique.
	Avoid using it in public and when she meets her friends.
Feeling restricted	Avoid using the IP in public.
Feeling pain	Replacing and changing the IP every 5 days instead of every 3 days.
Lifestyle	IP is a tool to improve the lifestyle with diabetics.

a. Lifestyle motivation

Lifestyle can be extremely important for different age groups. Additionally, the lifestyle of an adolescent (F. Pai) high school, is likely to be very different than that of a school aged child (M. Pai). The adolescent mentioned that she wants to improve her lifestyle

despite having diabetes her entire life, claiming that being a diabetic is frustrating because she has to monitor the food she eats and to keep injecting insulin. She explained that,

“When I go out in public shops or restaurant, I cannot eject insulin because some places don’t have restrooms, or if they do, they are dirty. The insulin pump is much better because I have the insulin with me all the time, I don’t need to store it in a cool place and it is programmed to give me insulin.” F. Pai

She had also identified that she does not want to remember to take insulin pens with her, because of the difficulty involved in storing them.

In the case of the younger child, his attitude when he was explaining about the needles of the insulin was one of disappointment that the other children in the house do not have to take needles. He said that he understands the reason for this, but still hates it.

“Ok, I know why I take the needles, but why is it me, and my other brothers do not feel the pain of the needles that I feel.” M.Pai

Therefore, the child stated a preference for the IP, because insulin injections are painful, restrict his food intake and make him feel uncomfortable if he needs to inject while with his friends.

b. The feeling of being odd in society

This section is based on the answers of the question “How others perceive you because of the IP?” The difference between the two cases are mainly due to their particular age and gender factors. In particular, the girl wants to be attractive, while the boy wants to be strong, leading them to behave differently from one another. Three behaviours were attributed to the feeling of being odd: hiding the IP in their clothes whenever they can; taking it, or not delaying the entry or input of data into the device to meet with her friends

in social gatherings, as well as wearing light clothes (female); and attempting to impress friends to avoid being seen as weak or ill when noticed with the IP (male).

Feeling	Behaviour	When
Feeling being odd	Hiding the IP in clothes	When they are out in public or with friends. Do not want to be perceived as different.
	Taking it off / delaying use	Female delays the entry of data into the device to avoid using it with friends and in social gatherings. Sometimes she even unplugs the device, depending on her clothes.
	Playing with it	The male, when friends notice the IP, he impresses them by playing with its buttons.

- Avoid Using the IP in the Public

The data show that the adolescent patient (F.Pai) stops using the IP in public places because of a perception that others view her negatively, thinking that she deserves pity or should be ashamed because she is ill. This perception was expressed by both the child and her mother. This view can encourage a diabetic child to avoid the use of the IP in public unless wearing dresses that hide the IP. However, in female gatherings where she can wear light clothes, she takes it off or unplug it from her body. So it does not show there is a device connected to her.

Due to a belief that others look at her negatively because of her diabetes, the adolescent beneficiary is trying to hide any manifestation of the illness, most visibly represented by the IP. During the observation and interviews, I told her that I really wanted to see how she used it, so she used it in front of me and became engaged because I told her that I was conducting research.

Perception	Quotation	Reflection on behaviour	Quotation
Using IP is shameful	<i>"People feel pity towards the IP. They feel sorry!" F.Pai</i>	Avoid using the IP in public/when going out	<i>"I cannot use the pump in public and take it out from my dress, I just cannot, it's embarrassing and I will wait until I go home and do it." F.Pai</i>
Being diabetic in Saudi culture is shameful	<i>"If people know you are a diabetic they will look at you as though you are defective, and I do not want that" F.Pai</i> <i>"You know how the cultural is, they think it's shameful to be diabetic. Especially if they see a device connected" [whispers] "It's hard to get married if people think you are diabetic." F.Mthr</i>		<i>"I do not like to use it in front of my friends and enter the carbohydrate of the food I eat... I usually mean to do it later, but sometimes I forget... It is very difficult for me to do it in front of my friends." F.Pai</i>

- Playing with the IP

Similar feelings were noted with the younger child (M.Pai), although this manifested in different behaviour. Both the young male child and his mother feel that society looks at him negatively. When his friends know about the IP, he tries to persuade them about its uniqueness in an attempt to avoid being labelled as weak or ill. When I asked to see the

IP, the boy initially refused to show it to me. However, after convincing him that I was interested, he showed me the device and started playing with buttons in an attempt to impress me, perhaps as a reflective behaviour.

Perception	Quotation	Reflection on behaviours	Quotation
Using IP is a shame	<i>"My friends look at me as if I am different or ill. But I am not!" M.Pai</i>	Attracting or impressing others because he has	<i>"<u>If they see my IP</u> I show them the buttons and how it works. I want to impress them with it." M.Pai</i>
Perception of being Odd	<i>"Mustafa feels like he is not normal like them because he is connected to a medical device." M.Pai</i>	something unique	<i>"He often plays with the IP in the school and puts several false entries. It won't harm him, but it will make noises and the teacher calls me." M.Mthr</i>

ii *The feeling of being restricted / lifestyle/ showing off*

This section is based on answering the question, "How do you perceive yourself with IP?" Once a diabetic child feels that they have had their freedom inhibited, with their behaviour being restricted and observed, they may psychologically react against this restriction. Lifestyle restrictions include food consumption, fashion, and daily activities. Freedom here not only refers to movement, foods and clothes, but also the freedom from being observed. When the child is young, the mother will ask all of the family to constantly watch their behaviour, which can lead young patients to resent the IP. However, the first perception of restriction is in terms of food consumption, as values need to be counted and the BG tested.

There are two main perceptions noted by the diabetic children here are the perception of being observed and the perception of being restricted. A feeling of constantly being under

observation can lead a child to lie and to eat when they are away from their supervisor, such as at school. One of the mothers (M.Mthr) stated that her son eats chocolate when is away from her, which she allows out of a feeling of mercy. In this case, the patient loves sweet foods, so is very involved and aware of how the IP shapes his relationship with what he loves (chocolate). This makes him very aware of being restricted because of the device, with the outcome being that eating too much chocolate becomes a psychological reactance to the perception of restriction. The result here is aligned with psychological reactance theory, which notes that people will attempt to retrieve freedom (such as by eating) when they are restricted from access to what they like (e.g. food) (Lauren et al., 2012).

For the older child, clothes and fashion are more important. Although she can use the IP underneath her clothes, she explains that she wears an ‘*abaya*’, a form of traditional gown that makes it difficult for her to take the device out and enter data, such as the correct carb count or the bolos. Her attitude is to avoid discussion of that problem and the attendant risk of high blood glucose, so rather than learn about her insulin value she prefers not to take the IP with her. Her mother noted that the child does not show rejection and loves to wear light clothes in female only meetings, so sometimes does not wear the device, which conflicts with the need to wear the IP at all time, except for shower or maximum 1 hr off. It seems that she may be intentionally picking these clothes as reflection that she is normal and is retrieving her the freedom that she feels has been seized by wearing clothes that nearly shows the IP to be attached to the body.

Feeling	Quotation	Behaviour	Quotation	When
Feeling being observed	<i>“I do not love the IP because it bothers me when Maria and my brother ask me what I eat. I can eat whenever I want and anything... I</i>	Doesn’t say how much he eats chocolates	<i>“Sadly, I know he eats lots of chocolates in</i>	When he knows that he is not supposed to eat and not saying the

	<i>get so angry when my sister asks me, I do not like that..." M.Pai</i>	Active resistance and complaining	<i>school. But he does not say."</i>	amount he ate for it to be recorded.
Feeling being restricted	<i>"The doctor told me that I have to watch what I eat, and not too much sweets, or hamburger and pizza! I have to do tests and put the carbs in the device. But he warned me a lot because it makes me fat." M.Pai</i>	Eating unproper diet	<i>"I prefer to wear light clothes in the female gathering... Yes, it does not fit with the IP. It's my decision, I can handle it" F.Pai</i>	When he gets the chance to see sweets.
		Wearing light clothes		In female only meetings.

5.8 Interpretations: Contradictions

Different discourses to the same thing is a sign of different understandings and different views towards the same objects (Wandel, 2001, White, 1992). This is also reflected in the implications and consequences of multiple realities as they are perceived by different actors (Parker, 2011). Contradictions (mismatch, non-alignment, discord) have been observed between the beneficiary discourse and change agent discourse. Therefore, because the caregiver and the diabetic children perceive and define the IP differently, this can result in the emergence of miscommunications and misunderstandings.

This is similar to the findings of the study by Herman (2006), who claims that beneficiaries almost always utilise social and soft emotional language rather than technical and medical language to explain the IP. This kind of discrepancy in discourse between different actors can result in conflicts in understanding and opinions about certain technology (Scott, 2012). Therefore, by consolidating different discourses in this

section, three main contradictions can be seen between the actors. These will be discussed below.

5.8.1 First contradiction: between change agent and the diabetic child

The first clear contradiction in viewing and understanding the IP is between the change agents and the main beneficiary of the device. Different discourses between actors can lead to weak communications and weak informal ties between them (Foucault, 1980). This is the case in this relationship, with doctors perceiving the IP as a medical device and diabetic children seeing it as a device that will make their lifestyles better, with the result that the communication and understanding between the two actors are weak. Diabetic children have a discourse full of soft language, using feelings, emotions and reflections on life, which is in stark contrast with change agent discourse, which is hard, medical and technical. As mentioned by (Appelboom et al., 2014) "Although healthcare is always trying to increase patient's autonomy and create a harmonious relationship between physicians and patients, endowed with this technology some patients could erroneously disregard the role of the physician"(p.6).

Firstly, as the IP is connected to the human body it can be expected to have psychological and social implications, as explained below. However, the change agents ignored these aspects in the interviews and instead continually blamed the final behaviour, which they labelled as careless, on the irresponsibility of the beneficiaries, instead of focusing on other factors that affect the use of the IP. In other words, the doctors' messages and authority constantly stress the idea of the important it is to use the IP for medical reasons. However, diabetic children often seem unable to comprehend the consequences of misusing the IP, leading their doctors to stop talking to the children and place blame on their caregivers. One doctor said,

"I do not blame the child; he is too young to understand and care. I always talk to the parents." DP.E

“It’s not the children who are mis managing the Insulin pump, it’s the parent who lack the responsibility” E.M

Differences in the level of perception influence the required need for constraint between different actors. Constraint can incite psychological reactance behaviour if the enforced person feels no necessity for the limitation (Lauren, 2014), as happened in the cases in this research. The doctors believe the IP to be a critical tool for improving the health of patients, whereas the patients perceive it more as a tool to improve their lifestyle. This pushed the children to react against the IP. As the older diabetic child said.

“I do not know why the doctor is always threatening me to use the IP! It seems silly, I hate this way of doing things. Ok I understand what he wants, but it’s my device in the end.” F.Pai

Therefore, the patient reacts against the perception of having unnecessarily lost their freedom by undertaking actions to restore that freedom by intentionally not using the IP in public.

Change Agent(CA)	Diabetic Child	Consequences
CA is looking at IP as a technical device	Defines IP as a machine for improving lifestyle	Communication and understanding between them are weak.
CA is enforcing and blaming for not using the IP properly	Feels restricted and that he seems odd	Psychological reactance: acting against the IP and internationally avoid its use or misusing it.

5.8.2 Second contradiction: between caregiver and change agent

The second contradiction is between the change agent, who views the IP as a medical tool that is dangerous if mismanaged, and the caregivers, who believe that the IP is safe for

their children. The role played by the IP in controlling glucose level means that doctors (change agents) stress the importance of educating caregivers about certain procedures in order to ensure that the IP is utilised properly.

“IP is important for patient health, but only if used in the right way. Otherwise, it will be harmful and I have to withdraw it. Actually, I see this case with lots of patients. They are not using it properly and I need to threaten the parents as well as the child... but it’s the parents who are the ones to blame! ”. DP.B

However, the caregiver has a very different perception and discourse towards the IP, viewing it as a safe tool that improves the lifestyle of their diabetic children. In other words, they do not perceive the device as being harmful, even if when misused or when the doctor’s rules are not followed closely. In terms of sociomateriality theory, they look at the tool as a techno-psychological element in their life, which is an object that affects users psychologically and sociably (Leonardi, 2013). This can be seen in the restrictions that the IP puts on lifestyle, even though the main intention to adopt it to bring about a better way of living. The IP affects the ability of their children to eat sweet foods like other children, to let their daughters wear light clothes easily, allowing them to simply count nutritional values each time they eat food. These factors encourage the caregiver to adopt more lenient rules on the use of the IP, which is perceived as careless by doctors.

“It is the family! They should take more care of their children. And this is the main problems we are having... they do not take enough responsibility in measuring their children’s blood glucose and doing the correct carb ratios. It seems a careless issue more than anything else” D.M

This pushes doctors to use stronger language and threaten the withdrawal of the IP in response to perceived misuse.

“The IP is a serious tool that must be used carefully, otherwise negative results can happen... they have to take responsibility for its management.” DP.As

Change Agent Perspective	Caregivers perspective	Reflection
Medical Tool	Perception of making their children feel odd	Doctors are blaming the caregivers for being careless or irresponsible.
Focuses on medical use without focusing on psychological reasons	Feeling sorry and mercy towards their children	Caregivers are not strict in applying the IP rules.
	Safe to use	

5.8.3 Third contradiction: the relationship between patient and caregiver

Because caregivers are most influential on the life view of their children (Morris et al., 2008), some of the discourses are not contradictory, but instead seem to be supportive. The supporting discourses pertain to the perceptions of being odd and restricted, whereas the contradicting discourses are those concerned with being safe and delegate against being a diabetic lifestyle tool.

i Supporting discourses: perceptions of being odd and restricted

The first discourse common between the patient and their caregiver are the perceptions of feeling odd or restricted. As the caregivers are looking sympathetically at their children with the IP, this can be translated in leniency, leading to intentional reduction of supervision and less enforcement of correct or regular IP use. Previous studies have shown that some parents of children with chronic medical conditions may feel overwhelmed and incompetent in dealing with the demands of the illness, leading them to withdraw from their child (Power and Franck, 2008; (Bevans and Sternberg, 2012).

