

# Patient and Spouse Expectations of and Reactions to Continuous Subcutaneous Insulin Infusion (CSII) Therapy: Case Report

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Six insulin-dependent women with diabetes and their spouses were assessed (1) prior to continuous subcutaneous insulin infusion (CSII) therapy, and (2) three months after implementation of CSII therapy. The pre-CSII interviews revealed that both patient and spouse were interested in the positive emotional consequences of improved metabolic control. However, patients were most interested in the personal benefits of metabolic stabilization, whereas spouses were more concerned about potential improvement of the marital relationship. Post-CSII interviews showed that most fears regarding CSII therapy expressed in the pre-CSII interview were not realized, but many unanticipated negative and positive responses to treatment were experienced.

Continuous subcutaneous insulin infusion (CSII) therapy has proved an effective form of treatment for many insulin-dependent diabetic patients.<sup>1</sup> It has been particularly efficacious in patients who have been unable to minimize rapid fluctuation of blood sugar levels or to achieve near-normal glycemia with intensive conventional insulin therapy (multiple daily injections of insulin combined with home blood glucose monitoring).<sup>2-3</sup> Preliminary data also suggest that the improved metabolic control achieved with CSII therapy is associated with improvement in retinal fluorescein leakage,<sup>4</sup> neuropathy,<sup>5</sup> and capillary basement membrane thickening.<sup>6</sup>

Recent reports indicate that not all patients are suitable candidates for this method of intensive insulin treatment. According to a study by Leichter et al.,<sup>2</sup> many psychosocial factors play important roles in determining the success or failure of CSII therapy.

This article reports the results of a pilot study in which six insulin-dependent diabetic patients and their spouses were assessed to determine their respective responses to CSII therapy. The aim was to identify psychosocial factors that may be crucial in determining which patients might be prone to succeed or fail with CSII treatment and how diabetes health care providers might intervene to maximize patients' success with CSII.

## Materials

Patients for this study, conducted in 1981, were six female insulin-dependent diabetic patients, selected consecutively to begin CSII therapy by the same diabetologist in private practice. All patients were married (mean age, 32.2 years); the mean duration of diabetes was 20.8 years, and the mean number of patient-reported diabetes-related hospitalizations was 10.8 (Table 1). Many chronic complications were reported. Only three patients claimed to have used home blood glucose monitoring techniques and self-management methods prior to implementation with CSII. Only one patient was attending a local "pumpers' support group" prior to CSII. All subjects were scheduled to use the same model insulin pump, the Auto Syringe AS-6C (Travenol).

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**Table 1. Patient Status Prior to CSII Therapy**

Subject	Age (Yrs)	Duration of Diabetes (Yrs)	Secondary Complications	Patient-Reported Hospitalizations Related to Diabetes	Pump Group Participation	Initiated Idea of CSII
A	52	24	Neuropathy Retinopathy Weight loss	30	No	Physician
B	30	22	Retinopathy Neuropathy	9	No	Physician
C	25	21	Neuropathy	10	No	Physician
D	25	17	Retinopathy	10	No	Relative
E	35	26	None reported	0	No	Self
F	26	15	Retinopathy	6	Yes	Physician

**Table 2. Patients' and Spouses' Positive Expectations and Outcomes of CSII Therapy**

Expectation	Patients' Positive Expectations and Outcomes (n=6)			Spouses' Positive Expectations and Outcomes (n=6)		
	Pre-CSII Positive Expectation	Post-CSII Positive Outcome	Unexpected Positive Outcome	Pre-CSII Positive Expectation	Post-CSII Positive Outcome	Unexpected Positive Outcome
Feel better	5	4	1	5	4	1
Increase flexibility	5	4	0	2	2	0
Improve control	4	4	1	1	1	0
Arrest complications	3	—	—	3	—	—
Extend life	2	—	—	0	0	0
Reduce hospitalization	1	0	0	0	0	0
Gain weight (attractiveness)	1	0	0	1	0	0
Improve health habits	0	0	2	0	0	2
Spouse become more positive minded about diabetes	0	0	2	0	0	2
Stop blaming self/increase self-esteem	0	0	1	0	0	0

