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Evaluating the Cancer Information Service

A qualitative study of evaluation criteria for the telephone service in Japan

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Abstract

Although cancer is the leading cause of deaths in Japan, cancer information available to the public is still insufficient. A telephone service providing cancer information was recently initiated; however, the quality of this service has not yet been investigated. Therefore, the aim of this study was to establish the evaluation criteria for the telephone cancer information service in Japan. This study was conducted at the Cancer Telephone Information Service of the NPO Japan Clinical Research Support Unit. Seventeen calls were purposively chosen. Ten researchers reviewed the voice data and the transcripts of the calls, and used these to determine criteria to independently evaluate the quality of the information service. We held eleven meetings to discuss and develop the final criteria. We identified two main categories to evaluate information specialists' performance: (1) complying with center policy; (2) properly assessing the caller's needs and responding to them with appropriate information and support. We also included two main categories focusing on callers' reactions: (1) whether the caller's expressed needs were understood by the specialist and met with satisfactorily provided information and support; and (2) whether the caller was satisfied with the session overall. Twenty and nine sub-categories were set for the categories of information specialist and callers have, respectively. The results suggest the process of providing an information service needs to be evaluated from the viewpoints of both providers and users.

Keywords：cancer information service, hotlines, criteria, quality management

1. Introduction

Countries around the world have public or private nationwide cancer information services that provide patients, family members and citizens with telephone consultations and other services through different means, such as e-mails and face-to-face sessions. Data from such services have been analyzed in various ways, and utilized to offer better services for meeting the needs of individuals seeking information[1-7]. In Japan, however, there was no nationwide information service until recently, although the incidence of cancer is one in two individuals. There was minimal provision of small-scale telephone cancer consultation services by non-profit organizations (NPOs), patient support groups, and healthcare professionals, but the quality of these consultation/information services was not investigated adequately. As a result, there was a tendency for some cancer patients and their family members, to be unsure of which hospital or type of care to choose, and to move around the country to seek an appropriate hospital and treatment. These people have been called “cancer refugees” 8).

However, since the initiation of the “Third-term Comprehensive 10-year Strategy for Cancer Control” in 2004, followed by the enactment of the “Cancer Control Act” in 2006, Japan has finally made a commitment at a national level toward a “system for providing cancer care information”, with the strategic goal of an even distribution of cancer care 9). In contrast to the situation in other countries, however, the information-providing service has been undertaken by the individual cancer consultation and support centers that have been newly established in 407 cancer medical care base hospitals around the country (as of 2014). To achieve equality in the provision of information, it is crucial to establish a structure that provides education to enhance the capabilities and skills of specialists in providing cancer information in all these centers, and improves the consultation quality of each center.

To manage consultation quality, the first requirement is a tool for its measurement. In other countries, tools have been developed to measure the quality of medical consultations and provision of medical information. These include, for example, the Reason for calling, Information gathering, Conclusion, and Evaluation rating scale (RICE) 7), the Roter method of Interaction Analysis System (RIAS) 10), and the Medical Interview Aural Rating Scale (MIARS) 11). Simple evaluation tools for cancer information services include quality management tools that are provided by the International Cancer Information Service Group (ICISG), such as: annual performance review form the American Cancer Society [ACS] 12); call monitoring tool from Cancer Information Service [CIS] of the National Cancer Institute 13); and the self-monitoring tool in Germany from German Cancer Research Center’s Cancer Information Service [KID] 14). A simple, easy-to-understand evaluation tool would be indispensable in Japan, where the local cancer consultation and support centers perform quality management individually, but there is no such tool available at present. To achieve high-quality cancer consultation and support that is available throughout the country, the development of a tool that enables simple measurement of service quality by each consultation and support center is an urgent necessity.

Thus, in 2007, a study group “Research on appropriate delivery of cancer information and support from the viewpoint of cancer patients, their family members, and the general public” was established to identify the cancer information needed by patients, family members, and the general public, and to explore an information-providing method accessible to every single person and the cornerstone of the information-providing system, with the intention of preventing the widening of an information gap. In cooperation with an NPO, the Japan Clinical Research Support Unit, the study group launched the “Cancer Telephone Information Service (CTIS)” in June 2008 to improve the quality of the cancer information provided to callers. The CTIS aims to train information specialists and to run the telephone consultation service, and the objectives of the study group include: preparing cancer information or cancer-related information; performing quality management of the cancer information service; developing support programs for the information specialists and medical staff members; and assessing or evaluating the effect of promotion activities. This paper reports a qualitative study that was undertaken to achieve one of the objectives described above. The study reviewed Japanese real-world cases of cancer consultation and support to identify the criteria needed to evaluate their quality, and, based on the results, developed the initial Japanese version of a simple cancer information service quality evaluation tool required for quality management of the service.

