

Patients' perspectives on taking insulin in diabetes - Perspectives of convergence

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인슐린 치료에 대한 당뇨병 환자의 지각과 경험 - 융복합적 관점

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Abstract The purpose of this study was to explore the cultural perspectives and experiences relating to insulin therapy among the diabetes. The authors conducted four semi-structured focus groups and individual interviews with 19 adults with type 1 and 2 diabetes, focusing on the personal experiences and thoughts regarding insulin therapy. Patients' perspectives and experiences relating to taking insulin formed three categories of themes: preoccupations about insulin, barriers to taking insulin, and benefits to taking insulin. The theme for preoccupations about insulin was "vague fear," while the theme of barriers to taking insulin were "worrisome insulin-related issues", "ambivalent feelings (trust/mistrust) about healthcare providers," "dependent life," "feeling about supporters(family, friends, and religion)," "inconvenience," "regret about the past," and "embarrassment." The theme of benefits to taking insulin were "recognition" and "physical recovery and confidence in regulating blood glucose". Based on this study, patients' feelings about their insulin should be respected by healthcare providers.

Key Words : Diabetes mellitus, Insulin, Focus group, Barriers, Facilitators, Convergence

요약 본 연구는 당뇨병 환자를 대상으로 인슐린 치료에 대한 문화적 관점과 경험을 탐색하기 위해 19명의 제1형과 2형 당뇨병 환자를 대상으로 포커스 그룹 인터뷰를 실시하였다. 인터뷰 내용을 기록하고 녹취한 후 내용분석을 통해 당뇨병 환자들이 경험하는 인슐린 치료에 대한 사전인식요인과 장애요인 및 촉진요인을 목록화하였으며 이들 3가지 목록에 포함되는 주요어를 도출하였다. 그 결과 인슐린에 대한 막연한 두려움이 사전인식요인의 주요어로 확인되었고 장애요인으로는 인슐린과 관련된 걱정(통증, 낮은 지식과 문해력, 자가 주사에 대한 낮은 자신감, 경제적 부담, 저혈당에 대한 두려움)과 의료진에 대한 양가감정, 의지하게 된 삶, 친구, 친척과 가족에 대한 감정, 불편감, 과거에 대한 후회, 부끄러움이 주요어로 도출되었다. 촉진요인으로는 깨달음과 신체적 회복 및 혈당조절에 대한 자신감이 확인되었다. 본 연구결과를 토대로 국내 당뇨병 환자의 인슐린 치료에 대한 경험과 지각에 대한 의료인의 이해가 필요하며 당뇨병 환자의 이러한 경험은 존중되어야 할 것으로 사료된다.

주제어 : 당뇨병, 인슐린 치료, 포커스 그룹, 장애요인, 촉진요인, 융복합

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1. INTRODUCTION

Clinicians recommend insulin therapy to achieve successful glycemic control for diabetes mellitus (DM), as it can compensate for adequate plasma glucose levels and reduce the micro/macrovascular complications of DM[1]. Unfortunately, many patients may delay beginning insulin therapy because of misconceptions about insulin and attitudinal barriers such as fears of needles or social stigma[1,2,3,4,5].

Researchers have termed this phenomena “psychological insulin resistance”(PIR)[4,5,6]. In a cohort study of veterans with type 2 DM in the United States, the average time to insulin initiation was 4.6years after initial discovery of an A1C of $\geq 8\%$ [3]. Furthermore, the refusal rates for insulin therapy(i.e., the proportion of prescribed insulin refused within given period) range widely—from 28.2% to 70%—depending on the region[7].

Researchers have attempted to investigate the factors that affect patients’ perceptions of insulin therapy from a cultural perspective, proposing that cultural beliefs and confidence will affect individuals’ perspectives and experiences related to insulin therapy. There is some support for this: in a qualitative study in the UK of participants with type 2 DM, patients reported feeling shocked or upset when advised by a clinician to begin insulin therapy, but very few showed resistance to initiating insulin[8]. Patients with diabetes in China also reported unpleasant feelings when advised by a clinician to start insulin therapy, but their refusal rate reached over 70%[7].

