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## **Development of a Support Group Using a Virtual Space for Cancer Patients**

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### **Development of a Support Group Using a Virtual Space for Cancer Patients**

#### **Abstract**

We report findings from a chat log analysis of a support group in which 2–5 patients and one or two facilitators chatted in a virtual space; weekly sessions lasted 1.5 hrs. each, and we followed them over five years. In the virtual space, participants were represented by avatars with emotional expressions. Chat messages were analysed with a text-mining tool, exploring whether positive emotion words (e.g., ‘happy’), medicine-related words (e.g., ‘symptoms’), and informational/emotional-support messages (giving and receiving) would increase over time. We found that frequency of positive emotion words increased in Years 1–3 and remained constant thereafter; medical-related words did not increase until Year 5. Support messages increased from Years 1 to 3. Analysis of messages indicated that the patients’ and facilitators’ conversational roles changed as a sense of community emerged. The virtual support group appeared to promote positive emotions, trust among members, and mutual supportive relationships within the group.

**Keywords:** support group, Computer-Mediated Communication (CMC), avatar, Multi-User Dungeon (MUD), cancer patients

## **Development of a Support Group Using a Virtual Space for Cancer Patients**

### **1. Introduction**

Support groups have been shown to benefit cancer patients when delivered face-to-face (e.g. Yoshida et al., 2004) or through electronic bulletin boards and forums (e.g. Alpers et al., 2005; Blank et al. 2010; Lieberman et al., 2003; Rodgers and Chen, 2005; Seale et al., 2006). There are several systematic reviews on online support for patients (e.g. Eysenbach et al., 2004; Griffiths et al. 2009), particularly for cancer patients (e.g. Hong et al., 2012), and these studies have indicated that a sense of community can reduce cancer patients' feelings of isolation, enabling them to face their disease more positively by sharing their feelings and exchanging information with other cancer patients. However, the majority of these studies examined the effect of online cancer communication in Western countries, and there are few detailing this topic in Japan (e.g. Setoyama et al., 2011). In addition, none of these studies investigated online support within a three-dimensional multi-user virtual space, which has certain advantages over traditional electronic bulletin boards and even face-to-face communication. First, these multi-user virtual spaces allow users to visually perceive other participants and facilitators by using avatars, which allows participants to discern the gestures and expressions of others in the group. This heightens people's perception of reality in that environment, producing a sense of closeness, comfort, and trust, which enables open consultation (e.g. Bente et al., 2008). Second, these online groups allow participants to join from home, the hospital, or their workplaces, which has great significance for patients who were previously unable to participate in a support group because of distance or the severity of their condition.

Multi-User Dungeons (also called Multi-User Dimensions or Domains; MUDs) are a type of chat system in which avatars participate in a virtual space over the Internet. Research on online support groups that utilize the Internet and virtual spaces is growing (e.g. Bambina, 2007; Eysenbach et al., 2004). However, no research has to date has examined how the use of a 3D MUD can affect people's mental health. Use of avatars with facial expressions in the 3D MUD facilitates active and enjoyable communication and emotional understanding (e.g. Cassell et al., 2000; Kusumi et al., 2008). In this study, we investigated the effectiveness of a support group that utilized a 3D MUD—specifically, we investigated how cancer patients' emotional expression and the frequency at which they sent messages offering informational and emotional support were affected by their participation in a virtual space support group.

Eysenbach et al. (2004) systematically reviewed evidence of the effectiveness of online peer-to-peer interactions, but so far effectiveness has most often been measured subjectively using post-hoc surveys of users, often containing psychological scales assessing depression, pain,

coping, post-traumatic growth, and other issues (e.g. Lieberman et al., 2003). On the other hand, the content of messages sent by users voluntarily on a moment-to-moment basis—or the entire interaction process within online communities—has not been thoroughly investigated.

Retrospective self-reports might be distorted when recalling events, or even if not distorted, the reflective state in which they respond to the measures may differ from their more naturalistic, on-going experience. To go beyond self-report, researchers might analyse participants' messages directly as a continuous measure of their emotions and cognitions, and this would help reduce recall biases and other memory distortions in responding.

In online support groups with text-based interactions, there are no nonverbal cues; therefore, the content of messages posted by participants—i.e. the language—is the only behavioural clue available to capture members' emotions and attitudes. There are two major types of message analyses.

The first type focuses on the emotional and medical-related words in messages. For example, Seale et al. (2006) analysed messages posted to a breast and prostate cancer forum over one year using comparative key word analysis. This study revealed that members in the prostate cancer group were more likely to use words associated with medical aspects of the disease, while members in the breast cancer group were more likely to use emotional words and to discuss feelings or issues related to their lifestyle.

Gooden & Winefield (2007) analysed messages of online discussion boards sent by cancer patients over one-month using grounded theory and quasi-numerative approaches. Their results indicated that patients with prostate cancer were more likely to discuss sexual dysfunction and medical findings, to exchange messages with jokes and humour, and to imply their emotions as compared to breast cancer patients. In contrast, breast cancer patients tended to express their emotions directly.

The second type of message analysis is focused on social support requests and the provision of support. Bambina (2007) analysed 1,149 messages of the SOL (Support OnLine) Cancer Forum over two weeks using modified traditional categories of face-to-face social support (e.g. emotional support, informational support, and companionship). The result indicated that 'companionship' was found in a greater amount of messages (41%) than were 'emotional' (35%) and 'informational support' (25%). On the other hand, Winzelberg (1997) analysed 306 messages from an online support group for eating disorders over three months. The most common message content involved 'self-disclosure' (31%), 'providing information on request' (23%), and the direct provision of 'emotional support' (16%). Finn (1999) analysed 718 messages from a bulletin board system (BBS) self-help group for issues related to disability over three months. The most frequent message classifications were 'providing support or empathy' (21%), 'providing information' (15%), 'problem solving' (14%), 'expressing feelings or

catharsis' (12%), and 'requesting information' (11%). The studies mentioned above and other related research (Tichon & Shapiro, 2003, three months; Weinberg et al., 1996, four months) used part of the traditional categories of face-to-face social support (e.g., emotional support vs. informational support, and support requests vs. support provision). These categories can apply to messages in online support. However, messages were examined at intervals ranging from two weeks to one year. These intervals are too short for examining the development of support groups.

