

# Usage of clinical trial information by self-help groups in Japan: A comparison between group and staff members

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## Abstract

*A self-help group provides mutual opportunities among peers who share common experiences and plays a supplementary role as a healthcare resource. Although some studies have developed the concepts and examined benefits of self-help groups, the function of these groups and their use of information among members has not been well documented. Therefore, the purpose of this study was to examine information usage among members of self-help groups using clinical trials as an example. A self-administered questionnaire survey was conducted among seven self-help groups established to primarily share information regarding intractable diseases throughout Japan. The questionnaire consisted of demographic information, usage of general medical and clinical trial information, and desired provision of clinical trial information. Of 2,324 questionnaires distributed to group members, 910 (39.2%) were returned and 850 (36.6%) with valid information were included for analysis. Of 452 questionnaires distributed to staff members, 205 (45.4%) were returned and 199 (44.0%) were eligible for analysis. Our results showed that for group members, general medical information was obtained primarily from physicians (94.6%) followed by that from within the group (77.8%), whereas clinical trial information was primarily obtained from within the self-help groups (36.9%). With regard to internet usage, staff members more frequently viewed websites that offered medical or clinical trial information than group members (79.4% and 37.1%, respectively). Our results confirmed that the self-help groups also significant information source for self-help group members, and group staffs have the function of collecting and disseminating relevant information as representatives of patient groups. Therefore, a system is required to allow self-help groups to work effectively as healthcare resources.*

**Key Words:** Self-help groups; Information usage; Clinical trials; Japan

## Introduction

Clinical trials are one of essential components for modern health care. In translating basic research into clinical practice, increasing numbers of clinical trials are performed to obtain regulatory approval of new drugs and devices. However, in clinical trial field, some problems are pointed out such as patients' low accrual and understanding (Ellis, 2000; Lara et al., 2001). Previous studies have examined the relationship between patient knowledge and participation for clinical trials (Comis, Miller, Aldige, Krebs, & Stoval, 2003; Ellis, Butow, Tattersall, Dunn, & Houssami, 2001; Joffe, Cook,

Cleary, Clark, & Weeks, 2001; Townsley, Selby, & Siu, 2005). Others, several studies have focused on the communication of clinical trials and how such explanations may influence understanding of patient, including effects on randomization and allocation (Agoritsas, Deom, & Perneger, 2011; Hietanen, Aro, Holli, & Absetz, 2000; Jenkins, Leach, Fallowfield, Nicholls, & Newsham, 2002).

To improve participants' understanding in clinical trials enrollment, various media tools are also developed. Some authors examined the effect of educational tool, such as seminar (Kimmick et al., 2005), video (Hoffner et al., 2012), computer program

(Llewellyn-Thomas, Thiel, Sem, & Woermke, 1995), and educational booklet (Ellis, Butow, & Tattersall, 2002). Though those educational tools have a certain amount of effect on knowledge and understanding in clinical trials, as Flory and Emanuel (2004) reviewed, the effect of multimedia usage had limited success to patients' understanding. Furthermore, as Brown et al. (2011) pointed out, there may be gaps between information needs and available information. Based on these, it would be useful to know patient information needs about clinical trials.

How people especially need for clinical trial information? For instance, we may imagine patients with intractable diseases because effective therapy has been limited for them and there are high needs for new drug and devices. However, to the best of our knowledge, the reports on information usage by self-help groups about clinical trials are limited. Additionally, Self-help groups tend to be well organized for those intractable diseases because of specificity of disease.

A self-help group is any organization that provides mutual opportunities among peers who share common experiences or situations (White & Madara, 2002). By participating in self-help groups, members attempt to develop techniques to cope with their problems and share information regarding treatment of specific diseases. In addition, it was indicated that the characteristics of self-help groups were different from those of professionally run groups. The staffs of self-help groups are generally patients or family of patients. Also, self-help groups are viewed as economical resources that help to prevent social isolation and perceived stigma for their group autonomy (Kurtz, 1997). White and Madara (2002) summarized that the primary functions of self-help groups are social support, education, and advocacy. However, the mechanism by which self-help groups function as social support and how they facilitate health-promoting behavior have not been well documented (Adamsen, 2002). These situations have been observed, particularly in Japan. Kotani and Sakane (2004) reported the benefits of self-help groups for elderly diabetic patients and concluded that the approach of the self-help group was an effective adjunct therapy for diabetes care. Other than this study, there is only one report on the historical development of self-help groups in Japan (Oka, 2013).