The prevalence of diabetes in South Korea has rapidly increased in the last decade, reaching 12.4% in 2011 from 9.1% in 2005, and a two-fold growth is expected for the next 40 years[9,10]. Furthermore, a recent study indicated that 67% of patients with type 2 DM showed unwillingness to take insulin[11]. Many researchers and health care providers in South Korea have attempted to promote diabetes self-care management, including insulin adherence, using various

intervention methods such as education and counseling. Despite the education offered in clinical and community settings, there are few reports confirming that glycemic control is successful in reducing the complications of diabetes in Korea. Specifically, Korean studies have only focused on the barriers of self-insulin injection skills based on the assumption that these barriers can be overcome by diabetes education without reflection on the meaning of patients’ experiences with insulin therapy[12,13].

As such, there is a predominance of one-sided education and injection training programs that do not consider patients’ perspectives on insulin, which may limit successful diabetes control outcomes[14]. Moreover, most quantitative research in South Korea on behaviors and attitudes related to insulin therapy has involved use of translated instruments that have not been culturally adapted to Koreans. Cultural factors may influence diabetes self-care such as insulin adherence as well as healthcare decision-making and communication with healthcare professionals[14]. Furthermore, to date, no studies have qualitatively examined the perspectives and experiences regarding insulin therapy of Koreans with diabetes.

The purpose of this study was to clarify the experiences and perspectives related to insulin therapy among Korean people with diabetes using qualitative methods. The research questions and topics were as follows: (1) Preoccupations about insulin: “How would you feel when you are recommended to take insulin by your doctor?” (2) Barriers to taking insulin: “What are the difficulties related to your insulin therapy that you have perceived?” (3) Benefits to taking insulin: “What are the benefits of insulin therapy that you have perceived?”

2. METHODS

2.1 Study design

This was a qualitative study involving semi-structured

focus group(FGI) and individual interviews. FGIs are useful for obtaining in-depth information about a sample's perceptions and experiences relating to a given topic or problem by exploring social norms and facilitating interactions among group members, which can in turn aid in the development of effective interventions[15]. The authors also conducted individual interviews to extract more meaningful and detailed data for saturation.

2.2 Study sample and data collection

Nineteen individuals with type 1 or type 2 DM were recruited, with 13 and 6 participating in the FGI and individual interviews, respectively, from June to September in 2015. Participants were recruited using convenience sampling from outpatients clinics and university hospitals located in a metropolitan area of South Korea. Among them, 13 participants who took part in the FGIs had been hospitalized because they had been unable to control their blood glucose levels and thus developed complications. Four different FGIs with the 13 participants were conducted, with each group comprising two to four participants. The 6 participants who took part in the individual interviews could not take part in an FGI due to their busy schedules, and were interviewed in outpatient departments at the university hospitals where they received their care. A FGI guide was developed according to the studied concepts, a literature review, and the research team's experiences in working with diabetes patients. After discussions among the research team, which included clinicians and nurses, the FGI guide questions were revised to increase their understandability to laypersons; all alterations were reviewed together by the research team. The primary investigator, who was experienced FGIs and has used them in several prior studies, facilitated conversation as a moderator while a co-author took field notes. Each FGI lasted approximately one hour. All interviews were recorded using an electronic recording device and transcribed verbatim. All participants received gifts (about \$50) for their time.

2.3 Ethical consideration

Before each FGI and individual interview, the authors conducted the informed consent process, ensuring that all participants understood the purpose, potential risks, and benefits of the study and that they were participating on a voluntary basis. Ethical approval for this study was obtained from the institutional review board of Chungnam National University.

2.4 Analysis

Descriptive statistics were used to analyze participants' demographics. To analyze the qualitative data, the authors conducted inductive coding and qualitative content analysis[16]. Such analyses require sufficient trustworthiness (i.e., internal validity [credibility], reliability[dependability], confirmability, and transferability). Credibility refers to researchers' confidence in how well the data and analyses address the intended research focus, while dependability refers to the degree to which data change over time and depends on researchers' decisions during the analysis process. Transferability requires "a rich and vigorous presentation of the findings" with appropriate quotations, while confirmability refers to the degree to which the findings can be corroborated by others[17]. To ensure the dependability, transferability, confirmability, and credibility, the authors took several steps. First, research team members discussed and reached a consensus regarding the research questions before conducting any interviews. Second, after all of the interviews, research members debriefed and discussed the interactions between FGI participants using verbatim transcripts and relevant quotes. Both the verbal and non-verbal behaviors of participants were recorded by a note-taker. Third, three coders reviewed each transcript and independently generated initial descriptive codes, after which they discussed and sorted these initial codes into content domains until a consensus was reached. Fourth, the content domains were grouped into categories, which in turn were grouped into themes and subthemes[16]. Fifth, the

themes and subthemes were reviewed for similarities and discrepancies by all researchers until an agreement was reached. Finally, the themes and subthemes were linked with the three research questions after multiple discussions between researchers. This process would allow transference of the findings to other settings or groups beyond those of the present study, given the clear and distinct description of the culture, context, selection and characteristics of participants, data collection, and analysis process.