We therefore performed a computerized textual analysis in which we evaluated the message content and interaction process in a virtual community. Specifically, we investigated the frequency of specific emotional words and medical terms in messages, along with transition patterns. We also investigated the transmission of social support using the frequency of requests and provisions of emotional or informational support messages over five years.

Two other important lines of related research should be noted. The first concerns participants' sequence transition patterns—that is, when a participant sends a message in a virtual community, who replies to that message? To investigate sequence transition patterns, we converted the frequencies of senders' transitions in turn taking (that is, how frequently they transitioned from being a sender to being a receiver) into probabilities. With these patterns, we can present a detailed view of human relations within this community, such as who tends to receive and continue others' messages and who does not often send messages. As this has a bearing on relationships within the virtual community, we investigated changes in participants' roles over time (Bakeman and Gottman, 1986).

The second line of related research concerns social capital. Many studies of computer-mediated communication have shown that involvement in online communities takes resources and attention away from local communities and reduces civic engagement, thereby impoverishing overall quality of life (e.g. Nie, 2001; Putnam, 2000). However, along with growth in Internet use and the proliferation of computer-mediated communication, there has been an increase in vibrant online environments that fit the community model. These are communities in which users create strong emotional and social bonds, share resources, stories, and information, enjoy their time together online, and work toward common goals (Haythornthwaite, 2007). Researchers have begun to investigate the synergy between online communication and face-to-face interactions. For example, in Japan, Kobayashi and Ikeda (2006) examined whether social capital (e.g. social networks, generalized trust and reciprocity; Coleman, 1988; Putnam, 1995) accrued through computer-mediated communication 'spills over' into offline behaviour. They found that participation in online communities could create social capital and that reciprocity online facilitated offline social participation, even after controlling for offline social capital and other determinants. This suggests that the development of social

capital online can facilitate participants' social activities in other contexts and even improve their mental health. These findings suggest that online support groups, rather than serving as an escape from reality, might promote positive adaptation to the reality of living as a patient with cancer. In the present study, we investigated an online support group for cancer patients for a period lasting longer than five years. We focused especially on messages sent by core members to investigate key factors of the group's sustainability. We also analysed the appearance frequency of medical terms, the use of which could indicate that participants talked about their own diseases within the online group.

We made four hypotheses at the outset of our five-year study. First, we hypothesized that positive emotion words (e.g. 'happy') would increase over time, whereas negative emotion words (e.g. 'sadness') would decrease, and both outcomes would be the result of patients' sharing their feelings and exchanging information with other patients in the virtual support group. We used the definitions of Russell (1991) for positive and negative emotion words. We considered these measures indicative of participants' mental health and the overall group atmosphere (e.g. Lieberman and Goldstein, 2006). Second, we hypothesized that messages requesting or providing informational and emotional support would increase over time. Interaction analysis was used to differentiate support-requested and support-provided messages (Bambina, 2007). These types of messages were considered indicative of the development of supportive relationships within the group (e.g. Bambina, 2007). Third, we hypothesized that the roles of participants would change over time. When new participants join an online community, it is typical for facilitators and participants who are accustomed to the community to send welcoming messages and actively reach out to them. When the new participants become accustomed to the community, more experienced participants no longer have to support them, and those who joined later feel free to participate more actively (e.g. Choudhury et al., 2008; Sakaida and Suwa, 2012). Fourth, we predicted that medical-related words (e.g. 'diagnosis', 'prescription', 'symptoms') would increase over time. This would be because continuous interaction over the years would foster interpersonal trust and familiarity among members in the group, thus creating a sense of community (e.g. Galegher et al., 1998); with such trust, participants would be more willing to disclose their real-life distresses, such as their health problems, more frankly to other participants. This, in turn, would lead to an increase in medical-related words in their interactions.

## **2 Method**

### ***2.1 Participants***

A total of twelve members (six men and six women) in a cancer patients' support group of a non-profit organization (the Wellness Community Tokyo) and a total of three facilitators, who were trained professionals (a counsellor, doctor, and nurse) participated in the study. The participants joined the group spontaneously after an announcement about the study by the Wellness Community Tokyo. All participants coming to the virtual community were required to register; consent for data collection was obtained during registration. The patients, who voluntarily took part in the study, were 39 to 69 years old ( $M = 55.0$ ,  $SD = 11.6$ ). The types of cancer represented were bladder, malignant lymphoma, myeloma, digestive organ, leukaemia, breast, bile duct, and lung cancers, with disease durations of 8 months to 13 years. Eight participants (patients A, B, C, D, E, F, H, and J) dropped out of this study and one participant (patient K) died over the five years. All of the participants participated in the virtual community from home. The facilitators had received training through the non-profit organization and were experienced in facilitating this support group for cancer patients. One hundred five of 158 analysed sessions) included facilitator participation (Figure 1).

