

# A Study on Patient's Decision-Making Process in Deciding Treatment Strategies: An Illustration of Using Grounded Theory Approach

LOW LEE LAN<sup>1\*</sup>, TONG SENG FAH<sup>2</sup>, LOW WAH YUN<sup>3</sup>

<sup>1</sup>Institute for Health Systems Research, Ministry of Health Malaysia.

<sup>2</sup>Department of Family Medicine, Universiti Kebangsaan Malaysia

<sup>3</sup>Faculty of Medicine, University of Malaya

\*Correspondence: [low.ll@moh.gov.my](mailto:low.ll@moh.gov.my)

## ABSTRACT

The learning curve for doing a good qualitative study is steep because qualitative methodologies are often vague and lack explicit steps. We detail the formulation of the grounded theory approach in a study of patients with type 2 diabetes mellitus who made decisions while strategizing their treatment types. This undertaking is to demonstrate how this systematic and yet flexible methods contributed to the understanding of the issue we were investigating. The process from deciding on research objectives and research questions, follow with systematic process for data collection and analysis allows us to generate a substantive theoretical model. By paying critical attention to theoretical saturation, grounded theory approach enabled us to construct all possible explanatory concepts related to decision making in strategizing diabetes treatment. We also describe the challenges throughout the whole research journey, including getting permission to interview patients, gaining the trust of research participants and staying open to the participants' views.

### Key words:

Grounded theory, constructive, challenges, lessons learned, diabetes, theoretical model, Malaysia

## BACKGROUND

Novice researchers often find adopting qualitative studies challenging. This is because qualitative methodologies are often vague and lack explicit steps. Guides for doing qualitative studies are often abstract. A good qualitative study requires researchers to consider the underpinning theoretical perspective and lens (Crotty, 1998), which can aggravate the steepness of the learning curve. The adoption of any specific theoretical perspective is often left to the researcher. Among novice researchers, this can be a difficult decision because theoretical perspectives are often closely linked to the researchers' philosophical stance and worldviews (Carter, Ritchie, & Sainsbury, 2009; Crotty, 1998). These require self-reflection, yet another jargon to many novice researchers. Although researchers may be familiar with research methodologies, the concepts involved in qualitative research, in particular, "convenience" sampling, "coding", identifying "significant" themes and "saturation", are key concepts that are not only difficult to comprehend but also lack explicit steps. Following this are other abstract concepts such as "immerse themselves into the data during analysis" and "saturation" (Patton, 2002). These are very different from the prescriptive nature of the quantitative approach, in which explicit steps are often provided, including how randomisation and selection of cases are done and the choice of statistical tests. Concepts noted in qualitative studies often better understood by undertaking a project in which explicit examples are provided and operationalisation is clearly demonstrated. This also implies that with the right understanding and clear theoretical perspectives, methods in qualitative studies can be better understood with experience before they can be used more flexibly and creatively.

For example, in the initial grounded theory writing, besides arguing for theory building through an inductive approach (Glaser & Strauss, 1967), Strauss and Glaser subsequently focused exactly on how that can be more systematically achieved and more explicitly operationalized (Glaser, 1978; Strauss & Corbin, 1990). Clearer and better systematic descriptions of the thematic analysis also served as another excellent guide for researchers (Braun & Clarke, 2014) after many years of thematic analysis originally used. Nonetheless, these may sometimes be insufficient to make novice researchers comfortable enough to undertake a qualitative study. For them, it is necessary that the concepts in qualitative methodologies be explicitly illustrated. In this paper, we share an example of the utilisation of a grounded theory approach in studying patients with type 2 diabetes mellitus (T2DM) and in how they strategized their treatments while in the Malaysian healthcare system.

## METHOD

We describe the steps involved in the entire study, the challenges faced and the lessons learned through the study. We reflected on our experience of undertaking this study, starting with justifying the grounded theory approach to revising our research objectives and research questions to finally generating a substantive theoretical model. Figure 1 illustrates the process we followed from developing the research questions and getting access to data collection, field work and analyses. This study was approved by the Institutional Review Board at the Institute for Health Systems Research, Ministry of Health Malaysia and the Medical Research and Ethics Committee, Ministry of Health Malaysia (NMRR-12-457-12193). Participants were provided with a full explanation and written information sheet prior to the interviews and focus group discussions. Informed consent and permission to audio record the interview were obtained from all participants.

A few challenges were experienced throughout the whole research journey include getting permission to interview patients from the private primary care clinics, gaining the trust of research participants and staying open to the participants' views. We also learned to examine our thought by "sketching" multiple times throughout the analysis, starting from the very beginning of the coding process until we arrived at the final product of the substantive model. Other useful lessons learned from this experience were self-reflexivity and the constant critique of our initial models.