2. Method

2. 1 Sample

From approximately 500 calls made to the CTIS over the course of about 6 months in 2008, we extracted 17 calls by purposive sampling 15), which involves fit-for-purpose case selection based on the duration of consultation, cancer type, information specialist's level of performance, and other parameters. The selected 17 calls concerned cancers which were common reasons for calls to the CTIS: breast cancer, colon cancer, lung cancer, liver cancer, gastric cancer, and hematologic cancer. Breast, colon, lung, liver, and gastric cancers are the five most common cancers in Japan. Hematologic cancer was included because it accounted for the majority of reasons for calls to the CTIS, which had previously served as a telephone consultation center specializing in hematologic cancer. To be selected, the call had to be of a duration similar to the mean duration (22 minutes) of calls that were made to the CTIS during the 6 months, and calls with a duration ranging from 15 to 30 minutes were selected. The selected calls were handled by a total of six information specialists, including five specialists and one chief specialist: seven were handled by the chief specialist and 10 by the other specialists. The callers consisted of nine patients and eight family members. They inquired about treatments, symptoms, adverse reactions, relationship with a healthcare professional, and vague anxiety, among other things.

2. 2 Analyses

Ten researchers reviewed voice records and transcripts of the 17 calls. Each independently determined what makes a good- or poor-quality consultation, and extracted evaluation factors for consultation quality. The 10 researchers included four nurses with practical experience, seven individuals with practical experience in telephone consultation, and five medical communication researchers (several were in more than one of these categories). Of these, two were managers of CTIS, the organization under investigation.

The evaluation factors for consultation quality were summarized and categorized at subsequent discussion meetings attended by all researchers, using literature reports addressing ideal communication leading to patient satisfaction as a guideline16-21). These factors were then conceptualized and analyzed to determine their position on the evaluation tool. The researchers also examined the composition, wording, evaluation method, and scoring procedures of the evaluation tool while actually evaluating the calls. Furthermore, the ten researchers then independently evaluated the same four calls using the evaluation tool. If there was disagreement between their scores, improvements were made to the wording of the evaluation criteria, evaluation method, and scoring procedures to enhance the tool's credibility15 [22-24]. Ultimately, the initial version of the evaluation tool was completed. A total of 11 discussion meetings attended by all researchers were held.

2. 3 Ethical considerations

Before being connected to the information specialist, each user of the CTIS telephone consultation service was informed by an automated voice that all calls would be recorded for quality management, some of the recorded calls might be used for research after being made anonymous, and any individual who disagreed with the use of the call for research should notify the information specialist. Similar information was presented in advertising posters, brochures, and the CTIS website. The information specialists were employed by the CTIS after they understood and agreed that the CTIS had been established in cooperation with the study group, and that recorded data from calls might be used for research purposes. The recorded data obtained in this fashion were provided to the study group after personal information was deleted or rendered anonymous by the CTIS. This study was approved by the ethical review board of the National Cancer Center.

3. Results

3. 1 Criteria for evaluating information specialist performance

The information specialist-based evaluation factors were divided into the following two major categories: "Complying with center policy" and "Properly assessing the caller's needs and responding to them with appropriate information and support."

3. 1. 1 Complying with center policy

This category consisted of what an information specialist should do. Basic acts complying with principles of an information specialist were successfully categorized. After the categorization, we realized that those were very similar to the eight policies in the CTIS operation manual. Therefore, to express these eight items, the wording of the operation manual was used. A binary-choice format was used for evaluation: complying with the policy (score: 1), or not complying with the policy (score: 0) (Table 1).

