Communication Considerations for Remote Contact with Cancer Patients During the COVID-19 Pandemic: Potential Harmful Situations

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Abstract

Background: Communication is important, especially in cancer care. Good communication can positively influence patient outcomes, whereas poor communication can cause harm. Due to COVID-19 physical contact decreased leading to remote communication. In addition, general health care was downscaled, resulting in patients potentially receiving limited information about (treatment) changes. Currently, we do not know whether these changes are considered harmful and whether that depends on certain characteristics.

Objective: This study aims to determine to which extent communication themes and communication situations within these two themes, are deemed harmful and by whom during the COVID-19 pandemic. Specifically, the relationship between patients' age, gender, education and information need, and the changed communication (remote consultations and limited information about (treatment) changes) and specific communication situations.

Methods: An online survey study was conducted based on a scoping review and input from researchers, clinicians, and patient representatives. Participants were eligible if they were 18 years or older, had advanced (incurable) cancer and had sufficient command of the Dutch language. Participants were presented with six potentially harmful communication situations (grouped under the themes remote consultations and limited information about (treatment) changes) which they assessed as harmful or not (yes/no). The background characteristics were dichotomised, and the relationships were measured using (logistic) regression analyses.

Results: The sample existed of 47 participants, aged between 44-81. Most participants (57%–87%) perceived the communication situations as harmful. The relationships between age, gender, education, and information need and remote consultations, limited information about (treatment) changes and specific communication situations were all non-significant ($p > .01$). The relationship between education and not checking if the discussed information is remembered was marginally significant, $\chi^2(1, N = 46) = 6.21, p = .013$ and recorded an odds ratio of 7.29 (95% CI: 1.31 – 40.54).

Conclusions: As we suspect telehealth to increase, we suggest creating specific guidelines for remote contact using harmful communication examples and helpful alternatives. Furthermore, we advise physicians to provide explanations about treatment changes and as to why patients are not (or less) involved in decision-making when information provision is limited. Larger and more representative research is needed to replicate and substantiate our findings.

Layman's abstract

Cancer is a very common disease that affects a lot of people worldwide. We know that the way doctors and patients communicate influences the patients' feelings and understanding of his or her disease. Because of the Coronavirus (COVID-19) the way of communicating changed. Before the Coronavirus, you could visit a doctor face-to-face, but this was not always possible during the pandemic. Instead of face-to-face appointments, more doctors would see their patients through (video) calls. Also, because health care was downscaled, patients received less information about their disease or possible changes in treatment. So far, we do not know if these changes are experienced as harmful or whether this depends on someone's characteristics.

This study wanted to find out to which extent patients find remote communication and receiving reduced information harmful. And, if this is related to someone's characteristics (age, gender, education, or need for information). To research this, the participants received an online questionnaire with six different situations where communication could possibly be harmful. The situations were grouped under the themes remote consultations and limited information about (treatment) changes.

In total, 47 people filled in our questionnaire, aged between 44 to 81 years. Almost two-thirds of the participants thought the communication situations could be harmful. No clear differences were seen regarding someone's age, gender, education, or need for information and the extent to which they thought the situations and the communication themes were harmful. However, there was an indication that participants with higher education would find 'not checking if the discussed information is remembered' more harmful than participants with lower education.

In conclusion, because most participants found the situations harmful and the situations were easy to avoid, we advise creating specific guidelines for online cancer communication. These guidelines should give examples of harmful communication and show alternatives for helpful communication. When patients are not (or less) involved in their treatment, or the treatment changes, we advise doctors to give more insights into the specific reason. Because of the small number of participants in this study, we believe more research is needed to replicate and support our findings.

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**Communication Considerations for Remote Contact with Cancer Patients
during the COVID-19 Pandemic: Potential Harmful Situations**

Cancer is a highly prevalent disease, as it is the second leading cause of death globally (World Health Organization, 2018). It is estimated that in the Netherlands one in three people will develop cancer (KWF, 2021; Nederlandse Kankerregistratie, 2021). When faced with advanced, incurable cancer, patients are forced to face complex medical information and difficult treatment options (Arora, 2003). In addition, diagnosis and treatment lead to emotional distress (Mitchell, 2007). Patients are in regular contact with their physicians to discuss disease care, treatment decisions and side effects (Ha & Longnecker, 2010). In general, a wide consensus exists about the importance of communication (Stajduhar et al., 2010; Thorne et al., 2008; Tulsky et al., 2017). Good communication can help patients by influencing several patient outcomes, such as quality of life and psychological well-being (Hack et al., 2005; Hoffstädt et al., 2020; van Vliet et al., 2013). However, communication can also cause harm. Research by Mazor et al. (2012) showed that almost half of the patients in their research reported complaints about patient-physician communication. Poor communication affects the physical and psychological suffering of patients and can influence patients' understanding of the illness, prognosis, and treatment options (Tulsky et al., 2017).

