Mind the Gap: The Discrepancies between Patient Self-Reported Quality of Life and Medical Staff-Estimated Quality of Life

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Abstract

Information on patient quality of life (QOL) is essential to many clinical decisions. Therefore, studies that aim to extract QOL information from patient narratives are increasingly drawing attention. Also, several studies have noted that web services for patients, such as patient social networking services, may represent promising resources for QOL research. However, it is still unclear whether patient narrative text contains corresponding amounts of QOL information as self-reported QOL. This study investigates if medical staff can accurately estimate patient QOL from only patient narrative texts. We analyzed (1) QOL of cancer patients estimated by medical staff from patient autobiographical texts and (2) self-reported QOL scores of cancer patients. We compared patients from the following 3 disease groups: (1) gastrointestinal cancer, (2) breast cancer, and (3) lymphoma. The SF-36v2^TM Health Survey was used to measure patient QOL in both materials, and the QOLs were compared. We found significant differences between self-reported QOL and estimated QOL in breast cancer patients and lymphoma patients, but not in gastrointestinal cancer patients. In particular, the medical staff tended to underestimate physical QOL scores. Medical staff may underestimate several aspects of QOL scores. On the basis of these results, we may be able to achieve more precise QOL estimation from patient narratives.

Keywords:

Quality of Life; Cancer; Self Report; Narrative Medicine; Social Network Service; Support Systems.

Introduction

Advancements in information and communication technology (ICT) have facilitated the collection of patient narrative data in the form of self-descriptions and self-reports, and the enormous amount of such information (so-called Big Data) is now actively used in medical analyses [1].

"*PatientsLikeMe*"[1] is one of the more successful examples of the use of ICT services in healthcare. In this network, people are able to connect with others with the same disease or condition and share their experiences. In addition to *PatientsLikeMe*, various other communication services for patients have been increasingly launched over the years [2-5]. "*LifePalette*" is one of the earliest patient communication services established in Japan, and focuses mainly on cancer patients. Another service, "*DIPEx-Japan*", provides patient narratives via videos of patient interviews. Similarly, the "*Healthcare Information Bookshelf Project*" also shares the same goal through the provision of illness narrative books [6]. ICT services are available not only for common diseases, as

several rare disease communities have also launched their own social network services (SNS) to communicate with one another. These include the *GISTERS* network for gastrointestinal stromal tumor (GIST) patients, the *Remudy* registry for dystrophy patients, and the *Re:me* network for general rare disease patients. One of the main purposes of such services is to allow patients to share their experiences and support one another. However, the possible secondary applications of such data are also drawing attention.

One promising application of patient narrative data is to understand personal experiences of illness, and to enable training medical staff to improve the quality of care [7-11]. Several studies have reported that patient narratives can provide insight into the feelings of patients. Another secondary use of patient narratives is in quality of life (QOL) research [12, 13]. If accurate QOL data can be obtained from these narratives, the rich amount of text in SNS could provide more patient QOL information than was previously available.

This study is a pilot study to compare narrative data and self-reported data from the viewpoints of QOL. We investigate if medical staffs are able to accurately estimate patient QOL from narrative texts. To investigate this preliminary question, we collected (1) QOL of cancer patients estimated by medical staff based on patient autobiography texts and (2) self-reported QOL scores of cancer patients.

Materials

We utilized 2 types of materials as data sources: Material A (estimated QOL) and Material B (self-reported QOL). In both materials, we used the SF-36v2^TM Health Survey (Japanese version) to estimate QOL[2].

Material A (Estimated QOL)

We identified illness narrative books written in Japanese by patients and had been published prior to June 2013. The initial sample comprised 53 books that were available at July 2013 (Authors: 23 men, 30 women; mean age: 36.7±19.7 years). From each of these books, 2 sets of 10 consecutive pages were randomly selected (10*2*53=1,060 pages in total).

These books were classified according to the ICD-10 disease codes for each author (Table 1). QOL estimations were conducted by 5 professional medical staff, comprising of 3 men and 2 women (mean age: 25.6±1.82 years). Each medical staff member read the selected passages, and then estimated the QOL of each patient author based on these passages. The estimations were conducted using the SF-36v2^TM Health Survey, which consists of 36 questions. Using information from the books, the medical staff answered the questionnaire by speculating on the author's perspective.

