Study Notes

An Attempt to Conduct ALS Patient Meetings Using the Internet[1]

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Patients suffering from amyotrophic lateral sclerosis (ALS) gradually become unable to move due to paralyses of the extremities and the trunk, and experience difficulties in speaking as the disease progresses. Under such circumstances, participation in patient meetings becomes a burdensome task. ALS patients, however, retain clear consciousness, and verbal communication is possible with the use of a personal computer or communication aid. In this study, by means of action research, we discussed issues associated with trials for an effective, simple, and low-cost real-time meeting system. Such a system would allow patients, their families, and caregivers to realize real-time communication on their own via the Internet, by connecting a meeting place, patients' homes and hospitals. Eventually, ALS patients and researchers collaboratively planned and conducted a patient meeting and made live coverage of the meeting possible along with interactive communication among the participants in a hall and patients at their respective homes in distant places using an instant messenger (IM). As a result, we confirmed the effectiveness of the IM, but we also found the need for detailed technical assistance for patients and their families, and identified the issue of balance between the use of IM software and the operation stability of communication aids.

Key words : ALS, communication, Internet, assistive technology, action research

1. Introduction

The purpose of this paper is to find problems when patients with Amyotrophic Lateral Sclerosis (hereafter ALS), who have difficulty speaking due to the progression of the symptom, get together and communicate using the Internet through detailed examples of practice.

ALS is a progressive, intractable disease that causes the neural system for body movement (motor neurons) to denature, causing muscle atrophy and eventually, a loss of motor function. Somewhere between 2 to 6 people out of 100,000 people in Japan are afflicted, and it is said that 80% of the cases in Japan have their onset in people in their 40s. To date, no effective curative treatment has been found. Because muscular power declines, motor function becomes deprived. The disease's progression differs in each patient, but at the onset, the patients' arm and leg strength weakens. Then, it becomes difficult to talk, swallow and even breath. Despite this, a patient's perception mechanism is retained, so their consciousness remains clear (Japan Amyotrophic Lateral Sclerosis Association, 2005). In other words, patients are clearly aware of what is going on around them, but they cannot control their bodies freely[2].

For patients' groups, getting useful information about their treatment and living conditions from medical and welfare specialists, working to improve medicines and welfare, and holding various sized gatherings to exchange information are important activities. Attending these gatherings not only improves their quality of life in their intimacy sphere, but they also increase the influence of what they say and their power of negotiation in public sphere. In recent years, information services and peer support using websites and mailing lists have become active thanks to the spread of the Internet. However, it is obvious that actual gatherings that supply places where ALS patients can physically attend and share their experiences and information are very meaningful to them, as these patients eagerly attend them while wearing ventilators and sitting in wheelchairs with batteries mounted on them.

However, when they start having difficulty talking due to the progression of the disease and wearing ventilators, it is difficult to conduct real-time communication at these meetings. To respect the independent participation of patients at a maximum scale, it is preferable that such gatherings are bidirectional so attendants having difficulty on their speech can easily share their opinions at the site and patients who have difficulty going out due to various conditions can attend these gatherings from homes and hospitals on the Internet in order to state their opinions[3]. Unfortunately, this is not easy to realize. The technologies and operation systems required for multiple ALS patients who have difficulty with their speech to get together and have real time communication, and the relationship of people who organize such communication,

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2) Regarding what ALS patients experience at outbreak and as the disease progresses, and how they have devised techniques and systems to help with the living process and the people around them, and how to created new systems, there is much to learn from Hatanaka (1999), Tateiwa (2002), Uetake et al. (2004), "Ikiruchikara (Power of Lives)" Editorial Board (2006) and Yamazaki (2006), etc.

3) Recently, the spread of broadband connections has developed a technical environment that makes it easy and convenient to hold Internet conferences using Instant Messenger (hereafter IM). IM is an application software that allows audio, visual and text information to be exchanged in real time through the Internet, and anybody can use it by downloading free software such as Yahoo! Messenger. A free phonovision software, Skype, can also act as an instant messenger.

has barely been discussed[4]. To develop an effective, convenient and low cost real-time conference system that enables synchronized communication between the conference site, patients' homes and hospitals in front of patients, their families and care givers, it is necessary to examine the technical, psychological and social phases in a diversified manner based on patients' physical conditions.

Under the awareness of such issues, we held an "ALS Living Technology Workshop" in Sakai City, Osaka on March 4, 2007 as both an experimental and practical activity. This workshop was held through the cooperation of labor between patients and researchers, from its planning and preparation to its operation on workshop day. What follows is a description, from planning to implementation, of the ALS Living Technology Workshop. It examines the issues toward realizing bidirectional communication in ALS patients' gatherings.

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4) Regarding communication support for people who have speech disorders, there are studies, such as Yoshihata and Watamori (2001), Yamamoto (2004) and Yasui and Mochizuki (2006), etc., in which they examine people who have speech function disorder including aphasia. On the other hand, in the case of ALS patients, the subject's sound function disorder derives from a decline of vocal and speech abilities, but language composition and comprehension is not affected. Therefore, the usage of an information handling tool to deliver one's intensions should be effective and it should be considered that symptoms and specific conditions exhibited by ALS patients. Including the attachment of artificial respirators, will affect that communication. Therefore, analysis and how aid should be supplied for ALS patients' communication should be approached in a different direction than that for people with other speech function disorders. To effectively help patients obtain augmentative and alternative communication （AAC） technology, there is an accumulation of many studies, including Toshima (2001).

