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## Communication during haematological consultations; patients' preferences and professionals' performances

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**Abstract** Many patients with haematological malignancies experience barriers in clinical communication. Reaching effective communication is of great importance as it has been linked to a range of improved patient outcomes such as satisfaction, compliance to treatment, perceived quality of life and physical and mental health. To get a better understanding how communication in haematological consultations can be improved, the current study focussed on patients' preferences and perceived performances regarding the communicative behaviour of their health care professional. Secondly, the mediation of an online communication tool for patients was analysed. Within a controlled pre- post-test design, 78 datasets of clinical consultations could be analysed. Patients considered both affective and instrumental communication aspects important. The affective communication behaviour of the health care professional met the patients' pre-visit preferences well. In the information exchange, more variability and discrepancies were found. Overall, the online intervention did not seem to influence the patients' perceived communication performance of their health care professional much. To further improve the communication during clinical consultations, health care professionals should inquire about patients' expectations, especially during the exchange of information and advices. At the same time, patients should be supported to express their preferences at the start of the consultation. The study was registered in the Netherlands Trial Register, number 3779 .

## INTRODUCTION

Communication is considered an essential part of high-quality patient care [1, 2]. In clinical communication, instrumental and affective components play an important role [3–5].

Instrumental communication relates to the necessary task-oriented information exchange, managing biomedical aspects and addressing patients' need to know and understand.

Affective communication relates to creating a therapeutic relationship, gaining patients' trust, managing psychosocial aspects and addressing patients' need to feel known and understood.

Reaching good communication is of great importance as it has been linked to a range of improved patient outcomes such as satisfaction, compliance to treatment, perceived quality of life and physical health [6–10]. To establish effective communication, both the health care professional (HCP) and the patient need to participate actively [11]. However, the complex nature of medical interactions challenges both parties, which is even more evident in oncology care where burdensome issues need to be discussed [12]. HCPs have been trained and they are responsible for facilitating the process and content of the clinical communication. At the same time, patients are increasingly expected to be informed participants and to be able to make conscious decisions [13]. In practice, their conversational contributions appear to be limited [14–16] and patients continue to have unmet needs [17, 18]. These findings have resulted in an increased focus on supporting patients with communication [19, 20].

Patients with malignant lymphoma (Hodgkin and non-Hodgkin lymphoma) have indicated to experience barriers in communicating effectively [21, 22]. They relate these difficulties to their own attributes (e.g. emotions, communication skills), the HCPs' attributes (e.g. attitude, communication skills) and external factors (e.g. time pressure) [21]. The often long periods of uncertainty around diagnosis and the emotional position of the patient pose a challenge to communicate effectively in the initial phase of the disease. After primary treatment, communication remains challenging when new issues arise, such as fatigue, depression, anxiety for second primary cancers or the fear to never reach a complete remission [23–25]. According to the biopsychosocial model [5], patients need room to communicate about these disease-specific issues and they also look for emotional support, i.e.

they need to be heard and taken seriously by an attentively listening doctor. How outpatients cope between hospital visits depends partly on the information and support they receive during the visits. Therefore, it is important for them to get the most out of these visits [26].

Addressing patients' individual preferences and needs is crucial in establishing trust, gathering information and assisting patients in making decisions [1]. To get a better understanding how patients and professionals in haematological care can be supported in reaching effective communication, the current study focussed on patients' communication preferences and perceived performances. We inquired patients' pre-visit preferences regarding to their forthcoming visit.

Post-visit, the affective and instrumental communicative behaviour of the HCP through patient's eyes was assessed.

Additionally, we evaluated to what extent an online communication intervention for patients mediated these perceptions.

This intervention aims to support patients with their communicative contribution [27]. Increased awareness of the importance of communication and an increased knowledge level about communication strategies may positively influence their perceptions as a *Byproduct* of the intervention .

However, it can also be hypothesized that the intervention raises expectations and causes a more critical attitude towards the doctor [28–30] .

### **Design and methods**

This study is part of a larger study evaluating the effects of the online tool for patients aiming to support them in clinical communication (PatientTIME) [27, 31]. Patients were randomized in two intervention groups (getting access to the online tool before their forthcoming visit) and a control group (getting access after participation) .

### **Setting and population**

Patients could express their interest in participation via online registration between March 2013 and May 2015. Patients were eligible for participation when diagnosed with a malignant lymphoma, aged 18 years or older, had at least one (follow-up) consultation with their HCP within a year, had a good understanding of the Dutch language and followed treatment or follow-up in a Dutch hospital .