So, while communication is inherently important, the COVID-19 pandemic changed physician-patient interactions tremendously. Concerning cancer care, two main aspects changed because of COVID-19, which might potentially be seen as harmful by patients. First, physical contact decreased due to the risk of contamination. This lead ultimately to remote consultations through telephone and video calls instead of face-to-face appointments at the hospital (Atreya et al., 2020; van Giessen et al., 2020). Before COVID-19, the overall utilisation of 'telehealth' (e.g., remote communication through online messaging, telephone, and video contact) was limited (Harvey et al., 2019). However, since the COVID-19 outbreak, healthcare systems rapidly had to adapt to these new forms of communicating (Wosik et al., 2020). Telehealth encounters have limitations, such as a lack of physical and direct contact with patients, creating potential harmful communication situations (Wosik et al., 2020). For example, does the patient have enough space to react after receiving bad news and does he or she remember the discussed information? Second, patients' involvement in the decision-making process and treatment changed as healthcare was downscaled, resulting in patients potentially receiving limited information about (treatment) changes (Ueda et al., 2020). To reduce the spread of the virus, procedures were postponed, and cancer care management and treatments were modified (Gasparri et al., 2020; Schrag et al., 2020). For example, treatment could be changed from surgery to radiotherapy (Greenwood & Swanton, 2021). This lack of information supply could potentially lead to situations where communication can be harmful.

With COVID-19 still being a novel virus, not much research has been done into the effects of harmful communication, such as remote consultations and limited information about (treatment)

changes, on patients. In addition, it is currently not known how various patients experience potentially harmful communication. Regarding remote consultations first, a Canadian study has shown that patients reacted positively to telephone appointments as a replacement for physical appointments during the pandemic (Locke et al., 2020). The study by Hasson et al. (2021) has shown that most patients wanted to continue remote communication. Unfortunately, not many other studies have yet researched the effects of replacing physical consultations with remote consultations on patients (in times of a global pandemic). Perhaps certain patients consider remote contact more harmful than other patients. Research by DeSouza et al. (2014) has suggested that male patients and patients without formal education were less likely to have telephone contact with their doctor in the management of illness. Older patients were less experienced in using telephone and video consultations (Hammersley et al., 2019). In addition, due to the narrow focus of telephone consultations, remote contact could possibly be more harmful when having a high need for information (Derkx et al., 2009). Considering receiving limited information about (treatment) changes second, the study by Hack et al. (2005) has suggested that changes in information provision (e.g., providing less information) are experienced differently by various patients. For instance, younger, female, and higher educated patients tend to have a higher need for information and are thus more reluctant towards change in information provision (Fujimori & Uchitomi, 2009; van Vliet et al., 2019). In addition, younger patients, and higher educated patients value shared decision-making more highly (Fujimori & Uchitomi, 2009). Receiving fewer explanations about patient involvement in decision-making could therefore be considered as harmful.

The current study aims to determine to which extent communication themes, namely remote consultations, and limited information about (treatment) changes, as well as specific communication situations within these two themes, are deemed harmful and by whom during the COVID-19 pandemic. More specifically, we will investigate the relationship between age, gender, education and information need and the communication themes (remote consultations and limited information about (treatment) changes) and the specific communication situations (*remote consultations*: beginning to talk without checking if it is an appropriate time; not giving the patient enough space to react after receiving bad news; not checking if the discussed information is remembered; during a video call: not checking if it is okay to continue speaking when someone enters the room, *limited information about (treatment) changes*: not explaining about treatment changes; not explaining about why the patient is not involved in the decision-making process). The following hypotheses are drafted to research the topic of harmful communication situations in times of a pandemic:

Communication themes:

Hypothesis 1: Older patients (a), male patients (b), patients with lower education (c) and patients with a high need for information (d) assess remote consultation more harmful than younger patients, female patients, patients with higher education and patients with a low need for information (Derkx et al., 2009; DeSouza et al., 2014; Hammersley et al., 2019).

Hypothesis 2: Younger patients (a), female patients (b), patients with higher education (c) and patients with a high need for information (d) assess limited information about (treatment) changes more harmful than older patients, male patients, patients with lower education and patients with a low need for information (Fujimori & Uchitomi, 2009; Hack et al., 2005; van Vliet et al., 2019).

