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#### **BRIEF REPORT**

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# Perceptions of Japanese and Dutch women with early breast cancer about monitoring their quality of life

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#### ABSTRACT

**Objective:** Monitoring quality of life (QoL) in patients with cancer can provide insight into functional, psychological and social consequences associated with illness and its treatment. The primary objective of this study is to examine the influence of cultural factors on the communication between the patient and the health care provider and the perceived QoL in women with breast cancer in Japan and the Netherlands.

**Methods:** In Japanese and Dutch women with early breast cancer, the number, content and frequency of QoL-related issues discussed at the medical encounter were studied. Patients completed questionnaires regarding QoL and evaluation of communication with the CareNoteBook.

**Results:** The total number, frequency and content of QoLrelated issues discussed differed between the two countries. Japanese women (n = 134) were significantly more reticent in discussing QoL-issues than the Dutch women (n = 70) (p < .001). Furthermore, Dutch patients perceived the CareNoteBook methodology significantly more positively than the Japanese patients (p < .001). Both groups supported the regular assessment via a CareNoteBook methodology.

**Conclusions:** Japanese women are more reluctant in expressing their problems with the illness, its treatment and patient-physician communication than Dutch women.

#### **KEYWORDS**

Breast cancer; cross cultural differences; Japan; patient perceptions; quality of life; The Netherlands

#### Background

There is increasing recognition of the importance of patient reported outcomes (PROs) in clinical care and research concerning patients with cancer.

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PROs are defined as 'any report coming directly from the patient about their health, an illness and/or its treatment using a self-reported measure.<sup>1</sup> PROs are essential tools for obtaining insight into patients' perceptions of treatment consequences and impact of their illness. The use of PROs has evolved from isolated attempts to assess patients' views, cognitions and emotions regarding their illness and its treatment, into achieving a solid position in guidelines for professionals in oncology care and manuals on assessing and analyzing PRO-data.<sup>2-7</sup> Studying PROs demonstrates respect for how persons with cancer make sense of their illness and the associated treatment, which ideally translates into medical professionals incorporating patients' views into regular medical care. Empirically, our research group and Greenhalgh et al. published papers on how feedback of PRO-data to patients and physicians resulted in facilitating the discussion of quality of life (QoL) issues and heighten physicians' awareness of patients' quality of life (QoL).<sup>8,9</sup> Major steps in PRO-research have involved studies that show how PRO-data helped to predict patient survival, strongly reinforcing the value of monitoring PROs in the care of patients with cancer.<sup>10-14</sup>

PROs in cancer care are determined by a wealth of factors, e.g., clinical, sociodemographic, and psychological factors.<sup>15</sup> Cross-cultural studies on PROs in patients with cancer have demonstrated that cultural factors can influence patient perceptions and experiences. Work by Dein and by Kleinman and colleagues has shown how the societal meanings attached to illness (any) and cancer (specifically) shape patients' QoL, their illness behavior, and their interaction with health care providers.<sup>16,17</sup>

Over the past 20 years, our cross-cultural research group has been studying the illness perceptions and experiences of patients with breast and lung cancer in Japan and the Netherlands. Traditionally, in the Japanese culture much value is placed on being modest and reserved.<sup>18</sup> Contrary to Western culture, verbalization of feelings and thoughts is not common. Furthermore, there is respect for the doctor's status and authority.<sup>19</sup> In Japan, the physician–patient relationship is often described as more hierarchical and paternalistic compared to Western countries.<sup>20</sup> Western patients are known for more critical assessment of their physicians' professionalism and communication skills.<sup>21</sup>

The first publication from our group reported comparable patterns in Japanese and Dutch patients with various diagnostic cancer categories regarding perceived QoL.<sup>22</sup> Despite cultural differences, a considerable degree of conceptual equivalence of QoL in Japanese and Dutch patients with cancer was observed.<sup>23-26</sup> This indicated a satisfactory structural and cross-cultural equivalence for the use of EORTC-QLQ-C30 with regard to items measuring QoL.<sup>21</sup> Subsequently, Japanese cancer researchers developed a methodology to assess QoL in a clinical setting. Kobayashi and colleagues reported on the development of the CareNoteBook: a self-report

measure that assesses three dimensions of QoL, i.e. physical well-being, mental well-being, and life well-being. Research from Japanese physicians on PROs in patients with cancer has illustrated the validity of this approach.<sup>27,28</sup> Further to our research program on cross-cultural issues in the care of persons with cancer in Japan and the Netherlands, we studied the perceptions of Japanese and Dutch women with early breast cancer about the monitoring of PROs with the use of the CareNotebook.