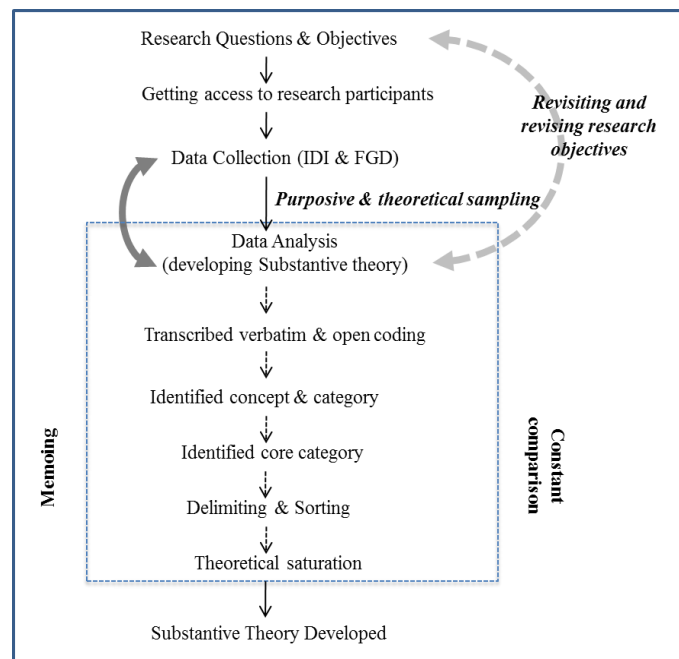


Figure 1: The Grounded Theory Process

---

## Justification for the grounded theory approach

### Study background

Diabetes mellitus is a multifaceted chronic illness. Its life-long treatment requires patients to be continuously engaged with the healthcare system (International Diabetes Federation, 2013; World Health Organization, 2003). Our initial intention in undertaking this project was to understand how patients with T2DM utilise the Malaysian healthcare system in seeking treatment for diabetes. This process was thought to be crucial in helping policy makers design a system that can optimally address the needs of patients with diabetes. Exploring how patients with T2DM utilise the healthcare system and how this affected their reasons to seek specific treatments would require an in-depth understanding of how these patients interact with the healthcare system. We also reckon that this would be a social process undertaken by the patients.

### Deciding on grounded theory approach

In line with the research question and subject matter, we adopted the grounded theory approach to enable us to develop a substantive theory that can use to explain the social process undertaken by the individual patients in the Malaysian healthcare system for their diabetes management.

Studying how patients with T2DM utilising the Malaysian healthcare system can take an objectivist stance on one end to a constructivist stance, on the other end. The objectivist view of knowledge suggests that meaning is independent of the individual mind and that the view of what it means to know and value is objectified by the research participants. As such, measuring the patients' characteristics and relating it with their utilisation of Malaysian healthcare system from a quantitative inquiry approach seems appropriate. The constructivist view, in contrast, assumes that there are multiple realities. Quantifying patients' characteristics including objectifying the meaning attached to any object is not feasible nor necessary as knowledge is constructed by the patients who are engaged with the world, particularly in seeking treatment for their illness. Thus, meaning is created based on their construction of reality, which may be fluid and varied between person and within a person over time. Undoubtedly, researchers are also constantly making active contributions and interpretations of data due to their personal worldviews and research stance. Therefore, meanings are constructed rather than discovered (Crotty, 1998).

We have adopted a constructivist view because it resonates with our understanding of the social world. Thus, the design of our research involves a constructivist view that regards knowledge as being constructed through interactions between researchers, participants and the objects around them. We believe that patients' particular utilisation of treatment is the outcome of the meanings they had constructed based on their interactions with society and the healthcare system.

Two sociologists, Barney G. Glaser and the late Anselm L. Strauss first introduced the grounded theory methodology in the late 1960s. They published their first book, *The Discovery of Grounded Theory*, in 1967 (Glaser & Strauss, 1967). Grounded theory methodology has since ventured into new perspectives and moved from the objectivist grounded theory (by Glaser) to one adapted to constructivism by Charmaz (2006). Charmaz generated a constructivist grounded theory approach that suggests that a grounded theorist should construct the story by researching participants' views, perceptions, beliefs and voices based on their personal experiences. This implies that participants' views and the way they construct their world are important features of their experiences, as does how researchers co-construct with participants the process and meaning of the actions under investigation. Thus, when explore insights into patients with T2DM and how they make meanings from their action, we can construct an in-depth understanding of their decisions in selecting treatment strategies. Hence, we adopted the constructivist grounded theory approach.

Patients with T2DM are actively constructing meanings and knowledge from their interactions with the healthcare system and learning to manoeuvre through the treatment-seeking process. The attempt to study the process of the patients' treatment utilisation would be difficult to achieve through a quantitative method that is based on a

deductive approach and tends to lean on an objectivist stance. Firstly, unlike the inductive approach, a deductive approach requires a hypothesis and *a priori* theory. Using generic theories to generate hypotheses might require

testing too many theories to identify the correct one. Furthermore, designing validated questionnaires to capture and measure the determinants would require the construction of a large set of items to ensure coverage of all possible determinants. This is too impractical.

Secondly, using statistical methods to explore human interactions and relationships as identified in these determinants would seem less efficient when the number of foreseeable variables is large. Increasing statistical procedures used would also increase the chances of random errors. Hence, an inductive, qualitative approach that considers the local context and cultural factors seemed more appropriate. Thirdly, the basis of the quantitative method is to evaluate the magnitude of an issue (Wertz et al., 2011), a problem, a phenomenon or a relationship. The quantitative method is often used to establish a normative pattern (Tong & Low, 2015), in which an inference to a population can be made.

In contrast, the qualitative method takes an individualistic approach such that an explanation about an individual patient's experience is made. The latter is more in line with our research question. The grounded theory process may seem challenging for a novice researcher (Evans, 2013; Virpi Timonen, Geraldine, & Conlon, 2018). However, the process provides a systematic approach to inductively examine the patterns and rationale of their actions (Birks & Mills, 2015). This study explores how patients utilised the treatments offered by the Malaysian healthcare system. Given that focus, the meanings derived from the patients' actions will serve as the underlying essence of this study. Consequently, symbolic interactionism was adopted as the overarching methodological framework so as to guide data analysis. Symbolic interactionism explains how human beings behave in society and how they act on meanings to generate meanings (Charmaz, 2006; Crotty, 1998). Thus, symbolic interactionism is a useful frame to study how patients with T2DM interact with the current healthcare system in search of diabetic treatment.