Thus, when the child does not like the procedure of changing the IP syringe every three days, even crying or panicking at the idea, parents may feel sorry for them and delay maintenance of the IP, as seen in this account:

“Well, because he takes a shower every day, the infusion is being cleaned. And when the reservoir still has insulin I sometime delay it to the fourth or fifth day, but not always.” M.Mthr

Another example of this relaxation of IP rules is the failure of parents to watch the weight of their children (Gender-Frederick et al., 2011; Scheiner et al., 2009). However, the IP can affect the weight of a child if it is used improperly. This was observed by some of the change agents:

“IP can affect the weight of the child, because he has flexibility in eating but needs to enter the carb of that food and his BG so the pump will produce the desired insulin. But if he is eating a lot, then it can affect that.” DP.E

The psychological reactance of children towards the IP due to the restrictions on their lifestyle results in their parents feeling sorry for them and giving them greater freedom in their use of the IP. This can manifest in different ways, with the young boy eating lots of chocolate without intervention from his mother, while the girl takes the IP off in public or when wearing light clothes, with her mother’s consent to do so. Both final behaviours are contrary to the correct use of the IP.

Caregiver Discourse	Patient Discourse	Reflections	Evidence
Feeling odd	Being odd	Using too much sweets and he knows his mother will not blame him.	In the interview, his mother stated that he was eating too much chocolate and that she

feeling of pain and sorry towards their children	Being Restricted		was feeling sorry for him.
		Taking off the IP when she goes out. Her mother accepts this behaviour without advising her otherwise.	<p><i>“My mom knows I am wearing these clothes, but she does not mind.” F.Pai</i></p> <p><i>“I am sorry for her. She is still young and she wants to enjoy her life. I cannot stop her from doing that.” F.Mthr</i></p>

ii Contradicting Discourses: Perception of Being Safe versus Perception of being a lifestyle tool

There are two different discourses between the caregiver and the child. The caregivers believe that the IP is safe and simple enough to be used without supervision, while the children believe that it is a tool that helps to improve their quality of life. The two discourses are not directly contradicting; however they are different and can lead to unintended consequences.

Because of the perception of the caregiver that IP is easy enough to be managed by anybody, the mother of the boy child delegated his sister (aged 10 years) and her servants (Servant), who is largely illiterate, to take responsibility for managing the IP on his behalf. During a conversation, she also added while laughing,

“...they fight a little, but hopefully they should get along” M.Mthr

Because of the immaturity of the child and the perspective that the tool is not critical or complex, despite being an important part of diabetes management, this constitutes misuse of the IP. In addition, the mother delegates management of the IP to her servants:

“Sometimes the servant and Mustafa’s sister count the carbs and of course measure his BG” M.Mthr.

Neither the servants nor the sister of the diabetic child received any orientation or training in the effective use of the IP by the diabetic educator. It is therefore anticipated that this delegation of authority can lead to unpleasant experience by the patient, especially when the siblings are young enough to bicker and argue:

“My sister does not know anything.” M. Pai.

This dissent and disagreement can cause the resistance of the child to the IP or the tasks involved in its correct usage. The sister affirmed this, by adding:

“My brother does not listen to me and be calm. He always panics and gives me a hard time, but I have to listen to my mother and do it for him. Mustafa is a stubborn boy.” M.Sis

Therefore, because the mother perceives the technology to be extremely simple and safe, she elects to delegate responsibility to another of her children, in turn increased resistance in her diabetic child with regards to the use of the IP. This kind of behaviour is seek by the change agents as a good example of carelessness. However, the problem is arguably more to do with the erroneous perception that the device is safe and uncomplicated.

Likewise, the mother (F.Mthr) delegated the responsibility of managing the IP to her diabetic daughter, who is currently only 15 years old, stating that:

“Nora is old enough to take her own responsibility.” F.Mthr

This has led to many problems between the child and her caregiver, directly affecting the correct usage of the IP. I saw continuous tension between the mother (F.Mthr) and the adolescent (F.Pai) during their daily life, with the mother continually blaming her

daughter for improper usage and management of the IP, but not interceding to ensure its correct application.

This may be because caregivers see the tool as being safe and straightforward, they do not believe that there is a need for excessive restrictions or regulations on its use. This in turn leads to tendency of carelessness in using the IP without much care from the patient perspective.

Other Actors Perception	Diabetic Child perception	Reflection on attitudes and behaviour
Caregivers believe the IP is safe and children are old enough to use it a lone	IP is a lifestyle tool to improve the quality of life.	Caregivers delegate the authority of managing the IP to the child, servant or sister.
Caregivers believe it is very safe and anybody can manage it to the children		Disputes between the child and other family members or servants. Also, the feeling of being observed by all family members, which pushes him to hate and avoid using the IP.

5.9 Summary

This chapter applied the analytical framework for understanding the reasons for the improper use of the IP, although the literature showed different benefits in this regard. The analytic framework provided a new understanding of this phenomenon, by illustrating that the different views of the IP between different actors lead to different expectations. Because of the mismatch of expectations, their behaviour differs from what is expected. In other words, the explanation is found in the contradictions between the expectations of the three types of agent involved – change agents, patients and caregivers.

Starting with a number of different initial assumptions about the purpose of IP – to control sugar levels (medics), to improve the patients' quality of life (parents), to make patients feel equal with their peers (patients) – the contradictions persist and may even increase. Because of these misunderstandings, the diabetic patient has a confused view towards himself/herself with the IP, with a corresponding resistance towards the device. This resistance is reflected in the improper use of the IP, such as failure to enter data (e.g. on the correct carbohydrate) regularly, failure to measure the blood glucose before and after food consumption, and failure to change the infusion sets every 3 days

This analytic framework helped in understanding the phenomenon from a new perspective. However, there are a few drawbacks and some weaknesses in the application of the framework. Therefore, the next chapter seeks to evaluate the analytic framework and the results found through the use of this framework.

CHAPTER 6 Discussion

6.1 Introduction

Wearable devices are an emerging research area in the field of assistive technologies, as discussed in Chapter 2. An innovative aspect of the current research is the view of Insulin Pump (IP) as a type of wearable device that is more closely connected with the user than many of the more common technologies, such as goggles, e-rings, or smart clothes. This makes the IP more intrusive and therefore its adoption presents greater challenges than is the usually the case with other wearable devices.

This chapter seeks to provide an explanation of the discovery results and the answer to the research question: *what are the barriers to successful adoption of IP?* In simple terms, the explanation seems to be found in the contradictions that exist between the differing expectations of the three types of agent involved in this context, namely the change agents, patients and caregivers, as discussed in chapter 5. This starts with variations in the initial assumptions of parties regarding the purpose of IP, namely to control sugar levels (medics), to improve the quality of life of patients (parents), and to help young users to feel comfortable and equal with their peers (patients). These contradictions persist through the pre-adoption to post-adoption phases.

The adoption of new products remains an important issue for both researchers and practitioners (Huh and Kim, 2008). Extensive research has been conducted in terms of technology adoption in the context of wearable devices, however most these studies have focused on the utilisation of the technology acceptance model (TAM) and its various extensions (Nasir and Yurder, 2015; Gao et al., 2015). For instance, the TAM was used to investigate consumers' intention to use smartwatches, one of the most popular types of wearable device (Chuah et al., 2016). It examined the adoption challenges mostly

associated with wearable devices or related technology issues. The focus was to investigate the relationships between the objective characteristics of wearable devices, user perceptions and attitudes, and the behaviours that exist towards the use and adoption of wearable devices. Although useful, this approach typically neglects the role of individual, family and social characteristics, all of which are critical in successful new product adoption. Little is known about the reasons why some people are more likely to adopt wearable devices, or about the effect that individual, family and social characteristics have on the use and adoption of wearable technology

6.2 Literature Review and Knowledge Gap

Initially, this research focused on attempting to understand why some patients are misusing the IP in the post-adoption phase, despite its obvious benefits. Based on a comprehensive review of literature, several different theories were found to explain this phenomenon. As an example of this, the theory of reasoned action (TRA) holds that the behaviour and, more specifically, the intention to use a given technology is subject to the attitude of the individual towards the object (the IP). Meanwhile, the health belief model (HBM) demonstrates that the more the trust in the technology and the greater the belief that it can contribute to the improvement of personal health status, the higher the intention to use. Although these theories explain certain factors, there are still cases in which patients continue to misuse the technology despite believing that it has the ability to improve their health. Therefore, a novel analytic framework is proposed to understand this phenomenon. This framework examines the misuse of the IP through the contradictions between different actors. In other words, if different actors have different views about the same thing, this can negatively affect the way that a diabetic child feels about and uses the IP.

6.3 The Research Analytic Approach: Evaluating the analytic approach

6.3.1 Summary of Analytic Framework

The first main contribution of this research is the framework developed to understand the misuse of the IP by diabetic children. A range of different theories have been offered to explain the general misuse of wearable technology (Gao et al., 2015, Rauschnabel et al., 2016, O'Kane, 2014), as well as medical wearable technologies (Li et al., 2016, Chan et al., 2012) and even more specifically, the use of medical wearable technologies by children (de Vries et al., 2010; Binek et al., 2016). In this capacity, the dominant theories are the TRA and the technology acceptance models (TAM) (Gao et al., 2015), which focus on the perceptions of benefits from the device, irrespective of whether they are intended for medical or sport applications (Lunney et al., 2016). In the medical context, this approach is referred to as the HBM (Rimer and Glanz, 2011; Montano and Kasprzyk, 2015). The case of Saudi Arabia remains highly unusual in this discipline (c.f. Rendell et al., 2013; Hayek et al., 2014), with Saudi people generally having a higher level of belief in the ability of IP to improve the quality of life than many other countries (Carter, 2014). According to these theories, it should therefore be expected that the use of the IP is better in the Saudi context. Meanwhile, there is some evidence that the IP is not well used and therefore does not have the anticipated successful output. The problem may therefore be that these theories fail to explain the phenomenon or, alternatively, there may be certain factors affecting the way that these patients perceive the IP. It is known that once the attitudes and belief in technology is positive, the motivation to use it improves, which is then generally reflected in the quality of usage (Ajzen et al., 1986; Montano et al., 2015; Şener et al., 2015; Nasir and Yurder, 2015). However, it is not yet known how these attitudes and perceptions are developed. This research contributes to the field by identifying a number of mechanisms that create different views toward the technology.

In order to answer this research question through a focus on contradictions, the analytic framework has been based on the differentiation between facts, interpretations and explanations. In other words, contradictions cannot be understood directly from facts, until those facts are consolidated into one context that can then be examined from different perspectives, which enables the contradictions to be seen. There are also different constructs that should be magnified to understand the contradictions. The first analytical construct is that the main actors in this research are the diabetic child, the medical personnel (doctors and educators) and the parents. The second analytical construct is the interaction of these actors with the technology.

The human logics towards technology are a key determinant of behaviour with devices and innovations (Hultin and Mähring, 2014). Logics are created through interactions, understandings and perceptions, and can control the human behaviour without a clear rationale or intention (Wandel, 2001; Foucault, 1988). Based on the theory of sociomateriality, which refers to the 'inherent inseparability' of social and material aspects of organizational work (Orlikowski and Scott, 2008), these logics are created by interactions with the technology and with people within the technology context (Hultin and Mähring, 2014). The main rationale in this aspect of the investigation is concerned with the way that individuals perceive themselves with the technology. In other words, the person (in this case, the diabetic child) can see his relationship with the technology by perceiving how others perceive him. These others include his friends, medical personnel, and most importantly, his parents, who typically exert a powerful influence over the health of their child (Miller and DiMatteo, 2013). Indeed, how others define and perceive the IP is assumed, and has been found, to affect the understanding that children have of the IP. What is interesting here in this research is that the contradictions between agents seem to create a resistance mentality towards the IP. In order to better understand this relationship, it is advised that the sociomateriality theory be utilised, due to its focus

on understanding relationships in recognition that the role of different actors with the technology shapes perceptions, attitudes and behaviours toward it (Leonardi 2013).

6.3.2 Analytic Framework Evaluation

i A holistic analytic framework

This research is the first to introduce an analytic approach to understand why diabetic children are misusing the IP in Saudi Arabia. The analytic approach is different in certain important aspects from other traditional approaches, such as HBMs (Gonder-Frederick et al., 2011) and TAMs (Gao et al., 2015). Firstly, this analytic approach is comprehensive and holistic, not being restricted to the perspective of the patient, instead incorporating those of related medical personnel and caregivers. The literature also recognises that the attitudes of caregivers towards the IP can affect their children (Forsner et al., 2014, Alsaleh et al., 2014), much like the behaviour of a patient towards the IP is also affected their own attitudes (Chen et al, 2012; Perry et al., 2017). Beliefs about the IP prior to adoption, which have been shown to affect the condition of the illness (Hirose et al., 2012, Grunberger et al., 2014; Horise et al., 2012), are also important in conceptual models of the possible relationship among factors that influence the adoption of diabetes technology. These results are all drawn from a mono-perspective analytic framework. In contrast, the analytic framework devised in the current research incorporates the three perspectives of the three actors under the same analytical umbrella.

ii Epistemological Stance

This research is novel in combining three levels of understanding for reality into a single epistemological stance in an attempt to derive a conclusive understanding of how the perspectives of different actors towards the IP and their dialectics are building the mental model in the minds of children with regards to technology. In this research, the construction of these mental models (Jones et al., 2014) is understood through the

perceptions and attitudes towards objects through dialogue of different actors, which is not new (Delgado-Galván et al., 2014). This approach was also used in teaching children new things and concepts, using what is called the Socratic approach (Helterbran and Strahler, 2013). The current research employed this approach in the investigation of medical wearable devices, in an attempt to understand how different actors with different discourses create a new mind-set that leads to unintended behaviour. This approach was provided helpful insights about the factors and metaphors controlling the mind and behaviour of diabetic children.

Research credibility is about ensuring the correctness and accuracy of the findings (Lincoln and Guba, 1985). Traditionally, credibility can be improved through the use of thematic analysis (Forsner et al, 2014), which is primarily focused on the repetition or recurrence of themes (Braun et al, 2013). This research contributes to this discussion by showing a new angle for the analysis and understanding of participants. It should also be noted that this research differentiated between facts, my interpretations and explanations. In other words, it is not necessarily essential to see recurrence of the codes among multiple responses to ensure the credibility of the results. Instead, the objective is to take the perspective of every actor as factual, when they talk about themselves and as opinions when they talk about others. In essence, therefore, all feelings, emotions and personal experiences are perceived as being factual from the individual perspective of each interviewee. However, when all of these facts come from different actors, the consolidated view can enable patterns and contradictions to be seen in those personal facts. This contradiction that exist in terms of understanding reality creates a unique perception of reality. This idea is not completely new, however, with many studies having used philosophies to differentiate between facts and interpretations (Ahlen et al., 2006; Sandelowski, 2000; Tellis, 1997).