2. Aspects of the ALS Living Technology Workshop

2-1. ALS Patients and Communication Technologies

For ALS patients whose symptoms have progressed, it is obvious that devices to support their lives, such as gastric fistula catheters and ventilators, have a very important meaning. However, at the same time, though clearly cognizant, it becomes very difficult for them to communicate with others through their bodies, such as by talking, nodding and moving their arms and legs. Thus, how to request things and express their wills becomes a very compelling issue. They have to deliver their requests, like the suctioning of phlegm and the changing of body position because of pain, to their care givers.

To combat this, various techniques to help ALS patients express their intentions and representations have been invented by patients, their families and care givers. Examples include a method that lets a patient follow a transparent ETRAN with his/her eyes so the care giver can read it, or having a care giver say Japanese syllabary for a patient who then acknowledges the correct syllable by blinking, etc, allowing the care giver to read a message out loud （Japan Amyotrophic Lateral Sclerosis Association, Niigata Branch, 2007）. Furthermore, devices to transmit intention, such as computer input support software and the system to operate computers and home electric appliances by remote control with an input switch adjusted to the condition of the disability, "*Den-no-shin*"

(Hitachi, Ltd.) have been developed. Also, appropriate input sensors that change with the symptom's progression is important. The development of sensors that respond to the movements of fingertips, eyebrows, cheeks as well as blinking and eye movement when moving lines of vision and input switches, and furthermore, the development and research of products that enable communication for patients with changes in brain waves and brain blood flow when symptoms worsen are promoted by specialists in electronic engineering and neurophysiology (Japan Amyotrophic Lateral Sclerosis Association, 2005, Nakamura et al., 2007 and Kano et al., 2007)

These techniques and communication devices don't only inform care givers about daily needs, but support communication in the areas of mental exchange and expression of opinions. Although each technique is quite important as a basic component, it is not possible to understand an aspect of communication by only reducing the cause to it. In regards to the organization of the ALS Living Technology Workshop in March 2007, both patients and researchers participated and observed how a communication site could be formed in collaboration. They set a goal of trying to understand the whole event in a comprehensive manner and find out new assignments for the next event in order to develop interactive communication from remote places based on real conferences.

2-2. ALS-IT Project and Action Research

The research technique based on the practice we conduct can be determined to be action research. The definition of action research is different for different research areas and researchers, but this research fits in an extended definition, "cooperative and practical research among people at site and researchers to look forward realizing certain social conditions" (Higashimura, 2006). Because action research assumes practical purposes, researchers' involvement toward subjects is stronger than a participating observation method, so researchers can become both practitioners and observers.

The first author of this paper, Matsubara, founded the ALS patients' IT project in fiscal year 2006 (hereafter ALS-ITP) as a part of "Basic Research to Establish Patient-Led Scientific Technology Research Systems" (Grant-in-Aid for Scientific Research in fiscal year 2006). The ALS Living Technology Workshop was the first attempt of ALS-ITP. The beginnings of ALS-ITP was a suggestion by research co-worker, Yumiko Kawaguchi (Executive Board Member of Japan Amyotrophic Lateral Sclerosis Association). From her abundant experiences with ALS patient support activities as the member of a patient's family, Kawaguchi thought it was necessary to develop a system for patients with speech disabilities to exchange their opinions at gatherings as well as participating in gatherings through the Internet from their homes and hospitals. This was because gatherings tends to proceed at the pace of people who don't have difficulty in linguistic communication, and therefore, when patients with speaking difficulties participate at such gatherings, they cannot make remarks as they wish and send complaints to group e-mails. Also, trials using speech synthesizers

at lectures（Tateiwa, 2004）and an Internet relay broadcast of ALS related conferences（Nakajima, 2006）had already been conducted, but according to Kawaguchi, no interactive conferences with patients' participation using IT existed before the development of ALS-ITP.

There are many stages until the technology of welfare engineering reaches patients, who are the end-users: from research and development at research organizations and manufacturers, commercialization at manufacturers, welfare systems including Services and Supports for Persons with Disabilities Act, distributing agents to families and care givers. However, the effective, convenient and low cost real-time conference system that we are looking to realize in front of patients, their families and care givers was considered appropriate when it was approached from a bottom-up manner. That means, it should be framed from patients' knowledge at the site and then requested of engineering and information network specialists according to the needs, based on the issues noted at the site. Additionally, it was indispensable to have patients who are familiar with the needs of those involved and appropriate technologies for them to operate ALS-ITP. Among those who have advanced ALS symptoms, there are always more than a few people who understand technology well, adjusting switches and software/hardware of IT equipment to make them easier to use and/or converting care equipment.

Thus, ALS-ITP started as an attempt to find new assignments from processes created through local knowledge（Geertz, 1983 and Fujigaki, 2005）. Local knowledge means, people who "are familiar about patients at the site", and researchers who are interested in the relationship between scientific technology and the human body, while respecting patient-led scientific technology research systems. There was no example of a gathering where patients at both the site and remote places had interactive communication. Therefore, this research started to plan such a gathering by trial and error. Also, even if it was an experimental attempt, it should be a meaningful and enjoyable gathering for participants, since for ALS patients with progressed symptoms and their families get together requires much labor. Furthermore, we wanted to plan a patients-led, real-time conference system with the technology and techniques suitable to the gathering in which even patients in remote places could feel they were actually attending the site of such intimate interchange, thus leading it to promote patients' participation in general society. For that, we thought it was appropriate to use the action research method, in which one finds out the problems in the action of planning an event, determines even new assignments and tries to solve them rather than conducting a practice method that just sets and solves assignments.

The following is a description and analysis of the co-working process between patients and researchers from the initial start up of the working team to the implementation of the ALS Living Technology Workshop to preparation and operation of the one-day event, and the determination of assignments for the next action. This paper mainly

discusses the issues of technology and operation. Regarding the analysis of on-site communications on the day of event, we examined it in a different paper (Hidaka, Mizuki, Sato, Matsubara, 2007).