This approach allows an in-depth understanding on of how patients actively interact with people and seek information related to diabetes when prioritising and deciding on their treatment. Furthermore, this approach is optimal in exploring the meaning of the actions patients take in making certain decisions as well as in creating meaning as a result of the outcomes of their actions.

Apart from enabling a suitable theory based on empirical data (as opposed to merely testing an existing theory) to be developed, grounded theory also is a methodology examining social processes (Charmaz, 2006; Glaser & Strauss, 1967) which provide a rich description that goes beyond experiences and perceptions of any investigative context; theory allows relationships between concepts to be established, to explain how diabetic patients utilised Malaysian healthcare system.

#### Revising research area and objectives

Because of the exploratory nature of qualitative research methodology, the actual issues of the subject, from the participant's perspective, may not be apparent at the initial stage. While starting a study with a research question in mind is important, the research question is tentative. Keeping an open mind of what the actual issue might be is paramount (Charmaz, 2006), that is, the research question might need to be revised as data collection and analysis evolved. Thus, in this study, we allowed the data to inform us whether our research question was indeed relevant. From this process, we noted that the actual issue differed from our original idea of studying "how patients with T2DM utilised the Malaysian healthcare system in getting treatments". We realised that patients with T2DM took a more active role in seeking treatment – they made decision what needed to be done.

*"I follow up with self-monitoring of blood sugar. I went to the pharmacy and paid RM5 to check my blood sugar level to see if it was up or down. Sometimes within a day I have experienced going to the pharmacy twice to have my blood tested – in the morning with fasting, and another time after lunch. This was just for my own satisfaction."*

*-58 year-old, diagnosed with T2DM 7 years ago*

The concept in our original objective, upon reflection, no longer fit their help-seeking behaviours. Consequently, we adopted the concept of patients “strategizing their treatment seeking” instead of patients taking on a passive role within the concept of “utilising”. Thus, we reformulated our research question to become “what is the patient’s decision-making process in deciding treatment strategies?” instead of “how patients utilise healthcare system”. We moved from a broad research question and to a more specific one. We focused on the “process of decision-making” rather than utilisation because the issue was not about utilising healthcare system but patients weighing on many factors against their treatment goal even before utilising what was offered by Malaysian healthcare system. Their process of decision making seemed to be the crucial step.

#### Data collection and analysis process

Charmaz’s (2006) work focused on interviewing patients with chronic illnesses about their illness experience. This enables an in-depth understanding of individual actions and perceptions (Charmaz, 1990). The conversation style of communication enhanced the sharing of information during the IDI and FGD sessions in which information was free flowing, with no right or wrong answers. We noted each individual’s perception and experiences, coupled with his or her decision in strategizing how to seek treatment, was clearly unique since no one individual shared the exact same experience. However, the process of arriving at this decision for each of the patients was surprisingly similar. In this study, we resorted to exploring the participants’ experiences because we found vivid descriptions of their experiences helpful in describing their exact process rather than asking about their decision-making process (how they had come to their actions). We observed that asking the “how” question was not helpful because we were presented with “analysed” responses by the participants.

Two sampling methods were employed for the selection of the participants: purposive and theoretical sampling. Purposive sampling is widely used in qualitative research; it involves the deliberate choice of study participants who fulfil the criteria relevant to research objectives (Creswell, 2007).

Since patients’ treatment options may vary depending on their socio-economic status (Ahmed, Tomson, Petzold, & Kabir, 2005; Mushtaq, Gull, Ahmad Shad, & Akram, 2011), severity of illness (Pourreza et al., 2011; Watson, Bluml, & Skoufalos, 2015), healthcare system and other factors (Chomi, Mujinja, Enemark, Hansen, & Kiwara, 2014; Shaikh & Hatcher, 2004), a desirable balance of patients’ characteristics and different treatment modalities was selected at this initial stage. With the healthcare system in Malaysia functioning as a dual parallel system of public and private sectors, the setting thus is comprised of primary care provided by both public and private facilities. Two public (government) primary healthcare clinics and five private clinics of general practitioners located in two districts were identified. These two districts were purposively selected to cover both urban and rural healthcare facility settings. The two public primary care clinics were chosen based on their geographical locations: one is located in an urban area, while the other is located in a rural area that is home to many people of different socioeconomic backgrounds.

In line with the grounded theory approach, the purpose of the theoretical sampling was to collect data from a specific group of patients to maximise opportunities to develop concepts in terms of their properties and dimension, to uncover variations and to identify relationships between the concepts (Corbin & Strauss, 2008). As the study progressed, more specific criteria were used for sampling. The aim was to target study participants who were able to provide data that can be used to address any gaps in the emerging analytic theory. As the coding evolved, the theoretical direction became more focused and clearer. During the analysis, we noted that people surrounding the patients were a significant source of information and support in helping them choose treatment options and hence their treatment strategy process. These patients’ circles include their family members or people close to them, as one participant stated: *“My wife gave lots of support, including food preparation. She cooked separately, cooked different types of rice... everything is controlled by her”*. In this regard, caregivers and patients’ spouses were thus recruited for subsequent interviews.

Sampling ceased when the sample reached theoretical saturation which occurs when all the categories (themes) were satisfactorily developed in terms of properties, dimensions (refer below for description on properties and dimensions) and variations, and the core category (Corbin & Strauss, 2008). In total, we conducted twenty-six IDIs and three FGDs. This stage of the process was crucial for developing the substantive theory derived from the empirical data. Here, we had to decide based on our discussions, whether the theory generated could explain all the experiences we had collected from the participants and we felt that it would be solid and good enough to explain the subsequent experiences, including those of future data collection. Thus, the theory fits (Glaser, 1978; Elliott & Lazenbat, 2005).