The use of socio-materiality in understanding the patient logics

In this study, the sociomateriality approach is used to examine the interactions between people and technology, as well as how the interactions between them affect perceptions about life and towards people (Orlikowski, 2010). A sociomaterial perspective builds upon research in sociology, the philosophy of technology, science and technology studies, and quantum physics (Barad, 2007, Leonardi, 2013); This useful theory has been widely used as an aspect in analytic approaches. Indeed, the idea of a sociomaterial model has also been developed “as an analytical framework that can assist in research and design of learning technology by providing a pertinent lens to examine emergent socially and materially intertwined learning practices” (Johri, 2011, p. 208). What is really new in the current context is the combination of sociomateriality with different levels of analysis. This approach clearly illustrates that technology enforces a certain life pattern on the user. The perspective of users towards technology begins to be shaped by their interactions with it, as well as with other people and the external environment. Although this approach not been used before in terms of the IP for adolescents, but it offers a useful tool to better understand the reality creation process in the minds of many different actors.

Indeed, the contradictions between the diverse perceptions of reality regarding the different factors at play in this study context can result in conflicting messages being presented to the minds of diabetic children. This is reflected by the various perceptions and understanding of the technology. The importance of studying the contradictions between different actors has been recognised in other studies, having been aligned with actor network theory (Prout, 1996) or used in assistive technologies research. In the latter discipline, studying contradictions showed that when disabled people perceive the community has certain perspectives and attitudes towards them that contradicts with their own views, they abandon using them (Shinohara and Wobbrock, 2011, Pape et al., 2002). However, the current research is the first to recognise the importance of understanding the way that these contradictions between actors on the perception, attitude and behaviour toward medical wearable devices inform its usage by children patients.

In summary, it can be claimed that these results would be difficult to achieve without combining multiple different analytic approaches in this way. Other important findings of the analytic framework are presented in section 6.5. It is believed that these also could not have been realised without the adoption of this unique analytic framework.

6.4 Areas of improvement in using the analytic framework to other domain

6.4.1 Sampling technique

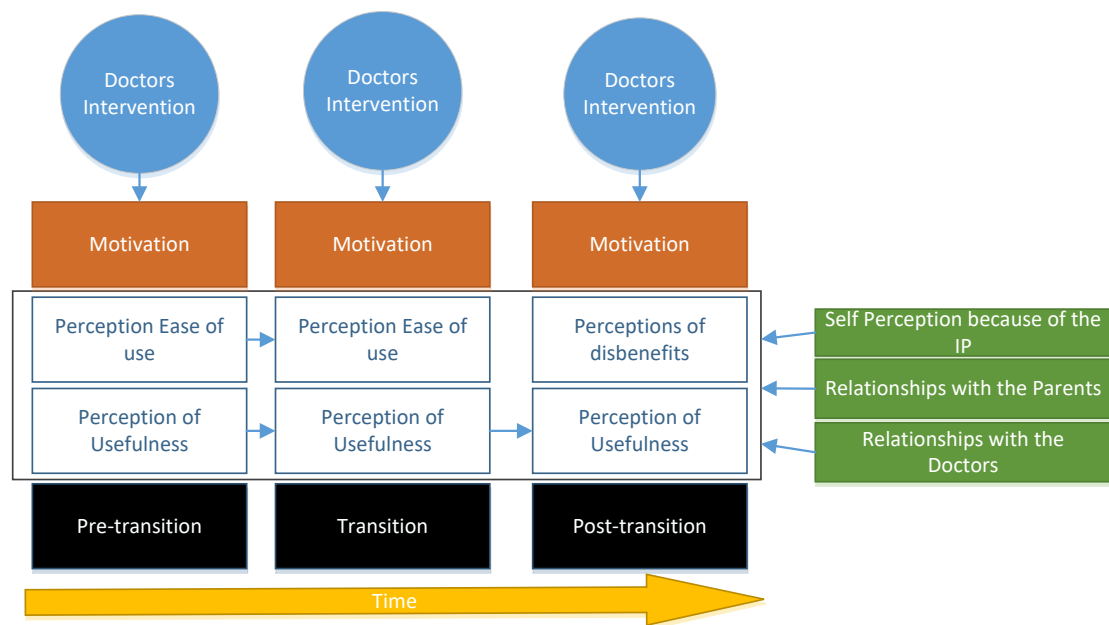
It is clearly shown that this analytic framework is based on case studies approach. However, the analytic approach does not clarify the basis for the selection of cases. Nor does this framework guide researchers with regards to sample size or the recruitment of sample participants. It is assumed that the researcher can identify the most relevant cases and participant population to address the research aims, which suggests that snowball sampling is likely to be the most relevant approach.

6.4.2 Evolving the level of contradictions among different actors through time

The current analytic framework does not note anything about the evolution of contradictions among different actors. However, my findings suggest that it would be beneficial to consider time as being a critical factor in understanding the contradictions. In addition, it should be noted that prior to the adoption of the IP, both the beneficiaries and change agent seem to share the same understanding of the logic. The reason for this may be that the IP is almost always introduced to the beneficiaries by the change agent. As found in interviews, in pre-transition, both doctors and educators strive to communicate the positive aspects of the IP to the patient, in terms of lifestyle, safety and mobility, with much less focus on the technical sides of its use. This is particularly important because patients do not usually have any background knowledge of the IP, the

change agent is the only player in creating and manipulating the reality in minds of diabetic patients and their family. However, after some time of the IP being used by the diabetic child, especially after the wearer has been exposed to the external environment, including friends and family, deviations may arise in understanding and defining the IP. These changes may lead to the conflict. The current framework does not address this point; however, it suggests that the time factor may be an important consideration.

With consideration of the time factor, it becomes apparent that the motivation can be viewed as an evolving process that is affected by the level of conflict. There is no clear evidence from the findings to support this observation, as it was not planned for in the analytic framework, and therefore the absence of the time factor from the current framework therefore potentially constitutes a legitimate criticism of its design.



6.4.3 Generalisability of the analytical framework

The generalisability or applicability of the analytic framework is accepted with certain conditions. This analytic framework has been evaluated in the context of Saudi Arabia,

which is profoundly different from many other contexts, such as the UK or Japan. However, the analytic framework may be useful if it is able to address the differences in defining the IP/wearable medical device among different actors, irrespective of their culture. This may be significant, given the substantial role that culture can play in the level of psychological reactance of some diabetic children towards the adoption and use of the IP. Therefore, application of this research in different cultures may be viable and valuable, taking into consideration these cultural implications on the findings. Regardless of the culture, however, the contradiction analytic framework could be extremely useful for contexts in which contradictions prosper. Therefore, the following assumptions would decrease the importance of using this analytic framework.

Assumption 1: if the parent of the diabetic child has a medical background (is a doctor or other medical personnel), they may adopt the same discourse and understanding as the change agent. This can decrease contradictions enough to be useful for analysis.

Assumption 2: if the wearable medical device is too small to be noticed by others, this might decrease its impact on patient self-perception. This may, in turn, decrease the contradictions.

Assumption 3: if the baby is too young to understand and to define the influence of the IP on how he looks like with it ‘because accepts the use of the IP unconditionally and incorporates it into his everyday life automatically’. This has precedence in literature, which has shown that the success of the IP success is generally more prevalent in infants than in older children (Phillip et al., 2007). It can therefore be presumed that resistance is often a function of the contradictions in defining the IP.

Assumption 4: if the change agents use psychological measures to ensure the mutual understandings between different actors, thereby lowering the number and severity of contradictions, which in turn decreases the need to utilise this analytic framework.

6.5 The Research Framework

The second contribution of this research is the application of the analytic framework to answer the research question of this thesis. The three actors are all interacting with the technology from different perspectives: the change agent looks at the IP as a medical device that improves the condition (Scheiner et al., 2009, Lawton, 2015, Blackman et al., 2014); the parents primarily look at it as something that may improve the quality of life of their children (Grunberger et al., 2014) and their diabetic children are more likely to look at it as something that is being forced on them. However, it should be borne in mind that the perception of children in this matter is often unclear and complex. This is an important consideration because it is this perception that is most likely to shape the attitude of a child towards these devices, in turn affecting their consequent behaviour (i.e. proper/improper use) towards the technology (Venkatesh, 2000). In this research, the perception of patients towards technology has been found to be determined by how the main stakeholders define the technology and the way in which they perceive the patient with the IP. In other words, as discussed later, when a mother is lenient towards her patient because of the IP, the child is likely to act and behave accordingly.

The third contribution is not only related to the way that the attitude and behaviour of the patient are affected by how others view the technology and view the patient using that technology; it has been shown that contradictions between different actors also serve to create different patterns of understanding and definitions towards the technology. It is already known that patient selection affects the success of IP therapy (Grunberger et al., 2014). However, it is less clear how certain factors can impact on the perceptions that the caregiver and the patient have of the IP. The following section will discuss the perspective of the three actors (change agent, caregiver and patient) toward the IP.

6.5.1 Change agent perspectives towards the IP

i Change Agent discourse towards the IP

This research captured the discourse, views, and perception of participants with regards to the IP. This has enabled an investigation of the change agent logic towards the IP. Previous studies have already noted that the logic of doctors is strictly determined by a deterministic view towards the world (Sidorkiewicz et al., 2016). In other words, medical personnel use assertive discourse in the management of hospitals (Witman et al 2011), followed by orders and care for the patient health (ibid; Ha and Longnecker, 2010). This research has contributed to the literature by showing that doctors are using the same discourse, not only in the management of hospitals, but in the direction and guidance of their patients, which here refers to diabetic children and their caregivers. The second change agent discourse is to transfer the main responsibility for the proper use of the IP to the parents alone, as found in other research (Taylor et al., 2013, Hilliard et al., 2014). This illustrates that the discourse has potentially serious implications, as medical personal stop thinking about improving their understanding of why a problem might exist in IP usage.

ii Change Agent Tools in Managing the IP performance

Lawton et al. (2015) state that doctors in the USA recommend “individuals for insulin pump based on their assessments of personal and psychological suitability, or in another word physical or mental capacity to manage an insulin pump”. Doctors in other countries, like the UK, Canada and the USA, have been found to use psychological indicators to ensure that diabetic children are using the IP (Grunberger et al., 2016, Lawton et al. 2015, Liberman et al., 2014). This research, contributes to this knowledge, by demonstrating that many Saudi doctors are adopting the same practices prior to the adoption of the IP by their patients.

A number of studies have expressed the position that these indicators are a continuous process (Lassmann-Vague et al., 2010, Phillip et al., 2008), however the current research suggests that Saudi doctors and educators stop using psychological indicators in the post-transition phase, shifting focus almost entirely to the medical readings of the patient blood tests. This can have serious consequences on their interactions with patients in the post-transition phase, as there are no mechanisms to follow up with the psychological motivations of the patient and their family to use the IP. This may, in turn, lead doctors to rely heavily or exclusively on medical examinations, which only show the problem of misuse after it happens.

Thus, the only tool that doctors use to improve the quality and effectiveness of IP use is to blame the family and patients, however this does not identify or resolve the real reasons for the problem. In the post-adoption phase, there are numerous mechanisms to motivate patients and ensure that they are using the IP appropriately. This is important, as technology combined with appropriate psychological support may be a powerful motivator for health behaviour change (Pickup et al., 2007; Tumminia et al., 2015).

This research is unique in addressing the importance of doctors, at least in Saudi Arabia, continuing to influence the perception of the current and future realities of diabetic children and their caregivers. In other words, the two main strategies found focus on the benefits of the IP, demonstrating that without the device managing the illness and maintaining a healthy glucose level will be much more difficult.

6.5.2 Perceptions of the Caregivers towards IP

Caregivers typically have different perceptions towards the IP than change agents. Other studies have shown that caregivers primarily perceive the IP as a tool to improve the lifestyle (Hirose et al., 2012, Cogan et al., 2002; Al Saleh et al, 2012), and health of their diabetic children (Mednick et al., 2009, Hirose et al., 2012). This research contributes to

this position, through the addition of two more dimensions to facilitate better understanding of the attitudes and perceptions of young patients towards the IP. Caregivers, at least in this study, generally perceive the IP to be very safe and easy to use. Trust and confidence in a given technology has been shown to motivate the beneficiaries to use it, leading to better quality of usage (Sousa et al., 2016). However, this research shows that too much confidence can also be harmful, because it leads to greater reliance on the technology to the degree that patients and their families may not be careful enough to ensure that they use the device correctly.

Indeed, caregivers may have different reasons for misusing the IP, such as carelessness or insufficient involvement and engagement in certain aspects of the daily life of their children (Telo et al., 2015, Georgeanna et al., 2001, Low et al., 2005, Telo et al., 2015, Klingensmith et al., 2001). However, this research plainly demonstrates that negligence does not necessarily arise as a consequence of being a busy parent, but can also be attributed to factors such as the belief that the IP is easy and safe, leading to negligent use of the technology in the management of the IP. These perceptions can lead delegation of managing the IP to the diabetic child or to the other members of the family before they are ready, so mistakes are made in the use of the IP.

A study in Saudi Arabia has claimed the main reason for misusing the IP in is that there is not enough training on the IP (Elzubier, 2002). However, the two case studies in this research suggest that sufficient training on the IP will not necessarily result in satisfactory use of the device. Moreover, although it has been claimed that the lack of parental knowledge of the IP device demonstrates the corresponding need for ongoing parental education regarding insulin pump features to improve IP usage (Mitchell et al, 2013), this research has not found similar results. Indeed, parents were very aware of the IP and its correct use. Instead, this research suggests that, at least in some cases, problems with IP usage can be attributed to parents feeling too comfortable in the use of the IP, leading

them to reduce supervision and delegate its use before the diabetic child or other family members are properly trained in its use.

6.5.3 Child perception towards the IP

Diabetic children view the IP as a tool that seeks to improve their quality of life through management of diabetes. However, after using the device and especially after being seen to use the technology by other people in their communities, many of these children begin to feel odd, restricted, or in pain. This may be partially attributed to over expectation of the usefulness of the medical device, which has been shown to lead to frustration after adoption (Franklin, 2016). Moreover, this study has shown that the IP is widely believed to be for the improvement of lifestyle rather than as a medical necessity, leading some users to remove the device, regardless of the consequences. One reason for this could be the fact the IP can adversely affect the body image of some women because of its size and obviousness in social situations (Chamberlain and Gilgen, 2015, Hains et al., 2007). This research found that many diabetic children in Saudi Arabia face the same problem, perceiving that others see the IP as a source of shame and weakness. This can result in children hiding their IP, as well as increasing the likelihood of the device being misused.