## ***2.2 Instruments***

The experimental system used in this research was a 3D interactive communication system (3D-ICS; Nomura Research Institute), which provided a 3D virtual environment over a network (Hamabe and Matsuda, 2002; Kusumi et al., 2008). This MUD system furnished a sense of reality through the 3D visualization of the virtual space and participants' avatars. Multiple participants were able to engage in text-based, many-to-many, real-time interactive communication. As shown in Figure 2, the user's screen contained a window with an image of the virtual world and the avatars of the current participants. The avatars' emotional expressions (e.g., happiness, sadness, anger) and movements (e.g., raising arms, waving goodbye) were controlled by five action buttons at the bottom of the window. The participant could click on an action button after sending a message. Up to 40 Japanese characters could be entered into a textbox by keyboard and sent by pushing the send button or the ENTER key. The text sent appeared in the textbox and in a dialogue balloon above the avatar. For each message, a chat log recorded the text, action buttons used, participant's name, and time.

## ***2.3 Procedure***

The participants used their real names in order to offer an environment relatively similar to an actual face-to-face support group. The virtual support group began on March 5, 2004, and sessions were conducted for one and one-half hours every week for more than five years. The

avatar faces that the participants first selected were used throughout the experiment. In early sessions, the participants first introduced themselves and stated their disease, their present mood, and their physical condition. The facilitators responded frequently in early sessions, directing the flow of topics (treatments, alternative medicine, food, bathing, exercise, shopping, work, etc.). Facilitators played a less active role in the discussions as the group became established.

#### ***2.4 Dataset and Analysis Framework***

We analysed all 29,571 messages from 158 sessions across six time periods during the study: (Year 1(0–9 months); Year 2(10 months–1 year 9 months); Year 3(1 year 10 months–2 years 9 months); Year 4(2 years 10 months–3 years 9 months); Year 5(3 years 10 months–4 years 9 months); and Year 6(4 years 10 months–5 years 9 months)). The frequency or rate of emotion words in text can be used as an indicator of participants' emotional expression in online chat (Back et al., 2010). Linguistic Inquiry and Word Count (LIWC) software (Pennebaker et al., 2001) has been widely used for text analysis, and preliminary evidence for the validity of its use as a method for analysing online support groups was provided by Alpers et al. (2005). However, this software, which maps several psychological and linguistic dimensions of written language, has no dictionary of Japanese words, and no equivalent program for the Japanese language has been developed. Therefore, in this study, frequency counts of emotion words in messages were conducted as follows: (1) a lexicon of emotional expressions was manually developed using the Japanese Mood Adjective Check List<sup>1</sup> (Terasaki et al., 1992) and a Japanese thesaurus (National Institute for Japanese Language, 2004); the entire contents of the checklist were used in the lexicon, along with synonyms from the thesaurus. (2) All 29,571 patient messages were decomposed into single words using Japanese language morphological analysis. Finally, (3) the frequencies of messages including words in the lexicon were calculated. The lexicon of emotional expressions was divided into six categories of emotions: positive feelings (47 words, e.g. 'happy', 'relaxed'), intimacy (14 words, e.g. 'like', 'love'), discomfort (21 words, e.g. 'tired', 'painful'), anxiety and depression (46 words, e.g. 'annoyed', 'depressed'), anger (18 words, e.g. 'angry', 'disgusted'), and surprise (10 words, e.g. 'surprised', 'astonished').

A sample of 2,299 messages from two time periods (Years 2 and 4) was coded according to two types of classification by two independent coders. There were two reasons for sampling Years 2 and 4: (a) core member Patients H and I joined the group in Year 2, and (b) new member



patient L joined the group in Year 4. The inter-coder reliability exceeded 80%, indicating good agreement in categorization between the two coders for all coding categories. Messages were first divided into support-requested and support-provided categories. In support-requested messages, the participants asked for information about or accounts of personal experiences concerning cancer or talked about their own physical condition or feelings. Support-provided messages included expressions of empathy, encouragement, and so forth, often in direct response to support-requested messages. The same messages were also classified into traditional categories of social support using an online social support coding schema (i.e. informational support and emotional support) and into two additional categories (companionship and usage of the system; Bambina, 2007). Informational support messages were those that provided advice, referrals, or knowledge related to coping with cancer. Emotional support messages provided understanding, empathy, encouragement, affirmation, sympathy, and caring. Companionship messages included chatting, humour and teasing, and expressions of inclusion. Messages about usage of the system included questions and answers concerning chat system problems, mostly from participants who were novice users.

Chat logs were edited to facilitate categorization of topic threads because adjacent pairs of messages (i.e. a question and an answer) frequently did not adjoin semantically and because topic threads intertwined (Herring, 1999). We identified the semantic relations of each message by using an algorithm for extracting topic threads from chat logs (Ogura et al., 2004).

### **3 Results**

#### ***3.1 Percentage of patient messages***

Figure 1 shows the mean number of messages per session. Sessions were divided into those with and without facilitator involvement. To promote initial adaptation of participants to the group, facilitators participated in all sessions in Year 1. The percentage of patient messages<sup>2</sup> increased during the first three years (Year 1, 49.4%; Year 2, 64.3%; and Year 3, 81.6%), whereas the percentage of facilitator messages decreased after Year 4 (Year 4, 67.3%; Year 5, 65.5%; and Year 6, 62.1%).

#### ***3.2 Interannual Variability in the Frequency of Emotion Words***

The total frequency of the six categories of emotion words in patient messages was 2,380 (positive feelings, 55.3%; intimacy, 6.7%; discomfort, 13.1%; anxiety and depression, 22.2%;

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anger, 1.2%; and surprise, 1.6%). Figure 3 shows changes in the percentages of the six emotion categories over the course of the study. The frequency of positive words (positive feelings and intimacy) increased during the first three years (Year 1, 55%; Year 2, 64%; and Year 3, 65%), whereas the frequency of negative words (anxiety, depression, and discomfort) decreased (Year 1, 44%; Year 2, 33%; and Year 3, 32%). We noted significant differences between the ratio of positive words ( $z = 2.67, p < .01$ ) to negative words ( $z = 2.22, p < .05$ ) only between Years 1 and 2. After the first three years, the ratio of positive to negative words remained almost constant at 6:4.