The data collection tool comprised semi-structured interview guides to facilitate the conversations, thereby easing the interview process. The semi-structured questions provide more structure while maintaining flexibility. During the field work, certain questions were revised and improved to clarify certain issues that emerged from previous interviews, which helped us gain more in-depth understanding.

Data analysis began soon after the first interview to gain in-depth understanding and further explore topics in subsequent interviews that generated new data (Liamputtong, 2013). The analysis involved various stages of coding, categorisation, constant comparison, memoing and sketching. Coding started with open coding followed by focused coding; the final stage was focus coding (Charmaz, 2006; Hallberg, 2006). The process started with immersion in the data. The texts were read several times before they were coded. Open coding is one of the processes noted in grounded theory because it uncovers the important information, which is an integral aspect of the grounded theory approach. As noted, symbolic interactionism served as the underpinning theory to guide analysis.

Hence, the focus of the coding was on the patients with T2DM and their created meanings that were associated with their interactions with society and the healthcare system in searching for specific treatments. Open coding is the stage at which data were breaking into distinct units of meaning. This involves line-by-line coding, which a label is given to a significant word, an incident or action, a phrase or a statement. The coding may also span many lines. Table 1 shows examples of the open coding process evidenced and the segments of the data taken from the verbatim conversations.

During the open coding process, a few questions were asked to further explore the meanings: “Why did this particular phenomenon happen?”, “What is actually happening in this statement?”, and “What is the main concern this participant faced and why?” The application of these questions helped us achieve more analytical thoughts and sensitivity to the meanings and concepts. Thus, the process opens-up the underlying meanings of patients’ experiences. The advantage of the open coding process is that it is a careful manner of processing data by identifying, labelling and coding the data word by word, line by line, or incident by incident. The open coding process fulfils two criteria for completing a grounded theory quality check for analysis: “fit” and “relevance” (Charmaz, 2006). The identified categories and themes were further defined, and subsequent verbatim texts were analysed using the initial categories as guides.

In line with the symbolic interactionism approach, which analyses people’s actions and the meanings behind their actions, the action code (gerunds words ending with “-ing”) were used as labels. Table 1 shows the codes with similar concepts that were reviewed and clustered into categories and sub-categories. The next step was focus coding which allows the “core category” that forms the substantive theory to be generated by integrating all other categories and sub-categories. Focus coding is performed when a code is perceived to be analytical during the open coding process. At this stage, the meaning derived from what participants had shared becomes clearer. In this process, we constantly reflected on the patients’ actions and sketched through papers to understand the flow of their decision-making process for treatment.

Table 1: Example of coding process

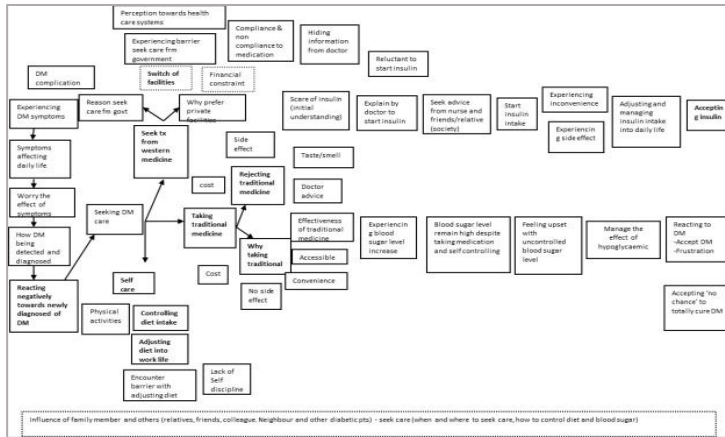
Verbatim (IDI)	Code (open coding, with gerund)	category (focus coding)
<i>When I came to this clinic [public primary care clinic], they [doctors] said your blood sugar levels are high [diagnosed with T2DM].</i>	Attending public clinic	Identifying a trigger for action
	Being diagnosed with diabetes	
<i>Then I followed up by monitoring my blood sugar levels and whenever I reduced sweet food on the whole...sweet food, I went to the pharmacy [private], paid RM5, checked my blood sugar, the levels were up and down ...up and down,</i>	Monitoring blood sugar frequently	Experimenting with self-care
	Reducing consumption of sweet foods	Learning from outcome of experimentation
	Testing blood at the private pharmacy and paying RM5 per test	
<i>When I ate less sweet food, the blood sugar levels reduced.... Okay, I can feel the effect</i>	Realising that blood sugar level decreases once intake of sweet food is reduced	
<i>Not that I like it, but I feel satisfaction if I do it myself, based on my own ability, my knowledge.</i>	Feeling satisfied because of being able to monitor and control blood sugar level	

Figure 2 shows the whole process of analysing the data is an evolving one because unexpected idea and issues regularly emerged while data were being analysed. The most significant and most frequent codes noted in the open coding process were then used tentatively as categories for the focus coding stage. For example, the focus code “triggering for experimentation” was examined throughout the data to see if it had the ability to hold large amount of data. This was how we verified how well the coding fits the meanings that emerged in the data.