3. Preparation of the ALS Living Technology Workshop

3-1. Starting work team between patients and researchers.

The first ALS-ITP attempts was planned for the Kansai area, the location of Matsubara's worksite. At the end of September 2006, Kawaguchi and Matsubara believed that Katsumi Wanaka, Chairman of the Kinki Area Block of the Japan Amyotrophic Lateral Sclerosis Association was the key to conducting the ALS-ITP and they asked for his cooperation. Mr. Wanaka is a generally impaired patient with limb trunk paralysis and resides at home using a ventilator. He noticed something unusual on his body in 1990 and announced he had ALS in 1992. In 1995, he decided he needed to start learning how to use a computer in order to compensate for the bodily functions he would lose as the disease progressed. He installed Ki:nex, an input assistance device for computers developed for Macintosh computers (hereafter, Mac) in 1996, and set it up in a way to make it most convenient for him, using the Mac for daily instructions to care givers including suctioning of phlegm, writing documents and communicating through the Internet, including e-mail[5]. Also, he is very much respected by patients and

their families as Chairman of the Kinki Area Block of the organization, thus making him indispensable for a project that wished to create a place of new communication with the knowledge of technology only close to patients.

Wanaka, who agreed to participate in the project, requested Junji Hisazumi (KAMON-no-kai, in a wheelchair due to paralysis caused by ALS), who held volunteer activities to support ALS patient communication using computers, to select a barrier-free facility where people had easy access and was equipped with a broadband environment. At the suggestion of Hisazumi in early October, it was decided that the "ALS Living Technology Workshop" would be held at Big i: International Communication Center for Persons with Disabilities on March 4, 2007. At the same time, Matsubara requested Hiroshi Mizushima (Tokyo Medical and Dental University) to be in charge of the Internet relay broadcast and received approval. The aspect of a "Convention where patients can participate in a real-time conference from remote places using the Internet" planned by Kawaguchi and Matsubara included a research report of Mizushima's previous achievements (Nakajima, 2006) regarding incurable diseases such as ALS conducted on Internet relay broadcasting. Matsubara, who learned that Mizushima had volunteered to bring in all the equipment and conduct the Internet relay

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5) For example, he can send e-mail from home to a cellular phone of a family member who is outside, asking them to "Please come back in 30 minutes" (Wanaka, 2007).

broadcast, told him about the ALS-ITP plan when they met at a workshop in June 2006, and secured Mizushima's agreement. Mizushima became an irreplaceable cog for the ALS Living Technology Workshop, along with Wanaka and Hisazumi.

Wanaka, Hisazumi, Kawaguchi and Matsubara worked over the plan via e-mail towards the end of December. We set the goals at the ALS Living Technology Workshop to be for patients to be able to exchange their information regarding the IT related systems they'd contrived and used and us finding assignments to actualize an easy workshop（gathering）on the Internet. With these goals, we started to prepare, including a discussion of participant candidates. From the workshop site, live images and audio data were compressed to be sent out to a external server and delivered to the Internet. On the other hand, from patients and their families' houses in places remote from the workshop site, we used an Instant Messenger system called Yahoo! Messenger（hereafter IM）and received images and text messages on the computer at the workshop site and projected them onto the projection screen, sharing them with participants at the site. Furthermore, Sato, a co-researcher of the "Basic Research to Establish Patient-Led Scientific Technology Research System" announced his participation in ALS-ITP, to record the phenomena at the ALS Living Technology Workshop with Mizuki, who established some achievements in fieldwork research, and Hidaka, who was interested in the analysis of scientific communication.

3-2. Embodiment of assignments and responses to the technical phase

On January 6, 2007, Hisazumi, Kawaguchi and Matsubara got together for the first time at Wanaka's house to discuss the project and check Wanaka's system and settings. That same day, Hisazumi installed Yahoo! Messenger on Wanaka's computer, Mac（OS9）and started to prepare it for remote communication. On January 10, Hisazumi opened the mailing list for ALS-ITP（"it-pro"）, mainly including work team members. Later, names of graduate students and researchers who supported this project were added to this mailing list and accomplished the function of a virtual conference room to prepare for the ALS Living Technology Workshop.

On February 13, Mizushima, Kawaguchi Hisazumi（with a care giver）, Kazuki Takada and Shintaro Aoki（both are graduate students on the operations staff）held a preparation meeting and checked the conditions for interactive communication on the day of the workshop and the required equipment, as well as straightening out assignments for computer use environment for patients in interactive communication. The first issue was to secure an Internet environment that enabled the uploading of a live motion picture relay broadcast to a server outside of the workshop site. It will be detailed later, but on the very day of the workshop, we were obliged to change this plan.

The second issue was to offer technical support for patients who were participating with remote communication. We had to install a motion picture replay software（this time,

we used RealPlayer) to reproduce the relayed image and audio, and the IM for remote communication to patients' computers. Additionally, a device to transmit a patient's intention, "*Den-no-shin*," is used by many ALS patients, but it was not possible to simultaneously operate "*Den-no-shin*" and view the Internet relay, so it was necessary to set up separate computers to view the Internet relay broadcasting. Including the support for patients to practice operating the IM with "*Den-no-shin*" and to test communication beforehand, a careful support system was required to ensure that patients could participate in remote communication. However, we could not secure enough staff members to visit their homes and hospitals to install this software at bedside and support their IM practice operation. Also, we could not establish a system to obtain and deliver the computers to view the Internet broadcasting for patients participating from remote places. Therefore, we asked patients who we anticipated would participate from remote places to come to the workshop site on the day, and 4 of them did. On the other hand, only one patient, Misao Hashimoto in Tokyo (Chairman of the Japan Amyotrophic Lateral Sclerosis Association, who resides at home using an artificial respirator), participated through remote communication. Hashimoto doesn't use "*Den-no-shin*" but uses infrared sensor that input data into her computer through the slight movement of her toes. Kawaguchi, who lives in Tokyo, supported Hashimoto, installing the software on the computer at her house and conducting IM practice sessions with her as well as

testing the communications beforehand with Wanaka and Hisazumi in preparation for the day.