Communication situations:

Hypothesis 3: Older patients (a), male patients (b), patients with lower education (c) and patients with a high need for information (d) assess beginning to talk without checking if it is an appropriate time more harmful than younger patients, female patients, patients with higher education and patients with low need for information (Derkx et al., 2009; DeSouza et al., 2014; Hammersley et al., 2019).

Hypothesis 4: Older patients (a), male patients (b), patients with lower education (c) and patients with a high need for information (d) assess not giving the patient enough space to react after receiving bad news more harmful than younger patients, female patients, patients with higher education and patients with low need for information (Derkx et al., 2009; DeSouza et al., 2014; Hammersley et al., 2019).

Hypothesis 5: Older patients (a), male patients (b), patients with lower education (c) and patients with a high need for information (d) assess not checking if the discussed information is remembered more harmful than younger patients, female patients, patients with higher education and patients with low need for information (Derkx et al., 2009; DeSouza et al., 2014; Hammersley et al., 2019).

Hypothesis 6: Older patients (a), male patients (b), patients with lower education (c) and patients with a high need for information (d) assess not checking if it is okay to continue speaking when someone enters the room more harmful than younger patients, female patients, patients with higher education and patients with low need for information (Derkx et al., 2009; DeSouza et al., 2014; Hammersley et al., 2019).

Hypothesis 7: Younger patients (a), female patients (b), patients with higher education (c) and patients with a high need for information (d) assess not explaining about treatment changes more harmful than older patients, male patients, patients with lower education assess and patients with low need for information (Derkx et al., 2009; Fujimori & Uchitomi, 2009; van Vliet et al., 2019).

Hypothesis 8: Younger patients (a), female patients (b), patients with higher education (c) and patients with a high need for information (d) assess not explaining about why the patient is not involved in the decision-making process more harmful than older patients, male patients, patients with lower education and patients with low need for information (Derkx et al., 2009; Fujimori & Uchitomi, 2009; van Vliet et al., 2019).

The potential implication of the research is to advise oncologists about what communication (situations) can be perceived as harmful in times of the current pandemic in which face-to-face contact is limited and (treatment) changes sometimes need to be made.

2. Methods

2.1 Research design and ethics

This study was part of a larger research project focussing on harmful and helpful communication in advanced cancer. This study focused on the extent to which certain communication themes and communication situations were deemed harmful and by whom during the COVID-19 pandemic. Participants were asked to complete an online questionnaire about communication. The study had a descriptive design (between-subjects). The study was approved by the Psychology Research Ethics Committee of Leiden University (2020-09-22-L.M. van Vliet-V1-2643).

2.2 Participants and sample size

Participants were eligible if they were 18 years or older, had advanced (incurable) cancer and had sufficient command of the Dutch language. The aim was to recruit 100 participants, however, due to a low response rate, adjustments to the inclusion criteria were made. Initially, only women with incurable breast cancer were included. The inclusion criteria were broadened to include males and other forms of cancers.

2.3 Recruitment

Participants were recruited between June and November 2020 through the channels of the Dutch Breast Cancer Organisation (Borstkanker Vereniging Nederland [BVN]), cancer.nl (kanker.nl), the Dutch Federation of Cancer Patient Organisations (Nederlandse Federatie van Kankerpatiënten Organisaties [NFK]), Foundation Optimal Support for Cancer (Stichting OOK [Optimale Ondersteuning Kanker]), the Netherlands Comprehensive Cancer Organisation (Integraal Kankercentrum Nederland [IKNL]) and AYA 'Young & Cancer' care network (AYA 'Jong & Kanker' zorgnetwerk) using an online advertisement text. The online advertisement text could freely be shared on social media. In addition, the advertisement text was also sent to participants from previous studies who had shown interest to be approached for follow-up research.

2.4 Procedure

Participants were invited through an online advertisement text. The advertisement text included a link to the questionnaire, which could be filled in online. The questionnaire was hosted using Qualtrics software. Interested participants first read an information letter and provided informed consent. Once informed consent was provided, participants entered the questionnaire. The estimated time to fill in the questionnaire was 30 to 45 minutes. The data was anonymously collected and stored separately and could therefore not be traced back to the participants. After completing the questionnaire, the participants were debriefed. The participants did not receive compensation for participating.

2.5 Measures

The content of the questionnaire was created based on a conducted scoping review and in collaboration with the project team consisting of researchers, clinicians, and patient representatives (including representatives from the Dutch Breast Cancer Organisation [BVN]). The questionnaire was piloted with involved patient representatives.