We have focussed mainly on patients with malignant lymphoma while these patients are on long-lasting outpatient treatment. The contacts with their treating physician are with variable intervals during a long period .

### **THE INTERVENTION**

PatientTIME aims to empower patients by supporting them in how to gain more control over the communication. The central information of the intervention consists of short video fragments (47–180 s) showing patients modelling different communication strategies during simulations of clinical consultations (e.g. utter the need for support, deal with emotions, ask questions). The fragments are based on communication barriers identified by the targeted population in a previous study [21] .

### **Design and measures**

In a controlled pre-post-test study, we measured to what extent patients' pre-visit communication needs were fulfilled during the clinical consultation. This concept was defined as the degree to which the HCP's communication performance meets the patient's preferences [32]. For the current study, a total of 15 of the 19 items of the original validated QUOTE-com questionnaire were used [33–35] (Quality of Communication Through the patient's Eyes). These items can be divided into an instrumental and affective category. The patients reported per item how important the communication aspects were for their forthcoming visit and afterwards whether these needs were met by their HCP, on a four-point Likert scale (Table 2) .

### **Statistical analysis**

Descriptive statistics were used to characterize the sample .

Differences between groups were analysed using t tests and chi-square tests, where appropriate. Four subscales of the QUOTE were created: a (1) pre-visit instrumental scale, (2) pre-visit affective scale, (3) post-visit

instrumental scale and (4) post-visit affective scale. The internal consistency of the four created sub-scales was high (Table 1). Linear regressions were conducted to analyse differences in perceived performance scores between the control and intervention group per item, adjusting for preferences score .

Initially, we also adjusted for time elapsed since diagnosis, as we expected this to influence the outcome .

However, only in 4 of the 15 items the influence was significant, with a very small effect ( $C \leq 0.00$ ). Therefore, this variable was excluded from the final analysis. We repeated the analysis with ordered logistic regressions.

#### [TABLE 1]

This led to the same conclusions and therefore only the regressions were presented. STATA 13.0 facilitated the analyses .

Statistical significance was tested two-tailed at 0.05 .

## RESULTS

### Participant flow

A total of 146 patients registered online of which total 97 were randomized in control or intervention group after providing informed consent. Registered patients who were not randomized did not meet the inclusion criteria ( $N=4$ ) or they did not return their informed consent form ( $N=45$ ). This group did not differ from the randomized patients regarding age, gender, ethnicity, internet use and stage of the disease. However, the randomized patients were highly educated, more often member of a patient organization, the time between diagnosed and registration for participation was longer and they had started treatment more often. Of the randomized participants, 19 participants did not complete their post-visit questionnaire ( $N=9$ ) or signed off before the start of the research ( $N=10$ ), leaving 78 datasets to be analysed .

### Baseline data

The baseline characteristics of the intervention group ( $N=50$ ) and the control group ( $N=28$ ) were similar, except for the elapsed time since diagnosis, which was significantly longer for the intervention group ( $p=0.01$ ). The majority of all participants were highly educated and a quarter of the participants were diagnosed in the last year. Most patients (97 %) had visited a physician .

### Preferred and perceived communication performance

The mean preferences and perceived performances scores are presented in Table 1. Results on item level are presented in Table 2. Overall, the perceived performance score on the instrumental scale is lower compared to the perceived performance score on the affective scale for both groups .

On the instrumental scale, six (of eight) items were considered (very) important by 90–99 % of the patients. Patients consider advice on what they can do as most important instrumental preference .

The two items Bthe HCP should examine me^ and Bthe HCP should diagnose what's wrong^ were less frequently indicated as (very) important (respectively 72 and 74 %). In the eyes of the patients, five needs were fulfilled in more than 70%of the cases. The items Bthe HCP should discuss different treatment options^ and Bthe HCP should give information about possible side effects^ scored lowest on perceived

performance. While patients considered these items as important needs (respectively 92 and 94 %), they were not often perceived as having been met (respectively 39 and 40 %).

On the affective scale, six (of seven) items were considered (very) important for their forthcoming visit (88–99 %) by most patients. The item Bthe HCP should be empathetic with me<sup>^</sup> was considered important (65 %) less often compared to items as Bthe HCP should be frank to me<sup>^</sup> (99 %) and Bthe HCP should take enough time for me<sup>^</sup> (97 %). Overall, the perceived performance met the pre-visit affective preferences well (84–96 %) and lesser discrepancies were visible compared to the instrumental scale.

### **Intervention effects**

Controlled for preference scores, there were no significant differences between the intervention and control group on perceived performance scales on item level. The similarities and discrepancies between the perceived performance are presented in the right columns of Table 2.