Wanaka was also going to participate in the communication using IM at the site on the day of workshop, and started to practice using IM on his favorite Mac with support from Hisazumi. However, there was a problem. For IM audio and visual communication, a web camera and headset are required, but Wanaka's Mac (OS 9) was an older type, so we could not obtain equipment that conformed to his computer. Therefore, taking higher versatility into consideration, we quickly decided to borrow a Windows installed laptop computer (Windows XP) from ALS-ITP. We installed IM and "*Den-no-shin*" (trial version)[6] on the laptop and Wanaka used it while Hisazumi, the supporter, monitored. For Wanaka, inputting text to IM for his first time use of "*Den-no-shin*" unexpectedly created many problems. In particular, since Wanaka was a user of "*Kotoeri*", a Japanese input software for Mac, there was a lot of pressure on him to become familiar with "*Den-no-shin*" operated by MS-IME (Japanese input software for Windows). Using "*Den-no-shin*", he didn't notice that the standard input system was set to Japanese syllabary input, and the letters emerged as gibberish, which put more pressure on him. For Wanaka, who creates

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6) "*Den-no-shin*" as a device to transfer one's intention, is manufactured only by Hitachi Keiyo Engineering & Systems as a software and hardware set (Hitachi Prius Series). The "*Den-no-shin*" software itself is not for sale, but one can download a 180-day limited use version of it from Hitachi's website for supporters' usage.

writing with auto-scan input[7] from an input switch by slightly moving his fingers, small troubles lead to great stress. However, Wanaka overcame these troubles by talking with Hisazumi, and by the day of the event, he had little if any trouble communicating through the IM.

3-3. Preparation at the site

The ALS Living Technical Workshop was set to start at 2 p.m. on March 4th. On the night of March 3rd and the morning of March 4th, working teams went to the event site and set up equipment and test the communication system (Photograph 1). After noon on the 4th, patients, their families and care givers started to arrive. Staff members including graduate students took care of securing electricity for artificial respirators and guiding the visitors. Being in charge of this project, Matsubara explained about participating in the research to each patient and all accompanying family members, obtaining agreement from everybody.

The large conference room at Big-i is an approximately $240m^2$ (for approximately 150 people), barrier-free open space. It was flexible enough that we could allocate several patients in reclining wheelchairs yet set up tables and chairs according to most any circumstance, taking into consideration the flow lines of care givers and researchers.

Additionally, securing electric power was very important for those using ventilators. There were 8 outlets (100V) in the room, and that was enough, even though we also had all of our equipment, like computers, plugged in, too.

Regarding communications, we took a wireless LAN router to the site and secured an environment that where multiple numbers of participants' computers, including Wanaka's and participants in remote places, could communicate via the IM. Regarding the Internet communication, Mizushima put an entire set of equipment into a large suitcase and brought it from Tokyo, beginning its preparation the previous evening. However, we had an unexpected problem. We had confirmed with the facility's personnel when reserving the site that it was possible to upload relayed pictures, but the relay broadcasting test on the Internet was not successful, so we asked the facility's personnel about it. They could not determine the cause of the problem and asked to the administrator of the communication facility. We found out that due to security reasons, we

Photograph 1　Hisazumi checks IM operation on the wireless LAN

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7) The input system that one selects the timing of the cursor place, which automatically moves on the computer screen dial. Compared to regular keyboard input, a user must push a switch several times to select one letter. When a conversion of letters is wrong, the user must input the letter again, so that it takes a lot of labor.

could not upload visual images from the site to an external server, and this security provision could not be released due to facility management security. So, Mizushima hurriedly reset the system so it would be able to relay broadcasts of the picture of the site via IM by switching multiple numbers of camera images and waited for the real event.

4. Operation of the ALS Living Technology Workshop

4-1. Program Implementation

The ALS Living Technology Workshop was held from 2:05 p.m. to 4:10 p.m. on Sunday, March 4th, 2007. The event's program is shown in Table 1. Matsubara took on the role of master of ceremonies.

In the greeting at the workshop's beginning, which was read out loud by his daughter,

Wanaka said when he started to use the computer at home 11 years before, using the Internet was only a "dream of dreams", and when he joined the ALS mailing list through the Internet, he felt that "the world opened up in front of me" and he "still can't forget the great feeling he had at that time". He concluded with the following words. "We are going to communicate with Ms. Misao Hashimoto in Tokyo using real-time audio and visual communication. It will give us great encouragement just to see each other in good spirits. There are many users of "Den-no-shin", and I think it will be easier for this to spread all over Japan if we can operate it with "*Den-no-shin*". I hope today's research will spread among ALS patients." Wanaka presented the characteristics of the plan for others to understand easily from the viewpoint of a patient, and called for the attention of all participants.