The IP needs a patient to be self-disciplined, because its correct use involves many activities that require accurate measurements (Shalitin et al., 2010). Saudi Arabia culture has a tendency to be less self-disciplined than western culture (Al-Kahtani, 2007), which might make patients feel restricted because of the IP and therefore less likely to use the device properly. A feeling of restriction in the use of the IP is a drawback that has been acknowledged in the literature and this is clearly the case in the context of Saudi Arabia.

6.5.4 Contradictions between different agents (the definition of contradiction)

The concept of 'contradiction' is rooted in institutional logics literature, which holds that different professions often utilise different logics to understanding the world (Thornton

et al., 2012); (Hultin and Mähring, 2014). This research borrowed this concept, applying it on a micro-level to examine the logics of doctors, parents and diabetic children. There are different occupations involved here: the technical and hard logic represented by the doctor (change agent); the parenthood occupation, which adopts the soft and caring logics, in terms of safety and mercy; and the childhood occupation, which adopts lifestyle logics.

This research, based on its findings, defines ‘contradiction’ as a conflict in the way that the change agent (doctors), sponsor of the change (parents) and the main beneficiary (the diabetic child) perceive, understand and define technology. This contradiction is reflected in the discourse by different actors. Although these contradictions are rooted in the logic literature, they could not be operationalised and analysed without proper understanding of the discourses. Therefore, it should be said that the analytic framework captured the discourse, which facilitates an understanding of the logics. Logics is “is the set of material practices and symbolic systems including assumptions, values, and beliefs by which individuals and organizations provide meaning to their daily activity, organize time and space, and reproduce their lives and experiences.” (Thornton et al, 2013). However, this research limits the understanding of the logics to perception and definition of the technology. This adaptation comes after application of the sociomateriality theory, which shows that technology affects how individuals perceive themselves with particular technology. Based on this, it can be said that people redefine technology based on their self-perception (Hultin and Mähring, 2014).

Contradictions between patients and doctors with regards to in the IP have been noted in previous literature. (Wackerbarth et al., 2007) found that most physicians delivered information to enrich the knowledge of patients in the technical aspects of the IP, but gave little regard to their true understanding, ideas, or preferences. ”Although healthcare is always trying to increase patient’s autonomy and create a harmonious relationship between physicians and patients, endowed with this technology some patients could

erroneously disregard the role of the physician”(p.6)This research has also identified the existence of a gap between the discourse of physicians and patients, which affects the relationship, in turn affecting the behaviour.

Change agents often claim that the main issue explaining the inappropriate use of the IP is patients' inability or lack of discipline in following the rules. As a consequence of this belief, they supply orientation and induction to stimulate the desire to use the IP correctly, through a focus on benefits and training to ensure that patients know how to use the device. Although these techniques are perceived to be useful and effective (Pickup et al., 2014; Shalitin and Phillip, 2008), parents nevertheless still struggle, as evidence by their failure to use the IP appropriately. Change agents believe this is because in following the rules or they are careless.

6.6 Chapter Summary

Wearable devices are an important subdivision of assistive technologies and can have a profound, diverse impact on the lives of those who use them. Devices like the IP have been found to be defined and understood very differently, depending on the interactions that people have with them. One original aspect of the current research is that the IP is a type of wearable device that is forced on the child, who feels obligated to incorporate its use into their daily life. In other words, the IP is unlike other wearable devices that are used for merely lifestyle reasons; it is integrated into the patient body for medical and lifestyle reasons. Once adopted, the IP should be used carefully and correctly, otherwise it may not actually be beneficial to the patient, or may even potentially harm them and lead to withdrawal.

The theory of reasoned action (TRA) predicts that because IP has various benefits listed in literature, so it can be expected that patients will use the device. However, some cases are exceptional because children do not make their own decisions and cannot be trusted.

Therefore, the new analytic framework is based on the way in which different perceptions, definitions, and understandings can create contradictions which in turn leads to attitudes and behaviours.

Application of this framework demonstrates the existence of numerous perspectives, discourses, definitions and perceptions towards the IP. Doctors typically perceive it as a medical device, parents perceive it as a tool that will improve the safety of their children, and the patients are likely to have yet another perspective, defining it as a diabetic lifestyle tool. In this way, the patient seems to perceive that the device affects their lifestyle in both positive and negative ways, which may be further complicated by the influence of the beliefs of the child about the perceptions of others about him because of the IP. The mismatch in understanding and definitions of the IP potentially creates different messages and understandings, resulting in a negative attitude towards the device and a correspondingly higher change of it being used incorrectly.

The analytic framework in this study has provided new insights into our understanding of the misuse of the IP. However, improvements could be made to this analytic framework through the integration of sampling techniques; considerations of the evolutionary nature of contradictions and the way they can change over the time; and improved generalisability of the framework. The next chapter seeks to conclude this study, critically examining the usefulness of the analytic framework, explicitly stating the contributions that have been to knowledge, outlining the limitations of this research, and mapping promising avenues of future research.

CHAPTER 7 Conclusion

This research belongs to multi-disciplinary research community concerned with the adoption of wearable technologies in real-life application domains. In this project the investigation was focused on the Insulin Pump as an example of wearable technology that is more closely connected with the patient's body than is the case with the more common devices such as goggles, rings, as well as more recent smart clothes. For this reason, the issues of technology adoption were addressed not only from technology but also from user perspectives. Literature traditions were brought together, namely technology adoption (Technology Adoption Model – TAM and Theory of Reasoned Action – TRA and health belief model) and relevant psychology sociology studies dealing with user readiness.

The research problem these communities share is how to explain the varying degrees of success in technology adoption, especially medical devices and other forms of assistive technologies. According to the most influential literature sources on technology adoption, it is difficult to predict how successful a device or a technology solution is likely to be with different kinds of users (for example, different age group, social status, medical condition, individual preferences). The main research question in this study is therefore “Why do patients misuse the Insulin Pump?” To answer this question, an analytical framework was developed to take into account the broader context of IP use, including diagnosed medical condition of the patient, other reasons for doctors' prescribing IP as a solution, together with the type of patient, home environment, life-style and social constraints that may have an impact on the successful adoption of IP.

The analytical framework was created and tested in Saudi Arabia, which presents a specific cultural and social environment that influence patients' views and attitudes towards new technologies, and which touch upon family relationships and social pressures. Particular focus was on young patients - children and adolescents - whose

dependence on caregivers (both within the family and within the medical profession) is much stronger than is the case with adults. The role of caregivers with these patients is therefore more prominent and can significantly influence success or failure of the IP adoption and this was particularly significant in the post-adoption phase. This has been relatively neglected in the literature where the main focus of investigation has been on the pre-adoption phase and on creating patient motivation to adopt IP, rather than on maintaining motivation and ensuring successful long-term use of IP.

Having applied the analytical framework in this particular context, the importance of the interactions between different people involved, medical personnel as change agents, family and friends as caregivers and patients themselves, not only as individuals but also as members of social groups appropriate for their age. The data analysis was focused on the discourse between these diverse agents involved and in particular on the contradictions that arose in the post-adoption phase that ultimately led to barriers and abandonment of the IP as a solution to medical problems. As supported from the literature, contradictions in discourse between different actors can lead to unintended and unexpected behaviour of the involved actors. Likewise, it is believed in this analytic framework, the main problem is in the contradictions in the understandings, definition and perspectives towards the IP is the main reason for the improper use of the IP.

7.1 Problem description

The IP is recognized as one of potentially successful tools to improve life styles of diabetic children (Reece & Williams, 2014; McAdams and Rizvi, 2016a) as discussed in chapter 2.4.

However, in spite of the widespread use of the IP among diabetic children, there are cases where patients and caregivers struggle with it (de Vries et al., 2015; Hofer et al., 2010; Heinemann et al., 2016). In the literature, possible solutions to this problem are reported in Chapter 2 including factors like training (Bolderman et al., 2013), improved perception

of benefits (Lange et al., 2014) and the belief in the IP as the solution to their medical problems (Grunberger et al., 2014) in Chapter 3. Although the existence of these factors improves the patients' condition and life-style in some cases, there are still many patients who struggle with it. Therefore, this research aims to improve our understanding of the reasons why an unacceptably large number of patients fail to benefit from IP. This is done in this project by examining interaction between different actors involved and how this interaction influences beliefs, perceptions and attitudes of the diabetic child towards the IP.

Research has been done in this area, specifically investigating doctors' perceptions of IP and also studying how child patients and their families perceive the IP in Saudi Arabia (Al hayek et al., 2014). However, none of the research in Saudi Arabia explained how the differences in perceptions among the medical personnel, patients and caregivers can demotivate children patients and consequently lead to improper use of the IP. Indeed, previous research has not answered the question why diabetic patients often struggle with the IP even though their families understand and know very well how to use the IP correctly. The issue is not entirely in the technology itself but needs to be addressed from a people-oriented point of view as well. Indeed, this research showed that the problem is in the interaction and misunderstandings between the people involved in ensuring proper use of IP in the daily lives of its patients. These misunderstandings created an indefinite loop of blaming between different actors that ended in decreased motivation to use the IP in a proper way, even leading to psychological resistance towards it.

7.2 Research Question: How contradictions between the different actors in defining and understanding the IP affect the main beneficiary (child) understand, define and be motivated to use the IP?

The findings of this study suggest that the main reasons for the improper use of the IP lie in the lack of communication and understanding between the physician and the diabetic

child and the parent, which often result in the child's psychological reactance towards the IP. In addition, too much criticism on the part of the doctor directed at the caregivers, claiming that caregivers are not strict in managing the IP for their diabetic children, results in the child's lack of awareness of the risks involved in misuse of the IP. The analytic framework developed in this study helped to establish the significance of these factors. In the literature, relationship weaknesses were known to be one of the reasons for the improper use of the wearable medical device (Appelboom et al., 2014) As discussed in Chapter 3.

This research, using the analytic framework developed here, has found that the main reason for the lack of mutual understanding of the benefits and shortcomings of IP is that change agent views the IP as a technical tool, whereas the patient looks at it as something integrated into his body, affecting his lifestyle and his relationships with others. Moreover, it is known that the psychological reactance affects the patient behaviour with medications (Darby et al., 2014). The findings of this study show that a very important reason for IP failure is that the change agents keep enforcing and blaming the patient for imperfect use of the IP, whereas the patients feels restricted using the technology. As blaming escalates, the patient's feelings of being restricted increases and ultimately causes the patient to react against it.

Moreover, it is known from the literature that the caregivers are major influencers of the quality of the IP use by their diabetic children (Wiebe et al., 2010; Streisand et al., 2014). Although they are expected to be aware of the importance of IP and its usefulness (Blackman et al., 2014), this research has found that caregivers do not take it seriously because they see that one of the consequences of wearing IP in public puts their children at a disadvantage socially. Doctors, on the other hand, do not appreciate these concerns; they keep blaming caregivers without understanding the root causes of the problem. The problem is mainly in mothers' feelings of sympathy and pity for their diabetic children and their expectations that IP will make them 'normal' just like their peers.

7.3 Uniform analytical framework

This research is organised into three phases. The first phase involved observing and interviewing the informants to elicit information about the problem situation. In this, discovery phase, what the informants said and did was recorded and used in subsequent analysis that aimed to capture their viewpoints, perspectives and attitudes. Three main sources were consulted – the informants’ discourse, explicitly expressed views and perceptions of IP.

In the second phase, the focus was on identifying regularities in the informants’ practice and the relationships that the informants were involved in. This was the basis for the interpretation of what the informants meant and reasons for their behaviour. By understanding the view of the world of each type of informant, and combining them into a unified analytical framework, the complete picture of the problem situation can be obtained. This analytical approach is adopted from (Seo and Creed, 2002) who shows how different facts may be understood differently by different actors thus creating different kinds of contradictions and resulting behaviours. Van Parijs (1982) work has provided the basis for the third phase, leading to the explanation of informants’ behaviour and explication of the causes for that behaviour, that is, explanation of the causes, reasons, and motivations, as well as interpretation of the beliefs and attitudes underlying the informants observed behaviour.

7.4 Contribution to knowledge

There are three main contributions to the knowledge.

- 1- A new analytic framework focused on contradictions in the discourse between different actors in order to define a type of technology, such as an IP, and to understand its impact on users. This discourse influences the differences in

perception among the main users, which often lead to unintended consequences. This research is the first to introduce an analytic approach to understand why the diabetic children are misusing the IP in Saudi Arabia, bearing in mind both the cultural and social factors influencing the take up of IP. Special requirements for child patient support from family members are also considered as the family relationships in the Saudi Arabian culture play a particularly important part in influencing child patient perception of the IP.

- 2- This study has also provided a new definition of contradictions which can help in understanding the misuse of the IP in a more insightful way. It offers novel definition of contradictions between actors as the conflict in the perceiving, understanding and defining a medical device, the conflict between the change agents (medical personnel), sponsor of the change (parents) and the main beneficiary (the diabetic child).
- 3- This approach has resulted in the development of a new framework that shows how different contradictions lead to different diabetic patient behaviours towards the IP. It is found in this research that patient perception of the technology is determined by the main stakeholders' view of this technology and their view of the patient with the IP. In other words, as discussed earlier, when the mother is lenient towards her child because of the inconvenience of having to wear and maintain the IP, the child is acting and behaving accordingly – he or she is more likely to misuse the IP.

7.5 Research methods

Since the focus is on broad social and cultural context of IP adoption, more specifically on the views, motives, attitudes and expectations of the three main types of agent, different qualitative methods were used in this empirical study - interviews, observations, case studies. This research used interviews and case studies to understand the

contradictions between different actors in each case. The number of case studies in this project is limited to the main types of agent to demonstrate and validate the application of the analytic framework. Further case studies are likely to increase the robustness of the findings, as discussed in the Future Research below. However, due to the sensitivity of the research topic there were difficulties in finding cases with improper use of the IP since strict legislation prevent scientific researchers from having free access to children diabetics with IP and with improper use. However, the two most representative cases were rich in detail and helped to accomplish in-depth understanding of the problems faced by children patients and their families in the Saudi Arabian culture. New studies applying the same analytic framework in different contexts will provide stronger basis for more generalizable and may be more insightful findings.

From the interviews, it seems that contradictions are evolving through time, from the pre-adoption to the post-adoption stages of the adoption process. It could be argued that longitudinal case study would benefit the academic study by observing and noting the evolving process of the contradictions through a set period. However, this was outside the scope of this project, as its main aim was to identify the causes of IP misuse. In addition, using this method it was not possible to establish how frequent such misuse is and whether there are any other significant reasons for it, especially with patients of different age groups and belong to different cultures. These are discussed further in Future Research. For the purposes of this study, the research methods used have been applied to a real-life problem in a particular medical, social and cultural context and have effectively explicated the implicit views and attitudes of the agents involved, thus leading to insight into the hidden causes of their behaviour.