3. 1. 2 Properly assessing the caller's needs and responding to them with appropriate information and support

Information specialist skills related to consultation quality that were extracted by the researchers were initially found to fall into two categories: "appropriate information-providing skills" and "communication skills." However, evaluation of the categorized skills revealed a phenomenon whereby the specialist's use of the skills scored high, even if it sounded like the caller was not satisfied. As a result of discussion meetings, the wording was changed to focus on whether the specialist had successfully achieved each of the consultation processes provided in the CTIS operation manual (starting with encouraging the caller's expression of his/her experience or emotions, followed by adequately understanding the caller's situation, assessing and accurately identifying the caller's chief complaint and needs, and providing support that met his/her needs, in this order), rather than listing skills as evaluation criteria. Therefore, the individual consultation processes were divided into the following four middle-level categories: (1) Encouraged the caller's expression of his/her experience and emotions; (2) understood and checked back with the caller about his/her situation and concerns adequately; (3) recognized and assessed accurately the caller's needs; (4) provided adequate information and support corresponding to the caller's needs. The information-providing skills and communication skills extracted constituted a total of 12 minor categories within these four categories. The four middle-level categories were then integrated into a major category entitled "Properly assessed the caller's needs and responded to them with appropriate information and support" (Table 2). A 4-point Likert scale was used for evaluation: 4, good; 3, barely acceptable; 2, poor; 1, very poor.

3. 2 Criteria for evaluating the reactions of the callers

Nine reactions from the callers were also extracted as evaluation factors. These reactions were classified into the following two major categories: "The caller's expressed needs were understood by the specialist and were met with satisfactorily provided information and support" and "overall, was the caller satisfied with the session?" The former category could be broken down into the following two middle-level categories: (1) "The caller was accepted and understood by the specialist"; (2) "the caller put his/her own present situation in perspective and found out about further directions" (Table 3). All of the callers' reactions were evaluated by a four-point: Likert scale: 4, extremely satisfied; 3, very satisfied; 2, a little satisfied; 1, not at all satisfied.

In addition, the overall impression of the session as experienced by the rater was included and rated on a scale from good (score: 4) to bad (score: 1). Reasons for the rating were expressed in written words.

4. Discussion

Table 1. Information specialist's score - Complying with center policy

1. Did not provide information not approved by the center.
2. Provided information with disclaimers and sources.
3. Did not provide medical advice.
4. Did not make any statements that interfered with the patient's or his/her family members' relationship with his/her doctor.
5. Did not make any statements containing personal situations, preferences, beliefs, or opinions.
6. Did not handle the caller's personal information inappropriately or gathered unnecessary personal information from him/her.
7. Did not provide the caller with personal information.
8. Ended the call with a remark to encourage the caller to call again when needed.

Rating score: complying with the policy = 1; not complying with the policy = 0; not applicable = /

Table 2. Information specialist’s score - Properly assessing the caller’s needs and responding to them with appropriate information and support

Encourage the caller’s expression of his/her experience and emotions.

1. Provided an atmosphere where the caller felt welcomed and found it easy to talk.
2. Paid adequate attention to the caller’s story while listening.
3. Accepted the caller’s experience and emotions while listening.

Understood and checked back with the caller about his/her situation and concerns adequately.

4. Was knowledgeable enough to understand the caller’s situation and concerns.
5. Comprehended the caller’s situation and concerns by directly checking back with him/her.
6. Summarized and checked back with the caller what the specialist understood about his/her experience, situation, emotions, and concerns.

Accurately recognized and assessed the caller’s needs

7. Directly checked back with the caller about his/her needs.

Provided adequate information and support corresponding to the caller’s needs.

8. Responded adequately to the caller’s needs.
9. When needed, provided the caller with evidence-based information that was appropriate and useful for his/her needs.
10. Used language that was easy for the caller to understand when giving information.
11. Understood the relationship between the patient/the family members and the physician, and supported good relations between them.
12. Gave the caller information that would help him/her act or use his/her own judgment in overcoming problems.

Rating score: good = 4; barely acceptable = 3; poor = 2; very poor = 1; not applicable = /

Table 3. The caller’s reactions score

The caller’s expressed needs were understood by the specialist and were met with satisfactorily provided information and support.

The caller was accepted and understood by the specialist.

1. Expressed that the caller successfully communicated what has been intended.
2. The caller’s expressions of his/her experience and feelings connected with the experience were understood by the specialist.
3. What the caller needed help for was understood by the specialist.