3. RESULTS

3.1 Participants' characteristics

Of the 19 participants, 11 were female and 18 were married. The mean age of participants was 59.4 years and mean years of having diabetes was 15.7. The prevalence of insulin use was 68.4% and duration of insulin therapy was 4.48 years<Table 1>.

<Table 1> Demographics of participant (N= 19)

Characters	Categories	n	%	M(SD)
Gender	Male	7	36.8	
	Female	12	63.2	
Marital status	Married	18	94.7	
Age (yrs)	Less than 30	1	5.3	60.3 (14.03)
	30	0	0	
	40	3	15.8	
	50	3	15.8	
	60	8	42.1	
	Over 70	4	21.0	
Locations of interview	Inpatient unit	13	68.4	
	Outpatient	6	31.6	
Duration of diabetes (yrs)	Less than 1	3	15.8	15.7 (11.99)
	1-5	2	10.5	
	5-10	1	5.3	
	11-20	5	26.3	
	Over 20	8	42.1	
Starting to Insulin therapy	Yes	13	68.4	
Duration of Insulin Therapy (yrs)	Less than 1	5	26.3	4.4 (4.92)
	1-5	2	10.5	
	5-10	3	15.8	
	10-20	3	15.8	

3.2 Preoccupations about insulin therapy

3.2.1 Vague fear

Participants first felt “vague fear” in relation to insulin when their doctors advised them to begin insulin therapy. Several participants expressed “shock” or “darkness.” When participants learned that they would require insulin, they had complicated feelings about their future life. They could not explain these feelings as related to a specific subject or cause. One participant, who had been recommended to begin insulin therapy upon his most recent hospital admission, was still in a state of desperation.

3.3 Barriers to taking insulin

3.3.1 Worrisome insulin-related issues

Pain: Participants reported that what first came to their minds upon hearing the word “insulin” was injection. “[It is so] difficult [to] even eat [the right] meal every day, [but] taking a painful injection [as well]!...I hate the injection itself” (male, age 60).). “At first, I did not know how to inject the insulin. So...I felt pain and frequently bruised my skin” (male, age 44). Concerns about pain caused by the injection were the most common worrisome issue. However, some participants did not feel as strongly about needle pain. Indeed, some participants, especially those who were older, felt that the injection itself was not painful because of the small bevel size of the needle.

Low knowledge and literacy: All participants stated that they had already learned self-care from the healthcare providers at their hospitals. However, their attitudes and degree of acceptance of diabetes education varied. Although some participants actively took part in diabetes management programs, some experienced a lack of interest in or ability for self-care.

Low confidence in self-injection: Although most participants had completed diabetes education programs on how to manage their diabetes, including insulin therapy through self-injection, many reported that self-injection was still challenging.

Financial burden: Most chronic diseases, including diabetes, are covered by the national health insurance system in South Korea. However, this insurance cannot cover all costs for insulin-related expenditures for self-care of diabetes patients. The cost for everyday use of insulin posed a considerable economic burden for several participants.

Fear of hypoglycemia as a side effect of insulin: Participants knew that hypoglycemia was a side effect of insulin therapy, and many had either directly or indirectly experienced it. *“Hypoglycemia might someday attack me suddenly because of insulin [as a side effect]”* (male, age 66).

3.3.2 Ambivalent feelings (trust/mistrust) about healthcare providers

Participants felt somewhat ambivalent about healthcare providers. One participant said *“I am probably going to die because of starvation if I follow my doctor’s guides (laughs)”* (male, age 73). Several participants mentioned physicians’ authoritative attitudes. *“My doctors colds me that I cannot control my food intake. He may be doesn’t respect this patients”* (male, age 44). In contrast, one elderly patient expressed her appreciation for her healthcare provider. *“I am an old woman, so when I heard [my doctor’s] request that [I be] hospitalized, I was happy. The doctor did not give up on me like I thought”* (female, age 87). In other words, this elderly participant had a strong faith that her doctor would help patients regardless of their old age.