7.6 Implications for Practice

Based on the findings from this research, the following recommendations can be made to improve on the successful adoption of IP with young diabetic patients. Following these

recommendations in practice can in turn provide additional data that will refine the research outcomes of this and of similar future projects:

- Doctors need to check the diabetic patients' readiness systematically and continuously to assure, and therefore to manage, the readiness level. Readiness level is not only behavioural readiness but also psychological readiness. The findings of this research indicate that checking readiness would start by understanding the diabetic patients' and their families' views of the IP, not only their willingness to use it. Readiness should not be limited to the diabetic patient only; but must extend to the family also. Additionally, it should be periodically reviewed and modified as necessary.
- Clear understanding between different actors should be well documented and agreed on from the beginning of the adoption process.
- A record should be provided for the child and the parent (caregiver) to look at when following up with the doctors, in order to remember the motivation that made the patient switch to the insulin pump.
- Reminders for the child and caregiver should be sent by email or post about the proper management of IP that should be made, mentioning the consequences of the misuse and improper management of the IP.
- Caregivers should attend a course on the awareness of their responsibilities, risks of mismanagement, in order to ensure that the families have realistic expectations of the IP.
- Patients and families should be assessed on the readiness to use IP outside of the medical sector who prescribes the insulin pump, not relying only on the doctor and the diabetic educator who assesses the patient and recommends the IP. This is because such assessment and recommendations can be a part of marketing the insulin pump and selling it. There should also be home visits from time to time.

- There can be a reminder on the actual device, to play music or talk about a controlled diabetes and having, or as a screen saver. Furthermore, the insulin pump can be designed as an accessory for the female, or it can contain video games for children. It can be designed to be very small that can be hidden under clothing so that it cannot be seen by others.

7.7 Research limitation

This research has certain methodological limitations. Limitations can be attributed to the final shape of the analytic framework. The analytic framework limitations are evaluated in section 6.4. The limitations discussed here is mainly about the final framework, in particular the access to the real-life cases. Because of the sensitivity of the topic, it was difficult to have access to patient's records and many cases in Saudi Arabia. That is why the informants were from the informal network of contacts who were familiar with the cases of patients struggling with the IP. The number of cases were sufficient to apply the analytic framework in this study. In addition, as is often the case with empirical research, the results pertain to the specific perceptions and definitions of the patients and their parents towards the IP and would be difficult to be generalised without validating the contextual assumptions. The contextual assumptions are to do with the same contradictions, the same type of family background, the same level of income, the same accessibility to the same doctor's mentality and way of managing insulin pump. These results are resultant from the use of the analytic framework which helped to understand these cases in depth. In order to generalise the results of the specific definitions and perceptions found in this research, further research, perhaps involving a quantitative survey to sample different patients/caregivers in different places in Saudi Arabia. Indeed, in the current laws, it would be virtually impossible to have access to a significant sample

size. This can be done only if this research is funded specifically from the health authority in Saudi Arabia.

In this study, the results were validated by communicating with the families with the results and they expressed their satisfaction with the understandings formulated. This kind of validation overcomes parts of the inability to test the results from the final framework of the perceptions and behaviours.

7.8 Future Research

This research has investigated two case studies of diabetic patients aged 8 and 15. Patients of different age can have different views and attitudes, with the resulting differences in behaviour. In other words, the older the child, the less reliance on the parents in understanding the world (Webb and Zimmer-Gembeck, 2014). The older the child, the more he or she is connected with friends and colleagues instead of their family. Therefore, it can be expected that the role of the mother as a main actor could be increasingly less significant. It could even change from that of a caregiver and decision-maker to that of a helper or a friend. Indeed, there is no clear evidence to suggest that this would be the case, but a longitudinal study can be conducted in future in order to discover how the agents' roles change as the patient grows older. A future study of this kind can be focused on the contradictions, not only between the physician and the caregiver, the caregiver and the patient. It could also include interactions with friends in older age groups in order to discover any further contradictions that may influence the take up of IP and similar technologies.

It is quite important to understand the evolving interactions between the different types of agent involved in IP adoption. The main determinants and understanding of the technology for the patient is the perceptions of ease of use and usefulness of the device, because these perceptions affect motivation (Giani et al., 2015). Although in the literature

motivation is fixed and determined by current perceptions, the research approach in this study argues for the possibility of different motivations in different times. Because the relationship between the actors are evolving over time, because their perceptions may change due to the experience with the technology (IP), the attitudes towards the IP may also change. Therefore, a longitudinal case study would throw light on the nature of adoption process as it evolves over time.

Another important extension of this study would involve broadening the social and cultural context of the investigation. It is more than likely that in cultures outside Saudi Arabia would have different relationships between children and young people and the rest of the family, different social pressures on diabetic patients, different roles of people in authority such as doctors and educators. All these differences, when addressed in future research, will serve to refine the analytical framework developed here and thus make it possible to broaden the range of social and cultural contexts, build a representative sample of informants thus making the outcomes more scientifically reliable.

References

- Aberle, I., Scholz, U., Bach-Kliegel, B., Fischer, C., Gorny, M., Langer, K. and Kliegel, M. (2009) 'Psychological aspects in continuous subcutaneous insulin infusion: a retrospective study', *J Psychol*, 143(2), pp. 147-60.
- Acerini, C. (2016) 'The rise of technology in diabetes care. Not all that is new is necessarily better', *Pediatric Diabetes*, 17(3), pp. 168-173.
- Adams, D. D. (2008) 'Autoimmune destruction of pericytes as the cause of diabetic retinopathy', *Clin Ophthalmol*, 2(2), pp. 295-8.
- Ahlen, K., Buckley, C., Goodale, D. and Pulsford, A. (2006) 'The 'propofol infusion syndrome': the facts, their interpretation and implications for patient care', *European journal of anaesthesiology*, 23(12), pp. 990-998.
- Ajzen, I. (1985) 'From intentions to actions: A theory of planned behavior', *Action control*: Springer, pp. 11-39.
- Ajzen, I. (1991) 'The theory of planned behavior', *Organizational behavior and human decision processes*, 50(2), pp. 179-211.
- Al Hayek, A. A., Robert, A. A., Al Dawish, M. A., Braham, R. B., Goudeh, H. S. and Al Sabaan, F. S. (2015) 'Efficacy of Insulin Pump Therapy on Diabetes Treatment Satisfaction and Glycemic Control Among Patients with Type 1 Diabetes Mellitus in Saudi Arabia: A Prospective Study', *Diabetes Therapy*, 6(2), pp. 227-236.
- Al-Ayed, I. H. (2010) 'Mothers' knowledge of child health matters: Are we doing enough?', *Journal of Family and Community Medicine*, 17(1), pp. 22-28.
- Almutairi, A. and McCarthy, A. L. (2012) 'A multicultural nursing workforce and cultural perspectives in Saudi Arabia: An overview', *TheHealth*, 3(3), pp. 71-74.
- Almutairi, K. M. (2015) 'Culture and language differences as a barrier to provision of quality care by the health workforce in Saudi Arabia', *Saudi Medical Journal*, 36(4), pp. 425-431.

- Alsaleh, F. M., Smith, F. J. and Taylor, K. M. (2012) 'Experiences of children/young people and their parents, using insulin pump therapy for the management of type 1 diabetes: qualitative review', *Journal of Clinical Pharmacy and Therapeutics*, 37(2), pp. 140-147.
- Alsaleh, F. M., Smith, F. J., Thompson, R. and Taylor, K. M. G. (2013) 'A structured educational insulin pump therapy programme: the views of children/young people and their parents', *European Diabetes Nursing*, 10(1), pp. 25-30.
- Appelboom, G., Camacho, E., Abraham, M. E., Bruce, S. S., Dumont, E. L. P., Zacharia, B. E., D'Amico, R., Slomian, J., Reginster, J. Y., Bruyère, O. and Connolly, E. S. (2014) 'Smart wearable body sensors for patient self-assessment and monitoring', *Archives of Public Health*, 72(1), pp. 28-28.
- Arksey, H. and Knight, P. T. (1999) *Interviewing for social scientists: An introductory resource with examples*. Sage.
- Atkinson, P. and Hammersley, M. (1994) 'Ethnography and participant observation'.
- Ayyagari, R., Grover, V. and Purvis, R. (2011) 'Technostress: technological antecedents and implications', *MIS quarterly*, 35(4), pp. 831-858.
- Badewi, A. A., Shehab, E. and Peppard, J. 'Benefit realisation modelling for ERP systems using system dynamics'. *Advances in Manufacturing Technology XXVII- Proceedings of the 11th International Conference on Manufacturing Research (ICMR2013)*, 225-235.
- Barnard, K., Crabtree, V., Adolfsson, P., Davies, M., Kerr, D., Kraus, A., Gianferante, D., Bevilacqua, E. and Serbedzija, G. (2016) 'Impact of Type 1 Diabetes Technology on Family Members/Significant Others of People With Diabetes', *Journal of Diabetes Science and Technology*, 10(4), pp. 824-830.
- Barnard, K. D., Wysocki, T., Allen, J. M., Elleri, D., Thabit, H., Leelarathna, L., Gulati, A., Nodale, M., Dunger, D. B. and Tinati, T. (2014) 'Closing the loop overnight at home setting: psychosocial impact for adolescents with type 1 diabetes and their parents', *BMJ open diabetes research & care*, 2(1), pp. e000025.

- Bereiter, C. and Scardamalia, M. (2014) 'Knowledge building and knowledge creation: One concept, two hills to climb', *Knowledge creation in education*: Springer, pp. 35-52.
- Bevans, M. and Sternberg, E. M. (2012) 'Caregiving burden, stress, and health effects among family caregivers of adult cancer patients', *JAMA*, 307(4), pp. 398-403.
- Bevier, W. C., Fuller, S. M., Fuller, R. P., Rubin, R. R., Dassau, E., Doyle, F. J., Jovanovič, L. and Zisser, H. C. (2014) 'Artificial pancreas (AP) clinical trial participants' acceptance of future AP technology', *Diabetes Technol Ther*, 16(9), pp. 590-5.
- Biernacki, P. and Waldorf, D. (1981) 'Snowball Sampling: Problems and Techniques of Chain Referral Sampling', *Sociological Methods & Research*, 10(2), pp. 141-163.
- Binek, A., Rembierz-Knoll, A., Polańska, J. and Jarosz-Chobot, P. (2016) 'Reasons for the discontinuation of therapy of personal insulin pump in children with type 1 diabetes', *Pediatr Endocrinol Diabetes Metab*, 21(2), pp. 65-9
- Bin-Abbas, B. S., Sakati, N. A., Raef, H. and Al-Ashwal, A. A. (2005) 'Continuous subcutaneous insulin infusion in type 1 diabetic Saudi children. A comparison with conventional insulin therapy', *Saudi Med J*, 26(6), pp. 918-22.
- Blackman, S. M., Raghinaru, D., Adi, S., Simmons, J. H., Ebner-Lyon, L., Chase, H. P., Tamborlane, W. V., Schatz, D. A., Block, J. M. and Litton, J. C. (2014) 'Insulin pump use in young children in the T1D Exchange clinic registry is associated with lower hemoglobin A1c levels than injection therapy', *Pediatric diabetes*, 15(8), pp. 564-572.
- Bode, B. W., Sabbah, H. T., Gross, T. M., Fredrickson, L. P. and Davidson, P. C. (2002a) 'Diabetes management in the new millennium using insulin pump therapy', *Diabetes Metab Res Rev*, 18 Suppl 1, pp. S14-20.
- Bode, B. W., Tamborlane, W. V. and Davidson, P. C. (2002b) 'Insulin pump therapy in the 21st century. Strategies for successful use in adults, adolescents, and children with diabetes', *Postgrad Med*, 111.

- Bolderman, K. (2002) 'Prepping pump patients', *Putting Your Patients on the Pump*. Alexandria, VA: American Diabetes Association, pp. 19-38.
- Bond, G. G., Aiken, L. S. and Somerville, S. C. (1992) 'The health belief model and adolescents with insulin-dependent diabetes mellitus', *Health Psychol*, 11(3), pp. 190-8.
- Borus, J. S. and Laffel, L. (2010) 'Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention', *Curr Opin Pediatr*, 22(4), pp. 405-11.
- Bouchonville, M., Jaghab, J., Duran-Valdez, E., Schrader, R. and Schade, D. (2014) 'The Effectiveness and Risks of Programming an Insulin Pump to Counteract the Dawn Phenomenon in Type 1 Diabetes', *Endocr Pract*, pp. 1-25.
- Bray, G. A. (2012) 'Potential Health Risks From Beverages Containing Fructose Found in Sugar or High-Fructose Corn Syrup', *Diabetes Care*, 36(1), pp. 11-12.
- Bruttomesso, D., Costa, S. and Baritussio, A. (2009) 'Continuous subcutaneous insulin infusion (CSII) 30 years later: still the best option for insulin therapy', *Diabetes Metab Res Rev*, 25(2), pp. 99-111.
- Bächle, C., Icks, A., Straßburger, K., Flechtner-Mors, M., Hungele, A., Beyer, P., Placzek, K., Hermann, U., Schumacher, A., Freff, M., Stahl-Pehe, A., Holl, R. W., Rosenbauer, J. and Mellitus, D. I. a. t. G. B. C. N. D. (2013) 'Direct diabetes-related costs in young patients with early-onset, long-lasting type 1 diabetes', *PLoS One*, 8(8), pp. e70567.
- Błazik, M. and Pańkowska, E. (2012) 'The effect of bolus and food calculator Diabetics on glucose variability in children with type 1 diabetes treated with insulin pump: the results of RCT', *Pediatric diabetes*, 13(7), pp. 534-539.
- Cade, W. T. (2008) 'Diabetes-Related Microvascular and Macrovascular Diseases in the Physical Therapy Setting', *Physical Therapy*, 88(11), pp. 1322-1335.
- Carter, L. B. (2014) *Parent Satisfaction with Diabetes Technology in Children with Type 1 Diabetes Mellitus*. The University of Mississippi.

