Impact on Quality of Life of a Telemedicine System Supporting Head and Neck Cancer Patients: A Controlled Trial During the Postoperative Period at Home

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Abstract

Objectives: Telmedicine applications carry the potential to enhance the quality of life of patients, but studies evaluating telemedicine applications are still scarce. The evidence regarding the effectiveness of telemedicine is limited and not yet conclusive. This study investigated whether telemedicine could be beneficial to the quality of life of cancer patients.

Design and Measurements: Between 1999 and 2002, we conducted a prospective controlled trial evaluating the effects of a telemedicine application on the quality of life of patients with cancer involving the head and neck, using quality of life questionnaires that covered 22 quality of life parameters. All patients had undergone surgery for head and neck cancer at the Erasmus MC, a tertiary university hospital in The Netherlands. Patients in the intervention group were given access to an electronic health information support system for a period of six weeks, starting at discharge from the hospital.

Results: In total, we included 145 patients in the control group and 39 in the intervention group. At 6 weeks, the end of the intervention, the intervention group had significantly improved QoL in 5 of the 22 studied parameters. Only one of these five quality of life parameters remained significantly different at 12 weeks.

Conclusions: This study adds to the sparse evidence that telemedicine may be beneficial for the quality of life of cancer patients.

Introduction

The Institute of Medicine’s (IOM) report, entitled From Cancer Patient to Cancer Survivor: Lost in Transition, exposes a gap in the follow-up care of cancer patients. Issues raised in the report include coordination between health care providers, and monitoring for consequences of cancer and its treatment, including psychosocial needs.

Information and Communication Technology (ICT) has been advocated as a possible solution for the communication and co-ordination needs of health care. There is increasing interest in the use of ICT2 and telemedicine3 as a means to deliver health care. Telemedicine is the use of information and communication technology to provide health care services to individuals who are at some distance from the health care provider.4,5 Although an abundance of telemedicine literature exists, studies evaluating telemedicine applications are still scarce,6 often have poor study designs,7 or are restricted to demonstrating a system’s feasibility.7 Evidence regarding the effectiveness of telemedicine is still limited and not yet conclusive.8-12 Some evidence exists that home based telemedicine has positive effects on clinical outcomes for management of chronic diseases such as hypertension and HIV/AIDS.8

Telemedicine applications are also believed to have the potential to enhance quality of life.14 Telemedicine evaluations having quality of life (QoL) as an outcome parameter are still rare, but results are promising. Out of 4,646 telemedicine publications, 11 addressed quality of life, of which most showed improvements.15

In this paper we will present the effects of a telemedicine application on the quality of life of head and neck cancer patients. Head and neck cancer has a major impact on the patients’ quality of life.16,17 Treatment for head and neck cancer often is disfiguring and accompanied by speech problems, for which electronic communication could be an
alternative. For patients who have been admitted to the hospital for treatment, the period following directly after discharge is characterized by uncertainty and fear. Discharge is an abrupt end to having care providers nearby; suddenly, doctors and nurses are no longer at verbal calling distance. Moreover, attention from friends and relatives often decreases.

The study provided head and neck cancer patients with an electronic health information support system during their first six weeks after discharge.

In a prospective controlled trial, we evaluated whether support from this telemedicine application had effects on the QoL of surgically treated head and neck cancer patients at home.

Methods

Setting
The study was performed in the Erasmus MC, a tertiary university hospital with more than 1,200 hospital beds in Rotterdam, The Netherlands. Erasmus MC has two locations in which head and neck cancer patients are treated. Treatment protocols and surgeons are the same at both locations.

Patients
We included patients from June 1999 through January 2002. Patients were eligible to participate after one of the following three surgical procedures for head and neck cancer:

- neck dissection (removal of the lymph nodes in the neck),
- total laryngectomy (removal of the voice box),
- commando procedure (resection of a tumor in the mouth or throat after splitting the lower jaw).

All patients needed to be able to read and write in Dutch, and have a phone at home. A physician who did not belong to the therapeutic team invited the patients to participate, typically one day before discharge from the hospital.

Standard Care
All patients received standard care: all had routine follow-up appointments in the outpatient clinic at two and at six weeks after discharge. Furthermore, all patients could contact their care providers, both in- and outside the hospital, if considered necessary.

None of the patients received chemotherapy during the study period. Most commando-procedure patients received radiotherapy, whereas most patients in the other groups did not.

