

Supplement 1. Theme and contents

| Participant | Theme | Contents | Overall theme |
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| A | (1) The life you obsessively record to survive | “I have a notebook and I write down my weight every day... When I was in the hospital, I weighed myself at 6:00 a.m. before breakfast, so I do the same at home. There is a 250–300 g difference between before and after eating breakfast. Stool is very important when you have decreased small bowel function. I track how much water I drink, how much urine I produce, how much I exercise. There is an app that calculates everything—I log it all. Everything is organized by date, month, year. It is all saved on CDs and an external hard drive—over two terabytes of organized data.” | Extreme sensitivity to symptoms |
| | (2) Commitment to disease-related information | “It was really stressful because there are limited resources for SBS. With cancer, if you search for resources, there is information. But for small bowel, there is nothing... (interruption) So I searched online—dietitians’ associations, the Food and Drug Administration, food-related websites. I looked up how to treat it, how to eat, what medications to take.” | |
| | (3) Hope with absolute trust in medical staff | “Code... I must now... match the code between the medical staff and me. It is the only way I can live. If I do not fulfill it, I cannot live. (interruption) When I say I am sick, my family, juniors, and seniors bring me food—herbal medicine, naturopathic medicine, things like that... Honestly, I have thrown away all that stuff, like the decoction and the Russian tea. I am just going to focus on the doctor, the nurse, the nutritionist, and what they are saying.” | |
| B | (1) Appreciation only found by comparing | “You cannot really see SBS—you do not look like a burn victim, your | Treat meals as another form of |

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| | to other patients | face is not disfigured, you do not have a malignant tumor, and that is a good thing. (interruption) My dad has been in a nursing home for over 2 years with chronic obstructive pulmonary disease. His mind is sharp, but he has a tracheostomy tube, his voice is a whisper, and he has been swallowing porridge... My life is better than that. I can walk, I have my arms and legs, I can use the internet, I can travel... So... I just think my illness is better than others.” | therapy |
| | 2) Reclaiming your life through work | “I really want to get off TPN. First, because I want to return to work; second, because I want to travel. (Tears) I had a bowel obstruction, kept vomiting, and then my intestines ruptured. I could not care for patients anymore because I could not survive without fluids... I had to quit; I had no choice. (Tears) My job is my reason for living—it keeps me going. (Interruption) I was crying in the hospital because I could not work; it was unbearable. So I need to go back—I feel brighter and more energetic when I work.” | |
| C | (1) Appetite control learned through experience | “I used to eat heavily, so I took a lot of supplements, but as my condition improved, I could eat normally without eating poorly. That was the turning point. I thought I was eating well, but I was not. I started with something light, like chilled cucumber soup with noodles. I was cautious... but soon I craved spicy food again. I added vegetables, eggs, chicken, bread—everything. I just ate it all. Suddenly I felt blocked, then vomited, and had diarrhea four or five times. Eventually, I had a rupture. (interruption) I could not eat well for a while, then I ate again, thinking I could handle it.” | |
| | (2) Total dependence on wife | “I have been very sick since I was admitted to the hospital, and if it were | Endure with Family Love |

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| | | not for my wife—my caregiver—I believe I would already be dead. (interruption) She does everything I need in order to live, because there is nothing I can do now. I ask her whether I should eat, and if she says yes, I eat. That is how I live now. I believe I am alive today because of my wife.” |
| D | (1) Voluntary isolation from relationships | “I was working hard and living life before I got sick. Among all my friends, I am the only one... No, I am the only one who ended up like this. Because I have been sick for years and years, I cannot go to the couple’s meetings, I cannot travel with them. (Interruption) When I am outside, away from home, I have nothing to eat, and my friends see that I cannot eat for a day or two.... I have my pride. I was the chairman, so I just don't go (to meetings). I feel better at home with my family, and I don't have to go to meetings with my friends and resist the urge to eat... I just... I just... I just don't go. I feel better.” |
| | (2) Forcing yourself to eat a given amount of food per day | “They say I need to reduce TPN because my liver is deteriorating, but that means I have to eat more than I do now. SBS is malabsorptive—you need to eat a lot just to absorb a little. But the amount... the amount I can eat is small. I could not eat anything during my 7-month hospitalization, so now my stomach has shrunk. I try to eat, but even my 2-year-old grandson eats more than I do. So I set an alarm. When it goes off, I force myself to eat something, like it is homework.” |

CD, compact disc; SBS, short bowel syndrome; TPN, total parenteral nutrition.