The caller put his/her own present situation in perspective and found out further direction.

4. The caller expressed an understanding of his/her own present situation.
5. The caller expressed satisfaction with the provided information.
6. The caller expressed an actual plan of specific actions for overcoming the caller’s problems.

Overall, was the caller satisfied with the session?

7. The tone of the caller’s voice changed.
8. The caller mentioned the usefulness of the service.
9. The caller expressed a willingness to use the service again.

Rating score: extremely satisfied = 4; very satisfied = 3; a little satisfied = 2;
not at all satisfied = 1; not applicable = /

4. 1 Criteria for evaluating information specialist performance: Complying with center policy

The eight items listed in this category are the same as the action goals based on the CTIS policy, which are provided in the operation manual. An NPO involved only in telephone consultations such as the CTIS may have policies and goals that are different from those of a consultation and support center belonging to a medical institution. This may lead to differences in evaluation criteria for compliance with the policies between these two organizations. However, the rules necessary for providing accurate and evidence-based information (“provided information approved by the center", "provided information with disclaimers and sources", and "not made any statements containing personal situations, preferences, beliefs, or opinions"), those necessary for respecting and supporting a good relationship between the patient and doctor ("not provided medical advice" and "not made any statements that interfered with the patient's or his/her family members' relationship with his/her doctor"), and providing a confidential and anonymous service ("not handled the caller's personal information inappropriately or gathered unnecessary personal information from him/her" and "not provided the caller with personal information") are similar to the Core values of a Cancer Information Service 25), and these appear to be universal values in handling calls. It was also evident during the process of extracting the evaluation criteria that non-compliance with these criteria decreases the total score even if scores for the other criteria are high. Therefore, it is expected that these criteria are common to all cancer information services and should be followed to ensure the minimum quality of the services.

4. 2 Properly assessing the caller's needs and responding to them with appropriate information and support

The extracted information specialist skills needed for high-quality consultation are information-providing and communication skills, which are virtually the same as items proposed by the American Cancer Society 12) and the CIS Call Monitoring Tool 13). This suggests that these skills are justified as those leading to a highly rated quality of consultation. However, our evaluation tool does not simply list the skills, but includes goals to be attained in each of the consultation processes in the middle-level categories and specific skills required to attain the goals in the minor categories. As a result, a failure to achieve the goals in any of the consultation processes was assessed as improper use of these skills, and this virtually eliminated previously recognized inter-rater variations in the results of the evaluation. In Japan, where the consultation and support centers operated by various organizations are scattered nationwide, uniform management of quality assurance is difficult. Thus, local information specialists at varying levels should individually be able to measure the quality of consultation using an evaluation tool. This means that an evaluation tool should also specify both what makes a high-quality consultation and what skills are required for providing a high-quality consultation. Since researchers who used the completed evaluation tool found it "easy to understand" and that it "facilitated evaluation," our quality evaluation tool may also be user-friendly for information specialists in the individual consultation and support centers.

4. 3 Criteria for evaluating callers' reactions

It is crucial to the satisfaction of the caller that the information specialist understands his/her concerns and emotions 26-28). Therefore, our evaluation tool includes the caller's reactions as evaluation criteria, unlike many other tools that only have evaluation criteria relating to the information specialist. However the validity and reliability of these evaluation criteria need further improvement since some researchers found it difficult to understand the caller's reactions based only on his/her voice on the phone. On the other hand, the information specialists themselves cannot identify the caller's needs or provide specific support without understanding every reaction from him/

her in the course of a consultation, and some researchers believed that these criteria were indispensable. The difficulty in evaluating the callers' reactions will be reduced by future quantitative studies of the reliability and validity of our tool.

4. 4 Conclusion

This study extracted factors leading to a high-quality consultation from telephone calls requesting cancer information, classified and categorized the factors, and developed a quality evaluation tool for the telephone cancer information service. Since this evaluation tool is intended to improve the quality of the entire Japanese cancer information service, an analysis of its transferability[22, 24)] to calls for the cancer consultation and support centers is an absolute necessity. Further quantitative reliability and validity studies of this tool are also needed. Moreover, its usefulness as an educational tool (e.g., the reliability and validity of self-evaluation by specialists, and the effect on the education of specialists) should also be examined.

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