3.3.3 Dependent life

Participants generally perceived taking insulin as a challenge to their independent living. They adopted two different positions regarding dependency. First, some participants believed that prejudiced people would see them as ill, and therefore dependent. Participants who had jobs reported that their work lives were challenging because of this prejudice. Second, some

participants had actually developed some form of physical dependence. *“Taking insulin is totally different from taking pills”* (female, age 59). In sum, many participants believed that taking insulin made it difficult for them to obtain an independent life.

3.3.4 Feelings about support system (family, friends, and religion)

Most participants reported feeling like a burden to their family, friends, and significant others, particularly with regard to their future. This was especially prominent for men, who felt that they could no longer take on the role of head of household. Women who were housewives also expressed worry about their future roles as mothers and wives, believing that they could not help their family as before. Some women expressed frustration about housekeeping and house chores such as cooking. Generally, women had mixed feelings of regret and blame—regret that they could not keep their role as caregivers for their family, and blame towards those same family, who did not help them enough. Most participants reported that they generally received help from their friends. Although participants wanted to manage diabetes by themselves because all of their family members were busy, participants talked with friends and received some consolation. In particular, older participants felt comfortable in receiving help from close friends. For some participants, religion became a primary support system.

3.3.5 Inconvenience

Participants reported that, compared to oral diabetes pills, insulin injections were rather inconvenient. The greatest inconvenience related to transporting insulin during travel. When participants planned to go abroad, they needed to prepare medical documents and a container that could keep their insulin safe. Participants also how long it took to properly perform an injection compared with taking pills; indeed, some occasionally worried about having enough time to inject insulin.

However, some participants who had diabetes for many years expressed that the current injection system for insulin (i.e., the pen) was easier to inject than was the previous injection method.

3.3.6 Regret about the past

Most participants exhibited feelings of regret about the past. In particular, participants who did not follow self-care guideline such as meal plans, frequent blood glucose monitoring, exercise, or medication tended to regret failing to control their glucose level.

3.3.7 Embarrassment

Participants stated that injecting insulin resembled drug addiction behavior. *"I think I look like a drug addict, when I see news on the TV about drugs. The shape of the syringe for drug injection is similar to an insulin syringe, right?"* (female, age 21). Some participants, however, did not agree that insulin injection resembled drug addiction behavior. Nevertheless, most participants agreed on feeling embarrassed if they had to inject insulin when co-workers or unfamiliar people were watching. Participants were also reluctant to talk about their insulin use for diabetes because of this embarrassment in injecting insulin in public places.

3.4 Facilitators to taking insulin

3.4.1 Recognition

Recommendations for insulin use became a crucial factor in self-care. Although starting insulin therapy was a shock to participants and was accompanied by feelings of personal failure in glycemic control, they also experienced a more positive awareness. Participants reflected on their own behaviors and took the opportunity to look back on their pasts.

3.4.2 Physical recovery and confidence in regulating blood glucose

Participants mentioned that taking insulin helped them to improve their physical conditions. After

<Table 2> Extracted themes and subthemes related to taking insulin

Themes	Subthemes	Concepts
Preoccup- ations about insulin	Vague fear	Shock, invisible state, complicated feeling, darkness, Sudden death, distressed life
		Pain: Needling pain, Bruised skin, Shot regularly until death Low knowledge and literacy: Lack of interesting and lack of ability to self-care, Lack of understanding, Lack of seriousness, Lack of enough information, Need to educate continuously, Incorrect information about change of body function Low confidence for self-injection:
Barriers to taking insulin	Worrisome insulin related things	Challengeable to educate, Need to receiving the helping for injection, Difficulty to measure, Poor eyesight Fear about injection itself Burden of cost: Cost for everyday insulin Fear of hypoglycemia as a side effect of insulin: Sudden attacked, Horrible event, Serious state, Preparing the sugar every time and everywhere, Most scared side effect
	Feeling of trust vs mistrust to health care providers	Mistrust about dosage of insulin. Experiencing the hypoglycemia, starving according to keeping the recommendation, Doctor's attitude that ignoring the patient, Appreciation for not giving up the patients
	Dependenc-y life	Treated as a sick person, Prejudice regarding dependency, Social stigma, Needing help actually, Difficult to take a responsibility
Barriers to taking insulin	Feeling about mother(farther), supporters (family, friends and religion)	Feeling of sorry, Useless family member, Worried about future role as a mother, Annoyance about not enough energy to teach the housework, Mixed feeling of sorry and blame, Receiving friends' help, Talking with friends, Depending on one's god, Receiving from one's religion
	Inconvenience	Discomfort on insulin injection, Difficult to transport, much easier than before insulin, Needing spare time to inject Regret for the past that did not follow a regular medical check-up
Benefits to taking insulin	Embarrassing	Look like a drug addicts, Embarrassing to shot in public
	Recognition	Aroused factor, Positive awareness, Willingness to keep the guideline, recognizing the importance of self-management
Benefits to taking insulin	Physical recovery and confidence in regulating blood glucose	Physical improved condition, Well-conditioned Confidence to well-manage, Controlled blood sugar level

beginning insulin therapy, many participants felt physically improved. Moreover, most participants felt more confident in managing their blood glucose (Table 2).