On all 15 items, the intervention group coefficient was negative (ranging from  $-0.06$  to  $-0.43$ ), indicating that they perceived the communicative performance of their HCP lower than the control group.

### **DISCUSSION**

In the present study, we investigated preferences and perceived performances regarding the communicative behaviour of their HCP, through the eyes of patients with malignant lymphoma. In agreement with comparable studies in general practice and oncology care, participants in the current study consider both affective and instrumental communication aspects important [32, 36–38]. Patients were predominantly satisfied with the affective communication style of their HCP, which is a positive result. They considered their HCP as friendly, frank and a good listener who took enough time.

There were more discrepancies between needs and perceived performance in instrumental, task-oriented domain.

Three items in particular stood out. Patients considered information about treatment options and side effects as important, but in practice these two needs were often perceived as unmet.

These topics may not have been relevant for the concerning consultation from a clinical point of view, but the patients did prefer to talk about them. In this respect, upfront agenda setting may help to establish consensus about the joint focus of the consultation [39]. Third, patients think it is highly important to get advice about what they can do. The need for clear information has been pointed out in other studies [22, 40], but the need to know how one can act seems a step further.

### **[TABLE 2]**

The increasing emphasis on patient autonomy, patient participation and shared decision-making may explain this development [41, 42]. Considering the relatively high average time elapsed since diagnosed, this pro-active attitude may be associated with the experience these patients had gained.

Experience can support patients to act more proficient and empowered to ask certain questions [21] .

In the second part of this study, we assessed to what extent the online communication tool BPatientTIME<sup>^</sup> influences patients' perceived performances regarding their HCP's communicative behaviour. The data indicated no significant differences between the intervention and control group. This suggests that the intervention does not influence the perceived performances but hopefully the patients' actual behaviour or confidence in their own communication performance. A lack of power may be a reason for the absence of significant results between the control and intervention group, because it is remarkable that the findings on item level demonstrate a negative trend on all 15 items. This indicates that the intervention group may have been more critical about their HCP's performance as a result of the intervention. Watching PatientTIME's video clips of best communication practices may have raised expectations, increased tensions or led to a more critical attitude towards the HCP, like suggested in other studies evaluating patient-targeted interventions [28, 29, 43] . The current study had the following limitations: first, the inclusion of participants was based on voluntary registrations .

This may have led to a group of participants with a relatively increased interest in (improving) the quality of clinical communication .

Second, the majority of the participants were highly educated and the time elapsed since diagnosis was quite long. This indicates that they were relatively experienced in the health care system, a known phenomenon in research that involves eHealth interventions (the inverse information law; Baccess to information is often most difficult for those who need it most<sup>^</sup>) [44]. This challenges the generalizability of our results to lower educated and less experienced patients .

Third, the QUOTE-com questionnaire has originally been developed and validated for primary care. In the current study, four items of the questionnaire were excluded because these were not applicable for patients diagnosed with cancer. Adapted versions of the scale have been frequently used in secondary care [32, 45], but alterations may influence the validity. Moreover, the participants in the current study may have multiple hospital visits planned for different purposes and therefore a Bnot applicable<sup>^</sup> answer option might have been of added value .

Fourth, it is likely that directly after having watched PatientTIME's video clips, the preferences and expectations of the intervention group about the upcoming conversation changed. Because we offered no post-website questionnaire, we do not know to what extent the intervention influenced the pre-visit preferences. It would be interesting to assess whether the intervention changes the expectations, which may also support the interpretation of data gathered post-visit .

At last, the setting and recruitment method provided us with information gathered via the patient only and little detailed information about the HCP (like years of experience) which could have enriched the interpretation of the results.

In conclusion, patients considered both affective and instrumental communication aspects important during haematological consultations. On the affective scale, the perceived performance of their HCP met their pre-visit preferences well. On the instrumental scale, patients' expectations were fulfilled less. Overall, the online pre-visit communication tool for patients BPatientTIME<sup>^</sup> did not seem to influence the patients' perceived communication performance of their own HCP much .

To further improve communication during clinical consultations, HCPs should inquire patients' communication preferences and expectations at the start of the consultation, especially on the instrumental domain. Improving this skill can be taught in communication skills training, which have proven to be an effective approach [46]. At the same time, patients should be supported to clarify their preferences .

#### **ACKNOWLEDGMENTS**

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#### **COMPLIANCE WITH ETHICAL STANDARDS**

##### **Ethics**

The research ethics committee of the Radboud University Nijmegen Medical Centre evaluated the protocol and concluded that the study did not fall within the remit of the Medical Research Involving Human Subjects Act (WMO) .