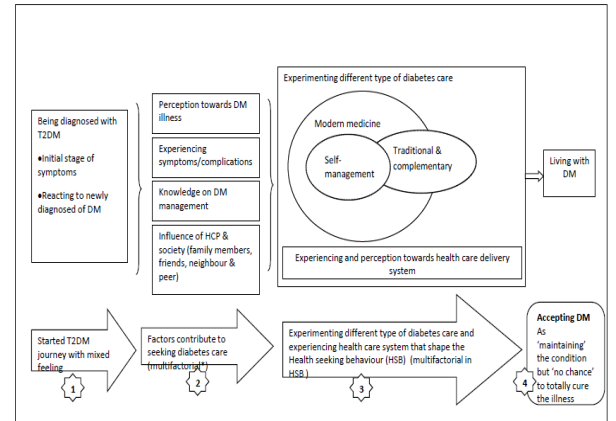
Although open coding did not directly generate some of the focused codes, it helped the analysis to move towards the level of focus coding. Through this process, some of the codes or concepts identified from the initial coding stage were further refined and reworded during the focus coding stage. Simultaneously, certain concepts were omitted when forming the categories because they were not able to carry any significant explanation of the decision-making process. Focus codes were more abstract and they possessed properties with dimensions. To illustrate, in “influence of family members, friends, peers, and healthcare providers”, the category of “Information seeking” Figure 3 has properties of “source” and “perceived treatment characteristics”. Both these properties carried dimensions of “how significant was the source of information and “how important was the perceived treatment characteristics”. Varying significance had an impact or influence that ranged from weak to strong on the patients’ perceived treatment characteristics, that is, the “significance of influence” can be *dimensionalised* as ranging from weak to strong.

During focus coding, the delimitation of data was done by selecting variables related to the core category (Glaser & Holton, 2004). The subsequent interviews, led by theoretical sampling to carefully select the participants, focused heavily on this core category. Although the focus coding process was much easier and more focused than the open coding process, it required the ability to think analytically so as to be able to select the concepts which are relevant to the core category. The whole process was facilitated by constant comparison, memo writings and further comparing the identified categories within the concept of “experimentation” in the patients’ treatment strategy.