4. DISCUSSION

The findings revealed that Korean participants with diabetes had both positive and negative perceptions of insulin therapy. In particular, they experienced feelings of shock and fear when they were recommended insulin therapy by their physicians. Previous studies have indicated that individuals' willingness to initiate insulin is affected by their perceptions and understanding of insulin therapy [18,19,20,21]. For instance, in a study by Karter et al [18], the commonly cited reason for not initiating insulin therapy was misconceptions regarding insulin risks. The participants of this study also feared future progress upon being recommended insulin therapy. Moreover, participants believed that starting insulin meant an abject failure to manage their diabetes. It may be possible to prevent people from

feeling this sense of failure by informing patients as early as possible—such as at diagnosis—on what would lead to their diabetes worsening and what would occur in that event (e.g., introduction of drugs including insulin) to promote greater psychological acceptance of insulin and other diabetes drugs [22]. Numerous studies have noted the social stigma, lifestyle changes, and fears related to insulin complications such as hypoglycemia and weight gain, which are all key components of PIR [5,22,23]. The barriers to taking insulin found in this study were consistent with those found in other populations. Among the barriers, participants mentioned only hypoglycemia as an insulin complication; surprisingly, nobody was interested in weight gain.

The possible reason for this low awareness of weight gain may be that healthcare providers in South Korea tend to focus on hypoglycemia as side effect of

insulin during education.

In previous literature, the most frequently cited potential barrier was the anticipated pain associated with insulin injection [24]. Such a barrier might be overcome by changing to insulin pens and better healthcare provider communication [25]. Regarding the latter, healthcare environments do not realistically allow sufficient time for communication between healthcare providers and patients. This lack of time may lead patients to distrust insulin prescriptions from their provider, something that participants of the present study reported. However, participants also noted some benefits of insulin therapy: namely, despite their feelings of failure, initiation and maintenance of insulin therapy motivated them to recognize the importance of self-management. Some participants also experienced greater physical stability due to good blood glucose control, which provides further motivation for adherence.

Support from family and loved ones was an important factor for patients with diabetes. Most participants reported feeling like a burden to these individuals, although not all did; for instance, some women reported mixed feelings of blame and burden in relation to their family and significant others. In general, women in Asian cultures tend to serve as primary caregivers for their families, which can force them to engage in self-sacrifice because they consider themselves to be nurturers of the good health of their families. Despite their self-sacrifice, some women felt disappointment that they had not received greater support from family members and loved ones when their diabetes worsened [26]. In a previous study, women tended to have more negative perceptions of insulin therapy than did men [27,28,29]. Gender difference in social support may also influence insulin acceptance. However, the gender difference in PIR should be investigated in various other populations in future studies, as the evidence remains somewhat unclear.

The qualitative nature of this study can be considered as limitation. For instance, the generalizability of these results can be limited because of convenience and small sample size. However, this study was the first attempt to explore the perspectives and experiences of patients about taking insulin therapy in Korea.

5. CONCLUSION

The findings of this qualitative study have several clinical implications for diabetes educators and further research. First, healthcare providers should attempt to understand patients' beliefs about and barriers to insulin therapy during prescription and diagnosis. Based on those assessments, individualized education and counseling early on may help to minimize or prevent PIR and insulin therapy delay. Second, more research on the most effective intervention times and methods should be performed. Although healthcare providers have also been found to show PIR, which makes them less likely to prescribe insulin, little is known about this phenomenon in healthcare providers in South Korea. This area should be investigated using qualitative and quantitative methods. Finally, from a health policy perspective, diabetes education programs should be covered by the national insurance in South Korea. To the best of the authors' knowledge, this is the first attempt to explore the perspectives and experiences related to insulin therapy among individuals with diabetes in South Korea. Ultimately, this study provides evidence that will help in developing culturally appropriate instruments that can measure behaviors and attitudes related to insulin therapy for Koreans with diabetes.

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