Table 1 Event Program (Patients are shown in gothic letters)

Time	Content
14:05	Opening Statement (Matsubara), Explanation of communication facilities (Mizushima)
14:10	Greeting (**Wanaka**, read by his daughter)
14:15	Report 1 (**Hisazumi**) * Around this report, chat preparation was ready.
14:42	Report 2 (Mizushima)
14:54	Break announcement
15:09	(After 15 minute break) Announcement of resumption * Starting real chat operation.
15:11	Greeting (**Hashimoto**), Explanation of the technology (Matsubara)
15:24	Impressions 1 (**Terada**)
15:25	Impressions 2 (**Hotta**, while waiting for the response, question 2 was made), Comment (Supporter 2)
15:28	Question 1 (**Sugimoto**), Response (**Hisazumi**)
15:34	Question 2 (Hotta, read by his wife), Responses (Matsubara, Mizushima, **Hisazumi**), Comment (Supporter 2)
15:40	Future technical assignments (Mizushima, **Hisazumi**)
15:45	Comments regarding equipment (Matsubara)
15:48	Comment (Patient's family)
15:52	Summary (Matsubara)
15:57	Impressions (Takada, Mizuki), Thank you (**Wanaka**, read by his wife), Thank you (**Hashimoto**)
16:10	Announcement of event's close (Matsubara)

Next, Hisazumi and Mizushima gave a PowerPoint report. Hisazumi introduced comments from users while explaining about nursing care goods and various supporting technologies, and also referred to the assignments of ALS-ITP. From the standpoint of a medical informatics researcher, Mizushima reported about the sharing of medical information using the Internet.

After a break, Hashimoto offered her greetings, then demonstrated and explained IM. Then, opinions and questions by patients, their families and supporters in attendance were proffered. After using a demonstration IM, a patient named Hotta asked, "I'd like to use IM, but the letters are too small. Can you do something about that?" Hisazumi replied, "Letters can be enlarged by the IM setting. However, the convenience of usage somewhat depends on the size of the computer, so I'd recommend using a bigger display." Comments from family members included, "It's nice to have the information in Hisazumi's report. We'd like to have a system that enables us to share and update

patients' knowledge and information," and "It's necessary to have a united system for patients and their families to actively use IM". Finally, Wanaka and Hashimoto made some further comments and closed the workshop. After completion of the event, we took some group pictures of all participants （Photograph 2）.

32 participants came to the site. There were 6 patients （all of them in wheelchairs, 3 with artificial respirators）, 13 family members, care givers and supporters, 4 researchers and 9 staff members including graduate students. Remote participants were Hashimoto and Kawaguchi from Tokyo.

4-2. Condition of the Internet communication

Figure 1 and Table 2 show the arrangement plan at the site and the equipment used. During the program, Mizushima switched pictures from the 3 network cameras and the computer's IM images by remote control and projected them on Screen 1 and relay broadcasted the scene at the site with IM （Photographs 3, 4 and 5）. Also, Wanaka's


Photograph 2 A real time picture of some workshop participants in Osaka and the real-time IM screen image of Hashimoto in Tokyo


Photograph 3 Mizushima sends a relay broadcast of the scene from the workshop site on IM.

computer screen was shown on Screen 2 with a projector and participants could see what Wanaka was communicating on IM using the trial version of "*Den-no-shin*" (Photograph 6).