Intervention
Patients in the intervention group were given access to an electronic health information support system for a period of six weeks starting at discharge from the hospital. After agreement to participate, intervention patients received instructions and were provided with a laptop for communication with a hospital team. Patients had to return their laptop six weeks after discharge; the laptop was then reused by a consecutive intervention patient. The laptop, use of the system, and dial-in connection were all free of charge for patients.

Using the system, patients could communicate (send messages), get access to information, have contact with fellow sufferers (via a forum), and could be monitored at home (by means of electronic questionnaires). A detailed description of the system and its use can be found elsewhere.

Study Design
In the study we aimed to compare quality of life between the control and the intervention group. In order to avoid contact between intervention and control patients, we assigned patients to either control or intervention group on basis of the hospital location where they underwent their surgery. However, such a design does not exclude location as a possible explanation for QoL differences. Therefore, from June 1999 through August 2000, we first performed a study comparing QoL between both hospital locations without any intervention. Results from that study showed that location did not account for QoL differences.

In the consecutive period, from September 2000 through January 2002, we then included patients into the intervention group in one location, while continuing to include patients into the control group in the other location. Table 1 shows the study design.

Quality of Life Questionnaires and Data Collection
We asked all patients to complete three paper quality of life questionnaires: at discharge, six weeks after discharge, and three months after discharge.

All three questionnaires addressed the same QoL dimensions, based on the theoretical model of coping with cancer developed by Van den Borne and Pruyn. The questionnaires contained a total of 22 QoL subscales, of which 19 had been validated and used in one or more previous studies.

For this study we additionally developed three subscales. Table 2 shows details of all (sub)scales used in this study: the subscale feelings of depression, for example, contains 10 different items, which are added to calculate the (sum-) score on the scale.

At discharge, we obtained the following patient characteristics: age, gender, previous computer experience, living single or together, highest level of education (on an eight-point scale), location and type of surgical treatment.

Statistical Analyses
We analyzed only data of patients who returned all three questionnaires. For each patient we first calculated the sum-scores of each of the 22 subscales at discharge (T1), at six weeks (T2), and at three months (T3). When more than one third of items for a subscale were unanswered, no sum-score was calculated. If fewer items were unanswered, missing values were replaced by the average score of items answered by that patient on the given subscale.

Using analysis of covariance (ANCOVA), we verified that no significant differences existed between the three control groups. Scores at discharge were taken as baseline scores. We then
determined changes in QoL scores between T1 and T2 (the change from baseline at six weeks), and between T1 and T3 (the change from baseline at three months). The changes from baseline in the intervention group were then compared to the changes in the combined control group for all 22 QoL parameters. For the analyses we used ANCOVA with the baseline evaluation as covariate. ANCOVA is a regression method that is unaffected by baseline differences between intervention and control groups.29

We finally repeated all analyses while adjusting for differences in patient characteristics between control and intervention groups. For all analyses, p<0.05 was considered as the limit of significance.

Results

ANCOVA analyses showed no significant differences in change from baseline for the 22 QoL subscales between the three control groups, thus permitting to combine these groups into one control group.

During the entire inclusion period (June 1999 through January 2002) 229 patients met the inclusion criteria: 59 for the intervention group and 170 for the (combined) control group. In the control group, 145 of 170 patients agreed to participate (85%) and 128 completed all three questionnaires, whereas 39 of 59 patients in the intervention group agreed to participate (66%) and 35 completed all three questionnaires. Of all 21 patients (17 control patients and four intervention patients) who dropped out of our study after inclusion, 18 dropped out between discharge and six weeks after discharge, and three patients dropped out between six weeks and three months after discharge. The flowchart in Figure 1 shows the flow of all patients, and provides reasons for non-participation and dropping out.

In Table 3, the patient characteristics from the 128 control patients are compared to the characteristics of the 35 patients in the intervention group. The table shows that intervention and control groups were well balanced, except for “type of operation.”

In Table 4 we provide some basic usage statistics of the system, as well as other findings in the intervention group.

For each of the 22 quality of life parameters, Table 5 shows the difference in change from baseline in QoL between the intervention group and the control group, while adjusting for baseline values. The table shows, for example, that at the end of the intervention (six weeks after discharge; T2) the change from baseline for “fear related to specific head and neck problems” was 2.59 lower (standard error of 1.05) in the intervention group as compared to the control group (p=0.02). Note that such a difference may indicate that (a) in both groups QoL improved but more so in the intervention group; (b) in both groups QoL deteriorated but deterioration
was worse in the control group; or (c) that QoL in the intervention group improved whereas QoL in the control group deteriorated. The table furthermore shows that the found significance for “fear related to specific head and neck problems” was not present anymore six weeks after the intervention ended (three months after discharge; T3).

