Development of a self-care support system for cancer outpatients undergoing radiotherapy: introduction of clinical path functions

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Objectives: To introduce "clinical path" (abbreviated below as simply "path") functions into the cancer outpatient support system to gain a complete perspective of radiotherapy and to establish a shared system to collect patient information for medical professionals.

Materials and Methods: In our system, path functions of radiotherapy were added to the existing system. Common items of the main content on displays for patients and medical professionals were noted. Assessment content was added to the path display for medical professionals concerning nursing. Patients' subjective information was gathered from the "current condition" display.

Results: Patients could get a complete picture of radiotherapy through the addition of path functions. Severity or changes in patients could be clearly indicated. Items concerning current condition were set up so that patients could easily and directly describe their conditions. Information could be gathered from the patient's physical and mental conditions. A two-way communication system allowed replies to patients.

Conclusion: This path affords a complete picture of examinations and therapy schedules, and the patient can be given information when adverse events occur. This leads to better self-care behavior, and chronical recording leads to better self-monitoring. A patient's self-care ability can be determined and appropriate intervention is possible. Via the "current condition" display, subjective patient information can easily be obtained, and the patient's condition can accurately be assessed.

Key words: cancer outpatients, clinical path, radiotherapy, self-care support system, telemedicine support, home health care

Introduction

Fifty percent of cancer patients undergo radiotherapy worldwide. In the United States, radiotherapy is used for approximately 65% of patients, while in Japan, the rate remains at approximately 25%.1 Recently, comprehension of the benefits of radiotherapy has led to a rapid increase in radiotherapy in Japan.1 Moreover, it has become possible to undergo radiotherapy as an outpatient, which further boosts its utilization rate. However, many outpatients are wary of adverse events, and of the therapy itself, and continue therapy in agony. Therefore, some patients need physical and mental self-care abilities and social support. A service that can provide information, and one that is easily accessible to patients, is necessary, e.g., a telemedicine support system.

On the other hand, since medical professionals do not know the patient's conditions at home, they cannot support the patient adequately. The goal of radiotherapy is to bring the exhaustive therapy to a successful conclusion while keeping adverse events at a minimum. If for any reason the therapy is postponed or discontinued, the expected effect cannot be obtained. Nurses are expected to support the patient physically and mentally so that the patient can proactively deal with the therapy while controlling the symptoms of adverse events. When using the "clinical path" (abbreviated below as simply "path") function, a complete examination and therapy schedule can be seen. While helping the patient to be more mentally prepared, it also helps the medical staff to provide therapy more smoothly, because the patient can reduce his or her anxiety towards the therapy by the fact

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that self-care is available.\textsuperscript{2} Therefore, in this study, path functions were added to the home support system for radiotherapy cancer outpatients. The contents of self-care of the existing system were explanation of the general solution for notes and the adverse experience in radiotherapy. In the conventional system, information service about time advance progress of the appearance time of an adverse experience, medical treatment progress, among others, was not completed. For this reason, the patient had the anxiety about incorrect recognition of an adverse experience. Moreover, the patient was also worried that the anticipation to medical treatment might not be formed. From these reasons, we built a system that cancels a patient's uneasiness using a path that can grasp the global image of a medical treatment schedule. Thereby, two systems were established: a radiotherapy cancer outpatient support system, and a shared system for collecting patient information for medical professionals and paramedical workers.

**Materials and Methods**

The system that we established adds path functions that can enter the radiotherapy path content shown below in the existing system (i.e., the cancer outpatient support system).\textsuperscript{3} With the conventional system,\textsuperscript{3} in order to measure each patient's pain condition quantitatively, an SDS value display (Samtel Display Systems, San Jose, CA, USA) can also be used.

**System design**\textsuperscript{1}

Figure 1 shows the system we developed, and Figure 2 shows an overview of the system in a patient's home. The system in the patient's home uses a personal computer (PC) (Dell Dimension 8100; CPU: Pentium4 1.3 GHz; memory: 392 MB) running Windows 2000 Professional (Microsoft). Table 1 shows the types of vital data obtained and the measurement instruments used. Table 1 also shows the accompanying software for data input into the PC. RS232C cables provided with the software from different manufacturers were used for the connections between these measurement instruments and the PC. In addition, this system has an RS232C automatic switching instrument (CONTEC, COM-4[USB; universal serial bus]) to obtain vital data from multiple measuring instruments in RS232C format. For the system in the medical facility, the server accumulating the vital data is running Windows 2000 Server (Microsoft), and it has a database from which the patient data, such as the password, the patient name, and vital data, can be accessed.
In addition, the system in the medical facility has software that integrates the above and a patient-support system.

