'Functioning as focus of care', an intervention to proactively discuss human functioning; a crosssectional study to evaluate patients' experience

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Abstract

Background: Offering Patient-Centered-Care including Shared Decision Making can improve patient well-being, satisfaction and improve the overall quality of care. The intervention: *Functioning as focus of care* is developed to offer patient-centered-care to patient with a hematological disease. Trained nurses conduct a nursing visit with a patient and discuss their current/desired status of functioning as described in the International Classification of Functioning, Disability and Health. Patients with a hematological disease are faced with problems in al domains of their life, when offering the intervention, the underlying biopsychosocial state will be assessed, and this will support the patient in their own self-management and daily functioning in relation to their health and treatment plan. **Aim:** to evaluate experiences of patients with a hematological disease with a nurse intervention compared to usual care.

Method: the Patient Experience Monitor (PEM) is used as a measurement instrument, in this cross-sectional study, to evaluate the intervention on patient experience before and after the launch of the intervention. Four variables of the PEM are chosen as the primary and secondary outcomes: shared decision making - time nurses - identifying problems - involving families during discharge.

Results: The primary outcome shared decision making was not significant different (p=0.693). This also implies tot the secondary outcomes; time nurses (p=0.084) - identifying problems (p=0.760) - involving family during discharge (p=0.973).

Conclusion: no significant difference was found in the primary- and secondary outcomes. However, a positive increase is demonstrated in all four outcomes.

Recommendations: the intervention provides Patient-Centered-Care and is the first study that integrates the PEM as a measurement instrument. To fully understand the impact of the intervention and the positive increase of the outcomes, a study with a qualitive design can provide more insights.

Keywords: Patient-Centered-Care, Nurse interventions, ICF, PEM, Shared Decision Making

Samenvatting

Titel: 'Functioneren als focus van zorg' een interventie om proactief menselijk functioneren te bespreken.

Achtergrond: Het aanbieden van patiëntgerichte zorg waarbij er aandacht is voor samen beslissen, kan het welzijn en de tevredenheid van de patiënt verbeteren en de algehele kwaliteit van zorg verbeteren. De interventie *Functioneren als focus van zorg* is ontwikkeld om patiëntgerichte zorg te bieden aan patiënten met een hematologische aandoening. Bij het aanbieden van de interventie, die bestaat uit een verpleegkundige visite zal de onderliggende biopsychosociale toestand worden beoordeeld en dit zal de patiënt ondersteunen bij hun zelfmanagement en problemen vroegtijdig aanpakken. De verpleegkundige visite is ontwikkeld op basis van het *International Classification of Functioning, Disability and Health.*

Doel: het evalueren van patiëntervaringen van hematologische patiënten met de interventie in vergelijking met de standaard zorg.

Methode: Een dwarsdoorsnede onderzoek is uitgevoerd waarbij de patiëntervaring monitor is gebruikt als meetinstrument. Het meetinstrument is zowel voor als na de officiële start van de interventie uitgevraagd bij patiënten. Er staan vier uitkomsten centraal: samen beslissen, tijd verpleegkundigen, signaleren van problemen familie betrekken bij ontslag.

Resultaten: De primaire uitkomst samen beslissen was niet significant verschillend (p = 0,693). De secundaire uitkomsten waren niet significant verschillend: tijd verpleegkundigen (p = 0,084) – signaleren van problemen (p = 0,760) - familie betrekken bij ontslag (p = 0,973) **Conclusie:** Er is geen significant verschil gevonden in de primaire- en secundaire uitkomsten. De patiëntervaring monitor laat wel een positieve stijging zien in alle vier de uitkomsten.

Aanbevelingen: Dit is een van de eerste onderzoeken waarbij de patiëntervaring monitor gebruikt is om een verpleegkundige interventie te analyseren. Om de impact van de interventie op patiëntervaring te onderzoeken, zal zowel een studie met een kwalitatief design als een experimenteel design meer gedetailleerde informatie kunnen opleveren.

Sleutelwoorden: Patiëntgerichte zorg, verpleegkundige interventies, ICF-raamwerk, Patiëntervaring Monitor.

Introduction

Healthcare organizations around the globe are using patient centered care (PCC) as a main strategy to improve the quality of healthcare¹⁻³. The Institute of Medicine⁴ defined PCC as "care that is respectful of and responsive to individual patient preferences, needs, and values"⁴. To incorporate patients' preferences during healthcare treatment, the concept of Shared Decision Making (SDM) is a key element⁴⁻⁷. SDM is an interpersonal communication process between the healthcare professional and the patient, in which both parties collaborate in making decisions about the patient healthcare treatment⁴⁻⁷. SDM incorporates elements like discussing relevant care options and involving family needs⁸. Studies show that implementing PCC including SDM improves patient well-being, satisfaction and self-management skills⁹⁻¹¹.