The following background characteristics were assessed:

i) *Sociodemographics:* gender (male/female), age (date of birth) and education (measured using 8 different educational levels and subdivided over three general levels: lower, intermediate, and higher education).

ii) *Information need:* measured using the question "To what extent do you want to receive information regarding, for example, treatment options, possible benefits, and possible risks?" and a self-created numeric rating scale (1 = *I would like to receive no information* to 10 = *I would like to receive as much information as possible*).

The harmfulness of COVID-19 related communication was assessed as outcome variables and was measured using six different communication situations. The communication situations were distributed over two communication themes. The communication theme *remote consultations* consisted of the specific communication situations: beginning to talk without checking if it is an appropriate time (1), not giving the patient enough space to react after receiving bad news (2), not checking if the discussed information is remembered (3) and during a video call: not checking if it is okay to continue speaking when someone enters the room (4). The communication theme *limited information about (treatment) changes* consisted of the specific communication situations: not explaining about treatment changes (5) and not explaining about why the patient is not involved in the decision-making process (6). See also Appendix A.

The questions to assess the situations were presented in the following format, see Box 1:

Box 1

Question format assessing harmfulness of situations.

Situation 4/6: During a video call: Not checking if it is okay to continue speaking when someone enters the room

Possible harmful communication: Oncologist: "I see someone walking in. Let's continue discussing the treatment options."

Possible helpful communication: Oncologist: "I see someone walking in. Can we still continue talking?"

Do you think this is a situation where communication can be harmful?

- Yes
- No

2.6 Statistical analyses

First, participants' background characteristics (age, gender, education, and information need) were described using descriptive statistics. Second, the percentage of participants who considered the specific communication situations harmful in general were described. Third, we determined the relationship between background characteristics and whether the communication themes were deemed harmful. We, therefore, grouped the four items under the communication theme remote consultation into a continuous variable (ranging 0-4). The reliability of this variable was checked with a reliability analysis (Cronbach's alpha). We used a simple linear regression analysis between each characteristic and the self-created linear variable to assess the relationship between the background characteristics and the communication theme remote consultations. Next, to assess whether background characteristics predicted if remote consultations were considered harmful or not (hypothesis 1), a multiple regression analysis (forced entry) was performed using the significant background characteristics. The assumption of normality of the residuals was checked using a histogram of the dependent variables showing standardised residuals. The assumptions of linearity and homoscedasticity were checked using a scatterplot of the dependent variables and the standardized residuals and predicted values. Then, the two items under limited information about (treatment) changes were combined to a dichotomous variable where 0 = 0 (not harmful) and 1 or 2 = 1 (harmful). The new variable was used as the dependent variable. We used simple logistic regression analyses between the characteristics and the self-created dichotomous variable to determine the relationship between the background characteristics and the extent to which the communication theme limited information about (treatment) changes was deemed harmful. Next, to assess whether background characteristics predicted if limited information about (treatment) changes were considered harmful or not (hypothesis 2), a multiple logistic regression analysis (forced entry) was performed, using the significant background characteristics from the simple logistic regressions. The assumptions were checked before performing the analysis. The assumptions of binary dependent variables, independence of observations, linearity of independent variables and log odds and sample size were checked by inspecting the data. Multicollinearity was checked using collinearity diagnostics using the Variance Inflation Factor (VIF) and the Tolerance values. Fourth, we determined the relationship between background characteristics and whether the communication situations were deemed harmful. We started with a simple logistic regression analysis between each characteristic and each situation. Next, to assess whether background characteristics predicted if specific communication situations were considered harmful or not (hypotheses 3-8), six multiple logistic regression analyses were performed. The background characteristics that were significantly related to the communication situations being seen as harmful in the simple logistic regressions were used to build the prediction model in the multiple logistic regressions (using forced entry). The following assumptions were checked before performing the analyses: binary dependent variables, independence of observations, linearity of independent continuous variables and log odds and sample size.

Multicollinearity was checked using collinearity diagnostics using the Variance Inflation Factor (VIF) and the Tolerance values.

      Analyses were conducted with SPSS version 26. To reduce the change of Type I error with the simple logistic regressions, a *p*-value of .01 (two-sided testing) was used. All other analyses used significance testing at $p \leq .05$ (two-sided testing).

3. Results

3.1 Background characteristics

      Ninety participants started the questionnaire ($N = 90$), of which 47 participants answered the COVID-19 related communication questions ($N = 47$). The mean age of the participants was 57.3 years. Most participants were female (91.5%) and higher educated (57.4%). Results of the question regarding the need for information showed to be skewed (Appendix B). More than half of the participants (59.6%) rated their information need as high (e.g., 'I would like to receive as much information as possible'). See Table 1 for more information regarding the background characteristics. To create equal groups for the analyses, the variables age and information need were dichotomised using a median split.