##### **Conflict of interest statement**

None declared

##### **Statement of informed consent**

Informed consent was obtained from all patients for being included in the study .

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## TABLES

**Table 1** Background characteristics and preference and performance scores

Participants		Control N= 28	Intervention N= 50
Age (at registration)	Mean years (SD)	56.7 (2.2)	55.6 (1.7)
Gender	Male	11 (39 %)	17 (34 %)
Education	Low	2 (7 %)	0
	Medium	6 (21 %)	11 (22 %)
	High	20 (71 %)	39 (78 %)
Member of a patient organisation	Yes	14 (50 %)	36 (72 %)
	No	14 (50 %)	14 (28 %)
Internet use	Daily	26 (93 %)	47 (94 %)
	Weekly	2 (7 %)	3 (6 %)
	Monthly	0	0
Disease-related information			
Diagnosis	Hodgkin lymphoma	3 (10 %)	13 (26 %)
	Non-Hodgkin lymphoma	24 (86 %)	34 (68 %)
	Other	1 (4 %)	3 (6 %)
Time elapsed since diagnosis <sup>a</sup>	Mean years (SD)	3.5 (0.7)	8.11 (1.5)
	<1 year	9 (32 %)	10 (20 %)
	>1 year	19 (68 %)	39 (80 %)
Treated	Yes	24 (86 %)	47 (94 %)
	No	4 (14 %)	3 (6 %)
Current status	Awaiting research results or treatment (plan)	4 (14 %)	5 (10 %)
	Currently getting treatment	6 (21 %)	9 (18 %)
	Wait-and-see	9 (32 %)	14 (28 %)
	Remission	9 (32 %)	22 (44 %)
	Palliative care	0	0
Details medical consultation			
Consulted professional	Physician	26 (93 %)	50 (100 %)
	Nurse	2 (7 %)	0
Familiar with professional	Yes	28 (100 %)	46 (92 %)
	No	0	4 (8 %)
With a companion	Yes	18 (64 %)	27 (54 %)
	No	10 (36 %)	23 (46 %)
Mean preference scores			
Pre-visit preference score (range 1–4)	Instrumental scale ( $\alpha = .82$ )	3.37 (.38)	3.19 (.53)
	Affective scale ( $\alpha = .78$ )	3.25 (.41)	3.36 (.38)
Mean performance scores			
Perceived performance score (range 1–4)	Instrumental scale ( $\alpha = .80$ )	2.94 (.62)	2.68 (.85)
	Affective scale ( $\alpha = .90$ )	3.72 (.49)	3.57 (.60)

<sup>a</sup> One missing

**Table 2** Perceived performance of the health care professional when pre-visit indicated as (very) important

The instrumental scale	Preferred by <i>N</i> (%)	<i>N</i> <sup>a</sup> (%) that perceived that the pre-visit need was met		
		Total	Control	Intervention
The healthcare professional...				
examined me	56 (72 %)	43 (77 %)	18 (75 %)	25 (78 %)
diagnosed what's wrong	58 (74 %)	41 (71 %)	17 (74 %)	24 (69 %)
explained well what's wrong	73 (94 %)	62 (85 %)	25 (96 %)	37 (79 %)
gave advice on what to do	77 (99 %)	55 (71 %)	21 (75 %)	34 (69 %)
helped me with my problem	70 (90 %)	43 (61 %)	15 (58 %)	28 (64 %)
informed well on the treatment	75 (96 %)	56 (75 %)	22 (79 %)	34 (72 %)
discussed different treatment options with me	72 (92 %)	28 (39 %)	12 (46 %)	16 (35 %)
gave information on possible side effects	73 (94 %)	29 (40 %)	11 (41 %)	18 (39 %)
The affective scale				
The healthcare professional...				
was friendly	69 (88 %)	66 (96 %)	24 (96 %)	42 (95 %)
took my problem seriously	77 (99 %)	67 (87 %)	25 (93 %)	42 (84 %)
listened well to me	77 (99 %)	69 (90 %)	25 (93 %)	44 (88 %)
was frank to me	77 (99 %)	73 (96 %)	26 (96 %)	47 (96 %)
took enough time for me	76 (97 %)	71 (93 %)	26 (96 %)	45 (92 %)
was empathetic to me	51 (65 %)	43 (84 %)	16 (89 %)	27 (82 %)
gave me enough attention	75 (96 %)	69 (92 %)	26 (96 %)	43 (90 %)

<sup>a</sup>Sample size varies due to pre-visit preference scores; only post-visit experience scores of patients who indicated these items pre-visit as important (scores 3 or 4) are mentioned