Initially, we were planning to have 2 dimensional system communication that sent out a live broadcast of the site on the Internet and received responses from remote sites through IM. However, as mentioned above, video distribution through the Internet was not possible due to conditions at the site, so both relay broadcasting and response were united with IM. Anybody can see the video distribution as long as they can open it with motion picture replay software, but for IM, users need to obtain IDs and correspondence is limited to members whose access is approved. However, we could not prepare a sufficient patient aid system, so there were no participants in remote places that would be in trouble if they could not see the picture distribution through the Internet on IM. Both relay broadcasting at the site and communication with remote places were conducted without any problems. To virtually experience remote communication, Takada, a graduate student, took a laptop computer to an outside corridor next to the conference site and tried to use the IM, allowing confirmation that both the audio and visual quality were realistic and satisfactory. Kawaguchi, who accessed the site from Tokyo, commented that the audio was of very good quality and that she could recognize each participant's face, saying "The image is beautiful" in the chat. However, Kawaguchi had a setting trouble while using IM and sometimes the audio from the workshop site was interrupted.
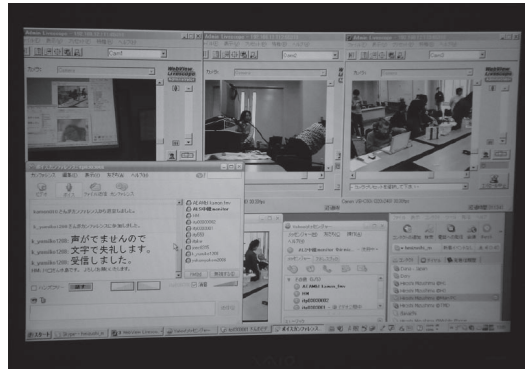
Photograph 4 Mizushima's computer screen, switching images. Images from 3 network cameras and the IM window.
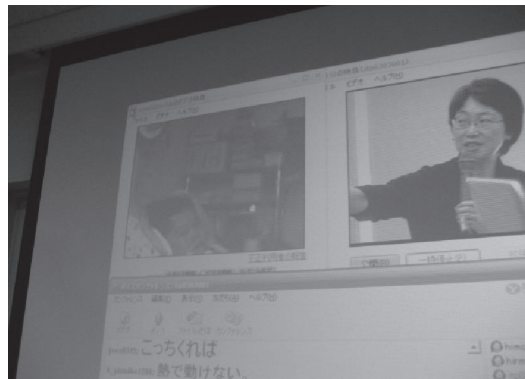
Photograph 5 Screen 1 showing Hashimoto in Tokyo (left), Matsubara at the workshop site (right) and the IM chat screen (bottom).
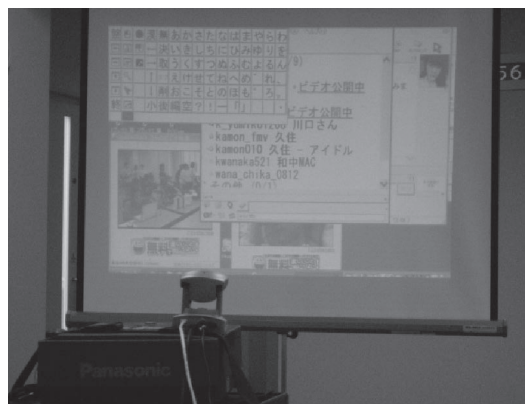
Photograph 6 Screen 2, showing Wanaka's computer screen. Text dial for the trial version of "*Den-no-shin*" and chat on IM, and the relayed broadcast picture on the IM are shown simultaneously.
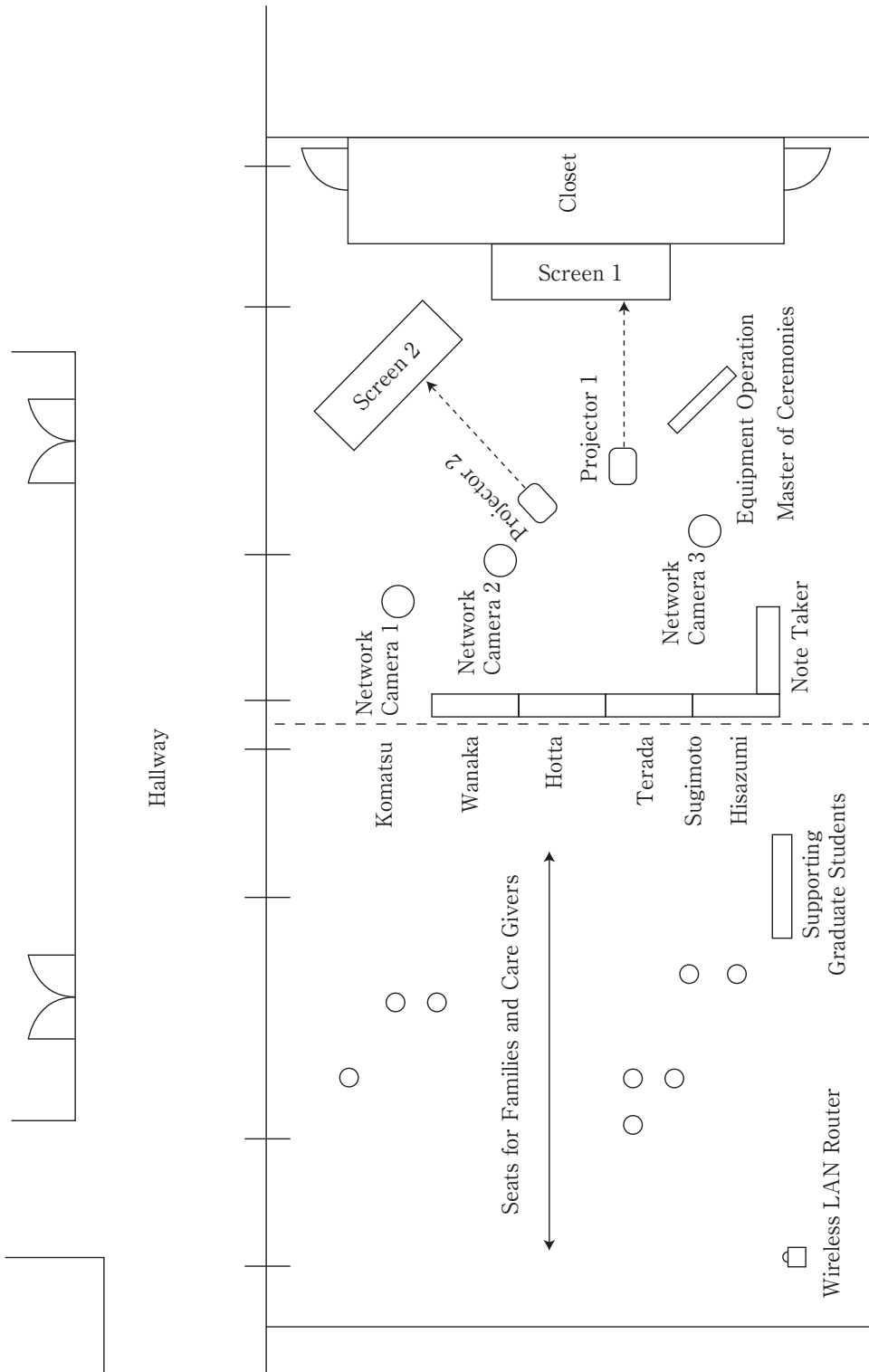
Figure 1 Arrangement Plan at the Site

Table 2 List of Equipment Used for Internet Communications at the Site

Equipment	Name (Model Number)	Usage, Unit, etc.
PC1	SONY VAIO VGN-TX51B/B	For encoder (process that makes it possible to see the image on a network camera via the network)
PC 1 (software)	Real Encoder	Software for encoder
PC 1	Yahoo! Messenger	IM software. In addition to text, it is possible to send and receive video (motion picture)
PC 2	SONY VAIO VGN-AS34B	For camera control
PC 2 (software)	Real Monitor, Server Monitor, Chat	Software for camera control
PC 2	Real Player	Software for playing back images
PC 2	Camera Controller	Software for camera control
PC 2	Server Monitor	
AV Switcher	SONY SEG-XV1000	Hardware to switch equipment
Game Selector	Victor JX-51	Hardware to switch image/audio
Down Scan Converter	ADTECHNO DSE-002	Hardware to imaging the content of projector
AC Extension Cords		3 units
AC Multiple Sockets		3 units
Wireless Microphone (battery charging, charging equipment)	SONY UTX-B1	Used for places wired microphone cannot reach.
Wireless Microphone Receiver	SONY URX-P1	Same as above.
Wireless LAN Router	Buffalo WHR-G54S	Used to enable an Internet connection at places away from LAN outlets in the conference room.
Network Cameras	Canon VB-C50i	2 for projector filming, 1 for filming the entire site. Each image was sent out via the Internet according to need.
Network Camera Adopters	Canon VB-EX50	3 units
Network Camera Power Sources		3 units
Tripod for Filming the Site	Velbon Z-5001	To immobilize the camera.
Ethernet Cables		3 for camera, 1 for upper connection, 1 for extension.
AV Codes		3 for cameras, 2 for mixers, 1 for extension.
Projectors		1 for presentations and broadcasting the scene at the site. 1 to display the image on Wanaka's computer.