The implementation of PCC including SDM fits the current paradigm shift in healthcare from the biomedical model, towards the biopsychosocial model¹², in which health is not merely the presence or absence of a disease, but the ability to adapt and self-manage in the face of social, physical and emotional challenges¹²⁻¹⁵.

A University Medical Center (UMC) in the Netherlands developed a nurse intervention to focus on PCC including SDM for patients with a hematological disease called: *Functioning as focus in care*^{15,16}. Patients treated for a hematological disease are faced with psychical, psychological and social problems¹⁷ and studies¹⁸⁻²⁰ report, in addition to a number of side effects of the medical treatment, a significantly high level of distress, depression and anxiety¹⁸⁻²⁰. To complete the treatment plan and to match the care needs of the patient, the focus of healthcare needs to broaden from a biomedical to a biopsychosocial model to enable patients to cope with their disease^{21,22}. When healthcare professionals, such as nurses, offer the intervention, the underlying biopsychosocial state will be assessed early on and offering PCC including SDM will support this patient group in their own self-management and daily functioning in relation to their health and treatment plan^{16,21,22}.

The intervention entails that nurses conduct Nursing Visits on a regular basis with patients. During the Nursing Visits, the current and desired status of human functioning is determined and discussed with the patients by using the International Classification of Functioning, Disability and Health (ICF)^{15,16,24}. The ICF covers all aspects of health and well-being, operationalized in terms of human functioning²³. Human functioning relates to how people function in everyday life, in the performance of activities and in the areas of life in which they participate^{15,21,23}. The ICF framework is chosen for this intervention because the biopsychosocial model is represented in the framework and the ICF has proven to be very useful in nursing care^{15,21,24}. The main goal of the intervention for the hematologic ward, is to improve PCC including SDM for patients during hospital admission^{15,16}.

The hospital launched a feasibility study to determine the usability of the intervention, with a positive result²⁵. In order to assess if the intervention truly captures the values of PCC including SDM, research about how the patients experienced the delivered care with the intervention is needed. Measurement of patients' experiences can be an effective tool to manage and monitor quality of delivered healthcare and provides opportunities to improve care²⁶⁻²⁸.

Aim

The aim of this study is to evaluate experiences of hospitalized patients with a hematological disease with an intervention focusing on human functioning compared to usual care.

Method

Design

A cross-sectional, observational design has been used to evaluate the intervention compared to usual care. A questionnaire that measures patient experience was distributed. The first questionnaire was distributed from January until June 2020 before the intervention was officially launched. The second questionnaire was distributed after the intervention was launched; it contains data from January until June 2021. The study will be conducted and reported by using the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement²⁹.

Intervention details

The intervention *Functioning as focus in care*, has been developed in recent years for the hematological ward in order to offer PCC in the biopsychosocial model of health and further improve SDM between patients and healthcare professionals^{15,16}. The hematological ward was missing a method and tool to provide care with attention to biopsychosocial issues. Twelve nurses were selected and enrolled in a specialized training program in order to learn how the nursing visits needs to be carried out. The structure of the nursing visit is based on a Dutch conversation tool called the GG/ZZ-tool^{15,30} (see Appendix A). The main goal of the intervention is to empower patients to take control over what is important for them in their daily lives and actively discuss their current and desired functioning. The hematological ward determined that each patient should receive a minimum of one nursing visit in a seven-day period. The first nursing visit should be offered in the first three days of the hospitalization. The intervention has been formally launched in July 2020.

Population and domain

The population of interest are adult patients with a hematological disease, who are admitted at the hematology ward in an academic hospital. A convenience sampling method is used.