#### Methods

#### Study design

This study was conducted as part of a larger trans-cultural randomized trial in the Netherlands and Japan. The detailed study design has been previously reported.<sup>8</sup> In brief, this open-label, multicentre study investigated the effects of introducing a QoL-monitor on aspects of communication, medical care and patient outcomes. The primary objective of this study was to assess the extent to which QoL-topics were discussed. Secondary objectives included the effects of these discussions on patient management; length of consultations; patients' perceived efficacy to communicate with healthcare providers (HCPs); patients' satisfaction regarding communication with their HCP; QoL and distress; patients' perceptions of their illness; and finally patients' perceptions of the use of the QoL-monitor. Patients were randomly allocated to receive usual care, or usual care with the use of the QoL-monitor before every chemotherapy cycle visit. The study was performed in accordance with the Helsinki Declaration of the World Medical Association. The institutional review boards of each participating institution approved the study protocol.

In this subsample we included the patients who completed a communication checklist before the start of their fourth cycle of chemotherapy, after the consultation with their healthcare provider.

The primary aim of this report is to examine differences in communication between the patient and the healthcare provider and the perceived QoL in women with breast cancer in Japan and the Netherlands.

#### Patients

Inclusion criteria were female patients with breast cancer stages I–III, performance status 0 (able to carry out all normal activity without restrictions) or 1 (restricted in physically strenuous activity but ambulatory and able to carry out light work),<sup>29</sup> scheduled to receive (neo)adjuvant first line intravenous chemotherapy. Eligible patients were invited to participate in this study by their treating physician before the start of chemotherapy. Patients who chose to participate gave written consent.

# Chemotherapy

Women in both countries had received one of the following chemotherapy regimens: TAC ( $75 \text{ mg/m}^2$  docetaxel,  $50 \text{ mg/m}^2$  adriamycin,  $500 \text{ mg/m}^2$ , cyclophosphamide), AC ( $60 \text{ mg/m}^2$  doxorubicin,  $600 \text{ mg/m}^2$  cyclophosphamide), FEC ( $500 \text{ mg/m}^2$  fluorouracil,  $100 \text{ mg/m}^2$  epirubicin,  $500 \text{ mg/m}^2$  cyclophosphamide) or TC ( $75 \text{ mg/m}^2$  docetaxel,  $600 \text{ mg/m}^2$  cyclophosphamide). The combination of concurrent TAC was used in the Netherlands only.

# Questionnaires

On the day of the consultation before the fourth cycle of chemotherapy, participants were asked to complete a communication checklist after the consultation with their healthcare provider (HCP). Women were free to do this at the outpatient clinic or at home, and were asked to return the checklist to the institutional clinical research coordinator. The questionnaires were anonymized, containing only a unique study number. The communication checklist used in the present study was an adapted version of the checklist designed by Hilarius et al.<sup>30</sup> and was validated in an investigation by our research team.<sup>8</sup> It consists of 19 questions that refer to a specific symptom (e.g. pain, nausea, sleeping problems) or domain of functioning (e.g., physical and emotional functioning). These items are derived from the function and symptoms scales of the cancer generic EORTC QLQ-C30 and breast cancer specific EORTC BR-23 quality of life questionnaires. Patients were asked to indicate for each topic whether it had been discussed (yes/no) with their healthcare provider. The outcome of this selfreport checklist is a composite index (the total number of QoL-related topics discussed) together with individual item scores (for each separate QoL topic). Evaluation of the QoL-monitor was carried out with a selfdeveloped questionnaire, consisting of 7 items.<sup>8,24</sup> All sociodemographic and clinical characteristics were obtained from patients' medical records.