Table 1

Participants' background characteristics

Variable	Mean *(SD)*	Median
Age (range 44 - 81)	57.3 (8.04)	57
Information need (range 1-10)	9.1 (1.61)	10
	N	**%**
Age		
Younger (< 57)	25	53.2
Older (≥ 57)	22	46.8
Gender		
Female	43	91.5
Male	4	8.5
Education[a]		
Lower Education	10	21.3
Intermediate Education	9	19.1
Higher Education	27	57.4
Other[b]	1	2.1
Information need		
Lower information need (< 10)	19	40.4
Higher information need (≥ 10)	28	59.6

Note. [a]For further analyses the variable education was dichotomised into lower education (*lower education*: no education, primary education, primary or preparatory secondary vocational education and general secondary education and *intermediate education*: secondary vocational education and apprenticeship training and higher general and pre-academic education) and higher education (higher professional education and academic higher education). [b]The option 'other' could not be specified.

3.2 Perceived harmfulness of communication situations

Figure 1 shows the distribution between the situations and whether they were perceived as a potentially harmful situation (yes) or not (no). The situations *not explaining about why the patient is not involved in the decision-making process* (87.2%) and *not checking if the discussed information is remembered* (80.9%) were perceived as most harmful. The situation *beginning to talk without checking if it is an appropriate time* (57.4%) was considered least harmful.

Figure 1

Percentage of COVID-19-related questions considered as harmful (yes) or not harmful (no) (N = 47)

3.3 The effect of background characteristics on the communication themes

Simple linear regressions were performed to measure if the background characteristics significantly influenced the communication theme remote consultation (consisting of the specific situations: beginning to talk without checking if it is an appropriate time; not giving the patient enough space to react after receiving bad news; not checking if the discussed information is remembered; during a video call: not checking if it is okay to continue speaking when someone enters the room). The data of 46 participants was used, as the data of one participant was unspecified for the predictor education. The Cronbach's alpha coefficient was .73, suggesting an acceptable internal consistency. Before analyses, the assumptions were checked. Regarding the simple linear regressions, the general rule of thumb suggests 15-20 participants per predictor, meaning the assumption of sample size ($N = 46$) was met. The histograms between remote consultation and the background characteristics indicated the data was not normally distributed and the Normal Probability Plot showed a rough linearity. Results should be treated with caution. The relationships between the communication theme remote consultation and age ($p = .710$), gender ($p = .185$), education ($p = .116$) and information need ($p = .688$) were not significant, as is shown in Table 2.

Table 2

Separate simple regressions for background characteristics and remote consultations

Predictor	β	SE	p-value
Age	-.06	.39	.710
Gender	.20	.69	.185
Education	.24	.39	.116
Information need	-.06	.40	.688

Simple linear regressions were performed to measure if the background characteristics significantly influenced the communication theme limited information about (treatment) changes (consisting of the individual situations: not explaining about treatment changes; not explaining about why the patient is not involved in the decision-making process). The data of 46 participants was used, as the data of one participant was unspecified for the predictor education. The assumption regarding the binary dependent variables, independence of observations and a sample size of minimal 10 cases per independent variable were met. The background characteristics: age ($p = .998$), gender ($p = .251$), education ($p = .186$) and information need ($p = .519$) showed to be not significant with the communication theme limited information about (treatment) changes, see Table 3.

Table 3

Separate simple logistic regressions for background characteristics and limited information about (treatment) changes

Variable	OR	95% CI	p-value
Age	.00	.00 – .	.998
Gender	4.44	.35 – 56.88	.251
Education	4.88	.47 – 50.98	.186
Information need	.46	.04 – 4.82	.519

Note. Abbreviations: OR, odds ratio; CI, confidence interval.

3.4 The effect of background characteristics on the communication situations

To measure if the background characteristics influenced whether participants deemed the individual COVID-19-related situations as harmful, a series of simple logistic regression were conducted with the communication situations as dependent variables and the background characteristics as independent variables. The data of 46 participants was used. Before performing the logistic regressions, the assumptions were checked. The dependent variables were all binary and the observations were independent to each other. The assumption of sample size (requiring a minimum of 10 cases per independent variable), which was met. The simple logistic regressions testing the significance of the background characteristics, and the communication situations were all non-

significant ($p > .01$). The results of the separate simple logistic regressions can be found in Table 4. The relationships between education and not checking if the discussed information is remembered was marginally significant, $\chi^2(1, N = 46) = 6.21$, $p = .013$. The predictor education recorded an odds ratio of 7.29 (95% confidence interval [CI]: 1.31 – 40.54), indicating that the odds of assessing not checking if the discussed information is remembered as harmful was estimated to be approximately seven times higher when one had a higher education as compared to participants who had lower education. This model was able to distinguish between participants who assessed the situation as harmful or not harmful. The model explained between 12.6% (Cox & Snell R square) and 20.1% (Nagelkerke R squared) of the variance and correctly classified 80.4% of the cases.