### ***3.3 Messages Requesting and Providing Support***

Table 1 shows the number of messages requesting and providing support in two of the study years and the proportion of each type as a percentage of all messages. The total percentages of messages requesting and providing support indicate that the support provided significantly increased between Years 2 (36%) and Year 4 (44%;  $z = 3.88, p < .001$ ). In particular, the percentage of informational support messages provided significantly increased from Years 2 (38%) to 4 (59%;  $z = 10.22, p < .001$ ), with the percentage of requests for informational support increasing from 43% to 69% ( $z = 10.37, p < .001$ ). In addition, cancer-related informational support messages increased from 4% to 18% ( $z = 10.72, p < .001$ ). The frequency of usage of system messages was initially small in Year 2, but they increased from 2% to 5% in Year 4 ( $z = 2.87, p < .01$ ). On the other hand, companionship (especially chat) decreased from 57% to 31% ( $z = 11.77, p < .001$ ).

### ***3.4 Sequence Transitions of Sent Messages***

Although a total of twelve patients and three facilitators participated in the support group, the number of people participating in each conversation varied, as participation in any given session was voluntary. As shown in Figure 1, only four patients and one facilitator participated for two or more years continuously. We analysed the messages of two different core-group combinations:

- a. Facilitator F1 and Patient G, who was involved in the group from the beginning, along with Patients H and I, who joined several months after Patient G.
- b. Facilitator FI and Patients G and I, along with Patient L, who joined during Year 4.

We also analysed messages from sessions in which only four patients participated, in order to compare the message content with and without a facilitator. However, the number of sessions without a facilitator was quite small; therefore, we were not able to select sessions for this comparison that contained only the core-group patients.

We computed the sequence transition patterns of participants<sup>3</sup> to observe user relations in conversations by examining the directions of each message. Figure 4 shows the transitions in the sequences of sending messages with and without a facilitator. The first row of Figure 4 reveals that newer members chatted with the facilitator more often in the early stages of group membership (see Figure 1), and the role of the facilitator gradually became less important. The middle row of Figure 4, containing only one newcomer, shows that both facilitators and patients who had been in the group for a long time sent messages to the newcomer. Meanwhile, those newer to the support group became more independent and chatted more with other patients as time passed. The bottom row of Figure 4, which shows the sessions participated in by only patients, shows that the frequency of exchanges between specific participants becomes flatter as these patients talked more with others over time, although as shown in the bottom row of Figure 4, participants H and L tended to talk frequently to participant G.

We also examined features of the messages used in the sequence transitions analysis. The Discourse Analysis model, at the level of exchange, was used to categorize each message according to the Initiation-Response-Follow-up structure (Sinclair and Coulthard, 1992): initiation (requested), [I], response (provided), [R], initiation and response [IR], and follow-up [F].

Examples 1, 2, and 3 below show message exchanges in conversations with a facilitator, while Example 4 shows a message exchange without a facilitator. The source and type of each message are indicated. These examples were extracted from ordinal chat logs in Japanese and translated into English.

#### Example 1 (with facilitator)

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 Patient G: I will be reinstated in July, so I'm still in \*\* now. [R]  
 Facilitator: I see ... [F]  
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#### Example 2 (with facilitator)

-----  
 Patient G: I can take another six months of sick leave, thanks to my boss. [R]  
 Facilitator: Oh really? [F]  
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In Examples 1 and 2, a patient responded to a question and the facilitator sent a follow-up message after the patient's response.

Example 3 (with facilitator)

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Patient H: How about you, Mr. G? [I]

Patient G: I'm in pain because this season is very cold. [R]

Facilitator: What's wrong? [I]

Patient G: I have a stomach-ache. [R]

Patient G: And blood in my urine, too. [R]

Facilitator: That's not good. [F]

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In Example 3, the facilitator asked Patient G for additional details as a follow-up to the patient's previous response.

These three examples show that facilitators recognized answers to other patient's questions and sent follow-up messages when they had a comment about a patient's message.

Example 4 (without facilitator)

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Patient G: I'm a little tired . . . (^;) [R]

Patient G: I'm probably going to be busy because I'm getting ready for \*\*\*. [IR]

Patient G: I get about 100 emails every day. [IR]

Patient L: Wow, that's a lot! [F]

Patient H: Oh . . . are you going to be okay tomorrow? Take it easy! [IR]

Patient G: I'll be all right because I sleep on the train. [R]

Patient H: Good luck getting through all those emails. [I]

Patient G: Thanks! [R]

Patient G: And you have to respond, too, don't you? [IR]

Patient H: Oh . . . that's terrible. [F]

Patient L: Answering all those emails sounds like hard work. [IR]

Patient G: I read them in my office and I return them after going home. [R]

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This example indicates that each patient thoughtfully replied and sent follow-up messages without facilitators. These exchanges enabled patients to carry on a conversation without facilitators.

### ***3.5 Core Patient Members of the Community***

In the last two analyses, we examined the messages sent by core members of the support group. Participant mobility is a typical characteristic of online communities. However, it is also not unusual for some core members to play a continuous and active role in the community. Their involvement often sets a general positive mood for the community, influencing group longevity and generating online social capital. We first selected three participants, Patients G, H, and I, who had participated continuously and actively in the support community for at least three years, and thus could be regarded as core patient members of the support group. Data on the 105 chat sessions in which the three patients almost always participated (from Year 2 to Year 5) were extracted for the analysis. Table 2 shows the yearly frequency of session participation and the number of messages sent by each core patient member. Patients G, H, and I participated in 91, 67, and 73 chat sessions and sent 6,461 messages, 3,701 messages, and 2,800 messages, respectively.