# Statistical analyses

Descriptive analyses were performed to investigate means and frequencies of the patients' sociodemographic and breast cancer and treatment characteristics. Differences between the two countries regarding the respondents' background characteristics and the evaluation of the QoL-monitor were analyzed using t-tests (means) and chi-square tests (frequencies). With regard to the communication content in Japan and the Netherlands, frequencies were calculated for the composite score (total number of QoLitems discussed) and for the separate items. Additionally, percentages per country were calculated for the visits that included discussion of at least

	Netherlands	Japan	
	(N = 70)	(N = 134)	p-value
Age (yr)	53.3 (9.2)	53.4 (10.4)	0.91 <sup>ª</sup>
Affected breast			
Left	27 (38.6%)	65 (48.5%)	0.40 <sup>b</sup>
Right	37 (52.9%)	60 (44.8%)	
Bilateral	6 (8.6%)	9 (6.7%)	
Cancer subtype			
Invasive ductal	58 (84.1%)	102 (87.9%)	0.54 <sup>b</sup>
Invasive lobular	8 (11.6%)	8 (6.9%)	
Other	3 (4.3%)	6 (5.2%)	
Cancer stage			
1	11 (15.7%)	26 (19.4%)	0.78 <sup>b</sup>
11	49 (70.0%)	88 (65.7%)	
111	10 (14.3%)	20 (14.9%)	
ER and/or PR positive	50 (71.4%)	89 (66.4%)	0.43 <sup>b</sup>
HER2 positive	17 (24.3%)	53 (39.6%)	0.03 <sup>b</sup>
Timing of chemotherapy			
Adjuvant	36 (51.4%)	95 (70.9%)	0.01 <sup>b</sup>
Neo-adjuvant	34 (48.6%)	39 (29.1%)	
Current chemotherapy			
TAC	27 (38.6%)	0 (0%)	< 0.001 <sup>b</sup>
AC	27 (38.6%)	96 (71.6%)	
FEC	12 (17.1%)	1 (0.7%)	
TC	3 (4.3%)	37 (27.6%)	
PTCptz	1 (1.4%)	0 (0%)	
Previous radiotherapy treatment	18 (25.7%)	18 (13.7%)	0.04 <sup>b</sup>

Table	1.	Sociodemographic	and	clinical	characteristics.
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a)differences in mean score tested with t-test; b) differences in frequencies tested with  $\chi^2$  test.

AC: adriamycin-cyclophosphamide; ER: estrogen receptor; FEC: 5 fluorouracil-epirubicin-cyclophosphamide; HER2: human epidermal growth factor receptor 2; PR: progesterone receptor; PTCptz: paclitaxel-carboplatin-trastuzu-mab-pertuzumab; TAC: docetaxel-adriamycin-cyclophosphamide; TC: docetaxel-cyclophosphamide.

one item falling within one of the four clusters of QoL-items (general physical symptoms, locoregional symptoms, role and physical functioning, and psycho-social functioning).

### Results

Seventy Dutch and 134 Japanese women with breast cancer were eligible for the analyses in this study sample of the trial between October 2012 and April 2016. Demographic and clinical variables are summarized in Table 1. Whereas age and breast cancer characteristics were mostly similar in Japan and the Netherlands, treatment details were different. Compared with Japan, respondents in the Netherlands more often received neoadjuvant chemotherapy, were prescribed different chemotherapy regimens, and had undergone radiotherapy before their chemotherapy treatment more often.

### **QoL-related topics discussed**

The total number of QoL-related topics that were discussed during the visit are summarized in Table 2 and Figure 1. These self-reports indicate that on

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	Netherlands	Japan
Number of QoL- related items discussed	N (%)	N (%)
0	0	36 (26.7%)
1	4 (5.7%)	17 (12.6%)
2	6 (8.6%)	18 (13.3%)
3	8 (11.4%)	14 (10.4%)
4	6 (8.6%)	20 (14.8%)
5	10 (14.3%)	5 (3.7%)
6	11 (15.7%)	8 (5.9%)
7	8 (11.4%)	7 (5.2%)
8	4 (5.7%)	3 (2.2%)
9	3 (4.3%)	3 (2.2%)
10	3 (4.3%)	2 (1.5%)
11	3 (4.3%)	1 (0.7%)
12	2 (2.9%)	1 (0.7%)
13-17	0	0
18	2 (2.9%)	0

Table 2. Total number of QoL-related items discussed during visit.



Number of QoL-related items discussed

Figure 1. Total number of QoL-related items discussed during medical visit (consultation before fourth cycle of chemotherapy).

average more QoL-related items had been discussed during the visit in the Netherlands compared with Japan (5.97 versus 2.90, t(203) = 6.83, p < 0.001). More than 25% of Japanese women indicated that no QoLrelated item had been discussed during the visit.