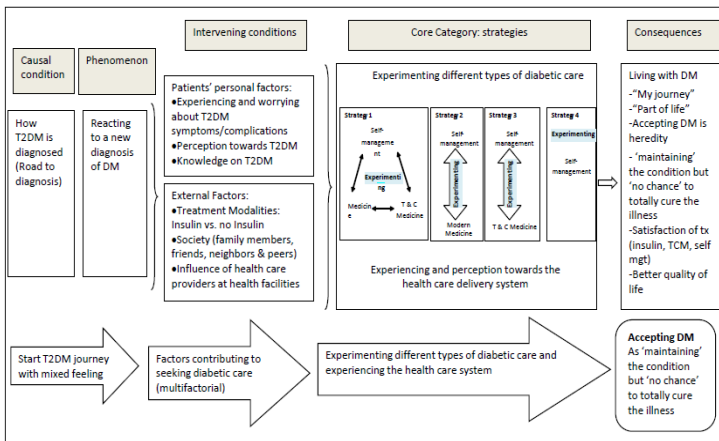
March 2013



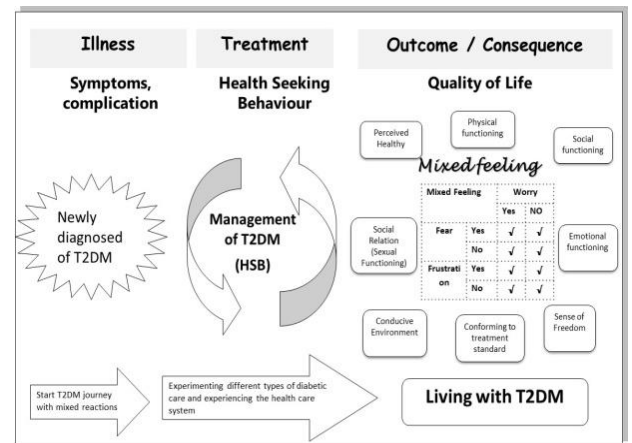
April 2013



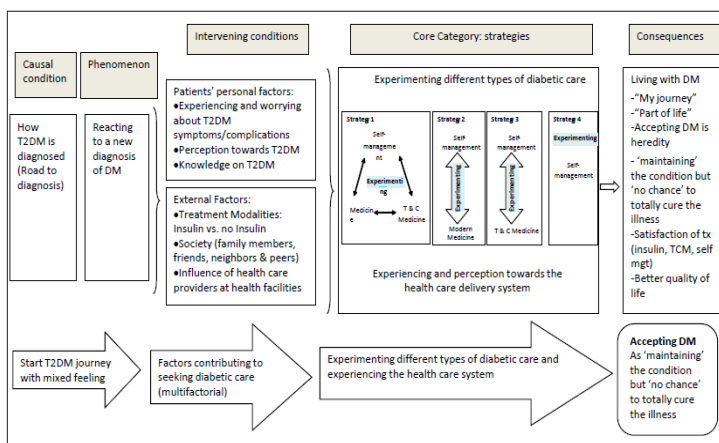
May 2013



September 2013



April 2014



May 2015

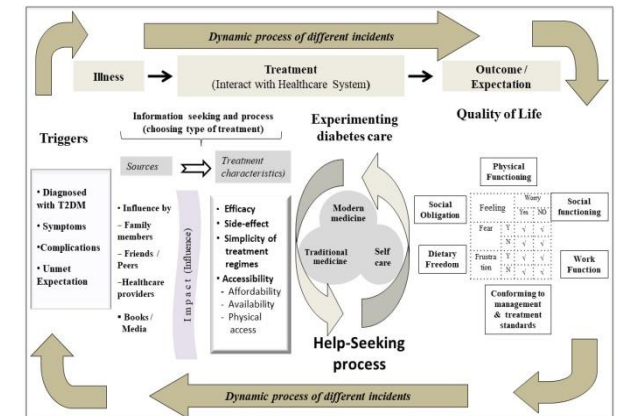


Figure 2: Constructing of substantive theoretical model



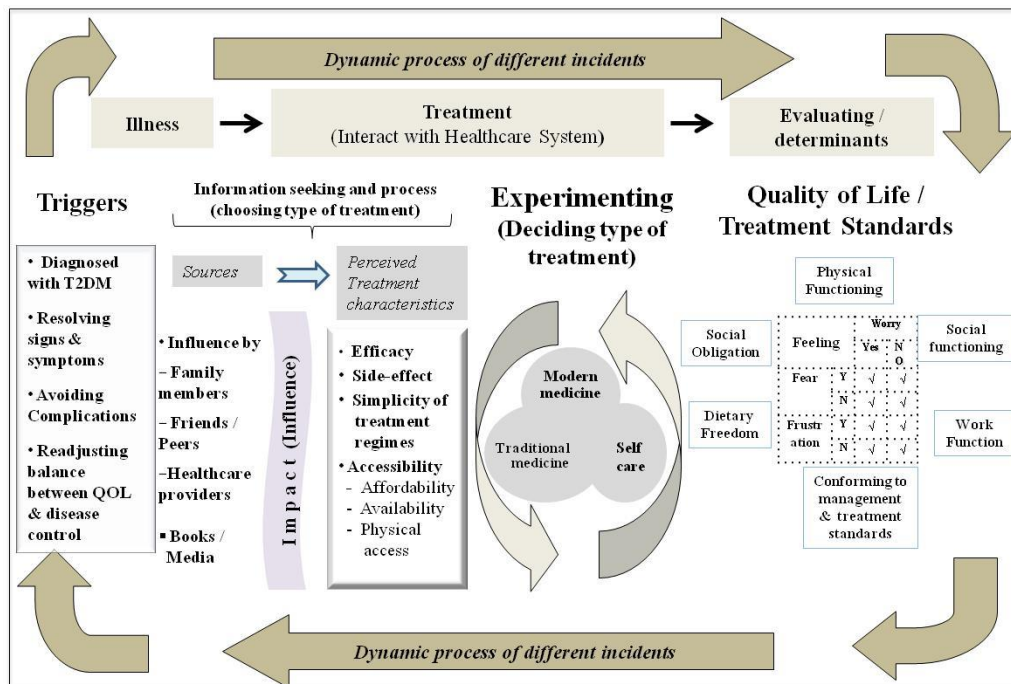


Figure 3: Model for treatment strategy among patients with Type 2 diabetes mellitus in a primary care setting

In this context, the word “experimentation” was chosen as the core category because it was relevant and it fit the emerging theory that explained the entire process. The term “experimenting” was an *in vivo* code, a word used by study participants during interviews to describe their treatment strategy process. As one participant stated, “Yes, I am testing! Actually, I am experimenting, experiment! Yes, to tell you the truth, I am not the clever type but I am experimenting with my own knowledge.” The concept of “experimentation” thus reflects the diversity of actions by the patients as well as their interactions with the people around them when they were searching for information related to diabetes treatment. This concept indicates that both the action and the process were key features of the theory. Experimentation provided an abstract concept that can subsume and link all the other categories that were identified. It linked all other categories explaining how patients with T2DM would decide to engage with different treatment strategies, where modern medicine was one of those. It linked triggers to information seeking, actual testing of chosen treatment and examining the outcome of treatment as illustrated in figure 3.

The constant comparison process was used in generating and refining the codes, themes and categories, followed by the theoretical framework. The codes extracted from the transcripts were constantly compared with the codes within the transcript or within other interview transcripts. Furthermore, transcripts that were coded under a specific code were constantly checked against others to ensure consistency. Subsequently, the categories and sub-categories were compared so as to examine their subsumed under the various categories. The transcripts and earlier data were thus constantly revisited. This included listening to the audio recordings several times so as to study the data anew. Following this, we completed a similar process of comparison of the theoretical codes and the framework with the categories and transcripts. Through this process, differences and similarities were sorted out. This comparison process also was used for the subsequent interviews. The process allowed patterns to emerge from the data. The information gathered was then used to produce a substantive theoretical model.

The analysis process was also facilitated by memoing. Memos were written to record the researchers' thoughts in the moment. The ideas, curiosity and flow that emerged during the analytical interpretation of data were thus captured in the memo through the sketching and sorting processes. Memoing also acted as a reminder during the data collection process and thus formed part of the reflective process that allowed questioning and observing issues during the data collection and analysis stages. Our ideas and curiosities were jotted down as they emerged during the progression from fieldwork to data analysis. Memoing was done concurrently throughout the fieldwork until the analysis stage. The process captured all our ideas and interpretations, particularly when identifying the theoretical codes and categories.

### **Construction of substantive theoretical model**

The final stage of theoretical coding aimed at linking the different codes with a comprehensible meaning and logic. It did not involve merely grouping the categories; instead, it involved connecting the categories and concepts with each other and identifying the properties and dimensions so as to provide understanding as described above. This was accomplished by abstracting the data and moving from concepts towards generating a substantive theory. Throughout the entire process, we refrained from imposing a forced framework; we reminded ourselves

about the objectives of our study. The literature review was also conducted at this stage so as to review the emerging substantive theoretical model with analysis about existing models or theories.