- Cerkoney, K. A. and Hart, L. K. (1980) 'The relationship between the health belief model and compliance of persons with diabetes mellitus', *Diabetes Care*, 3(5), pp. 594-8.
- Chamberlain, J. J. and Gilgen, E. (2015) 'Do perceptions of insulin pump usability impact attitudes toward insulin pump therapy? A pilot study of individuals with type 1 and insulin-treated type 2 diabetes', *J Diabetes Sci Technol*, 9(1), pp. 105-10.
- Chan, M., Estève, D., Fourniols, J.-Y., Escriba, C. and Campo, E. (2012) 'Smart wearable systems: Current status and future challenges', *Artificial Intelligence in Medicine*, 56(3), pp. 137-156.
- Chase, J. M. (2010) 'Stochastic community assembly causes higher biodiversity in more productive environments', *science*, 328(5984), pp. 1388-1391.
- Chiauzzi, E., Rodarte, C. and DasMahapatra, P. (2015) 'Patient-centered activity monitoring in the self-management of chronic health conditions', *BMC Medicine*, 13, pp. 77.
- Chuah, S. H.-W., Rauschnabel, P. A., Krey, N., Nguyen, B., Ramayah, T. and Lade, S. (2016) 'Wearable technologies: The role of usefulness and visibility in smartwatch adoption', *Computers in Human Behavior*, 65, pp. 276-284.
- Cogen, F. R., Streisand, R. and Sarin, S. (2002) 'Selecting Children and Adolescents for Insulin Pump Therapy: Medical and Behavioral Considerations', *Diabetes Spectrum*, 15(2), pp. 72-75.
- Cohen, K., Finney, S., Gibbard, P. and Fan, J.-X. (2013) 'The ICS international chronostratigraphic chart', *Episodes*, 36(3), pp. 199-204.
- Comeaux, S. J. and Jaser, S. S. (2010a) 'Autonomy and insulin in adolescents with type 1 diabetes', *Pediatric diabetes*, 11(7), pp. 498-504.
- Comeaux, S. J. and Jaser, S. S. (2010b) 'Autonomy and insulin in adolescents with type 1 diabetes', *Pediatr Diabetes*, 11(7), pp. 498-504.
- Compeau, D. R. and Higgins, C. A. (1995) 'Computer self-efficacy: Development of a measure and initial test', *MIS quarterly*, pp. 189-211.

- Cope, J. U., Samuels-Reid, J. H. and Morrison, A. E. (2012) 'Pediatric use of insulin pump technology: a retrospective study of adverse events in children ages 1-12 years', *J Diabetes Sci Technol*, 6(5), pp. 1053-9.
- Cryer, P. (2012) *Hypoglycemia in diabetes: Pathophysiology, prevalence, and prevention*. American Diabetes Association.
- Cummins, E., Royle, P., Snaith, A., Greene, A., Robertson, L., McIntyre, L. and Waugh, N. (2010) 'Clinical effectiveness and cost-effectiveness of continuous subcutaneous insulin infusion for diabetes: systematic review and economic evaluation', *Health Technol Assess*, 14(11), pp. iii-iv, xi-xvi, 1-181.
- Danne, T., Battelino, T., Jarosz-Chobot, P., Kordonouri, O., Pánkowska, E., Ludvigsson, J., Schober, E., Kaprio, E., Saukkonen, T. and Nicolino, M. (2008) 'Establishing glycaemic control with continuous subcutaneous insulin infusion in children and adolescents with type 1 diabetes: experience of the PedPump Study in 17 countries', *Diabetologia*, 51(9), pp. 1594-1601.
- Darby, W. (2006) 'The experiences of school nurses caring for students receiving continuous subcutaneous insulin infusion therapy', *J Sch Nurs*, 22(6), pp. 336-44.
- Davidson, P., Hebblewhite, H., Steed, R. and Bode, B. (2008) 'Analysis of Guidelines for Basal-Bolus Insulin Dosing: Basal Insulin, Correction Factor, and Carbohydrate-to-Insulin Ratio', *Endocrine Practice*, 14(9), pp. 1095-1101.
- Davis, F. D. (1989) 'Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology', *MIS Quarterly*, 13(3), pp. 319-340.
- de Vries, L., Grushka, Y., Lebenthal, Y., Shalitin, S. and Phillip, M. (2011) 'Factors associated with increased risk of insulin pump discontinuation in pediatric patients with type 1 diabetes', *Pediatr Diabetes*, 12.
- de Zoysa, N., Rogers, H., Stadler, M., Gianfrancesco, C., Beveridge, S., Britneff, E., Choudhary, P., Elliott, J., Heller, S. and Amiel, S. A. (2014) 'A psychoeducational program to restore hypoglycemia awareness: the DAFNE-HART pilot study', *Diabetes Care*, 37(3), pp. 863-866.

- Delgado-Galván, X., Izquierdo, J., Benítez, J. and Pérez-García, R. (2014) 'Joint stakeholder decision-making on the management of the Silao–Romita aquifer using AHP', *Environmental Modelling & Software*, 51, pp. 310-322.
- DeVries, J. H., Snoek, F. J., Kostense, P. J., Masurel, N. and Heine, R. J. (2002) 'A Randomized Trial of Continuous Subcutaneous Insulin Infusion and Intensive Injection Therapy in Type 1 Diabetes for Patients With Long-Standing Poor Glycemic Control', *Diabetes Care*, 25(11), pp. 2074-2080.
- Donovan, J. L. (1995) 'Patient decision making. The missing ingredient in compliance research', *Int J Technol Assess Health Care*, 11(3), pp. 443-55.
- Duffy, O. (2015) *An exploration of parents' views of managing their children's type one diabetes using the insulin pump*. University of Glasgow.
- Elzubier, A. G. (2002) 'Doctor-patient communication: a skill needed in saudi arabia', *J Family Community Med*, 9(1), pp. 51-6.
- Faulkner, M. S. and Clark, F. S. (1998) 'Quality of life for parents of children and adolescents with type 1 diabetes', *Diabetes Educ*, 24(6), pp. 721-7.
- Ford, J. D. and Ford, L. W. (1994) 'Logics of Identity, Contradiction, and Attraction in Change', *The Academy of Management Review*, 19(4), pp. 756-785.
- Foucault, M. (1980) *Power/knowledge: Selected interviews and other writings, 1972-1977*. Pantheon.
- Foucault, M. (1988) 'Technologies of the self: A seminar with Michel Foucault (LH Martin, H. Gutman, & PH Hutton, Eds.)', *London: Tavistock*.
- Franklin, V. (2016) 'Influences on Technology Use and Efficacy in Type 1 Diabetes', *J Diabetes Sci Technol*.
- Fuenfschilling, L. and Truffer, B. (2014) 'The structuration of socio-technical regimes—Conceptual foundations from institutional theory', *Research Policy*, 43(4), pp. 772-791.
- Gao, Y., Li, H. and Luo, Y. (2015) 'An empirical study of wearable technology acceptance in healthcare', *Industrial Management & Data Systems*, 115(9), pp. 1704-1723.

- Garvey, W. T., Olefsky, J. M., Griffin, J., Hamman, R. F. and Kolterman, O. G. (1985) 'The effect of insulin treatment on insulin secretion and insulin action in type II diabetes mellitus', *Diabetes*, 34(3), pp. 222-34.
- Georgas, J. (2003) 'Family: Variations and changes across cultures', *Online readings in psychology and culture*, 6(3), pp. 3.
- Giani, E., Scaramuzza, A. E. and Zuccotti, G. V. (2015) 'Impact of new technologies on diabetes care', *World Journal of Diabetes*, 6(8), pp. 999-1004.
- Godoe, P. and Johansen, T. (2012) 'Understanding adoption of new technologies: Technology readiness and technology acceptance as an integrated concept', *Journal of European Psychology Students*, 3(1).
- Golden, S. H. and Sapir, T. (2012) 'Methods for insulin delivery and glucose monitoring in diabetes: summary of a comparative effectiveness review', *J Manag Care Pharm*, 18(6 Suppl), pp. S1-17.
- Gonder-Frederick, L., Shepard, J. and Peterson, N. (2011) 'Closed-Loop Glucose Control: Psychological and Behavioral Considerations', *Journal of Diabetes Science and Technology*, 5(6), pp. 1387-1395.
- Grunberger, G., Abelseth, J. M., Bailey, T. S., Bode, B. W., Handelsman, Y., Hellman, R., Jovanovič, L., Lane, W. S., Raskin, P., Tamborlane, W. V. and Rothermel, C. (2014) 'Consensus statement by the american association of clinical endocrinologists/american college of endocrinology insulin pump management task force', *Endocr Pract*, 20(5), pp. 463-89.
- Gummesson, E. (1991) 'Marketing-orientation revisited: the crucial role of the part-time marketer', *European journal of Marketing*, 25(2), pp. 60-75.
- Güemes, M., Rahman, S. A. and Hussain, K. (2016) 'What is a normal blood glucose?', *Arch Dis Child*, 101(6), pp. 569-74.
- Hains, A. A., Berlin, K. S., Hobart Davies, W., Smothers, M. K., Sato, A. F. and Alemzadeh, R. (2007) 'Attributions of Adolescents with Type 1 Diabetes Related

- to Performing Diabetes Care around Friends and Peers: The Moderating Role of Friend Support', *Journal of Pediatric Psychology*, 32(5), pp. 561-570.
- Hamburg, B. (1998) 'Psychosocial development', *Comprehensive adolescent health care*, 2, pp. 38-49.
- Hanas, R. and Adolfsson, P. (2006) 'Insulin pumps in pediatric routine care improve long-term metabolic control without increasing the risk of hypoglycemia', *Pediatr Diabetes*, 7(1), pp. 25-31.
- Heinemann, L., Fleming, G. A., Petrie, J. R., Holl, R. W., Bergenstal, R. M. and Peters, A. L. (2015) 'Insulin Pump Risks and Benefits: A Clinical Appraisal of Pump Safety Standards, Adverse Event Reporting, and Research Needs', *Diabetes Care*, 38(4), pp. 716-722.
- Heinemann, L. and Krinelke, L. (2012) 'Insulin infusion set: the Achilles heel of continuous subcutaneous insulin infusion', *Journal of diabetes science and technology*, 6(4), pp. 954-964.
- Helterbran, V. R. and Strahler, B. R. (2013) 'Children as Global Citizens: A Socratic Approach to Teaching Character', *Childhood Education*, 89(5), pp. 310-314.
- Hilliard, M. E., Holmes, C. S., Chen, R., Maher, K., Robinson, E. and Streisand, R. (2013) 'Disentangling the roles of parental monitoring and family conflict in adolescents' management of type 1 diabetes', *Health Psychol*, 32(4), pp. 388-96.
- Hilliard, M. E., Powell, P. W. and Anderson, B. J. (2016) 'Evidence-based behavioral interventions to promote diabetes management in children, adolescents, and families', *American Psychologist*, 71(7), pp. 590.
- Hirose, M., Beverly, E. A. and Weinger, K. (2012a) 'Quality of life and technology: impact on children and families with diabetes', *Curr Diab Rep*, 12(6), pp. 711-20.
- Hirose, M., Beverly, E. A. and Weinger, K. (2012b) 'Quality of Life and Technology: Impact on Children and Families with Diabetes', *Current diabetes reports*, 12(6), pp. 711-720.

- Hofer, S. E., Heidtmann, B., Raile, K., Frohlich-Reiterer, E., Lilienthal, E. and Berghaeuser, M. A. (2010a) 'Discontinuation of insulin pump treatment in children, adolescents, and young adults. A multicenter analysis based on the DPV database in Germany and Austria', *Pediatr Diabetes*, 11.
- Hofer, S. E., Heidtmann, B., Raile, K., Fröhlich-Reiterer, E., Lilienthal, E., Berghaeuser, M. A., Holl, R. W. and for the, D. P. V. S.-I. a. t. G. w. g. f. i. p. t. i. p. p. (2010b) 'Discontinuation of insulin pump treatment in children, adolescents, and young adults. A multicenter analysis based on the DPV database in Germany and Austria', *Pediatric Diabetes*, 11(2), pp. 116-121.
- Holterhus, P. M., Odendahl, R., Oesingmann, S., Lepler, R., Wagner, V., Hiort, O., Holl, R., Initiative, G. A. D. and Group, G. P. C. W. (2007) 'Classification of distinct baseline insulin infusion patterns in children and adolescents with type 1 diabetes on continuous subcutaneous insulin infusion therapy', *Diabetes Care*, 30(3), pp. 568-73.
- Hood, K. K., Butler, D. A., Volkening, L. K., Anderson, B. J. and Laffel, L. M. (2004) 'The Blood Glucose Monitoring Communication questionnaire: an instrument to measure affect specific to blood glucose monitoring', *Diabetes Care*, 27(11), pp. 2610-5.
- Hoogma, R. P. L. M., Hammond, P. J., Gomis, R., Kerr, D., Bruttomesso, D., Bouter, K. P., Wiefels, K. J., De La Calle, H., Schweitzer, D. H., Pfohl, M., Torlone, E., Krinelke, L. G., Bolli, G. B. and on behalf of the 5-Nations Study, G. (2006) 'Comparison of the effects of continuous subcutaneous insulin infusion (CSII) and NPH-based multiple daily insulin injections (MDI) on glycaemic control and quality of life: results of the 5-nations trial', *Diabetic Medicine*, 23(2), pp. 141-147.
- Hultin, L. and Mähring, M. (2014) 'Visualizing institutional logics in sociomaterial practices', *Information and Organization*, 24(3), pp. 129-155.

- Jarcho, J. M., Berkman, E. T. and Lieberman, M. D. (2011) 'The neural basis of rationalization: cognitive dissonance reduction during decision-making', *Soc Cogn Affect Neurosci*, 6(4), pp. 460-7.
- Johnson-Laird, P. N. (1983) *Mental models: Towards a cognitive science of language, inference, and consciousness*. Harvard University Press.
- Jones, N. A., Ross, H., Lynam, T. and Perez, P. (2014) 'Eliciting Mental Models: a Comparison of Interview Procedures in the Context of Natural Resource Management', *Ecology and Society*, 19(1).
- Kamble, P., Kawtikwar, P., Sakarkar, D., Ghuge, G., Gaikwad, D. and Hattiambire, K. (2013) 'INSULIN PUMP: AN OVERVIEW', *Indo American Journal of Pharmaceutical Research*, 3(4), pp. 3065-3079.
- Khan, A. R., Al-Abdul Lateef, Z. N., Al Aithan, M. A., Bu-Khamseen, M. A., Ibrahim, I. A. and Khan, S. A. (2012) 'Factors contributing to non-compliance among diabetics attending primary health centers in the Al Hasa district of Saudi Arabia', *Journal of Family and Community Medicine*, 19(1), pp. 26-32.
- Kim, K. and Park, Y. (2011) 'Cultural and individual differences in the generalization of theories regarding human thinking', *Behavioral and Brain Sciences*, 34(05), pp. 259-260.
- Kirk, J. and Miller, M. L. (1986) *Reliability and validity in qualitative research*. Sage.
- Klingensmith, G. J., Temple-Trujillo, R. and Johnson, D. (2001) 'Pump Therapy for Children: Weighing the Risks and Benefits: View 1: The Cons of Insulin Pump Therapy in the Young Child', *Diabetes Spectrum*, 14(2), pp. 81-83.
- Kristiansen, M., Obstfelder, A. and Lotherington, A. T. (2015) 'Nurses' sensemaking of contradicting logics: An underexplored aspect of organisational work in nursing homes', *Scandinavian Journal of Management*, 31(3), pp. 330-337.
- Krzymien, J., Rachuta, M., Kozłowska, I., Ladyzynski, P. and Foltynski, P. (2016) 'Treatment of patients with type 1 diabetes – Insulin pumps or multiple injections?', *Biocybernetics and Biomedical Engineering*, 36(1), pp. 1-8.