According to the Japanese women, items that had been discussed most frequently during the visit were common side effects of chemotherapy (e.g. feeling ill, taste differences, hair loss, hot flushes; 64%), pain (33%) and constipation (26%). Dutch women indicated that side effects of

	Netherlands	Japan
QoL domain	N (%)	N (%)
a) General physical symptoms		
Pain	30 (42.9%)	44 (32.6%)
Fatigue	45 (64.3%)	29 (21.5%)
Dyspnea	17 (24.3%)	12 (8.9%)
Nausea	44 (62.9%)	31 (23.0%)
Sleep problems	27 (38.6%)	14 (10.4%)
Appetite	32 (45.7%)	25 (18.5%)
Constipation	30 (42.9%)	35 (25.9%)
Diarrhea	14 (20.0%)	22 (16.3%)
Chemotherapy side effects	49 (70.0%)	86 (63.7%)
b) Locoregional symptoms		
Arm symptoms	23 (32.9%)	28 (20.7%)
Breast symptoms	14 (20.0%)	19 (14.1%)
c) Physical and role functioning		
Physical functioning	21 (30.0%)	12 (8.9%)
Role functioning	12 (17.1%)	10 (7.4%)
d) Psycho-social functioning		
Sexual functioning	5 (7.1%)	0 (0.0%)
Body image	4 (5.7%)	8 (5.9%)
Future health	14 (20.0%)	6 (4.4%)
Social functioning	12 (17.1%)	3 (2.2%)
Cognitive functioning	7 (10.0%)	0 (0.0%)
Emotional functioning	18 (25.7%)	7 (5.2%)



 Table 3. Discussion of QoL-related items in the Netherlands and Japan.

Figure 2. Frequency of discussion of 19 QoL-related items during the medical visit.

chemotherapy (70%), fatigue (64%) and nausea (63%) had been discussed most frequently (see Table 3 and Figure 2).

Overall, the majority of Dutch (97%) and Japanese (71%) women remembered discussing one or more general physical complaint (see Figure 3). According to Dutch women, items relating to locoregional symptoms (reported complaints by patients about the breast or the arm), role and physical functioning, and psycho-social functioning had been discussed in



**Figure 3.** Proportion of visits that included discussion (at least 1 item per domain) about: general physical symptoms (Panel A), locoregional symptoms (Panel B), physical and role functioning (Panel C) and psycho-social functioning (Panel D).

37-40% of the visits. For Japanese women these three domains of QoL had been discussed in only 13-30% of the visits.

Table 4 shows the evaluation of the QoL-monitor by the patients of this study sample who were randomized to the interventional study arm (63 Japanese and 28 Dutch patients). Patients in both countries appear to evaluate the QoL-monitor overall positively, with the Dutch patients reporting a higher perceived usefulness and a lower perceived burden.

### Discussion

There are two key findings from this study. First, Japanese breast cancer patients were more cautious and reluctant in reporting physical, psychological, and social consequences and problems associated with the illness and its medical treatment than their Dutch counterparts. Second, compared with the Japanese women with breast cancer, the Dutch women with breast cancer in our study had a significantly more favorable attitude to monitoring and discussing their quality of life during the medical treatment. They

	Netherlands (n = 28)	Japan $(n = 63)$	p-value
Average time to fill out guestionnaires (min.)	10.12 (3.68)	11.64 (7.51)	0.20 <sup>a</sup>
Usefulness for reporting problems and questions*	4.33 (0.71)	3.15 (0.85)	<0.001 <sup>a</sup>
Usefulness for communication with healthcare provider**	3.50 (1.14)	2.60 (1.00)	<0.001 <sup>a</sup>
Burden to complete QoL questionnaires***	1.50 (0.57)	2.32 (0.99)	<0.001 <sup>a</sup>
Difficulty to understand QoL questionnaires****	1.62 (0.78)	2.43 (0.95)	<0.001 <sup>a</sup>
QoL monitoring as standard element of clinical care?	26 (93%)	53 (84%)	0.26 <sup>b</sup>
(% Yes)			

#### Table 4. Evaluation of QoL-monitor use.

a)differences in mean score tested with t-test; b) differences in frequencies tested with  $\chi^2$  test.

\*Scale from 0 to 5, 0 = not useful at all, 5 = very useful.

\*\*Scale from 0 to 5, 0 = not useful at all, 5 = very useful.

\*\*\*Scale from 0 to 5, 0 = no burden, 5 = very burdensome.