The username and password, which were published by the hospital, were used to login to the system. Moreover, the fingerprint authentication system was also used, thus, enhancing users' convenience.

In the experimental system providing telesupport, two systems, the home care, patient-side system and the system in the medical facility, the hospital-side system, were connected by the public telephone lines or the Internet, or both, sending and receiving real-time visual and audio data and biological information, such as body temperature, blood pressure, pulse, and respiration.

System configuration and implementation
After login from the patient home system as well as the medical professionals system, a menu panel is displayed. Figure 3 shows the login display for patients, and Figure 4 shows the login display for medical professionals. This menu panel is separated into 3 items: consulting support, self-care, and physical condition, and buttons related to their content are set up. To the self-care and physical condition items of the existing system, a path and a select button for "current condition," respectively, were added.

Path content
Regarding path content, the path display for patients and the path display for medical professionals differ slightly.

Integration software was self-developed to unify the functions of each software type.

<table>
<thead>
<tr>
<th>Vital data</th>
<th>Manufacturing company</th>
<th>Hardware</th>
<th>Software</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood pressure, pulse</td>
<td>OMRON</td>
<td>HEM747-IC</td>
<td>HEMSOFT IC3</td>
</tr>
<tr>
<td>Blood sugar level</td>
<td>ARKRAY</td>
<td>GT-1660</td>
<td>MEQNET DM Manager</td>
</tr>
<tr>
<td>Weight and body fat ratio</td>
<td>OMRON</td>
<td>HBF-3541T</td>
<td>Self-development</td>
</tr>
<tr>
<td>Body temperature</td>
<td>TERUMO</td>
<td>ET-C202P</td>
<td>Self-development</td>
</tr>
</tbody>
</table>

Table 1. Vital data measurement instruments and accompanying software
Self-care support system for radiotherapy cancer outpatients

**Figure 3.** Clinical path login system for patients (Patients name, address, etc., alias)

**Figure 4.** Clinical path login system for medical professionals (Patients name, address, etc., alias)
Figure 5. Clinical path system for patients

Figure 6. Clinical path system for medical professionals
Figure 7. Differences between the clinical path systems for medical professionals and those for patients

<table>
<thead>
<tr>
<th>目標</th>
<th>有害事象</th>
<th>自己ケアケア</th>
<th>説明</th>
</tr>
</thead>
<tbody>
<tr>
<td>介人内容</td>
<td>有無事象</td>
<td>セルフケア</td>
<td>説明</td>
</tr>
</tbody>
</table>

Figure 8. Assessment content of the clinical path system for medical professionals

有害事象について理解はされている。しかし、倦怠感が強く、特に照射をおこなった午前中は寝て過ごすこと多い。午後から活動し始め家事をこなしている。夫の理解や協力もあり妻の支えとなっている。
Figure 9. “Current condition” system (Patients name, address, etc., alias)

Figure 10. Display of “current condition” in the clinical path system
The main content of items shared by both displays are irradiation therapy, examination, medication, procedures, medical chart, progress, consultation day, nursing (purpose and intervention content), anticipated acute reactions, as well as care, and current condition, among others. As shown in Figure 5, path display for patients, and in Figure 6, path display for medical professionals and assessment content for nursing (purpose, intervention content, and assessment) have been added. Figure 7 shows the differences between the path displays for patients and medical professionals.

Path functions are sorted out in different colors for the day concerned and other days. To confirm items, check boxes are available. When any of these are checked, the color of the respective item column changes. In this way, the status of confirmation can be viewed.

Path display for patients
Content related to the irradiation therapy period, examinations, procedures, etc., and medical care; and content related to nursing goals, nursing intervention, etc., and nursing support were added to the system (Figure 5). Nursing goals are set up for shared awareness of patients and nurses. For example, the nursing goal before medical treatment is begun sets up the nursing goal based on time progress of "understanding about the flow of medical treatment" and "understanding about an adverse experience." From Day 1 of irradiation, nursing goals based on the following time progress will be set up, "medical treatment being received favorably," "change of the body being observed and being able to tell a medical staff about that change," "being able to cope with an adverse experience related to that change," etc. Content related to an anticipated period during which adverse events occur and the content of care was set up. For example, since dermatitis may be worsened by ultraviolet rays for the acute reaction and management of the skin on Day 1 of irradiation, one should wear a hat, a mask, sunglasses, etc. And the skin of an irradiated part may be dry or may become red on Day 5 of irradiation.