Five of the 22 QoL subscales showed significant differences in change from baseline at the end of the intervention: “state anxiety,” “fear related to specific head and neck problems,” “physical self efficacy,” “perceived abilities in swallowing and food intake,” and “general physical complaints.” In all five changes the intervention group had better QoL compared to the control group. At three months, six weeks after the end of the intervention, only “physical self efficacy” remained to have a significant difference in change from baseline.

Control and intervention groups were not balanced for “type of surgery” (see Table 3). However, adjusting for “type of surgery” did not alter the above results.

For each of the five significant QoL parameters Figure 2 shows the mean level (± one standard error) for both control

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**Figure 1.** Patients’ flow into the various groups during this study. The reasons for not participating or dropping out are also shown. Out of 229 potential patients (all groups), 184 patients were included, of whom 163 completed all three questionnaires.
Table 3 • Patient Characteristics (n=163)

<table>
<thead>
<tr>
<th>Patient Characteristic</th>
<th>Control Group (n=128)</th>
<th>Intervention Group (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (range)</td>
<td>61 (29–84)</td>
<td>59 (38–78)</td>
</tr>
<tr>
<td>Gender (number and %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>93 (73)</td>
<td>25 (71)</td>
</tr>
<tr>
<td>Female</td>
<td>35 (27)</td>
<td>10 (29)</td>
</tr>
<tr>
<td>Previous computer experience (number and %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“None” or “a little”</td>
<td>98 (77)</td>
<td>26 (74)</td>
</tr>
<tr>
<td>“Quite some” or “a lot”</td>
<td>30 (23)</td>
<td>9 (26)</td>
</tr>
<tr>
<td>Living single or together (number and %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>28 (22)</td>
<td>7 (20)</td>
</tr>
<tr>
<td>Together</td>
<td>100 (78)</td>
<td>28 (80)</td>
</tr>
<tr>
<td>Mean level of education* (range)</td>
<td>3.75 (1–7)</td>
<td>3.76 (2–7)</td>
</tr>
<tr>
<td>Type of surgery (number and %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total laryngectomy</td>
<td>26 (20)</td>
<td>14 (40)</td>
</tr>
<tr>
<td>Commando procedure</td>
<td>50 (39)</td>
<td>6 (17)</td>
</tr>
<tr>
<td>Neck dissection</td>
<td>52 (41)</td>
<td>15 (43)</td>
</tr>
</tbody>
</table>

*Level of education was scored on an 8-point scale; 1 = no education, 8 = university level.

of the 22 studied QoL subscales, five showed significantly improved QoL in the intervention group as compared to the control group at the end of the intervention. Moreover, at three months after discharge, and thus six weeks after the end of the intervention, four of the five QoL parameters did not differ significantly any longer: an indicator that the use of the telemedicine application indeed had a positive impact on QoL during the intervention. These results may suggest that the application helped the intervention patients improve some components of QoL more quickly than the controls, although they ultimately reached the same level of improvement. Unfortunately, our study does not permit any conclusions as to what effect on QoL we might have found if use of the system had continued during the second six weeks.

Further research is also required to study possible (causal) mechanisms and explanations. The observed effect at the end of the intervention on “general physical complaints,” for example, can be explained as an actual improvement in symptom control (e.g., by more timely and more appropriate advice), but may also simply indicate that symptoms were only perceived as less burdensome simply because patients were able to report symptoms more often.

Although five of the 22 QoL parameters were positively influenced, we did not find any effect on the two subscales on feelings of insecurity. A subjective evaluation, however, showed that many patients in the intervention group (83%) stated that being able to contact care providers in the hospital by means of the system gave them a feeling of security.21 So, perhaps these subscales on feelings of insecurity, which had not been used in previous studies, were not sensitive enough to objectify QoL differences.

We believe that this study adds to the sparse evidence that telemedicine may also be beneficial for the QoL of cancer patients. In a randomized controlled trial with a telemedicine application for younger women with breast cancer, Gustafson et al. reported significantly improved social support and information competence after five months of use.30 They furthermore found some positive effects on QoL in a subgroup of underserved patients. A study where breast cancer patients were provided with a...