**Table 3. Patients' and Spouses' Negative Expectations and Outcomes of CSII Therapy**

Expectation	Patients' Negative Expectations and Outcomes (n=6)			Spouses' Negative Expectations and Outcomes (n=6)		
	Pre-CSII Negative Expectations	Post-CSII Negative Outcomes	Unexpected Negative Outcomes	Pre-CSII Negative Expectations	Post-CSII Negative Outcomes	Unexpected Negative Outcomes
Pump visibility	4	0	0	0	0	0
Relationship to pump	3	2	0	0	0	0
Insulin reactions	2	2	0	0	0	0
Pump interferes with recreation/bathing	2	0	0	0	0	0
Abscesses at needle site	2	1	2	0	0	0
Pump interferes with sexual activities	2	0	0	0	0	0
Pump malfunctions	1	1	2	0	0	3
CSII will not improve medication control	0	0	0	1	0	0
Increased dependency on physician	0	0	2	0	0	0
Depressed because pump does not "cure" diabetes	0	0	2	0	0	0
Expense of CSII supplies	0	0	3	0	0	3
Physical problems	0	0	3	0	0	0
Pump management interferes with daily routine	0	0	3	0	0	0
Increased fear of diabetes	0	0	1	0	0	0
Fearful patient will abandon CSII	0	0	0	0	0	3

**Methods**

Two standardized psychological instruments were administered to patients before and three months after implementation of CSII therapy. To assess patients' level of depression, the Beck Depression Inventory<sup>7,8</sup> and the State-Trait Anxiety Inventory<sup>9</sup> were given.

In addition, patients and their respective spouses were interviewed before and three months after implementation of CSII therapy. The design of the interview schedule was semi-structured,<sup>10</sup> facilitating spontaneous responses by both patient and spouse to a series of specific, open-ended questions. All patients and their spouses were interviewed together in their homes by the primary investigator, the interviews being tape recorded.

In pre-CSII interviews, questions focused on expectations of both patient and spouse regarding hoped-for and feared changes in their lives that might be associated with the introduction of CSII therapy. Questions to patients included, "What are you hoping the pump will do for you?" and "Do you have any cautions or concerns about pump therapy?" Questions directed to the spouse included, "What are you hoping the pump will improve?"

Three months after introduction of CSII therapy, patients and spouses were again interviewed. The second interview

(1) reviewed for each couple their pre-CSII expectations (positive and negative) and asked them to discuss the extent to which these expectations had been realized; (2) solicited from both patient and spouse unanticipated positive and negative reactions to the three months' experience with CSII therapy; and (3) solicited couples' recommendations to health care providers for better preparation and implementation of CSII therapy.

**Results**

The results of the pre-CSII and three-month post-CSII interviews with patients and spouses are given in Tables 2 and 3. Table 2 indicates that both patients and husbands were primarily interested in CSII therapy as enabling the wives to "feel better" and "have increased flexibility in their lifestyle." Undoubtedly this was hoped for as an outcome of improved metabolic control, though not explicitly stated by half the husbands. Patients had a higher investment than did their husbands in more *personal* aspects of feeling better and more flexible lifestyle, eg, having increased energy and enthusiasm to pursue work activities, being able to eat when they wanted, and not needing to take as many injections. The husbands' investments in their wives feeling better and having greater flexibility in lifestyle seemed to emphasize more *interpersonal* (marital) matters, eg, reduction of interpersonal conflict, reduced emotional lability, and increased ability and desire to travel and socialize. Four of five couples reported initially realizing these positive expectations within three months of CSII therapy.

Two couples reported significant unanticipated positive outcomes: an overall improvement in patients' attendance to other aspects of health care (diet and exercise), and a positive increase in husbands' involvement with diabetes management.

Table 3 shows that patients who were concerned about their ability to minimize the pump's visibility or possible interference of the pump with recreational or sexual activities were apparently able to avert these potential problems. Husbands reported few, if any, concerns about CSII therapy prior to its introduction. Patients reported anticipated and unanticipated physical problems associated with CSII therapy, including needle site abscesses, increased number of insulin reactions, and other physical problems such as headaches and blurring of vision.

From a psychosocial perspective, two patients unexpectedly felt increased resentment over their greater dependency on their physician, ie, for proper management techniques with CSII therapy; one of these two patients also found that the pump was a constant negative reminder of her diabetes and that it increased her fear of the illness. In addition, two patients had some negative emotional reactions to previously unexpressed fantasies that the insulin pump would function as an artificial pancreas, resulting in a "cure" of the diabetes. Two others

**Table 4. Pre-CSII and Three Months' Post-CSII Depression Scores**

Subject	Depression*	
	Pre-CSII	Post-CSII
A	24	16
B	9	5
C	8	3
D	8	10
E	9	0
F	6	4

\*Persons with "mild" and "moderate" depression averaged 18.7 (SD=10.2) and 25.4 (SD=9.6), respectively, in a norming study of 409 individuals.

**Table 5. Pre-CSII and Three Months' Post-CSII Anxiety Scores**

Subject	Anxiety*			
	Pre-CSII		Post-CSII	
	State	Trait	State	Trait
A	69	49	56	24
B	40	46	44	36
C	39	45	38	45
D	33	32	26	37
E	42	50	31	38
F	35	46	38	49

\*Normal state anxiety ranges from 32.2 to 36.2 (SD=8.7 to 11.0) for these age ranges. Normal trait anxiety ranges from 31.8 to 36.2 (SD=7.8 to 9.5).