\*\*\*\*Scale from 0 to 5, 0 = not difficult at all, 5 = very difficult.

perceived the CareNoteBook methodology more helpful in encouraging them to report problems, to formulate questions, and to communicate about this with their physician. Also, they perceived the CareNoteBook less burdensome or difficult to complete. Nevertheless, the large majority of Dutch and Japanese women in this study endorsed introducing the monitoring of QoL during chemotherapy treatment. Earlier research findings are in line with our current work. Women with breast cancer welcomed physicians' requests to report their responses to the illness and its treatment.<sup>21,28</sup> In 2017 we reported the differences in QoL between Japanese and Dutch women after one cycle of chemotherapy in this randomized trial.<sup>23</sup> Japanese patients reported higher scores on several domains of QoL compared with the Dutch patients. If Japanese patients perceive fewer problems affecting their QoL, they may feel less need to discuss QoL-related issues with their physician.

Responses to inquiring about the impact of breast cancer were generally viewed positively by the patients concerned.<sup>24,31</sup> Previous research showed a similar reticence in reporting problems with the medical treatment of breast cancer in Japanese patients. For example, Matsui et al. uncovered a fairly large set of problems in four domains (psychological and existential; physical; social relations; social living) in Japanese patients with cancer.<sup>32</sup> Okuyama et al. reported similar findings, and also a reluctance among Japanese patients with cancer to disclose their emotional distress to their physicians.<sup>18</sup> These findings were reinforced in the study by Sakai et al. who identified differences in perceptions of breast cancer treatments between patients, physicians and nurses regarding unmet information needs in Japanese settings.<sup>33-35</sup>

Our study results are in line for the greater part with the body-of-knowledge on how women with breast cancer perceive their illness and its medical treatment. Nevertheless, a limitation of our current work pertains to possible selection effects. The women who participated in the study may be more positive and less critical about the medical care they received than "the average patient with breast cancer"- which would imply that our findings reflect too much of a positive result overall of monitoring QoL. On the other hand, one may argue that particularly women who have strong opinions are more willing to participate in a trial with focus on communication. Furthermore, it should be taken into account that the reported results have been obtained from the checklists, filled in by patients after their consultation with their healthcare provider (HCP). Not all discussed QoL-issues may have been remembered or possibly interpreted differently. We have previously shown in this trial that there were some small differences in reporting the items that were discussed between observers that evaluated the content of audio-recordings of consultations and patients who completed the questionnaires.<sup>8</sup>

Regarding clinical practice implications, this study shows that despite the small differences in reporting psychosocial aspects of their disease and patient-physician communication, Japanese and Dutch patients are committed to participate in QoL-research. Modern oncology care in Japan is moving in the direction of what applies in Western societies, namely a focus on shared-decision making, QoL, self-management, patient-reported outcomes and patient-physician communication. For example, Fujimori et al. reported effects of a communication skills training for Japanese oncologist which led to a decreased level of distress in patients.<sup>36</sup> Sakai et al. showed that Japanese patients have mainly nonphysical concerns during cancer treatment.<sup>36</sup> Incorporating assessments of functional, psychological and social problems associated with living with breast cancer into regular medical care, allows clinical interventions aimed at improving QoL.<sup>9,37-40</sup>

As we outlined in a previous publication, we suggest a number of recommendations for daily clinical practice:<sup>41</sup>

- 1. Incorporate assessing QoL into clinical care, similar to incorporating laboratory values into diagnostic and therapeutic policy.
- 2. Sensitize health care providers about the importance of QoL in patients with cancer.
- 3. Introduce regular collection of PRO's for patients with cancer during their treatment. This can help identify symptoms and concerns that otherwise would stay undetected.

Very recently, similar results were reported by Jabbarian and colleagues.<sup>42</sup> Negative illness perceptions (IP) were associated with worse QoL in patients with advanced cancer. Targeting specific symptoms like anxiety and depression, through modification of IPs, may improve QoL in these patients.

Further research would allow the use of methods that assess more specifically and more in depth the functional, psychological, and social issues associated with the medical treatment for patients with breast cancer. Various medical professional organizations appear to support this suggestion.<sup>7,43</sup> Review papers on self-management in patients with cancer offer the scientific context for this development. These suggestions support the work by various research groups on the importance of monitoring PROs in patients with cancer, with its potential of improving overall survival.<sup>44-46</sup>

#### Declarations

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Authors contributions: all authors contributed to the design, data collection and analysis, and writing of the manuscript.

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