#### ***3.5.1 Quantitative analysis of messages by core patient members***

We examined whether the core patient members played central roles in the activity of their community. Table 3 shows the changes in the percentages of messages sent by the facilitators, the three core patient members, and the rest of the patient members. The total percentage of messages sent by the three core patient members consistently accounted for around 60% of all community messages over time. Furthermore, more than one-third of the 105 analysed sessions consisted of either only the core patient members or these members with one facilitator, whereas there was only one session with none of the core patient members in these 105 sessions. None of these sessions included more than one facilitator.

Did the participation of the core patient members activate the overall community? Table 4 shows Pearson's correlation coefficients among the total number of messages, and the number of messages sent by the facilitators, the core patient members, and the other patient members in these 105 sessions. The number of messages sent by both the core and other patient members had strong positive correlations with the total, suggesting that messages from not only the core but also the other patient members significantly contributed to community activity. The positive correlation between the number of messages sent by core members and by the other members ( $r = .36$ ) was not as strong, but it was significantly different from zero and increased gradually over time, with occasional dips ( $r_s = .37, .20, .80, .67$  in Years 2, 3, 4, and 5, respectively). On the other hand, the correlation between the number of messages sent by the facilitators and that sent by non-core members was significantly negative during these years. In other words, the more the facilitators actively participated in chat sessions, the more silent the non-core members tended to be. This result suggests that non-core members' motivation for commenting might have been

blocked or reduced by facilitator participation, but not by the participation of the core patient members. These tendencies did not change when we calculated partial correlations between the two variables (i.e., facilitators and core patients) after removing the effects of the other variable (i.e., other patients). Thus, the messages sent by core patient members were not exclusive; that is, the core patients did not function as a private inner circle, but rather made a contribution to the overall activity of the support community.

### *3.5.2 Qualitative analysis of messages by core patient members*

All messages by the core patient members were analysed morphologically by use of McCab (a Japanese morphological analyser; Kudo et al., 2004), whereby nouns (including compound nouns) appearing more than 10 times were extracted. From these extracted nouns, we selected 34 medical-related words associated with illness, medical treatments, organs, and so forth (e.g., 'blood', 'bone', 'cancer', 'bladder', 'steroid', 'muscle', and 'virus').

The appearance rate was calculated as the total frequency of medical-related words included in the messages sent by each core member in each year divided by the total number of messages sent in that year. Figure 5 shows the interannual variability of the appearance rate of the medical-related words in Years 2 through 5. Overall, although medical-related *topics* (e.g., members' disease symptoms or condition) came up continually in the chat conversations, the percentage of medical-related *words* was not high. The rate of medical-related words included in messages sent by the three core members increased significantly in Year 5 compared with Year 2, which was still an early stage of the support group, when the participants might be expected to share less about their medical conditions with each other.

## **4. Discussion**

In this research, a communication system using a three-dimensional virtual space was introduced as an environment for a self-help group for cancer patients.

The frequency of positive words (words expressing positive feelings and intimacy) increased during the first three years, whereas negative words (words expressing discomfort and anxiety) decreased with time, especially after the first year (Figure 3). Thus, our first hypothesis—that positive emotion words would increase over time and negative emotion words would decrease—was partially supported. However, the results of the analysis of emotion word frequency showed that the group atmosphere became more positive overall from Years 1 through 3, and the expression of negative emotions was entirely acceptable to participants. Furthermore, the ratio of expressions of positive and negative feelings was constant during the last three years of the study. Similar results were observed in research on the use of an electronic bulletin board

for breast cancer patients (Lieberman and Goldstein, 2006), in which expressing negative feelings tended to mitigate sadness and anger.

Our second hypothesis was that messages requesting or providing informational and emotional support would increase over time. Indeed, the percentage of informational support, especially of cancer-related information (e.g. group activities for patients, treatments, alternative medicine) increased from Years 2 to 4 (Table 1) as the community developed. Members of the support group, after getting to know one another through online chatting, sometimes met in person and exchanged information. The members often mentioned these face-to-face meetings during support group sessions.

Analysis of the sequence transitions of messages (Figure 4) indicated that facilitators were helpful to newcomers who were becoming accustomed to the community, as were patients who had been members of the support group for some time. Both facilitators and senior group members actively welcomed newcomers and made efforts to integrate them into the group. After patients became accustomed to the community, patients were able to communicate without a facilitator, as core patients took on a role similar to that of a facilitator. We also confirmed that they communicated more with other patients and less with facilitators. These results support our third hypothesis that participant roles would change over time. In addition, we found that facilitators tended to send follow-up messages to patients' answers and to answer questions from patients to facilitate conversations.

Our results also revealed that informational support and medical-related words increased in Years 2 through 5 (Figure 5). These results support our fourth hypothesis, i.e. that the frequency of medical-related words would increase along with the trust and familiarity among members and the development of a sense of community. Although changes in the patients' physical conditions should also be considered a reason for the increased use of medical-related words (unfortunately, we were not able to obtain information about participants' medical conditions, except what was inferable from the messages), this increase could be interpreted as evidence of the maturation of a sense of community and trust among participants, so that participants felt more comfortable sharing personal medical details. These tendencies were similar to those seen in a face-to-face support group for cancer patients (Yoshida et al., 2004).

Shimura and Ikeda (2004) conducted a panel survey of players of online games in which participants used 3D avatars, and were interested in the effects of an online social network on feelings of loneliness. They found that a higher level of satisfaction with the interpersonal network formed in the game community significantly decreased feelings of loneliness, even after controlling for size of and satisfaction with offline interpersonal networks and other determinants. This finding contradicts results from an 'Internet Paradox' study (Kraut et al., 1998), which revealed that people who used the Internet reported increased loneliness. Though there are

important differences between participants of an online gaming community and an online cancer support group, certain similarities are worth noting. In both communities, for example, participants usually communicated using avatars in a chat format, although some of them sometimes met offline. Therefore, it is reasonable to suppose that members of the online support group in this study, especially the core patient members, would experience improved mental health through a 'spill over' effect of social capital accrued online, such as the development of a close interpersonal network and feelings of trust. In the future, this assumption should be tested by a questionnaire or interview survey of online support group participants to compare their online and offline behaviour.