Table 4

Separate simple logistic regressions for sociodemographics (independent variables) and communication situations (dependent variables)

Variable	OR	95% CI	*p*-value
Situation 1 *Beginning to talk without checking if it is an appropriate time for the patient*			
Age	.56	.18 – 1.81	.335
Gender	2.726E+9[a]		.999
Education	1.53	.46 – 5.04	.484
Information need	2.00	.61 – 6.55	.252
Situation 2 *Not giving the patient enough space to react after receiving bad news*			
Age	.85	.21 – 3.44	.820
Gender	1.26	.12 – 13.60	.849
Education	2.65	.63 – 11.16	.183
Information need	.98	.24 – 4.07	.975
Situation 3 *Not checking if the discussed information is remembered*			
Age	.65	.15 – 2.79	.560
Gender	1.46	.13 – 15.92	.757
Education	7.29	1.31 – 40.54	.023*
Information need	.35	.07 – 1.93	.229
Situation 4 *During a video call: Not checking if it is okay to continue speaking when someone enters the room*			
Age	1.50	.43 – 5.20	.523
Gender	2.31	.29 – 18.20	.427
Education	1.39	.40 – 4.81	.608
Information need	.41	.11 – 1.57	.194

Variable	OR	95% CI	*p*-value
Situation 5 *Not explaining enough about treatment changes*			
Age	1.32	.35 – 4.98	.680
Gender	3.30	.41 – 26.51	.261
Education	2.57	.67 – 9.86	.170
Information need	1.07	.28 – 4.06	.919
Situation 6 *Not explaining about why the patient is not involved in the decision-making process during the Corona crisis*			
Age	.39	.06 – 2.38	.309
Gender	2.53	.22 – 29.29	.457
Education	1.50	.27 – 8.38	.644
Information need	.71	.12 – 4.30	.706

Note. *p < .05, [a]data showed large numbers due to skewed data and a small number of participants. Abbreviations: OR, odds ratio; CI, confidence interval.

3.5 Multiple (logistic) regression analyses

Initial research design aimed to use multiple (logistic) regression analyses to assess whether background characteristics predicted if the communication themes and communication situations were considered harmful or not. Preconceived conditions for performing these analyses were that only the significant background characteristics from the simple (logistic) regression analyses would be used in building the prediction model of the multiple (logistic) regression analyses. Since there were no significant relationships in the simple (logistic) regression analyses, the multiple (logistic) regression analyses were not performed.

4. Discussion

This descriptive research aimed to determine to which extent communication themes, namely remote consultations and limited information about (treatment) changes, as well as specific communication situations within these two themes, were deemed harmful and by whom during the COVID-19 pandemic. Following existing literature, it was expected that different characteristics such as age, gender, education, and information need would influence the extent to which communication situations would be deemed harmful. Most patients considered the presented communication situations as potentially harmful. However, few background characteristics were related to perceived harmfulness.

4.1 Remote consultations

Contrary to our expectations, our results indicate there is no statistically significant relationship between a patients' age, gender, education, and information need and receiving remote consultations. While we did not find significant results, almost two-thirds of the participants assessed the remote consultations communication situations as harmful. The two aspects considered most harmful were

physicians not checking if the discussed information was remembered and physicians not providing space to react after patients receive bad news. The ask-tell-ask principle from Back et al. (2005), suggests alternating questions with short statements of information to make the patients feel heard and make sure the information is remembered. When receiving large amounts of information, patients may not absorb the information or become overwhelmed by emotions or worry (Back et al., 2005). Patients' information recall is limited, being able to recall on average 60% of the discussed information (Westendorp et al., 2021). It is, therefore, important to notice that this aspect of remote consultation showed to be most harmful. Physicians-expressed empathy increases information recall (Westendorp et al., 2021). However, expressing empathy is difficult during remote consultations (Holstead & Robinson, 2020). Furthermore, having a lower educational level seems to be a predictor of health information overload (Khaleel et al., 2020). It is therefore notable that we found a marginally significance indicating that participants with a higher educational level perceive physicians who do not check if information is remembered as more harmful, as opposed to lower educated participants. It could be possible that higher educated patients try to prevent information overload from happening and would therefore assess this situation as potentially harmful.