Procedures

The digital questionnaire that was used to measure patient experience is the Patient Experience Monitor (PEM)^{28,31}. The PEM is the Dutch version of the Picker Patient

Experience Questionnaire-15 (PPE-15), which is a validated guestionnaire by the Picker Institute and is used internationally to monitor the quality of the delivered healthcare^{32,33}. The PEM measures fifteen variables relating to the end-to-end care provided by a hospital. These variables are categorized in four themes: during the hospital admission, treatment and delivered care, during the discharge process and general questions about the hospital. See appendix B. Implementation of the PEM in all eight UMC's was performed by the Dutch federation of University Medical Center (NFU) and the Dutch federation of hospitals (NVZ)^{31,34}. The NFU and the NVZ wanted a uniform patient experience questionnaire in order to compare the quality of care of each UMC's as experienced by patients^{31,34}. The PEM is controlled in all UMC's by an external data company called Expoint. This company analyzes the PEM data and provides each UMC's with their specific data of patient experience as measured with the fifteen variables. Expoint receives a patient e-mail address and demographic data from the UMC's when a patient is discharged and forwards the digital PEM guestionnaire between one and four days. An electronic reminder is sent after two weeks. The PEM is voluntary and anonymous, ergo PEM data cannot be traceable to a specific patient. The PEM will only be distributed to patients who haven't participated in the last six months.

Outcomes and characteristics

In this study, the researchers IB and HS decided with the management staff of the hematological ward that four variables of the PEM are chosen as a primary and secondary outcome, based on relevance to the intervention. The primary outcome shared decision making and the secondary outcomes; time nurses, identifying problems and involving family during discharge, are related to nursing care with the concept of PCC. The data of these four outcomes may show a difference in patient experience with nursing care when the intervention is received during hospitalization.

The primary outcome shared decision making was stated as follows: *Were you able to make a shared decision about your treatment?* The five response options where: 1) Yes, I was always able to make a shared decision. 2) Sort of, I was not always able to make a shared decision. 3) No, I was not able to make a shared decision. 4) It was not necessary to make a shared decision. 5) can't remember. These five response options are depicted as; "yes", "sort of", "no", "not necessary" and "can't remember". The primary outcome can reach a maximum score of 100 percent, if all participants answer with the response option "yes". If a participant fills in the response option "yes", the participant confirms that, he/she, has positively experienced SDM during hospitalization.

The secondary outcome time nurses was stated as follows: *Did the nurses have enough time to take care of you*? The four response options where: 1) Yes, there was

always enough time for me. 2) Sort of, there was usually enough time for me. 3) No, there wasn't enough time for me. 4) can't remember. These response options are depicted as: "yes", "sort of", "no" and "can't remember".

The outcome identifying problems was stated as follows: *Did a healthcare professional tell you which problems you should be aware of after discharge?* The four response options where: 1) Yes, I was told. 2) Sort of, some things are told but not enough. 3) No, nothing is told. 4) It wasn't necessary. These response options are depicted as: "yes", "sort of", "no" and "not necessary".

The outcome involving families during discharge was stated as: *Did a healthcare professional give your family or someone close to you, all the information they needed to help you recover?* The five response options where: 1) Yes, I was told. 2) Sort of, somethings are told but not enough. 3) No, nothing is told. 4) It wasn't necessary. 5) can't remember. These response options are depicted as: "yes", "sort of", "no", "not necessary" and "can't remember". All three outcomes can reach a maximum score of 100 percent, if all participants answer with the response option "yes".

Basic characteristics

Age and gender of the participants of the PEM were collected by the company Expoint. The average admission stay on the hematological ward from January till June 2021, was analyzed by the management team of the ward. This data was provided to the researcher IB.

In order to analyze if participants were provided the intervention during the time period of January till June 2021, two questions were added to the PEM. The first question asked if the participant received the intervention during admission. This could be answered with the response options "yes" and "no". The second question asked if the participant could provide an assumption of how many nursing visits, he/she received. The response options were: 1) No, can't remember. 2) One or two times 3) Three or four times 4) Five or six times 5) Seven or more times.

Sample size

To calculate the required sample size, the researchers IB and HS, hypothesized that as a result of the intervention, the primary outcome shared decision making, should be scored with a 72% score or higher on the response option "yes". The response option "yes" means that the patient positively experienced SDM during admission.

Previous data from the PEM is used to calculate a sample size, the outcome shared decision making scored a 32% score on the response option "yes" between January till June 2020. In order to receive the 72%, a chi-square test for two dichotomous proportions with alpha set at

0.05 and a power of 80%, calculated that a sample size of 23 participants for both groups is needed to reject the null hypotheses.

Data Collection

Nursing staff was informed about the research in September 2020. Patients were informed of the study by offering a specialized flyer from the start of the study in January till June 2021. Nurses offer more detailed information about the study and the PEM during discharge procedures. In order to examine whether the intervention affects patient experience, a comparison is made with the PEM before and after the formal launch of the intervention. The company Expoint provided the researcher IB with two datasets; the first dataset contains data from January until June 2020 and is referred to as PEM-1. The dataset contains the variables: age, gender and the scores of the four outcomes. The second dataset contains data from January until June 2021 and is referred to as PEM-2 and contains the same variables as the PEM-1.