There were several limitations to this study. First, this study lacked a control group made up of an offline, or face-to-face, support group. Eysenbach et al. (2004) evaluated the effects of online peer-to-peer interactions by systematic review and concluded that the effects on well-being and health and cancer outcomes were unclear and that there was a lack of high quality controlled trials. Second, we might also collect a larger sample of cancer patients to avoid selection and survival bias. This could be done by including several online support groups in the analysis. Third, we analysed chat logs without considering such unique situations as multithreaded conversations within chat conversations (Sullivan, 2003). If these situations were considered, we might be able to analyse the quality of communications—for example, whether patients and facilitators converse in the same conversational floor. In the future, we hope to analyse chat logs by considering multithreaded conversations within chat conversations. Fourth, we did not record log data of avatar action buttons along with the related messages. Use of more detailed log data that includes avatar actions might enhance our understanding of the merits of a 3D online chat environment for patient support groups.

This paper demonstrates how cancer online support groups can promote patients' positive emotions, mutual trust, and supportive relationships within a three-dimensional virtual space over five years. We found that positive emotion words and informational/emotional support messages increased in Years 1 through 3. The complexities of the effects of online support using a virtual space on the member patients' community remain to be explored in future research.



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#### Footnotes:

1. The category of emotion words was based on a factor analysis of the rating data.
2. The percentage of patient messages is defined as the number of messages of participants divided by total number of messages of patients and facilitators.
3. If three participants (A, B, and C) talked in this order,  $A > B > C > A > A > B > C$ , we can see that A spoke three times: A talked to B twice and addressed himself/herself once in three messages. In this case, the transition probability of participant A sending a message to A is  $1/3$ ; to B,  $2/3$ ; and to C, 0.

Table 1: Number and percentage of messages requesting and providing support in Years 2 and 4

Message topics	Requested	%	Provided	%	Total	%
Year 2						
Informational support	332	43	131	30	463	38
Cancer	40	5	12	3	52	4
Health	46	6	22	5	68	6
Other subjects	246	32	97	22	343	28
Emotional support	30	4	6	1	36	3
Companionship	393	51	295	67	688	57
Chat	328	42	110	25	438	36
Others	65	8	185	42	250	21
Usage of system	23	3	7	2	30	2
Total	778	45	439	36	1217	100
Year 4						
Informational support	450	69	237	46	687	59
Cancer	144	22	66	13	210	18
Health	19	3	16	3	35	3
Other subjects	287	44	155	30	442	37
Emotional support	40	6	23	5	63	5
Companionship	129	20	232	45	361	31
Chat	63	10	40	8	103	9
Others	66	10	192	38	258	22

Table 2: Frequency of session participation and number of messages sent by the core patient members in Years 2 through 5

Core Participants	Year 2		Year 3		Year 4		Year 5	
	(10 m to 1 yr 9 m)		(1 yr 10 m to 2 yr 9 m)		(2 yr 10 m to 3 yr 9 m)		(3 yr 10 m to 4 yr 3 m)	
	Par	Mes	Par	Mes	Par	Mes	Par	Mes
Patient G	31	1,838	21	1,317	21	1,890	18	1,416
Patient H	32	1,850	14	936	18	764	3	151
Patient I	29	1,149	15	585	15	546	14	520
Total		4,837		2,838		3,200		2,087

Abbreviations: Par: Participation, Mes: Messages, m: months, yr: year

Table 3: Changes in percentages of messages sent by facilitators and patient support-group members in Years 2 through 5

	Year 2			Year 3			Year 4			Year 5		
	(10 m–1 yr 9 m)			(1 yr 10 m–2 yr 9 m)			(2 yr 10 m–3 yr 9m)			(3 yr 10 m–4 yr 3 m)		
	Par	Mes	%	Par	Mes	%	Par	Mes	%	Par	Mes	%
Facilitators	28	2,197	24.8	7	334	6.9	8	507	11.5	15	946	26.6
Patient G	31	1,838	20.8	21	1,317	27.3	21	1890	42.9	18	1,416	39.8
Patient H	32	1,850	20.9	14	936	19.4	18	764	17.3	3	151	4.2
Patient I	29	1,149	13.0	15	585	12.1	15	546	12.4	14	520	14.6
Other Patients	26	1,808	20.4	16	1,645	34.1	9	697	15.8	9	526	14.8
Total	40	8,842	100.0	22	4,817	100.0	23	4,404	100.0	20	3,559	100.0

Abbreviations used: Par: Participation, Mes: Messages, m: months, yr: years

Table 4: Pearson's correlation coefficients among the total number of messages from 105 sessions and the number of those messages sent by two facilitators, the core patient members, and the other patient members

	Total	Facilitators	Core Patients	Other Patients
Total	—	0.28*	0.69**	0.65**
Facilitators	58	—	0.14	-0.42*
Core Patients	104	58	—	0.36**
Other Patients	60	32	59	—

Note. Upper right: Correlation Coefficients. Lower Left: Session N.

\*\*  $p < .01$ . \*  $p < .05$ .