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[1] http://www.patientslikeme.com/

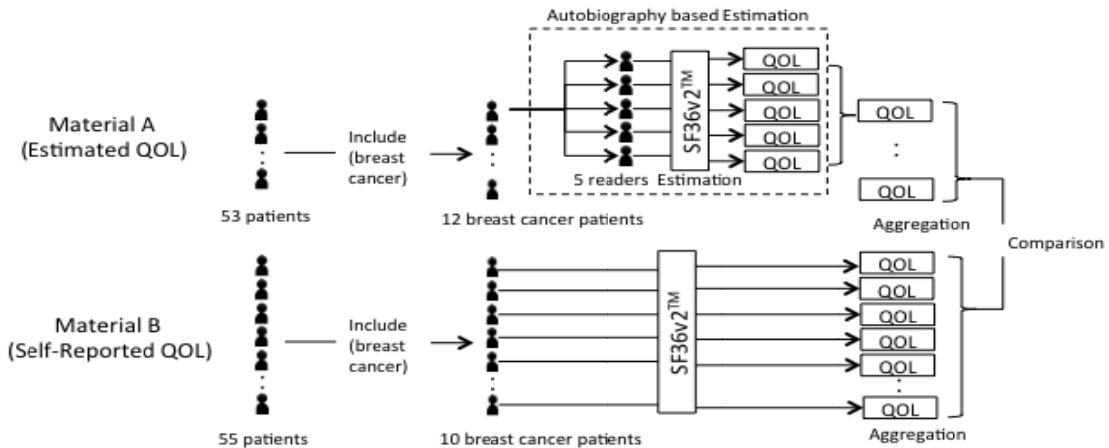[2] This study does not deal with human subjects.

Figure 1– Workflow design of the study in the case of breast cancer patients (ICD-10: C50-58)

Table 1– Material A: Patient Characteristics of the Illness Narrative Book Authors

		n = 53
Age (years)		36.7±19.7
Sex	Male	23 (43.4%)
	Women	30 (56.6%)
ICD-10 Codes	(C00-C14)	3 (5.5%)
	(C15-C26)	11 (20.0%)
	(C30-C39)	6 (10.9%)
	(C40-C41)	1 (1.8%)
	(C43-C44)	0
	(C45-C49)	2 (3.6%)
	(C50-C58)	12 (21.8%)
	(C60-C63)	1 (1.8%)
	(C64-C68)	1 (1.8%)
	(C69-C72)	1 (1.8%)
	(C73-C75)	0
	(C76-C80)	2 (3.6%)
	(C81-C96)	15 (27.3%)

Table 2– Material B: Patient Characteristics of the "LifePalette" Users

		n = 55
Age (years)		52±9.9
Sex	Male	13 (24%)
	Women	28 (51%)
	Unknown	14 (25%)
ICD-10 Codes	(C00-C14)	1 (1.8%)
	(C15-C26)	4 (7.1%)
	(C30-C39)	1 (1.8%)
	(C40-C41)	0
	(C43-C44)	0
	(C45-C49)	1 (1.8%)
	(C50-C58)	10 (17.9%)
	(C60-C63)	1 (1.8%)
	(C64-C68)	0
	(C69-C72)	0
	(C73-C75)	1 (1.8%)
	(C76-C80)	2 (3.6%)
	(C81-C96)	4 (7.1%)
	(C97)	0
	Other disease	12(21.6%)
	Unknown	19 (33.9%)

Material B (Self-Reported QOL)

In order to obtain self-reported patient QOL scores, which is the gold standard, we asked 56 patients from *LifePalette*[3] (an SNS for Japanese cancer patients) to participate in the SF-36v2[TM] Health Survey. The results were classified according to the ICD-10 codes of each respondent's disease (Table 2). This survey was conducted online through a dedicated website; the evaluation period was from June 16 to June 27, 2014. The effective response rate was 98.2% (13 men, 28 women, and 14 respondents of unknown sex; mean age: 52±9.9 years).

The SF-36v2[TM] Health Survey (Japanese Ver.)

For the investigation of both materials, we used the SF-36v2[TM] Health Survey (Japanese ver.)[4] to evaluate the health-related QOL of the cancer patients. The Japanese version of the SF-36v2[TM] questionnaire produces results in 8 sub-scales and 3 component summary scores (Table 3) [14-16].