4-3. Progress at the site with IM

The latter half of the program began with greetings from Hashimoto (patient) in Tokyo (Table 1). The master of ceremonies (Matsubara) requested a message from Hashimoto, and participants waited for it to appear on the screen while watching the picture of Hashimoto projected on the screen. The following is the scenes that featured communication through IM at the conference. Numbers (1) to (9) are spoken by the emcee (Matsubara). The bold letters inside the < > are chat log in IM and those inside [ ] from participants who sent messages. [→( ) sec.] is the duration from the emcee's words to the next words, and the majority of that time was the waiting time for IM messages.

(1) I'd like Ms. Misao Hashimoto to send us a message. Ms. Hashimoto, please give us a message. The message from Ms. Hashimoto will appear on the lower part

of this screen. Let's wait a moment.
[→ 8 sec.]

(2) Here it is. I'll read it out loud. (Hashimoto's face is shown on Screen 1 together with the message) **<Good afternoon>** **[Hashimoto 1]** [→13 seconds]

(3) **<How's the weather there?>** **[Hashimoto 2]** [→6 seconds]

(4) (Participants now urged Matsubara to respond) Yes, it's my turn (laughter). It is nice here. Very warm as we are sweating a little. How's it there? [→12 seconds]

(5) **<It's hot>** **[Hashimoto 3]** So she says (laughter).

It seems to be the same. [→6 seconds]

(6) There was a momentary glitch… (a small problem with the screen). (Misuzhima's voice, "It is only here.") [→13 seconds]

(7) Now, we that we've received the message, **<I'd like to ask Ms. Kawaguchi to join us, but it doesn't work well. It is very fine weather in Osaka today>** **[Takada 1]** from somebody. Who is it? itpXXX… (Yahoo! Messenger's ID number is displayed with the message, but Matsubara doesn't know the ID belongs to Takada) (Mizushima says, "That's Mr. Takada, from outside." Participants at the site laugh) Probably, it is Mr. Takada, a graduate student who is monitoring outside this room. The context is strange and I don't know why this message came out (laugh). So, Ms. Hashimoto, would you give us another message? [→14 seconds]

(8) **<Excuse me. I'm Takada, a graduate student>** **[Takada 2]** is on the screen

(laughter). Ms. Hashimoto, how about you? We are waiting. Would you give us your message? [→42 seconds]

(9) Now, the display says, <Kawaguchi has joined the conference>. (Looking at the display, **<Oh, I can hear>** **[Kawaguchi 1]**), I guess Ms. Kawaguchi couldn't hear it but now, she can. Ms. Kawaguchi, you can hear it now… Now… a new message has come in. **<Mr. Wanaka, I'll be looking forward to chat with you since we can only see each other once a year>** **[Hashimoto 4]**… Oh, this is from Ms. Hashimoto.

For many participants, this was their first experience of communicating through IM, so everybody closely watched the screen with interest and listened to the emcee's explanations. It was a very friendly atmosphere with smiles and laughs. Hashimoto, who was at a remote location, delivered a message to a care giver with a phonetic dial and the care giver input the message on IM. The duration required to this was approximately the same as that of waiting for a return message. During this time, participants quietly waited for responses. Although it was rather a long 42 seconds from (8) to (9), participants just watching the screen in a relaxed manner and waited. [→ 6 seconds] on (3) was a "false waiting time" because Matsubara misunderstood there was a message coming after [Hashimoto 2].

When multiple numbers of people chat on IM, there are occasions when neighboring messages on the chat log don't appear in order. (7) [Takada 1] seems like he responded

to（3）[Hashimoto 2] but didn't realize that
（3）was the response to the question from the
emcee. Before the break, Takada and
Hashimoto were communicating about
Kawaguchi's audio trouble using the IM chat
and（7）was a response concerning this
communication.（8）[Takada 2] was probably
following the statement made by（7）
Matsubara. So the chatting on IM is not
always shown in actual order, and as a result,
messages get confused. When a member
needs more time to input a response, this
tendency may increase, but it would be
possible to a certain degree to reconstitute
them in actual order to understand the flow.

However, even while the program was
proceeding without dealing with IM chat,
Wanaka, Hashimoto, Kawaguchi and Takada
were continuously "chatting" as they
checked their audio and video conditions and
made light conversation. The log of this
chatting was constantly showing on the
screen, so the participants could see this
"chat" while watching the program proceed.
Since Wanaka and Hashimoto use ventilators,
they cannot conduct real-time conversation.
However, though the timing was slightly off,
they were enjoying an easy conversation in a
somewhat settled manner. Participants could
visually "monitor" it as a chat log on the
screen. Sometimes, their chat caused
participants to laugh（Hidaka, Mizuki, Sato,
Matsubara, 2007）.

5. Implication

In this paper, we have examined the
processes used to plan and implement the
ALS patients' meeting, mainly the technical
and operational phases.