Therefore, the aim of this study was to understand the use of information by self-help groups of clinical trials and how information should be offered to convey effectively. If it is confirmed that the self-help staffs are important information offers for members, clinical trial information could be effectively conveyed by self-help group staffs. To know these, we distributed a questionnaire among the members and staffs of self-

help groups 1) to determine the role of self-help group by comparing members and staffs for getting clinical trial information and 2) to know whether there is the difference of usage between general medical information and clinical trial information for offering information effectively.

## Methods

### *Study subjects*

A self-administered questionnaire survey was conducted between January and February 2013 for members and staffs of self-help groups in Japan. We contacted the following seven self-help groups primarily for intractable diseases: National Friendship Society of Connective Tissue Disease, Japan Friendship Society of Rheumatism, National Friendship Society of Parkinson's Disease, Tokyo Inflammatory Bowel Disease, Kanagawa Colon, Habataki Welfare Services Foundation, and Japan Liaison Council of Liver Ailment Associations. The questionnaire was distributed by the staffs of each group bureau because of protecting patients' personal information. About four hundred subjects were set on each group as samples for ensuring enough subjects for statistical analysis. The method of drawing those samples was basically random sampling. However, the groups of Tokyo Inflammatory Bowel Disease, Kanagawa Colon, and Habataki Welfare Services Foundation were complete sampling because the number of members was less than four hundred. With regard to the survey for the staffs of self-help groups, we directly distributed the questionnaires to the addresses of the indicated organizations. The addresses were extracted from the "directory of self-help groups" of Japan Intractable Diseases Information Center and "Directory of patients and self-help groups all over Japan (*Zenkoku Kanjakai Shogaisha Dantai Yoran*)."

The criterion of extraction was whether the organization had websites because self-help groups run by volunteers are often abruptly disband; therefore, the benchmark of activity was considered an active website (Fox, 2001).

### *Question items*

The questionnaire consisted of the following items: demographic information (gender, age, occupation, education, and household income), usage of general medical and clinical trial information (information sources and internet access of website), and desired provision of clinical trial information (method, website provider, and period).

### *Statistical analysis*

All answers were considered categorical variables and converted into dummy codes where needed. We compared general medical information

usage and clinical trial information usage of both group members and staffs. The chi-square test was used to compare categories. Stata /SE 12.1 for Windows software (StataCorp LP, College Station, TX, USA) was used to perform all statistical analyses. A probability (*p*) value of <0.05 was considered statistically significant.

*Ethical consideration*

The study protocol and questionnaire were approved by the institutional review board of the National Institute of Public Health in Japan (approval number: NIPH-IBRA#12029).

**Results**

*Subjects demographics*

Of a total of 2,324 questionnaires mailed to

self-help group members, 910 (39.2%) were returned and 850 (36.6%) with valid demographic data were eligible for analysis. Of the 452 questionnaires distributed to staffs of the selected self-help groups, 205 (45.4%) were returned and 199 (44.0%) were eligible for analysis. The demographical data were presented in Table 1. Of the responding self-help group members, 31.9% were male and 68.1% were female, and of the responding staff members, 54.3% were male and 45.7% were female. The age of the participants ranged from <20 to >70 years, and most respondents in both groups were in their 60s. Of the responding group members, 41.7% had studied till high school, whereas, 62.2% of the staff members had a university or graduate school degree. Unemployed or retired respondents accounted for 34.7% of the group members and 39.5% of the staff members.

**Table 1. Demographic variables of study subjects**

	Members (n = 850)	Staffs (n = 199)
	%	%
<i>Gender</i>		
Male	31.9	54.3
Female	68.1	45.7
<i>Age</i>		
≤ 20	0.1	0.0
20-29	1.9	0.5
30-39	6.6	2.0
40-49	16.5	20.3
50-59	21.8	26.4
60-69	27.8	33.0
≥ 70 years	25.4	17.8
<i>Education</i>		
Junior high school	8.4	2.0
High school	41.7	15.8
College	22.8	19.9
University and more	25.1	62.2
Others	2.1	0.0
<i>Occupation</i>		
Self-employed worker	5.7	7.2
Company worker	13.1	18.5
Public officer	3.2	2.6
Homemaker	32.5	9.7
Student	0.8	0.5
Unemployed or retired	34.7	22.1
Others	10.1	39.5