Path display for medical professionals
As shown in Figure 8, the current condition of symptoms, self-care, and family support, among others, items that assess the patient's self-care ability and the degrees of the patient's comprehension of the therapy and his or her anxiety are added to the system for medical professionals.

Current condition display
To find out the patient's condition as shown in Figure 9, the "current condition" button on the menu panel is selected. In the patient home system, the patient is asked about his or her physical and psychological condition. The patient is asked, "How is your current physical condition?" And, "How is your current state of mind?" Items are preset and listed for the patient that could describe the patient's current condition in a simple and clear manner. For example, "I feel a little anxious. Since my irradiation will start tomorrow." "I am somewhat worried." And for the facility, a comment field is set up. Comments appropriate for each patient's condition are described, so when the comment button is pushed, a comment is sent to the patient. Furthermore, from the patient's "current condition," the medical professionals gain information on the patient's needs. In order to understand the patient's condition, which changes during therapy, it appears as, "current condition" and is easily understood by the patient.

The item "current condition" shown in Figure 10 is set up on the path display and on the menu panel shown in Figure 9. The current condition can be entered from both the path display as well as from the menu panel. Letters are entered in the display shown in Figure 9. Furthermore, after entering letters in the path display, the current condition is displayed.

Results
The following feedback was obtained from 2 nurses and 1 medical doctor after implementing the system that we established.

Through the addition of path functions, it has become easy for the patient to get a complete picture of his or her own radiotherapy. The patient's radiotherapeutic events have also become easy to understand. Indicating irradiance levels (Gy) by the number of exposure areas to make it possible to explain that therapeutic effects and adverse events do not occur directly after irradiation due to their relationship to the irradiance levels would have made them easier to understand. Since, by these path functions, therapy progress could be added or amended as needed, severity and changes in the patients could be displayed clearly. It was necessary to add a pain scale and items by which an understanding of the patient's pain could be gained to understand the patient's physical condition. Furthermore, since outpatients lead a life within society, they require lifestyle-related information. The patient's self-care ability could be assessed and linked to nursing goals, the nursing-care plan, and nursing intervention on the display for medical professionals.

Through display of the patient's current condition, a
subjective understanding of the changes in the patient's condition resulting from therapy could be gained. Information of both the patient's physical and psychological conditions could also be obtained. Furthermore, through the two-way communication system, it became possible to respond to patient information from the facility system "side comment" field.

Discussion

Through the path display of this system, a complete picture of examinations and therapy schedules can be obtained, and the patient can be provided information about when adverse events will occur. This ought to lead to better patient self-care behavior. Furthermore, it was useful that additions and amendments of the path could be made as needed because self-care ability changes throughout the period of therapy. The patient's cooperation is indispensable in order to achieve the treatment goal. The patient must understand the necessity of their therapy, examinations, and self-care guidance so that he or she can take self-initiative to maximize his or her self-care. Moreover, recording by chronological entry also leads to better patient self-monitoring. With these communicating devices for the patient's daily life and assessment of measures to cope with adverse events, the patient's self-care ability is further encouraged, becoming a driving force for developing his or her self-control. Because radiation therapy usually requires many courses over a long period of time, depending on the disease condition and site, physical and mental strength may decrease. It has been reported that anxiety and pain in particular increase in Week 6 following treatment. Therefore, mental support is necessary while adjusting physical symptoms as well. Nurses need to continuously intervene so that the patient complies with proper self-care. Regarding the nursing goals, it was possible to establish them in concert with the patient's condition and to realize shared awareness with the patient. By adding assessment items to the path for medical professionals, the patient's self-care ability could be evaluated and the appropriate intervention provided.

Although it is possible to gain information leading to an understanding of the patient's distress through this system, e.g., when undergoing daily courses of radiotherapy, the patient has to lie still in the same position on a hard table, and pain, and nausea make it difficult to stay in that position. Therefore, it is necessary to make attempts to alleviate symptoms focusing on the treatment period.

Because this system is for outpatients, items for the assessment of lifestyle regulations will be added. It is also a manifestation of what has become a common understanding among medical professionals that social pain is closely related to physical, mental, and spiritual pain.

Conclusions

A system was established in this study that supports the proper self-care behavior of radiotherapy cancer outpatients. It is a self-care support system that cancer patients can use at home as well as during their visits to the outpatient department. Furthermore, because patients and medical staff can easily communicate, it is a system by which the cancer patients developed a feeling of security, and the medical staff could successively gain an understanding of the cancer patient's physical and mental conditions.

References