In developing the theory through the grounded theory approach, the systematic process of coding, memoing and constant comparison enabled us to observe the logical links between the categories. The following questions help us reflect on several points of the study.

- Does experiencing symptoms lead patients to seek treatment and confirm the diagnosis?
- How would experiencing T2DM diagnosis and treatment lead to further action?
- What triggered patients to try alternative treatments apart from regular follow-ups at the primary care clinics?
- When and how do patients receive support from family members or people around them? What are the influences of these people?
- What was/were the action(s) taken after exploring the different types of treatments provided by their respective social networks and upon receiving information related to the treatment characteristics?

Consequently, the process of data analysis and generating the theoretical model was not linear but iterative. The modelling process within the analysis, as figure 2 shows, reflects the extent of the critical analysis of the data, which had been explored in layers. This helped capture the actual process of patients' choice of treatment modality being influenced by family members and other social networks. These people provided advice and acted as a source of information for patients.

Nonetheless, the final decision for choosing the treatment option was dependent on treatment characteristics such as effectiveness, side effect, simplicity and accessibility. Analysing the process by looking at the data layer by layer enabled us to understand how patients prioritised their treatment options and their decision-making process. The sorting process took place several times until an integrated idea was formed and theoretical saturation was achieved. Figure 3 shows the substantive model that was developed at that point. The process demonstrates the complexity of treatment strategies and decision-making processes among patients with T2DM.

### **Challenges**

The challenges we faced throughout the whole study were inevitable, particularly during the data collection process. To start with getting permission to interview patients from the private primary care clinics posed some challenges because a few of the general practitioners were reluctant to allow their patients to be interviewed, citing a lack of interest in research. Two general practitioners said they were too busy and had no time to accept proposal, be briefed about the study and recruit their patients

Another challenge we faced was gaining trust from study participants and getting them to open about their experiences. Maintaining an open mind to the participants' views and ensuring the confidentiality of their information were important. One participant noted, "*It is because of you... for the purpose of research and your knowledge that I am sharing with you*". Without doubt we appreciated the participants' honesty, and we valued the researcher-participant relationship. We learned that maintaining the trust of participants and ensuring the confidentiality of all information obtained from the interview are crucial. This close relationship between the researcher and participants is important, because participants were willing to confide in us with their personal information. This, from our perspective, was an indicator of a good rapport and hence, higher quality data.

### **Lessons Learned**

We acquired valuable lessons from using the grounded theory approach. In particular, managing the overwhelming data was eased through the systematic process offered by the grounded theory approach. Spending more time on the first interview transcript and then carefully coding it line by line enabled us to proceed to the focus coding after we had analysed the first three transcripts. However, such a large amount of information can be overwhelming. Memo writing and frequent discussions among the research team members further elevated the research focus during the analysis. It was critical to involve other members' perspectives to reduce any personal influence that may have been occurred during the analysis and thereby ensure the validity of the process.

Reflecting on the data was also important as the researcher's reflexivity must be taken into account. The approach was based on the constructivist grounded theory approach. The theoretical perspective and experience helped shape the research questions and the analysis. We also learned that the focal point of the research question may change. Apparently, the change was induced by the initial data collection process which allowed us to narrow our research area.

Since the process of the grounded theory approach began at the point of entering the research field, the experiences and skills we had gained throughout the process are invaluable. We note that the activity of memoing and the constant self-reflections helped us maintain openness to the ideas and concepts generated from the data. In addition, work experience is equally important. For instance, the first author's (LLL) experience of working in the field of health systems at the Ministry of Health Malaysia had made that author familiar with the current healthcare system in Malaysia. By sensitising ourselves to the Malaysian healthcare system, the research process became much easier to comprehend. This is important because the information was helpful and essential for any researcher to truly understand the patients' sentiments during their treatment and their decision-making about selecting treatment types. Furthermore, the experience with the healthcare system also sensitised us to the jargon used by healthcare providers.

As Malaysians conducting an exploratory study of local patients with T2DM, we found that we were advantaged. We were able to gather an understanding of the participants' impediments that had been compounded by their cultural and language barriers. The experience also provided us with the opportunity to appreciate the patients' stories, thereby facilitating the research procedure. It also made us more sensitive to the actions they took and their particular decisions in strategizing their treatment types.

## **DISCUSSION AND CONCLUSION**

Strauss and Corbin wrote (Strauss & Corbin, 1998), "*Analysis is the interplay between researchers and data. It is both science and art*". As human beings, we are prone to an inherent bias that is based selectively on our individual interests. Constantly reminding ourselves of the research questions during the analysis helped us focus on the study objectives. Consequently, the data were coded analytically, by simply making sense of the data one step at a time. The initial line-by-line coding was followed closely by reflecting on the data before moving on to the

higher abstract level of focus coding. This is a crucial stage because all the processes involved help minimise the possibility of researchers imposing their personal perspectives onto the data. It also allowed the data to speak to the researchers. It is this interplay that had led to the construction of a substantive theory.

Clearly, the researcher-participant relationship is paramount to gaining insight into understanding each other's lives (Charmaz, 2006). A study that focusses on patients' decision-making and their strategies for managing their illness requires a researcher to enter the patients' world, learn about their actions and perceptions and listen to their stories (Charmaz, 2004). The advantage of the IDI and FGD method are that it provided a platform for study participants to voice their experiences and concerns and to vent their frustrations about the healthcare delivery system. The participants shared their opinions and also placed their trust in us without any worries about the information they shared; these ideas had clearly been hidden from their healthcare providers. Such information was based on their actual experiences and perceptions and therefore is considered trustworthy.