Table 3– Sub-scales of the SF-36v2[TM] Health Survey

Sub-scales	PF	Physical Functioning
	RP	Role Physical
	BP	Bodily Pain
	GH	General Health
	VT	Vitality
	SF	Social Functioning
	RE	Role Emotional
	MH	Mental Health
Summary Scores	PCS	Physical Component Summary
	MCS	Mental Component Summary
	RCS	Role-social Component Summary

Methods

The narrative books were obtained in June 2013. The investigation period for Material A was from August 2013 to September 2013. We compared the estimated QOL (Material A) scores and the self-reported QOL (Material B) scores for each disease. From Material A, each of the 5 medical staff members who read the autobiographies produced a QOL value for each patient, resulting in a total of 5 QOL values for that patient. We calculated the average of these 5 QOLs as the estimated QOL of each patient author.

We then classified the patients according to their ICD-10 code disease categories in both Materials A and B (shown in Tables 1 and 2). We calculated the average QOLs in each category, which were regarded as the category QOL.

Comparisons were conducted for categories that had 4 or more patients (n>=4).

Patients were classified into the following 3 categories according to their ICD-10 codes: (1) C15-26 (Malignant neoplasms, digestive organs; or "gastrointestinal cancer"), (2) C50-58 (Malignant neoplasms, breast and female genital organs; or "breast cancer"), and (3) C81-96 (Malignant neoplasms, stated or presumed to be primary, of lymphoid, hematopoietic and related tissue; or "lymphoma"). Figure 1 illustrates the workflow design of this study using the example of breast cancer patients.

Results

The results are shown in Figure 2 for ICD-10 codes C15-26 (gastrointestinal cancer), Figure 3 for C50-58 (breast cancer), and Figure 4 for C81-96 (lymphoma).

In gastrointestinal cancer patients (Figure 2), the results showed no significant differences between Material A (n = 11) and Material B (n = 4) in all sub-scales.

In breast cancer patients (Figure 3), there were significant differences observed between Material A (n = 12) and Material B (n = 10) in 3 of the sub-scales (PF, RP, and GH) and one of the 3 summary scales (PCS).

Lymphoma patients (Figure 4) showed smilar results to the breast cancer patients (Figure 2): there were significant differences observed between Material A (n = 15) and Material B (n =4) in 4 of the sub-scales (PF, RP, VP, and SF) and one of the 3 summary scales (PCS).
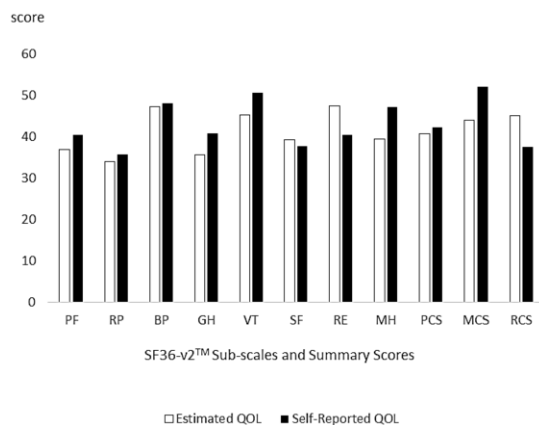

Figure 2– C15-26 (Differences between estimated QOL and self-reported QOL in gastrointestinal cancer patients)
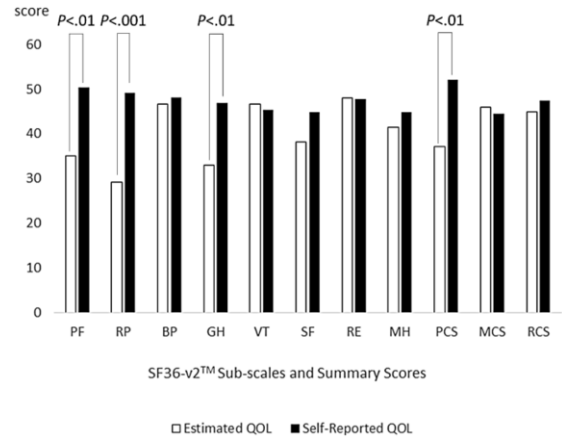