- Laffel, L. M., Vangsness, L., Connell, A., Goebel-Fabbri, A., Butler, D. and Anderson, B. J. (2003) 'Impact of ambulatory, family-focused teamwork intervention on glycemic control in youth with type 1 diabetes', *J Pediatr*, 142(4), pp. 409-16.
- Lange, K., Swift, P., Pańkowska, E. and Danne, T. (2014) 'Diabetes education in children and adolescents', *Pediatric Diabetes*, 15(S20), pp. 77-85.
- Latour, B. (1987) 'How to follow scientists and engineers through society'. *Science in action* Harvard University press.
- Lawton, J., Kirkham, J., Rankin, D., White, D. A., Elliott, J., Jaap, A., Smithson, W. H., Heller, S. and Group, R. (2016) 'Who gains clinical benefit from using insulin pump therapy? A qualitative study of the perceptions and views of health professionals involved in the Relative Effectiveness of Pumps over MDI and Structured Education (REPOSE) trial', *Diabet Med*, 33(2), pp. 243-51.
- Lee, J. M., Sundaram, V., Sanders, L., Chamberlain, L. and Wise, P. (2015) 'Health Care Utilization and Costs of Publicly-Insured Children with Diabetes in California', *J Pediatr*, 167(2), pp. 449-54.e6.
- Leonardi, P. M. (2009) 'Why Do People Reject New Technologies and Stymie Organizational Changes of Which They Are in Favor? Exploring Misalignments between Social Interactions and Materiality', *Human Communication Research*, 35(3), pp. 407-441.
- Leonardi, P. M. (2013) 'Theoretical foundations for the study of sociomateriality', *Information and Organization*, 23(2), pp. 59-76.
- Li, H., Wu, J., Gao, Y. and Shi, Y. (2016) 'Examining individuals' adoption of healthcare wearable devices: An empirical study from privacy calculus perspective', *International Journal of Medical Informatics*, 88, pp. 8-17.
- Liberatore, R., Perlman, K., Buccino, J., Artiles-Sisk, A. and Daneman, D. (2004) 'Continuous subcutaneous insulin infusion pump treatment in children with type 1 diabetes mellitus', *J Pediatr Endocrinol Metab*, 17(2), pp. 223-6.

- Liberman, A., Buckingham, B. and Phillip, M. (2014) 'Diabetes Technology and the Human Factor', *Diabetes Technology & Therapeutics*, 16(Suppl 1), pp. S-110-S-118.
- Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic inquiry*. Sage.
- Low, K. G., Massa, L., Lehman, D. and Olshan, J. S. (2005) 'Insulin pump use in young adolescents with type 1 diabetes: a descriptive study', *Pediatr Diabetes*, 6(1), pp. 22-31.
- Lunney, A., Cunningham, N. R. and Eastin, M. S. (2016) 'Wearable fitness technology: A structural investigation into acceptance and perceived fitness outcomes', *Computers in Human Behavior*, 65, pp. 114-120.
- Maitlis, S. and Christianson, M. (2014) 'Sensemaking in Organizations: Taking Stock and Moving Forward', *The Academy of Management Annals*, 8(1), pp. 57-125.
- Malik, F. S. and Taplin, C. E. (2014) 'Insulin Therapy in Children and Adolescents with Type 1 Diabetes', *Pediatric Drugs*, 16(2), pp. 141-150.
- Marcus, A. O. and Fernandez, M. P. (1996) 'Insulin pump therapy: acceptable alternative to injection therapy', *Postgrad Med*, 99(3), pp. 125-32, 142-4.
- Mathieson, K. (1991) 'Predicting user intentions: comparing the technology acceptance model with the theory of planned behavior', *Information systems research*, 2(3), pp. 173-191.
- McAdams, B. H. and Rizvi, A. A. (2016a) 'An Overview of Insulin Pumps and Glucose Sensors for the Generalist', *Journal of Clinical Medicine*, 5(1), pp. 5.
- McAdams, H. B. and Rizvi, A. A. (2016b) 'An Overview of Insulin Pumps and Glucose Sensors for the Generalist', *Journal of Clinical Medicine*, 5(1).
- Mednick, L., Cogen, F. R. and Streisand, R. (2004) 'Satisfaction and Quality of Life in Children with Type 1 Diabetes and Their Parents Following Transition to Insulin Pump Therapy', *Children's Health Care*, 33(3), pp. 169-183.

- Miller, T. A. and DiMatteo, M. R. (2013) 'Importance of family/social support and impact on adherence to diabetic therapy', *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy*, 6, pp. 421-426.
- Millstein, R., Becerra, N. M. and Shubrook, J. H. (2015) 'Insulin pumps: Beyond basal-bolus', *Cleve Clin J Med*, 82(12), pp. 835-42.
- Mitchell, K., Johnson, K., Cullen, K., Lee, M. M. and Hardy, O. T. (2013) 'Parental mastery of continuous subcutaneous insulin infusion skills and glycemic control in youth with type 1 diabetes', *Diabetes Technol Ther*, 15(7), pp. 591-5.
- Montano, D. E. and Kasprzyk, D. (2015) 'Theory of reasoned action, theory of planned behavior, and the integrated behavioral model', *Health behavior: Theory, research and practice* (
- Morris, D., Schazmann, B., Wu, Y., Coyle, S., Brady, S., Fay, C., Hayes, J., Lau, K. T., Wallace, G. and Diamond, D. (2008) *Wearable technology for bio-chemical analysis of body fluids during exercise*.
- Morrison, G. and Weston, P. (2013) 'The role of continuous subcutaneous insulin infusion in the management of diabetes', *Journal of Diabetes Nursing*, 17(1), pp. 32-37.
- Moser, C., Maurer, K., Binder, E., Meraner, D., Steichen, E., Abt, D., Freund-Unsinn, K. and Hofer, S. E. (2015) 'Needle detachment in a slim and physically active child with insulin pump treatment', *Pediatric Diabetes*, pp. n/a-n/a.
- Mueller, B., Renken, U. and van den Heuvel, G. (2016) 'Get Your Act Together: An Alternative Approach to Understanding the Impact of Technology on Individual and Organizational Behavior', *ACM SIGMIS Database: the DATABASE for Advances in Information Systems*, 47(4), pp. 67-83.
- Müller-Godeffroy, E., Treichel, S. and Wagner, V. (2009) 'Investigation of quality of life and family burden issues during insulin pump therapy in children with Type 1 diabetes mellitus—a large-scale multicentre pilot study1', *Diabetic Medicine*, 26(5), pp. 493-501.

- Neylon, O. M., O'Connell, M. A., Skinner, T. C. and Cameron, F. J. (2013) 'Demographic and personal factors associated with metabolic control and self-care in youth with type 1 diabetes: a systematic review', *Diabetes Metab Res Rev*, 29(4), pp. 257-72.
- Nicholls, A. and Partridge, H. (2015) 'An introduction to insulin pump therapy', *Prescriber*, 26(5), pp. 11-14.
- Nicolucci, A., Maione, A., Franciosi, M., Amoretti, R., Busetto, E., Capani, F., Bruttomesso, D., Di Bartolo, P., Girelli, A. and Leonetti, F. (2008) 'Quality of life and treatment satisfaction in adults with Type 1 diabetes: a comparison between continuous subcutaneous insulin infusion and multiple daily injections', *Diabetic Medicine*, 25(2), pp. 213-220.
- Nishio, I. and Chujo, M. (2015) 'Type 1 Diabetes Patients Using Continuous Subcutaneous Insulin Infusion Therapy: Feeling Burdened Correlated with Factors', *Yonago Acta Medica*, 58(3), pp. 123-128.
- O'Kane, A. A. (2014) 'Using a third-wave HCI approach for researching mobile medical devices', *Toronto, ON, Canada: ACM*.
- Orlikowski, W. J. and Scott, S. V. (2008) '10 sociomateriality: challenging the separation of technology, work and organization', *The academy of management annals*, 2(1), pp. 433-474.
- Pantzar, M. and Ruckenstein, M. (2015) 'The heart of everyday analytics: emotional, material and practical extensions in self-tracking market', *Consumption Markets & Culture*, 18(1), pp. 92-109.
- Pape, T. L.-B., Kim, J. and Weiner, B. (2002) 'The shaping of individual meanings assigned to assistive technology: a review of personal factors', *Disability and rehabilitation*, 24(1-3), pp. 5-20.
- Patton, S. R., Dolan, L. M., Henry, R. and Powers, S. W. (2007) 'Parental fear of hypoglycemia: young children treated with continuous subcutaneous insulin infusion', *Pediatr Diabetes*, 8(6), pp. 362-8.

- Pańkowska, E., Błazik, M., Dziechciarz, P., Szypowska, A. and Szajewska, H. (2009) 'Continuous subcutaneous insulin infusion vs. multiple daily injections in children with type 1 diabetes: a systematic review and meta-analysis of randomized control trials', *Pediatr Diabetes*, 10(1), pp. 52-8.
- Phillip, M., Battelino, T., Rodriguez, H., Danne, T., Kaufman, F., Endocrinology, E. S. f. P., Society, L. W. P. E., Diabetes, I. S. f. P. a. A., Association, A. D. and Diabetes, E. A. f. t. S. o. (2007) 'Use of insulin pump therapy in the pediatric age-group: consensus statement from the European Society for Paediatric Endocrinology, the Lawson Wilkins Pediatric Endocrine Society, and the International Society for Pediatric and Adolescent Diabetes, endorsed by the American Diabetes Association and the European Association for the Study of Diabetes', *Diabetes Care*, 30(6), pp. 1653-62.
- Pickup, J., Mattock, M. and Kerry, S. (2002) 'Glycaemic control with continuous subcutaneous insulin infusion compared with intensive insulin injections in patients with type 1 diabetes: meta-analysis of randomised controlled trials', *BMJ*, 324(7339), pp. 705.
- Pickup, J. C. and Sutton, A. J. (2008) 'Severe hypoglycaemia and glycaemic control in Type 1 diabetes: meta-analysis of multiple daily insulin injections compared with continuous subcutaneous insulin infusion', *Diabet Med*, 25(7), pp. 765-74.
- Pickup, J. C., Yemane, N., Brackenridge, A. and Pender, S. (2014) 'Nonmetabolic complications of continuous subcutaneous insulin infusion: a patient survey', *Diabetes Technol Ther*, 16(3), pp. 145-9.
- Plotnick, L. P., Clark, L. M., Brancati, F. L. and Erlinger, T. (2003) 'Safety and effectiveness of insulin pump therapy in children and adolescents with type 1 diabetes', *Diabetes Care*, 26(4), pp. 1142-6.
- Pollack, J., Costello, K. and Sankaran, S. (2013) 'Applying Actor–Network Theory as a sensemaking framework for complex organisational change programs', *International Journal of Project Management*, 31(8), pp. 1118-1128.

- Potti, L. G. and Haines, S. T. (2009) 'Continuous subcutaneous insulin infusion therapy: a primer on insulin pumps', *Pharmacy Today*, 1, pp. 54-71.
- Prout, A. (1996). Actor-network theory, technology and medical sociology: an illustrative analysis of the metered dose inhaler. *Sociology of Health & Illness*, 18(2), 198-219.
- Ramchandani, N. and Heptulla, R. A. (2012) 'New technologies for diabetes: a review of the present and the future', *International Journal of Pediatric Endocrinology*, 2012(1), pp. 1-10.
- Rankin, D., Harden, J., Noyes, K., Waugh, N., Barnard, K. and Lawton, J. (2015) 'Parents' experiences of managing their child's diabetes using an insulin pump: a qualitative study', *Diabetic Medicine*, 32(5), pp. 627-634.
- Ratheau, L., Jeandidier, N., Moreau, F., Sigrist, S. and Pinget, M. (2011) 'How technology has changed diabetes management and what it has failed to achieve', *Diabetes & Metabolism*, 37, Supplement 4, pp. S57-S64.
- Rauschnabel, P. A., Hein, D. W., He, J., Ro, Y. K., Rawashdeh, S. and Krulikowski, B. (2016) 'Fashion or Technology? A Fashnology Perspective on the Perception and Adoption of Augmented Reality Smart Glasses', *i-com*, 15(2), pp. 179-194.
- Reece, S. W. and Williams, C. L. H. (2014) 'Insulin Pump Class: Back to the Basics of Pump Therapy', *Diabetes Spectrum*, 27(2), pp. 135-140.
- Reznik, Y. and Cohen, O. (2013) 'Insulin Pump for Type 2 Diabetes: Use and misuse of continuous subcutaneous insulin infusion in type 2 diabetes', *Diabetes Care*, 36(Suppl 2), pp. S219-S225.
- Ritholz, M. D., Smaldone, A., Lee, J., Castillo, A., Wolpert, H. and Weinger, K. (2007) 'Perceptions of psychosocial factors and the insulin pump', *Diabetes Care*, 30(3), pp. 549-54.
- Rosenstock, I. M., Strecher, V. J. and Becker, M. H. (1988) 'Social learning theory and the Health Belief Model', *Health Educ Q*, 15(2), pp. 175-83.