Figure 1

Time				Year 1	Year 2	Year 3	Year 4	Year 5	Year 6
Start time - End time				0-9m.	10m. - 1yr.9m.	1yr.10m.-2yr.9m.	2yr.10m.-3yr.9m.	3yr.10m.-4yr.9m.	4yr.10m.-5yr.9m.
Number of sessions (without facilitator) <sup>a</sup>				14 (0)	40 (12)	22 (15)	23 (15)	33 (7)	26 (4)
Mean number of messages per session									
Participants with facilitator (without facilitator) <sup>a</sup>				94.5	141.6 (223.3)	211.0 (200.4)	130.6 (190.1)	113.9 (94.1)	86.0 (118.3)
Facilitators				96.8	78.5	47.7	63.4	59.9	52.5
Patients	Cancer	Sex	Age						
A	Bladder	M	58						
B	Lymphoma malignum	F	51						
C	Myeloma	M	66						
D	Digestive organ	M	67						
E	Digestive organ	F	42						
F	Digestive organ	M	69						
G	Leukemia	M	39						
H	Breast	F	52						
I	Breast	F	55						
J	Breast	F	39						
K	Bile duct	F	68						
L	Lung	M	-						
Facilitators	Specialities								
F1	Counselor	M	30'						
F2	Surgeon	M	60'						
F3	Nurse	F	30'						

Note: <sup>a</sup>Number in parentheses indicates sessions without facilitators.

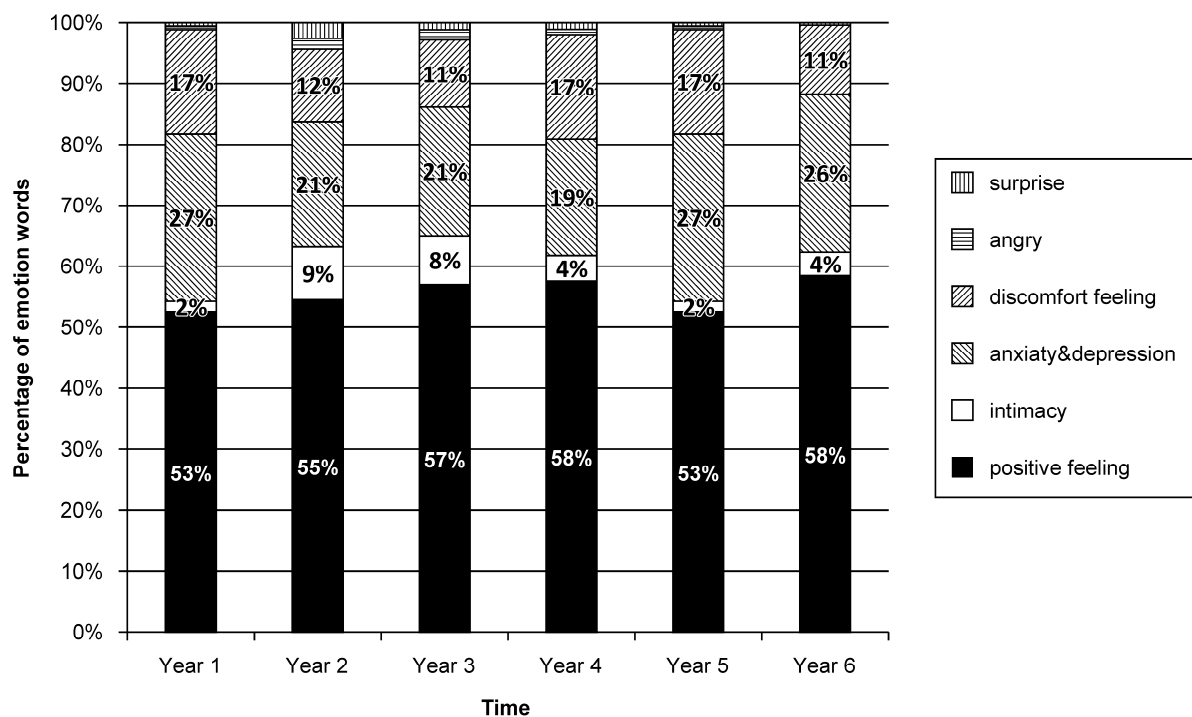
**Figure 1.** Mean number of messages sent per session in the virtual support group for each study year. Participants' types of cancer are indicated, along with the duration of their participation in the group and frequency of chatting (dots indicate participation in one of the sessions analysed for this study).