Although psycho-oncology COVID-19-research by Millar et al. (2020) suggests that remote consultations can suit some patients and harm others, few COVID-19-studies have focused on which patients would feel affected, or who would prefer remote consultations. We expected males to find remote consultations more harmful, however, our results indicate no difference between males and females. Our previous expectations and findings are conflicting with the COVID-19 research by Wang and Roubidoux (2020). Their research suggests that females would perceive the use of videoconferencing as more harmful due to their different style of communication. However, it should be noted that this research took place in the business environment, as opposed to the health care environment. As we found no differences between males and females and literature indicates conflicting results it remains uncertain whether males, females or both experience remote communication as harmful. Moreover, we also expected older patients to experience remote communication as more harmful; however, our results indicate no difference between both age groups. Suggesting it can be possible that patients are affected by remote consultations regardless of their age. However, the recent cancer-COVID-19-research by John et al. (2021) supports the notion that older patients assess remote consultation as more harmful than younger patients. They state that the need for face-to-face contact becomes more important as age increases. Our population was relatively broad (aged between 44 and 81), however, the average age was 57, as well as the median. It could therefore be that our sample of 'older' patients did not necessarily exist of relatively older patients.

4.2 Limited information about (treatment) changes

Against our expectations, we did not find a statistically significant relationship between a patients' age, gender, education, and information need and receiving limited information about

(treatment) changes. While we did not find significant results, three-quarters of the participants assessed receiving limited information about (treatment) changes as harmful. The aspect most participants (87%) were concerned about, was receiving fewer explanations about why patients are not being involved in the decision-making process. COVID-19-research by Abrahams et al. (2020) stated that the degree to which patients want to participate in decision-making is variable, meaning the need for contributing to the decision-making process differs per patient, as well as per physician. As we found no differences between patients' characteristics it remains uncertain which patients would be harmed. In addition, it is not clear to which extent the experience of harmful communication negatively influences patient outcomes. Soriano et al. (2021) stated in their research that about half of their participants indicated that their oncologist never discussed a treatment disruption due to COVID-19. Notably, only a quarter of their participants experienced psychosocial distress, despite treatment changes (Soriano et al., 2021). Our results show that almost 75% of our participants consider receiving limited information about (treatment) changes harmful. However, we did not look into whether this affects patient outcomes. It is possible that receiving limited information about (treatment) changes is experienced as harmful but does not negatively affect patients. Currently, few COVID-19-studies have done research whether participants' characteristics would influence assessing receiving limited information about (treatment) changes as harmful.

4.3 Additional context

Literature was gathered to provide context and shape our expectations; however, pre-existing literature was based on studies performed before the pandemic. Regarding remote consultations, research such as from DeSouza et al. (2014), Derkx et al. (2009) and Hammersley et al. (2019) mainly focused on using telephone or video consultations as (positive) additions to existing face-to-face consultations, not as a replacement for face-to-face consultations. It is therefore possible that our study does not measure the same underlying psychological aspects, as we measured the potentially harmful aspects of remote consultations during a pandemic, not the potential positive aspects outside of a pandemic.

4.4 Strengths and weaknesses

The strengths of this study were that it was one of the first studies to research the effects of background characteristics and potentially harmful communication between physicians and patients in times of a pandemic. Moreover, this study used a broad set of specific communication situations to test the potential harmfulness. Nonetheless, this study had some limitations. Firstly, the sample within our study was not representative of the population. The small study sample (47 participants) and skewed distribution regarding gender, education and information need were at the cost of the reliability, generalizability, and statistical power of the analyses. In addition, only participants with internet access could fill in our questionnaire, automatically excluding all patients without internet access or who feel uncomfortable with online questionnaires. Secondly, we provided the participants with closed-ended,

potentially suggestive questions, prohibiting participants from providing nuances in their answers. As participants received two answer options, opinions could possibly be framed due to obvious contrasting. Thirdly, our study presented hypothetical situations and measured the expected harmfulness, not the actual harmfulness that is done in practice. It was, therefore, difficult to determine if the perceived harmfulness was experienced to the same extent as actual physician-patient interactions. A final limitation was the statistical analyses. Initially, we planned on performing multiple (logistic) regressions to measure the harmfulness. We intended to use only the significant background characteristics as we assumed there would be a relationship. However, due to the fact we did not find significant relationships, we could not perform the final analyses.