- Rossmann, G. B. and Rallis, S. F. (2003) *Learning in the field: An introduction to qualitative research*. Sage.
- Rubin, R. R. and Peyrot, M. (2010) 'Patient-reported outcomes and diabetes technology: a systematic review of the literature', *Pediatr Endocrinol Rev*, 7 Suppl 3, pp. 405-12.
- Saboo, B. D. and Talaviya, P. A. (2012) 'Continuous subcutaneous insulin infusion: practical issues', *Indian Journal of Endocrinology and Metabolism*, 16(Suppl 2), pp. S259-S262.
- Sandelowski, M. (2000) 'Focus on research methods-whatever happened to qualitative description?', *Research in nursing and health*, 23(4), pp. 334-340.
- Schade, D. S. and Valentine, V. (2002) 'To Pump or Not to Pump', *Diabetes Care*, 25(11), pp. 2100-2102.
- Schaepelynck, P., Darmon, P., Molines, L., Jannot-Lamotte, M., Treglia, C. and Raccach, D. (2011) 'Advances in pump technology: insulin patch pumps, combined pumps and glucose sensors, and implanted pumps', *Diabetes & metabolism*, 37, pp. S85-S93.
- Scheiner, G., Sobel, R. J., Smith, D. E., Pick, A. J., Kruger, D., King, J. and Green, K. (2009) 'Insulin pump therapy: guidelines for successful outcomes', *Diabetes Educ*, 35 Suppl 2, pp. 29S-41S; quiz 28S, 42S-43S.
- Scott, W. R. (2013) *Institutions and organizations: Ideas, interests, and identities*. Sage Publications.
- Seereiner, S., Neeser, K., Weber, C., Schreiber, K., Habacher, W., Rakovac, I., Beck, P., Schmidt, L. and Pieber, T. R. (2010) 'Attitudes towards insulin pump therapy among adolescents and young people', *Diabetes Technol Ther*, 12(1), pp. 89-94.
- Seiffge-Krenke, I. (1998) 'Chronic disease and perceived developmental progression in adolescence', *Dev Psychol*, 34(5), pp. 1073-84.

- Seo, M.-G. and Creed, W. D. (2002) 'Institutional contradictions, praxis, and institutional change: A dialectical perspective', *Academy of management review*, 27(2), pp. 222-247.
- Shah, R. B., Patel, M., Maahs, D. M. and Shah, V. N. (2016) 'Insulin delivery methods: Past, present and future', *International Journal of Pharmaceutical Investigation*, 6(1), pp. 1-9.
- Shalitin, S., Gil, M., Nimri, R., de Vries, L., Gavan, M. Y. and Phillip, M. (2010) 'Predictors of glycaemic control in patients with Type 1 diabetes commencing continuous subcutaneous insulin infusion therapy', *Diabet Med*, 27(3), pp. 339-47.
- Shalitin, S. and Phillip, M. (2008) 'The use of insulin pump therapy in the pediatric age group', *Horm Res*, 70(1), pp. 14-21.
- Shepard, J. A., Gonder-Frederick, L., Vajda, K. and Kovatchev, B. (2012) 'Patient perspectives on personalized glucose advisory systems for type 1 diabetes management', *Diabetes Technol Ther*, 14(10), pp. 858-61.
- Sherr, J. and Tamborlane, W. V. (2008) 'Past, Present, and Future of Insulin Pump Therapy: A Better Shot at Diabetes Control', *The Mount Sinai journal of medicine, New York*, 75(4), pp. 352-361.
- Shinohara, K. and Wobbrock, J. O. 'In the shadow of misperception: assistive technology use and social interactions', *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Vancouver, BC, Canada. 1979044: ACM, 705-714.
- Shorer, M., David, R., Schoenberg-Taz, M., Levavi-Lavi, I., Phillip, M. and Meyerovitch, J. (2011) 'Role of Parenting Style in Achieving Metabolic Control in Adolescents With Type 1 Diabetes', *Diabetes Care*, 34(8), pp. 1735.
- Shulman, R., Miller, F. A., Daneman, D. and Guttmann, A. (2016) 'Valuing technology: A qualitative interview study with physicians about insulin pump therapy for children with type 1 diabetes', *Health Policy*, 120(1), pp. 64-71.

- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., Deeb, L., Grey, M., Anderson, B., Holzmeister, L. A., Clark, N. and Association, A. D. (2005) 'Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association', *Diabetes Care*, 28(1), pp. 186-212.
- Sousa, S., Lamas, D. and Dias, P. (2016) 'Value creation through trust in technological-mediated social participation', *Technology, Innovation and Education*, 2(1), pp. 1-10.
- Steineck, I., Cederholm, J., Eliasson, B., Rawshani, A., Eeg-Olofsson, K., Svensson, A.-M., Zethelius, B., Avdic, T., Landin-Olsson, M., Jendle, J. and Gudbjörnsdóttir, S. (2015) 'Insulin pump therapy, multiple daily injections, and cardiovascular mortality in 18 168 people with type 1 diabetes: observational study', *BMJ*, 350.
- Sulli, N. and Shashaj, B. (2003) 'Continuous subcutaneous insulin infusion in children and adolescents with diabetes mellitus: decreased HbA1c with low risk of hypoglycemia', *J Pediatr Endocrinol Metab*, 16(3), pp. 393-9.
- Sullivan-Bolyai, S., Knafl, K., Tamborlane, W. and Grey, M. (2004) 'Parents' reflections on managing their children's diabetes with insulin pumps', *J Nurs Scholarsh*, 36(4), pp. 316-23.
- Tarnow, L., Groop, P. H., Hadjadj, S., Kazeem, G., Cambien, F., Marre, M., Forsblom, C., Parving, H. H., Trégouët, D., Thévard, A., Farrall, M., Gut, I., Gauguier, D., Cox, R., Matsuda, F., Lathrop, M., Vionnet, N. and Consortium, E. (2008) 'European rational approach for the genetics of diabetic complications--EURAGEDIC: patient populations and strategy', *Nephrol Dial Transplant*, 23(1), pp. 161-8.
- Taylor, M. J., Gregory, R., Mitchell, H., Alblihed, M., Alsabih, A., Tomlins, P. and Sahota, T. S. (2014) 'Insulin pump users would not rule out using an implantable artificial pancreas', *Practical Diabetes*, 31(1), pp. 18-23a.

- Telo, G. H., Volkening, L. K., Butler, D. A. and Laffel, L. M. (2015) 'Salient characteristics of youth with type 1 diabetes initiating continuous glucose monitoring', *Diabetes technology & therapeutics*, 17(6), pp. 373-378.
- Thompson, R. L., Higgins, C. A. and Howell, J. M. (1991) 'Personal computing: toward a conceptual model of utilization', *MIS quarterly*, pp. 125-143.
- Thong, J. Y. L., Hong, S.-J. and Tam, K. Y. (2006) 'The effects of post-adoption beliefs on the expectation-confirmation model for information technology continuance', *International Journal of Human-Computer Studies*, 64(9), pp. 799-810.
- Thornton, P. H. (2015) 'Culture and Institutional Logics A2 - Wright, James D', *International Encyclopedia of the Social & Behavioral Sciences (Second Edition)*. Oxford: Elsevier, pp. 550-556.
- Thornton, P. H., Ocasio, W. and Lounsbury, M. (2012) *The institutional logics perspective: A new approach to culture, structure, and process*. Oxford University Press on Demand.
- Tumminia, A., Crimi, S., Sciacca, L., Buscema, M., Frittitta, L., Squatrito, S., ... & Tomaselli, L. (2015). Efficacy of real-time continuous glucose monitoring on glycaemic control and glucose variability in type 1 diabetic patients treated with either insulin pumps or multiple insulin injection therapy: a randomized controlled crossover trial. *Diabetes/metabolism research and reviews*, 31(1), pp. 61-68
- Turhan, G. (2013) 'An assessment towards the acceptance of wearable technology to consumers in Turkey: the application to smart bra and t-shirt products', *The Journal of The Textile Institute*, 104(4), pp. 375-395.
- van Bon, A. C., Brouwer, T. B., von Basum, G., Hoekstra, J. B. and DeVries, J. H. (2011) 'Future acceptance of an artificial pancreas in adults with type 1 diabetes', *Diabetes technology & therapeutics*, 13(7), pp. 731-736.
- van Bon, A. C., Kohinor, M. J. E., Hoekstra, J. B. L., von Basum, G. and DeVries, J. H. (2010) 'Patients' Perception and Future Acceptance of an Artificial Pancreas', *Journal of Diabetes Science and Technology*, 4(3), pp. 596-602.

- Van Parijs, P., Boudon, R. and Elster, J. 1982. Perverse Effects and Social Contradictions: Analytical Vindication of Dialectics? : JSTOR.
- Venkatesh, V. (2000) 'Determinants of perceived ease of use: Integrating control, intrinsic motivation, and emotion into the technology acceptance model', *Information systems research*, 11(4), pp. 342-365.
- Venkatesh, V. and Davis, F. D. (2000) 'A theoretical extension of the technology acceptance model: Four longitudinal field studies', *Management science*, 46(2), pp. 186-204.
- Venkatesh, V., Morris, M. G., Davis, G. B. and Davis, F. D. (2003) 'User acceptance of information technology: Toward a unified view', *MIS quarterly*, pp. 425-478.
- Venkatesh, V., Thong, J. Y. and Xu, X. (2012) 'Consumer acceptance and use of information technology: extending the unified theory of acceptance and use of technology', *MIS quarterly*, 36(1), pp. 157-178.
- Wackerbarth, S. B., Tarasenko, Y. N., Joyce, J. M. and Haist, S. A. (2007) 'Physician colorectal cancer screening recommendations: an examination based on informed decision making', *Patient Educ Couns*, 66(1), pp. 43-50.
- Walsh, J. and Roberts, R. (2006) 'Pumping insulin', *Everything you need for success on a smart insulin pump, 4th edition. Torrey Pines, San Diego, USA.*
- Wandel, T. (2001) 'The power of discourse: Michel Foucault and critical theory', *Cultural Values*, 5(3), pp. 368-382.
- Webb, H. J. and Zimmer-Gembeck, M. J. (2014) 'The Role of Friends and Peers in Adolescent Body Dissatisfaction: A Review and Critique of 15 Years of Research', *Journal of Research on Adolescence*, 24(4), pp. 564-590.
- Weber, K. and Glynn, M. A. (2006) 'Making sense with institutions: Context, thought and action in Karl Weick's theory', *Organization Studies*, 27(11), pp. 1639-1660.
- Weintrob, N., Benzaquen, H., Galatzer, A., Shalitin, S., Lazar, L., Fayman, G., Lilos, P., Dickerman, Z. and Phillip, M. (2003) 'Comparison of continuous subcutaneous

- insulin infusion and multiple daily injection regimens in children with type 1 diabetes: a randomized open crossover trial', *Pediatrics*, 112(3 Pt 1), pp. 559-64.
- Weinzimer, S. A., Ahern, J. H., Doyle, E. A., Vincent, M. R., Dziura, J., Steffen, A. T. and Tamborlane, W. V. (2004) 'Persistence of benefits of continuous subcutaneous insulin infusion in very young children with type 1 diabetes: a follow-up report', *Pediatrics*, 114(6), pp. 1601-5.
- White, D., Waugh, N., Elliott, J., Lawton, J., Barnard, K., Campbell, M. J., Dixon, S., Heller, S. and group, R. (2014) 'The Relative Effectiveness of Pumps Over MDI and Structured Education (REPOSE): study protocol for a cluster randomised controlled trial', *BMJ Open*, 4(9), pp. e006204.
- White, H. C. (1992) *Identity and control: A structural theory of social action*. Princeton University Press.
- Winkelman, W. J., Leonard, K. J. and Rossos, P. G. (2005) 'Patient-Perceived Usefulness of Online Electronic Medical Records: Employing Grounded Theory in the Development of Information and Communication Technologies for Use by Patients Living with Chronic Illness', *Journal of the American Medical Informatics Association : JAMIA*, 12(3), pp. 306-314.
- Witman, Y., Smid, G. A., Meurs, P. L. and Willems, D. L. (2011) 'Doctor in the lead: balancing between two worlds', *Organization*, 18(4), pp. 477-495.
- Wolfsdorf, J., Glaser, N., Sperling, M. A. and Association, A. D. (2006) 'Diabetic ketoacidosis in infants, children, and adolescents: A consensus statement from the American Diabetes Association', *Diabetes Care*, 29(5), pp. 1150-9.
- Wu, Y. P., Rausch, J., Rohan, J. M., Hood, K. K., Pendley, J. S., Delamater, A. and Drotar, D. (2014) 'Autonomy support and responsibility-sharing predict blood glucose monitoring frequency among youth with diabetes', *Health Psychol*, 33(10), pp. 1224-31.
- Şener, S., Saridoğan, E., Staub, S., Nasir, S. and Yurder, Y. (2015) 'World Conference on Technology, Innovation and Entrepreneurship Consumers' and Physicians'

0 References

Perceptions about High Tech Wearable Health Products', *Procedia - Social and Behavioral Sciences*, 195, pp. 1261-1267.

Appendix

Appendix A

Interview Consent Letter

My name is Abeer Almakky, I am a PhD student from Software Engineering department in De Montfort University in United Kingdom. I am researching on the IP adoption by diabetic children and young adults. I am particularly interested in these main areas:

(1) Under what circumstances pumps are being suggested and recommended to particular patient and who are the perfect candidate to use insulin pump. (2) Under what circumstances that the introduction of these pumps are successful, how do you decide. (3) How do you encourage reluctant patient irresponsible patient (4) Under what circumstances are pump sometimes being abandoned?

This research will add to the body of knowledge about the need to build on the existing knowledge of patient interaction with medical devices.

Your participation is voluntary. You do not have to answer any questions you do not want to answer. If at any time you do not want to continue with the interview, you may decline. Your time and involvement is profoundly appreciated. The entire interview will take approximately 30 minute to 40 minute. To maintain the essence of your words for the research, I will record the information. At any time you may request to see or hear the information I collect. This is done for data analysis. The recording will be transcribed and kept confidential. All individual identification will be removed from the hard copy of the transcript, and Quotations will be kept anonymous. Data will be disposed after the completion.

However, under no circumstances will your name or identifying characteristics appear in writings. If, at a subsequent date, biographical data were relevant to a publication, a separate release form would be sent to you.

I would be grateful if you would sign this form on the line provided below to show that you have read and agree with the contents.

Signature

Date

Appendix B Codes used for the interviews with the Change agent

Code	Position	Years of Experience
D.H	Physician endocrinologist	2010-present
DP.Ab	Consultant paediatric endocrinologist	2002- present
D.M	Consultant physician endocrinologist	2013- present
DP.B	Paediatric endocrinologist	2009 -present
DP. A	Consultant Paediatric endocrinologist	2004- present
DP.M	Consultant Paediatric Endocrinologist	2001-present
DP.N	Consultant Paediatric endocrinologist	2013-present
DP.Ad	Consultant Peadiatric endocrinologist	1999-present
E.E	Insulin pump educator Supervisor	2011-present
E.H	Insulin pump educator	2013-present
E.A	Insulin pump educator	2014-present
E.M	Insulin pump educator	2012-present
ES.E	Diabetic Educator supervisor	2013- present
EP.As	Insulin pump educator Supervisor	2013-present

Appendix C Observing the patient on using the IP