A development in the technical phase that
we didn't expect was that the Internet
distribution of a relayed broadcast of the
meeting could not be actualized. To ensure
this, it would be preferable to take some extra
days on the schedule and conduct tests at the
actual site beforehand. In fact, we tried to
schedule a meeting at the site with
Mizushima in February, but we couldn't
work it out. Had we known the actual
communicating conditions through testing
and had a more thorough facility investigation,
we could have requested a communication
business agency to set up the ADSL line
beforehand. However, it is doubtful that
commissioning such an agency would conform
to the purpose of "establishing an effective,
simple and low cost real-time conference
system that can be actualized in front of
patients, their families and care givers". In
any case, it was very difficult to foresee the
actual conditions at the time, especially
considering the burden on Mizushima, who
had to take all the equipment from Tokyo to
Sakai City in Osaka, as well as limitations in
scheduling and on the number of people for
adjustment. We were slightly worried about
visual image uplink, but we prepared under
the assumption that the relay was possible,
since the person in charge of the facility
guaranteed it.

On the other hand, it was an unexpected
plus that though we gave up the Internet
distribution, we succeeded by switching to
the IM relay. Anybody can download IM

from a website, for free. It doesn't require any technology or special equipment, nor an external server, which is required for Internet distribution. It is "convenient and low-cost". Also, as Wanaka demonstrated, it is possible for patients to broadcast live audio and visuals from the meeting site with text messaging using a computer downloaded with "*Den-no-shin*", a microphone and a web camera, as long as he/she can receive support from others to set it up. However, at this time, we must admit that we had the advantages of securing relay broadcasting on IM and good screen quality at the site, largely because we had high-performance network cameras for remote operation, devices and equipment that allowed multiple images to be switched according to circumstances, as well as Mizushima's high degree of knowledge.

Overall, it became clear that within the scale of an event like the ALS Living Technology Workshop, image distribution could be conducted with IM, even if it was not possible to do it on the Internet. And when interactive real-time communication is assumed, it was more appropriate to use IM than Internet distribution because the system could be centralized. However, Internet distribution is superior to IM in the areas of high quality image and sound. Also, IM can select members to exchange information, but it is not possible to deliver information to an unspecified number of people like the Internet. Even if one doesn't have IM knowledge or technology, one can watch distributed images as long as there is a computer with software that can play moving images. However, distribution on the Internet is one possible

way. Since ALS-ITP is seeking interactive real-time communication at gatherings, how IM can "establish an effective, simple and low cost real-time conference system that can be actualized in front of patients, their families and care givers" remains an issue.

During preparation, it became apparent that there are several difficulties for "*Den-no-shin*" users to make a good use of IM. As a device to communicate, "*Den-no-shin*" usage is easy for patients, even if he/she doesn't have any experience using computers. There are many ALS patients with progressed symptoms who use "*Den-no-shin*", since it can be obtained as an "prosthesis", and they bear only 10 percent of the cost. Wanaka proved he could use IM with "*Den-no-shin*", but he had to very patiently go through trial-and-error testing, and it required a lot of practice. Also, without Hisazumi's technical support, it would probably have been difficult to learn in a short period. We need to investigate what kind of problems ALS patients who already use IM had to solve to use it, and just how they did so. It should not only look at cases like Wanaka and "*Den-no-shin*", but at users of other computer input support devices, including operating navigation and XS switches. If we can use what we learn from it, and share it with supporters and companies that offer IM, it could lead to increased IM accessibility.

This time, Wanaka used IM after installing "*Den-no-shin*" (trial version) on a Windows computer sold on the market. Hitachi's communication device "*Den-no-shin*" takes priority to secure safety and stability as a tool to deliver user's intention, so it doesn't

guarantee proper operation if other software is installed on the computer. That means, the device for transmitting intention, "*Den-no-shin*", is a personal computer but set up as specialized in the intention transmission device. Therefore, it is difficult to input text to "*Den-no-shin*" and operate the IM at the same time.

We would like to examine how a user of "*Den-no-shin*" can use IM, or if there are any other future possibilities to conduct similar type real-time communications besides IM.

Furthermore, for patients to use IM, it is necessary to have support, including advice about obtaining equipment, including a web camera, installing a system and learning how to use it. How can these patients obtain easy, convenient and proper support? We must come up with ways and knowledge to ensure that.

On the other hand, we discovered something on the operating phase that we could have only found out from a real-time gathering using IM. Participants shared the progressing program at the site or from remote places through IM image and sound. There was a flowing communication as time went on. However, at the same time, it must be noted that the "chatting" participants on IM were discussing issues not directly related to the program. The chat log was both slightly different and matched the neighboring messages, which made for communication with a complex time flow vector. Furthermore, the chat log shown on the screen and the participants at the site could

visually "monitor" it in real-time manner. Thus, the ALS Living Technology Workshop did not have one communication shaped by all participants, but instead established a unique style of communication, as patients and people at the site were united while a number of communications were going on at the same time between people chatting on IM.

There seemed to be a multi-layer type communication, different from the communication born from regular conversation, which arose because of "silence" and "waiting" time. During the program, when the emcee asked a patient something and the response time became long, there was an occasion when the right to speak moved from the patient to his accompanying wife. In this case, "silence in waiting" in an ordinary time flow program happened to have the effect of "invoking power without intention" (Hidaka, Mizuki, Sato, Matsubara, 2007). Compared with this, the chat communication on the IM and program were going together as noted in section 4-3, and it seemed that "waiting" and "silence" became more natural "intervals" through the action of watching the messages show up on the screen. What is needed for communication between people with speaking difficulties so they can get together and state their opinions and intentions to each other in a comfortable manner? With the future assignment for technical use of the IM mentioned above, we'd like to continue inspecting social and psychological feature of communications at real-time conferences using IM.

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