Table 4 • Basic usage statistics of the system and summary of other findings in the intervention group*.

Basic usage statistics:

- All patients used the system.
- The average number of sessions per patient was 27 (SD 18, range 4–69) in the six weeks study period.
- On average, a patient-session lasted 12 minutes. The longest patient-session lasted 1 hour and 38 minutes.
- Of all patient-sessions, 16 percent took place after office hours (between 19:00 and 07:00 next day).
- On average, each patient completed 12.6 monitoring questionnaires.
- 21 patients sent, on average 4.5 messages. Half of these messages contained a question, and half were personal reports on how the patient was doing.

Summary of other findings:

- Using the system, in eight patients potential problems requiring direct medical actions were detected.
- 56% of the patients had no experience with computers before participation.
- Overall appreciation score for “the system as a whole” was 8.0 on a 10 point scale.
- 86% of patients felt that health care providers could keep a better eye on their illness, and 83% felt that the system provided a feeling of security.
- 89% of patients would advise other patients in similar situations to use the system as well.

Table 5  Change in Scores of the 22 QoL Scales. For Each of the 22 QoL Parameters, This Table Shows the Baseline-adjusted Difference in Change (intervention minus control), Standard Error, and p-value at T2 (six weeks after discharge) and at T3 (three months after discharge).*

<table>
<thead>
<tr>
<th>(Sub)Scale</th>
<th>Baseline Adjusted Difference in Change at T2 (6 weeks), Standard Error, and p-value</th>
<th>Baseline Adjusted Difference in Change at T3 (3 months), Standard Error, and p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 State anxiety</td>
<td>-4.53 1.82 0.01</td>
<td>-2.13 1.76 0.23</td>
</tr>
<tr>
<td>2 Fear for consequences of the illness</td>
<td>-1.53 0.94 0.10</td>
<td>-0.80 1.03 0.94</td>
</tr>
<tr>
<td>3 Fear related to specific head and neck problems</td>
<td>-2.59 1.05 0.02</td>
<td>-1.02 1.14 0.23</td>
</tr>
<tr>
<td>4 Fear for (additional) treatment</td>
<td>-0.12 0.61 0.84</td>
<td>-0.10 0.55 0.80</td>
</tr>
<tr>
<td>5 Fear for social interactions</td>
<td>-0.16 0.22 0.46</td>
<td>-0.05 0.24 0.83</td>
</tr>
<tr>
<td>6 Fear related to interaction with care providers</td>
<td>-1.29 0.79 0.10</td>
<td>-0.08 0.89 0.93</td>
</tr>
<tr>
<td>7 Feelings of depression</td>
<td>-1.05 0.85 0.22</td>
<td>-0.74 0.87 0.39</td>
</tr>
<tr>
<td>8 Uncertainty–prospects of disease and treatment</td>
<td>0.06 1.25 0.66</td>
<td>-1.40 1.35 0.30</td>
</tr>
<tr>
<td>9 Uncertainty–access to help and problem solving</td>
<td>-0.94 1.06 0.40</td>
<td>-0.81 1.04 0.44</td>
</tr>
<tr>
<td>10 Uncertainty–how to handle practical consequences of the illness</td>
<td>-0.72 1.37 0.60</td>
<td>0.43 1.30 0.74</td>
</tr>
<tr>
<td>11 Uncertainty–how to cope with one’s own emotions</td>
<td>-0.60 0.84 0.48</td>
<td>0.12 0.89 0.89</td>
</tr>
<tr>
<td>12 Feelings of insecurity related to accessibility of aid</td>
<td>0.18 0.72 0.80</td>
<td>1.34 0.73 0.07</td>
</tr>
<tr>
<td>13 Feelings of insecurity related to surveillance of the illness by care providers</td>
<td>-0.03 0.47 0.95</td>
<td>0.34 0.50 0.50</td>
</tr>
<tr>
<td>14 Loss of control</td>
<td>0.28 0.37 0.44</td>
<td>0.31 0.40 0.44</td>
</tr>
<tr>
<td>15 Physical self efficacy</td>
<td>2.39 1.07 0.03</td>
<td>3.08 1.29 0.02</td>
</tr>
<tr>
<td>16 Self confidence in oral presentation</td>
<td>1.20 1.29 0.35</td>
<td>1.59 1.39 0.25</td>
</tr>
<tr>
<td>17 Perceived abilities in swallowing and food intake</td>
<td>2.63 1.29 0.04</td>
<td>1.62 1.31 0.22</td>
</tr>
<tr>
<td>18 Perceived speech abilities</td>
<td>0.77 0.90 0.39</td>
<td>-1.33 0.87 0.13</td>
</tr>
<tr>
<td>19 Loneliness</td>
<td>0.10 0.22 0.67</td>
<td>-0.14 0.24 0.57</td>
</tr>
<tr>
<td>20 General psychosocial complaints</td>
<td>-0.82 0.75 0.27</td>
<td>-0.91 0.72 0.21</td>
</tr>
<tr>
<td>21 General physical complaints</td>
<td>-1.27 0.52 0.02</td>
<td>-1.23 0.65 0.06</td>
</tr>
<tr>
<td>22 Head and neck specific complaints</td>
<td>-1.95 1.59 0.22</td>
<td>-2.97 1.59 0.06</td>
</tr>
</tbody>
</table>