4.5 Future research

The use of telehealth has shown benefits to health care provision, such as better time management and costs saving (Song et al., 2020). In addition, some patients consider remote contact useful (Millar et al., 2020). It is therefore expected that remote consultations will remain present in daily health care, even after the pandemic (Harvey et al., 2019; Nieuwsuur, 2020; Penedo et al., 2020). As it is still unknown which patients would benefit from remote consultations and which patients would consider it harmful, future studies should research whether remote consultations will help or will harm patients and to whom they will be helpful or harmful. A larger and more representative participants sample would be advised. Thereby, it might be worthwhile to provide the participants with ways to address aspects they would consider as harmful by using a more qualitative research approach. In addition, we would advise researching the effects of the communication situations on patient outcomes, as we know from previous literature that communication can influence quality of life and psychological well-being, as well as psychological suffering and illness understanding (Hack et al., 2005; Kreps, 2003; Tulsky et al., 2017). This way, participants can expand our understanding as to what is considered harmful communication or not. Thereby, we would advise future studies to research whether receiving limited information about (treatment) changes affects patients' outcomes.

4.6 Practical implications

Despite our study not finding significant results, it has provided us with valuable insights. As almost two-thirds of the participants considered the presented situations to be harmful, we believe physicians need to be aware of these possible harmful situations. Regarding remote consultations first, we expect this topic to remain relevant. The behaviours within this theme are easy to avoid and can be prevented. For instance, physicians should ask the patient if the discussed information is remembered or check whether it is okay to continue to speak if someone enters the room. In addition, when physicians deliver bad news, they should keep in mind to give the patient enough space as they cannot see their response. These behaviours could easily be implemented in remote physician-patient conversations. Furthermore, we suggest creating specific guidelines for remote contact through telephone and video calls instead of face-to-face consultations. Currently, some guidelines for remote contact regarding

cancer care (during COVID-19) exist, for example, the guidelines for environmental factors in telehealth (Duane et al., 2021), the patient-centred framework to address uncertainty (Dhawan et al., 2020), the Dutch guidelines for communication in uncertain times (van Vliet et al., 2020) and the COVID ready communication playbook (VitalTalk, 2020). These guidelines address the telehealth technology, treatment uncertainty or general COVID-19-related-care or changes. However, these guidelines do not suggest behaviours or actions to prevent harmful communication situations. Our research could supplement these existing guidelines by providing overviews of potential harmful communication situations when using remote consultations together with helpful alternatives.

Secondly, as health care is restored and more treatments can be provided again, we expect the changes in information provision to restore to how it was before COVID-19. If – and when – information provision (or contact) is limited, we suggest providing patients with explanations about why the patient is not (or less) involved in the decision-making process. Physicians who aspire to facilitate patient involvement in decision-making should address potential changes in disease care and treatment to prevent harmful communication.

4.7 Conclusion

In general, the presented communication situations were considered harmful by most of our patients (57% - 87%). However, we found no relationship between patients' age, gender, educational level, or information need and the extent to which they consider receiving remote consultations, limited information about (treatment) changes and specific communication situations as harmful. It is expected that the use of telehealth will increase outside of the pandemic. More research is needed to provide better insights as to which patients would consider remote consultations harmful and to whom it could be beneficial. We suggest that specific guidelines should be created to provide an overview of potential harmful communication situations and helpful alternatives when using remote consultation. When information provision is limited, we suggest providing explanations about treatment changes and as to why patients are not (or less) involved in decision-making. As remote communication keeps being used in patient care, we should take the time to ask what the patients prefer to make communication help patients, and not harm them.

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Appendix A

COVID-19 related questions
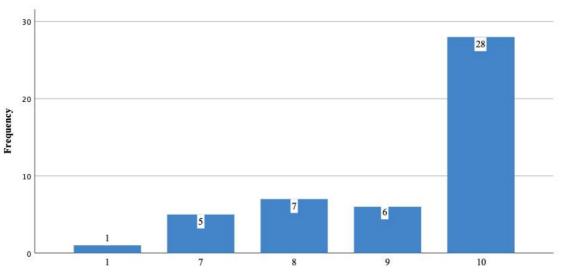
i)   <u>Remote consultations:</u>

    1. Beginning to talk without checking if it is an appropriate time for the patient

    2. Not giving the patient enough space to react after receiving bad news

    3. Not checking if the discussed information is remembered

    4. During a video call: Not checking if it is okay to continue speaking when someone enters the room

ii)   <u>Limited information about (treatment) changes:</u>

    5. Not giving enough explanation about treatment changes

    6. Not giving an explanation about why the patient is not involved in the decision-making process during the corona crisis

Appendix B

Responses regarding the question about information need (*N* = 47)

Please indicate to what extent you would like to receive information during the conversations with your oncologist
(e.g., about treatment options, possible advantages and disadvantages/side effects)?

1 = I want to receive no information   10 = I want to receive as much information as possible