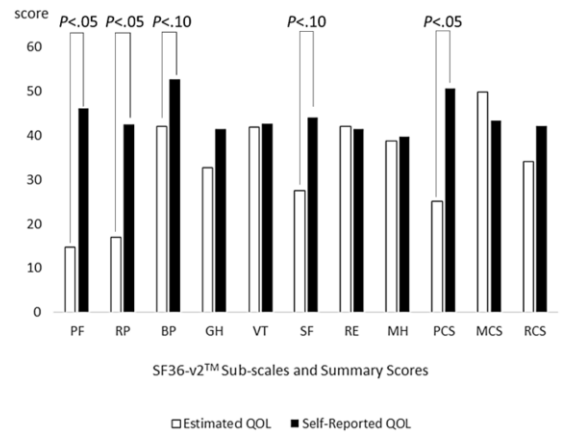*Figure 3– C50-58 (Differences between estimated QOL and self-reported QOL in breast cancer patients)*

Figure 4– C81-96 (Differences between estimated QOL and self-reported QOL in lymphoma patients)

Discussion

Our findings showed that among the 3 summary scores of the SF-36v2[TM] Health Survey, there were statistically significant differences in the Physical Component Summary (PCS) score between medical staff-estimated QOL and self-reported QOL in 2 of the 3 types of cancers analyzed. Although various studies have addressed patients suffering from these diseases, our study, surprisingly, indicated that the medical staff tended to underestimate patients' physical QOL. This difference in PCS scores between the medical staff and patient authors suggests that patients may tend to speak out explicitly regarding their pain. If so, patients may suffer from less pain than expected by the medical staff. In the near future, we would have more precise techniques to estimate the level of patient pain.

The other QOL summary scores (mental component and social component) did not show any significant differences between medical staff estimations and self-reporting. This suggests that the patient narratives contain much more information on mental and social activities, thereby enabling the medical staff to have a better interpretation of these aspects of QOL. As most patient narratives focus on their daily lives, it is reasonable that the medical staff were able to accurately estimate the mental and social aspects of patient QOL. In most cases, the QOL gap was due to underestimations by medical staff. In other words, medical staff rarely overestimated the patient

QOL scores. One of the possible reasons for this bias is that the medical staff may have been too intent on empathizing with the patients and sharing their feelings, which resulted in the gap.

Among the 3 cancer groups, the most precise QOL estimation was achieved in gastrointestinal cancer (Figure 2). In Japan, the mortality risk of gastrointestinal cancer is the second highest after lung cancer. This study showed that even in such a serious disease, there was little difference between the medical staff-estimated QOL and patient self-reported QOL; this suggests a degree of success in information sharing for this disease. In contrast, there were gaps between the 2 methods of QOL assessment in the other 2 cancer groups.

The results for breast cancer were not unexpected, as breast cancer has a relatively low mortality risk. In contrast, the mortality risk of lymphoma is higher than many other types of cancers. The reasons why the medical staff tended to underestimate the QOL for this disease require further study.

A surprising finding was that the self-reported QOL scores tended to be relatively high. For example, the Bodily Pain (BP) sub-scale in lymphoma patients was higher than the Japanese average (in this QOL scale, the average Japanese person has a score of 50 in each of the QOL scale components). In addition to the BP value, most of the other QOL sub-scales were over 40. This result suggests that cancer patients may be happier than we had expected.

Limitations

A limitation of this study is that the 2 aspects of the analysis were obtained from different media, which may have biased the results: Material A was acquired from autobiographical books and Material B from patients through SNS. However, we analyzed the same diseases in order to reduce the possible bias.

Conclusions

In this study, we compared medical staff-estimated QOL and patient self-reported QOL scores in 3 categories of cancer patients. Our findings demonstrate that the medical staff tended to underestimate the physical QOL of patients based on autobiographical text. In contrast, there were no significant differences between the 2 types of QOL assessments in the mental and social aspects. Care should therefore be taken when estimating QOL from illness narratives, particularly for the physical component of QOL. These results indicate a need to create support systems that can improve patient conditions by using the gaps in physical QOL assessment. In the future, if a technique for automated QOL estimation is developed, the result of this study will contribute to effective communication between patients and medical professionals.

Acknowledgments

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