*Information sources of general medical and clinical trial information*

Table 2 shows the sources used by self-help group members and staffs to obtain general medical and clinical trial information. There were statistically significant differences in the sources used to acquire general medical information and clinical trial information, including websites, between the two groups. For group members accessing general medical information, physicians were important sources of information (94.6%), followed by information shared among other self-help group members (77.8%) and newspaper articles (75.3%). In contrast, group staffs selected other self-help groups (78.9%) and newspaper articles (78.4%) as information sources, followed by physicians (77.9%).

Group differences between members and staffs were characteristically observed in the use of medical journals (40.4% and 64.8%, respectively). With regard to clinical trial information usage, self-help group (36.9%), physicians (33.8%), and newspaper articles (31.1%) were more frequently used by group members. Among staffs, clinical trial information was primarily obtained from physicians (57.3%), newspaper articles (36.7%), and other self-help groups (31.7%). The main differences between group members and staffs were characteristically observed in the use of medical journals (5.1% and 13.6%, respectively) and seeking advice from physicians (33.8% and 57.3%, respectively) about clinical trial information.

**Table 2. Information channels about general medical information and clinical trial information of self-help group members and bureau staffs**

	General medical information			Clinical trial information		
	Members %	Staffs %	<i>p</i> value	Members %	Staffs %	<i>p</i> value
<i>Information sources</i>						
Physician	94.6	77.9	***	33.8	57.3	***
Nurse, pharmacist	66.5	52.3	***	5.4	10.1	*
Self-help group <sup>†</sup>	77.8	78.9		36.9	31.7	
Newspaper	75.3	78.4		31.1	36.7	
Medical journal	40.4	64.8	***	5.1	13.6	***
<i>Websites of</i>						
government	37.1	79.4	***	5.5	29.2	***
medical facility	5.3	68.3	***	8.4	20.6	***
newspaper company	3.9	62.3	***	4.4	9.1	**
disease information	9.1	67.8	***	6.9	14.1	**
individual patient	4.0	36.7	***	5.1	4.5	
board or personal communication	21.9	32.7	**	2.4	2.5	

<sup>†</sup>This means "other" self-help groups for bureau staffs of self-help members.  
\* *p* < 0.05, \*\* *p* < 0.01, \*\*\* *p* < 0.001

Regarding internet usage, group staffs accessed websites more often to gain not only general medical information but also clinical trial information. Self-help group members were comparatively more likely to access government websites (37.1%) and websites of board or personal communications (21.9%) than other websites on general medical information. Group staffs frequently used government websites (79.4%) and those of medical facilities (68.3%), or those addressing specific disease information (67.8%), and newspaper publishers

(62.3%). In contrast, with regard to websites on clinical trial information, slightly more group members accessed general medical facility websites (8.4%) than other websites. Group staffs primarily used government websites (29.2%), those of medical facilities (20.6%), and others designated for specific diseases (14.1%).

*Desired providing method education period of clinical trials*

Table 3 lists the desired methods to obtain clinical trial information between the members and staffs,

and the preference of public education to address these issues among the general public. The upper part of the table shows the results of the questionnaire with regard to the desired method. Although statistically significant differences were observed for all desired types of information sources, both group members and staffs mostly acquired clinical trial information through internet websites (71.3% and 81.3%, respectively), followed by brochures distributed in hospitals (50.4% and 63.0%, respectively), and oral information (30.2% and 56.8%, respectively). Among the group members and staffs, clinical trial information was primarily accessed through government websites, followed by those of pharma-

ceutical companies (43.7% and 40.2%, respectively), medical facilities (22.2% and 65.6%, respectively), and local governments (13.3% and 37.6%, respectively). With regard to the desired education period about clinical trials, both groups mostly selected "at medical facility when necessary" (members 72.7%, staffs 63.7%) and subsequently selected lifelong education (members 37.1%, staffs 53.4%). In contrast, desires for dissemination of clinical trial information at the high school or university level were comparatively not high (high school or university: members 23.0%, staffs 40.4%; compulsory education: members 21.3%, staff 30.1%).