*Significant p-values (p<0.05) are shown in italic bold. For subscales 15 though 18, a positive baseline-adjusted difference means better QoL in the intervention group; for all other subscales a negative baseline-adjusted difference means better QoL in the intervention group.

CDROM containing information from physicians and fellow sufferers also showed positive effects on the QoL of patients.31 Goldsmith et al. described a feasibility study of an Internet-based system to support collaboration between patients and providers in cancer-related symptom management.32 Although 77% of the patients in that study believed that the system could improve their pharmacologic pain treatment, objective effects on QoL were not studied.

In our trial, the studied population suffered from a specific form of cancer. Surgery for head and neck cancer is often accompanied by speech problems, a factor that may have contributed to the positive influence on QoL of our telemedicine system. Thus, we do not know whether results can be extrapolated to other forms of cancer. On the other hand, as compared to other studies in this area, our population was relatively old and computer illiterate, showing that this is not a disincentive for telemedicine applications.

A further limitation of our study may be that patients were assigned to either the control or the intervention group on basis of location rather than randomly. The reason for choosing to do so lies in the fact that we had to include and instruct patients while they were still admitted in the hospital, and that we wanted to avoid contact between the two groups. We also believe that the need for randomization was further reduced by the fact that we first ruled out QoL differences based on hospital location. Furthermore, surgeons and treatment protocols were the same at both hospital locations.

As our trial was an exploratory study we did not, for example, beforehand formulate ranking orders regarding the priority of the used scales. We performed multiple tests without a priori hypotheses about which scales we expect to be significant. This may be considered a limitation of our study.

Our results may additionally have been influenced by selection bias: the inclusion rate in the intervention group was lower than in the control group. As Figure 1 shows, nine out of 20 refusals to participate in the intervention group were computer related. We believe, however, that it is unlikely that selection bias accounted for the results of our study: the different inclusion rates in intervention and control group did not result in different patient characteristics such as age, gender, living single or together, and more importantly, level of education and previous computer experience. As type of surgery was different in both groups we also performed adjusted analyses. We emphasize that, for a telemedicine study, we were dealing with a relatively old, and computer illiterate population (56% had no previous computer experience). Excluding patients with no computer experience would not have provided us the insight whether studies with telemedicine applications are also possible in such patient groups.

In summary, our telemedicine system to support head and neck cancer patients in their post discharge period at home positively affected five of the 22 studied QoL parameters. As patients will become more and more computer literate and will increasingly have access to computers and the Internet, we believe that studying the possibilities and effects of
Figure 2. Mean level (± 1 SE) for both the control group and the intervention group at T1, T2, and T3 for the five significant QoL parameters. p-values are also shown.

State anxiety: the change from baseline differs significantly at T2 (p=0.014). Lower scores indicate better quality of life.

Fear related to specific head and neck problems: the change from baseline differs significantly at T2 (p=0.015). Lower scores indicate better quality of life.

Physical self efficacy: the change from baseline differs significantly at T2 (p=0.026) and at T3 (p=0.019). Lower scores indicate poorer quality of life.

Perceived abilities in swallowing and food intake: the change from baseline differs significantly at T2 (p=0.043). Lower scores indicate poorer quality of life.

General physical complaints: the change from baseline differs significantly at T2 (p=0.015). Lower scores indicate better quality of life.
extending cancer care beyond conventional hospital care through telemedicine is warranted. Research in this area should focus on determining the optimal length of time for telemedicine support, and extending the use to other patient groups such as palliative patients and cancer survivors. References