The whole journey of the grounded theory approach is certainly long and challenging, but in return, much knowledge was acquired. The detailed process of our experiences and steps applied in developing a substantive theoretical model were aimed at making it a reference for other qualitative researchers, particularly those interested in deploying the grounded theory approach in healthcare research.

## REFERENCES

- Ahmed, S. M., Tomson G., Petzold M., & Kabir N. (2005). Socioeconomic status overrides age and gender in determining health-seeking behaviour in rural Bangladesh. *Bulletin of the World Health Organization*, 83, 109-117.
- Birks, M., & Mills, J. (2015). *Grounded Theory: A Practical Guide (Second Edition)*. London UK: SAGE Publications Inc.
- Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-being*, doi: 10.3402/qhw.v9.26152
- Carter, S. M., Ritchie, J. E., & Sainsbury, P. (2009). Doing good qualitative research in public health: not as easy as it looks. *NSW Public Health Bulletin*, 20(8), 105-111.
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine*, 30(11), 1161-1172. doi: [http://dx.doi.org/10.1016/0277-9536\(90\)90256-R](http://dx.doi.org/10.1016/0277-9536(90)90256-R)
- Charmaz, K. (2004). Premises, Principles, and Practices in Qualitative Research: Revisiting the Foundations. *Qualitative Health Research*, 14(7), 976-993. doi: 10.1177/1049732304266795
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*: SAGE Publications, Inc.
- Chomi E. N., Mujinja P. G. M., Enemark U., Hansen K., & Kiwara, A., D. (2014). Health care seeking behaviour and utilisation in a multiple health insurance system: does insurance affiliation matter? *International Journal for Equity in Health*, 13(25). doi:10.1186/1475-9276-13-25
- Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory*: SAGE Publications, Inc.
- Creswell, J. W. (2007). *Qualitative Inquiry & Research Design: Choosing Among Five Approaches (Second Edition)*. USA: SAGE Publications Inc.
- Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process*: SAGE Publications Inc.
- Evans, G. L. (2013). A Novice Researcher's First Walk Through the Maze of Grounded Theory: Rationalization for Classical Grounded Theory. *An International Journal of Grounded Theory Review*, issue 1.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: strategies for qualitative research*. London: Weidenfeld & Nicolson
- Glaser, B. G. (1978). *Theoretical Sensitivity: advances in the methodology of Grounded Theory*. Mill Valley, CA: Sociology Press.

- Glaser, B. G., & Holton J. (2004). Remodeling Grounded Theory. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 5(2), Art. 4. Hallberg L. R. M. (2006). The “core category” of grounded theory: Making constant comparisons. *International Journal of Qualitative Studies on Health and Well-being*, 1, 141-148.
- International Diabetes Federation. (2013). IDF Diabetes Atlas, 6th ed. Retrieved 16th March 2015, from <http://www.idf.org/diabetesatlas>
- Liamputtong, P. (2013). *Qualitative research methods Fourth Edition*: Oxford University Press.
- Mushtaq M. U., Gull S., Ahmad Shad M., & Akram J. (2011). Socio-demographic correlates of the health-seeking behaviours in two districts of Pakistan's Punjab province. *Journal of Pakistan Medical Association*, 61(12):12059.
- Elliott, N., & Lazenbat, A. (2005). How to recognise a 'Quality' Grounded Theory research study. *Australian Journal of Advanced Nursing*, 22(3), 48 - 52.
- World Health Organization. (2003). *Adherence To Long-Term Therapies: Evidence For Action*. Retrieved from [http://www.who.int/chp/knowledge/publications/adherence\\_report/en/](http://www.who.int/chp/knowledge/publications/adherence_report/en/)
- Patton, M.Q. (2002). Qualitative research and Evaluation Methods. Chapter 1: The Nature of Qualitative Inquiry. Third Edition. SAGE Publications, Inc
- Pourreza, A., Khabiri, R., Foroushani, A. R., Akbari Sari, A., Arab M., & Kavosi, K. (2011). Health Care -Seeking Behavior in Tehran, Islamic Republic of Iran. *World Applied Sciences Journal*, 14(8), 1190-1197.
- Shaikh, B.T., & Hatcher, J. (2004). Health seeking behaviour and health service utilization in Pakistan: challenging the policy makers. *Journal of Public Health*, 27(1), 49 - 54.
- Strauss, A., & Corbin, J.M. (1998). Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory: SAGE Publications, Inc.
- Strauss, A., & Corbin, J. (1990). Grounded Theory Research: Procedures, Canons, and Evaluative Criteria. *Qualitative Sociology*, 13(1), 3-21
- Tong, S. F., & Low, W. Y. (2015). Making Sense of Mixed Method Design in Health Research: Reconciliation of the Findings in a Study of the Doctors' Decision Making Process in Engaging Male Patients in Health Checks. *Malaysian Journal of Qualitative Research*, 2(1), 18-26.
- Virpi, T., Geraldine, F., & Conlon, C. (2018). Challenges When Using Grounded Theory: A Pragmatic Introduction to Doing GT Research. *International Journal of Qualitative Methods*, 17, 1-10.
- Watson, L. L., Bluml, B. M., & Skoufalos, A. (2015). Patient credentialing as a population health management strategy: a diabetes case study. *Popul Health Manag*, 18(3), 179-185. doi: 10.1089/pop.2014.0069
- Wertz, F. J., Charmaz, K., McMullen, L. M., Josselson, R., Anderson, R., & McSpadden, E. (2011). *Five ways of doing qualitative analysis*. New York, NY: Guilford.