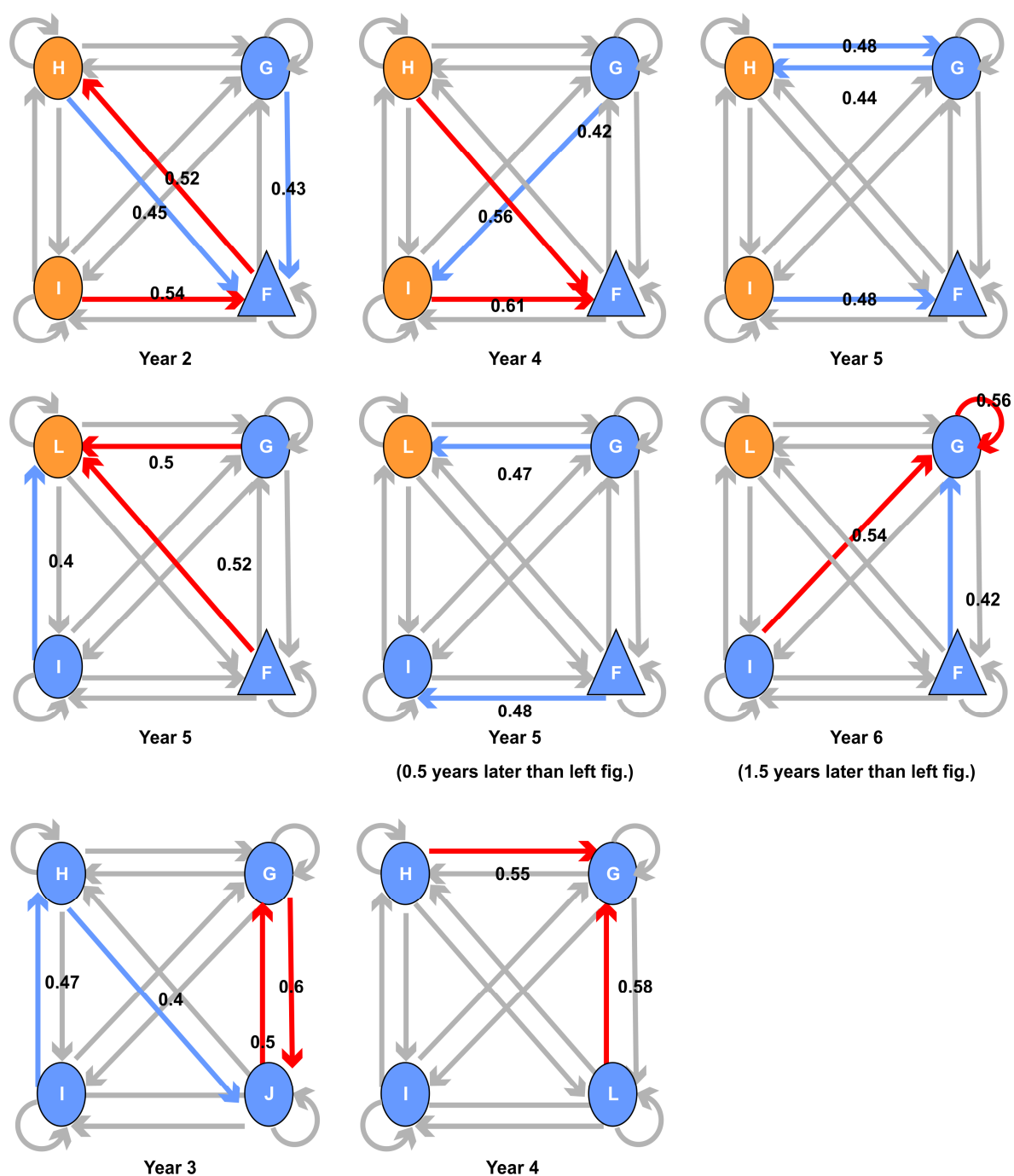


**Figure 2.** A sample image of the three-dimensional interactive communication system (3D-ICS) display and its input systems (© Nomura Research Institute).

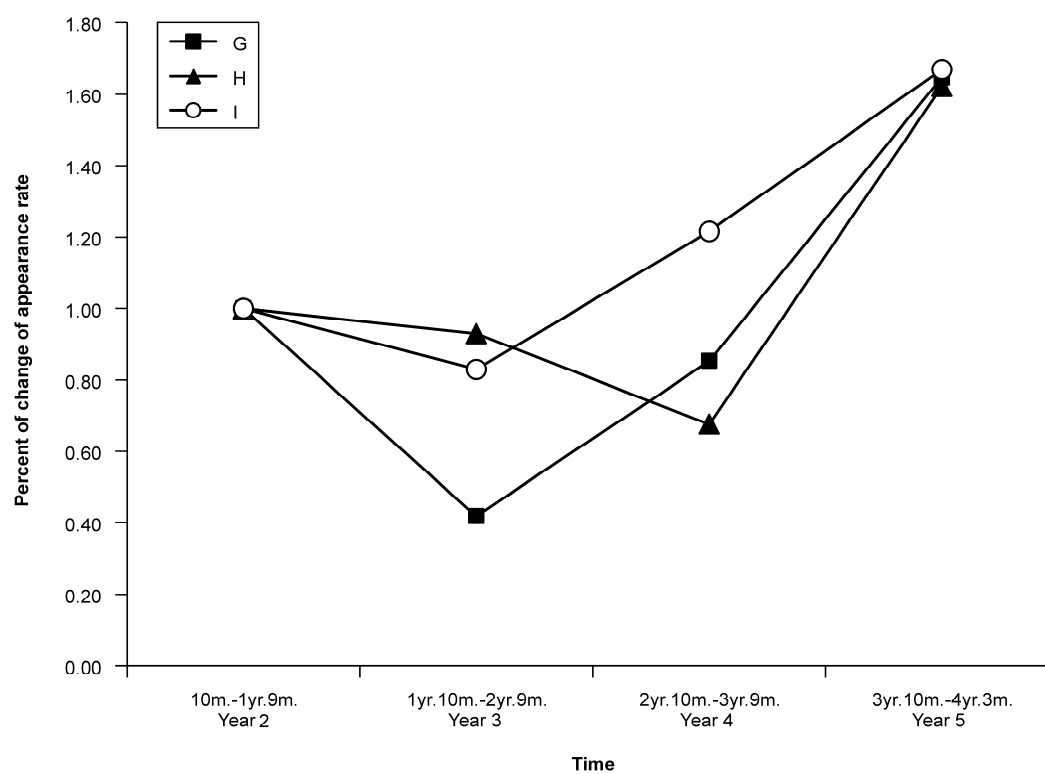
**Figure 3**



**Figure 3.** Percentages of each type of emotion word out of the total number of emotion words in the sample messages for each study year.

**Figure 4**

**Figure 4.** Transitions in the sequences of sending messages over time. Triangles indicate the facilitator, blue circles show patients who had participated for a long period of time, and orange circles show patients who were newer to the group. The blue lines show probabilities over 40% and red lines show probabilities greater than 50%. Upper and middle figure: Sequence transitions of messages sent by a facilitator and three patients. Bottom figure: Sequence transitions of messages sent by four patients in sessions without a facilitator.

**Figure 5**

**Figure 5.** Inter-annual variability in the appearance rate of medical-related words in the messages sent by Patients G, H, and I.