**Table 6. Patient Reports Three Months' Post-CSII**

Patient	Overall Reaction to CSII Therapy*	Overall Hospital Experience*	Participating in Support Group	Number of Hospitalizations Since CSII	Patient-Perceived Adjustment Period to CSII
A	-	+	Yes	0	Not adjusted
B	0	+	No	0	1 mo
C	+	+	Yes	3	3 wks
D	+	-	No	0	2 mos
E	+	0	Yes	0	2 mos
F	+	-	Yes	0	3 wks

\* - = negative; + = positive; 0 = neutral.

felt overly dependent on the insulin pump and felt "controlled" by it.

Three couples reported mechanical failure of the pump, requiring manufacturer repair, and three other couples reported negative reactions to the unanticipated expenses for daily management of CSII therapy (eg, tubing, needles, batteries, blood-monitoring reagent strips).

Tables 4 and 5 give the results of patients' depression and anxiety scores before and after introduction of CSII therapy. ("State" anxiety refers to situational or transient anxiety; "trait" anxiety refers to a more characterological state.) Patient A's depression scores were clinically elevated. Her situational anxiety level was high prior to CSII therapy; after CSII therapy, she remained more depressed and situationally anxious at a clinically significant level than did the other patients. Also, as Table 6 indicates, patient A was the only one with an overall negative reaction to CSII therapy. Patients who felt they had adjusted to CSII therapy required from three to eight weeks to achieve a sense of mastery and comfort with the techniques of CSII.

### Discussion and Implications for Health Care Providers

Even this limited pilot investigation of a few patients over a short period reveals pertinent data regarding patients' and spouses' expectations for CSII therapy. These couples were primarily interested in the psychosocial benefits of improved metabolic control, which they hoped could be attained with CSII therapy. An important difference between patient and spouse was the expressed emphasis of wives on *personal* benefits versus the husbands' expectations of *interpersonal* benefits. If a patient should experience improved metabolic control and resultant increased energy and enthusiasm for the pursuit of her own personal interests, the spouse might grow increasingly disappointed and resentful if his own interpersonal expectations are not realized. He might come to blame the pump for his dissatisfactions and consequently fail to support his partner's continuing use of CSII therapy. The dynamic quality of CSII therapy in the context of a marital relationship requires further investigation.

Spouses seemed reluctant to voice their concerns about CSII therapy, possibly in an effort to maintain their wives' optimistic approach to this treatment. This became more evident in the post-CSII interview, when spouses were more likely to verbalize their fears that the wife would abandon the pump in the face of initially discouraging problems.

The one patient (A) who was significantly depressed and anxious was probably not a good candidate for CSII therapy—a reaction that is difficult to generalize to the larger population of CSII therapy candidates. Prospective studies investigating the relationship among depression, anxiety, and CSII success/failure are needed.

The final aspect of the post-CSII interviews focused on the couples' recommendations to health care providers for improved methods of implementing CSII.

**Education.** Five patients wished they had been better informed about the benefits and the limitations of this therapy. In their perception, physicians, nurses, and other CSII users had been biased toward the potential benefits, while de-emphasizing inherent limitations and obstacles. Patients and spouses also believed that information, gathered from successful CSII users

in the context of a support group setting prior to CSII use, would assist in minimizing anxiety and ignorance during efforts to cope with daily problems of the regimen. They suggested that successful pump users might model for others adequate styles of coping with the pump.

**Hospitalization procedures.** Many patients reported both ignorance and fear of the hospitalization procedures that were employed for pump implementation. They wanted a more specific explanation of the necessity for hospitalization as well as more education about the required CSII implementation procedures. They also suggested that the general ward staff, rather than only diabetes team members, be more informed about the procedures. Further, they believed that an opportunity to manipulate the pump apparatus prior to their own metabolic dependency on it would have alleviated many of their fears.

**Technology and supplies.** Both patients and spouses wished they had been alerted to potential reliability problems of the pump unit. They had received excellent service from the pump manufacturer, but the problems they experienced had only increased anxiety about mechanical failure. Also, a more adequate preparation regarding the cost of supplies might have reduced their negative reactions.

**Psychological issues.** The two patients (A and D) who were depressed about the limitations of the pump wished they had been more extensively challenged about their unrealistic expectations for CSII treatment. They also suggested that patients be prepared by the health care team for the possibility of a transient depression following introduction of the pump. Furthermore, during the transitional period of adjustment to the pump, physicians, nurses, and spouses could be more sensitive to and supportive regarding patients' fears about their adequacy to adjust to the demands of the regimen.

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