**Table 3. Desired providing method and education period of clinical trials**

	Members %	Staffs %	p value
<i>Desired providing method about clinical trial information</i>			
Website	71.3	81.8	**
Brochure	50.4	63.0	**
Oral	30.2	56.8	***
Not necessary	27.4	1.0	***
<i>Desired provider of websites about clinical trial information</i>			
Each medical facility	22.2	65.6	***
Government	55.1	76.7	***
Local government	13.3	37.6	***
Pharmaceutical company	43.7	40.2	
<i>Desired period to educate general public about clinical trials</i>			
Compulsory education	21.3	30.1	**
High school or university	26.0	40.4	***
Lifelong leaning	37.1	53.4	***
At medical facility when necessary	72.7	63.7	*

<sup>†</sup>The sample is limited to those who answered yes to "have experience of information seeking about clinical trials."

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$

### Discussion

We demonstrated that among group members, general medical information obtained from self-help groups was secondly important following that obtained from physicians. On the other hand, clinical trial information obtained from self-help groups was the most significant source for members. These results confirmed that physicians were the primary source of information, and showed the self-help groups also significant information source for self-help group members. However, staff members more often obtained information from medical journals than group members. Thus, it is suggested that staff members have a function to collect professional information and act as

representatives of patient groups. To convey clinical trial information to specific patients effectively, the group staffs are important roles.

Until now, several studies have investigated the information-seeking behavior of patients, i.e., how and what type of health information is sought (Richter et al., 2011; Weaver et al., 2010), characteristics of information seekers (Cotten & Gupta, 2004; Rooks, Wiltshire, Elder, BeLue, & Gary, 2012; Weaver et al., 2009), information sources (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Pennbridge, Moya, & Rodrigues, 1999; Powell & Clarke, 2006), and seeking information for decision making or physician consultations (Buzaglo et al., 2007; McMullan, 2006; Sillence, Briggs, Harris, & Fishwick, 2007; Tozzi et al., 2013). These studies primarily

investigated ordinary medical information; thus, little is known about the use of clinical trial information. Currently, information of general medical information and clinical trial information is provided independently or differently. However, if those information is all together (or tie-in), user could get medical information easily. From our results, the trend of information usage of staffs and patients was similar between general medical information and clinical trial information. On the other hand, staff members more frequently accessed government websites, and the self-help group members mostly preferred government websites as a provider of clinical trial information. Thus, governmental policy should consider centralization of information or establishment of tie-ups with other websites to provide convenient access to clinical trial information. For example, effectively linking websites of self-help groups and governmental agencies could also enhance the function of self-help groups.

With regard to educational opportunity about clinical trials, our subjects did not express a major preference for school education compared with education at medical facilities, when necessary. This may show patients need the information when they need and want to access, and self-help group could play important role. However, In Japanese context, the government plans to implement a policy to provide drug and risk-benefit education aimed at schools, including information on clinical trials, to increase the understanding of the general public and for future drug development (Ministry of Health, Labour and Welfare, 2012). Our results also suggested the existence of a gap between the intentions of policymakers and the preferences for learning expressed by the general population. Future studies should examine appropriate periods and methods of education for the general population that can effectively improve the

understanding of clinical trials.

There were several limitations to our study. First, our questionnaire was specifically distributed to self-help group members, primarily consisting of members with intractable diseases and was not representative of other self-help groups, which could have biased our results. In addition, the sample of staff members included only those affiliated with organizations with active websites, although this practice is not a unique method to confirm group activity. Second, the questionnaire distribution method was not uniform among all respondents. The survey was conducted by mail to protect the privacy of the self-help group members, whereas the questionnaire was directly distributed to the staff members, which also could have introduced bias to the replies of the respondents. Finally, though each country has different health system, each country's context of self-help groups is important information. Therefore, the results could not be generalized. In future studies, closer examination is needed by comparing cultural or medical background of each country.

In summary, we demonstrated that part of the function of self-help groups is to disseminate information among the members and staffs. For members, it was confirmed that participation in a self-help group was an important source of information, and staff members also play roles in the dissemination of information as well as acting as representatives of patient groups. Based on these results, it was suggest as follows: first, it is important to recognize self-help groups as effective healthcare resources. Second, in addition to enhancing the quality of governmental websites on medical and clinical trial information, linking government websites to those of self-help groups could enhance the efficacy of self-help groups.

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