Data analysis

Data analysis was executed using the Statistical Package for Social Sciences (IBM SPSS, version 25). Demographic characteristics, intervention questions and response options of the four PEM outcomes were analyzed with descriptive statics.

The primary and secondary outcome were statistically analyzed by using the chisquare test of independence. In the Chi-square test, the proportion of the response option "yes" is used to determine whether there is a significant difference between the proportions of PEM-1 and PEM-2. The chi-square test uses nominal data; therefore, the multiple response options of the PEM had to be dichotomized. The response options are dichotomized into option "yes" and "not yes". In this study the researchers IB and HS, decided to include all response options, in order to understand the full context of how participants interact with the PEM. Only the dichotomized option "yes" included the response option "yes", this is because the intervention is meant to improve PCC including SDM. The response option "sort of" is not considered as "yes" and is therefore included in the dichotomized option "not yes'. This also applies to "no", "sort of", "not applicable" and "can't remember". A p-value of < 0,05 for the chi-square test was considered significant. Prior to the start of the analyses, assumptions of the chi-square test were tested. The first assumption is that the value of the expected cell count should be five or more in 80% of the cells. This assumption is calculated by the SPSS software. Before the start of the data analysis, it was checked whether both datasets contain missing values. Missing values in demographic data are described accordingly. Missing values in the four outcomes were not detected.

Ethics

The study was assessed to be non-WMO compliant by The Medical Ethics Review Board of the University Medical Center Groningen (Ref. M20.266203). The PEM is used as standard instrument to measure patient experience in the UMCG. As this study uses existing data, it is considered a secondary analysis by the METC board and therefore did not require collection of informed consent forms. The study was conducted according to the principles of the Declaration of Helsinki³⁴ and all data was treated according to the General Data Protection Regulation (AVG).

Results

Basic characteristics and additional questions

The dataset of PEM-1 consists of 30 participants. Demographic data is only known of ten participants. The dataset of PEM-2 consists of 54 participants. Demographic data is known of 23 participants. In both datasets the majority of participants were male, 80% (n=8) in PEM-1 and 61% (n=14) in PEM-2. The median age for PEM-1 was in the age range 61-70 and for PEM-2 the median was in the age range 55-64. See table 1.

In PEM-2, The average length of stay in hospital was seventeen days. Data of the two questions that were added to PEM-2 is depicted in table 1. In total 30 of the 54 participants filled out the added questions. Fourteen participants received the intervention between three-and seven-times during admission. This demonstrate that fourteen of the 29 participants, received the correct amount of the intervention: one intervention per seven days of hospital admission.

[insert table 1]

Primary outcome

The primary outcome shared decision making was not significant different between PEM-1 and PEM-2 (p=0.693) as presented in table 2. In PEM-1, twelve participants answered with the response option "yes" (40%). In PEM-2, 24 participants answered with the response option "yes" (44.4%).

In table 3 and 4, frequencies for all five response options are depicted for PEM-1 and PEM-2. The highest percentages per dataset are the response option "yes" and "not necessary". The response option "not necessary" scored 36.7% for PEM-1 and 44.4% for

PEM-2. Meaning that for PEM-1 and PEM-2, almost half of the participants filled out that shared decision making was not necessary.

[insert table 2] [insert table 3 and 4]

Secondary outcome

Table 2 shows the values of the chi-square test, for the secondary outcomes. The outcome time nurses was not significant different (p=0.084) when compared between PEM-1 and PEM-2. The response option "yes" shows an increase between PEM-1 (60.0%) and PEM-2 (77.8%). Table 3 and 4 shows that the highest percentages per dataset are the response options "yes" and "sort of". In PEM-2, no participants used the response option "no".

The outcome identifying problems was not significant different (p=0.760). The response option "yes" shows an increase between PEM-1 (73.3%) and PEM-2 (81.5%). When analyzing all the response options, the highest percentage are the response options "yes" and "not necessary". In PEM-2, one participant used the response option "no".

The outcome involving family during discharge was not significant different (p=0.973). The response option "yes" was equal between PEM-1 (63.3%) and PEM-2 (63.0%). The response options "yes" and "not necessary" was used most frequent for PEM-1 and PEM-2. The response option "not necessary" was given 23.3% for PEM-1 and 20.4% for PEM-2.

Discussion

Based on the results, no significant difference was found in the primary outcome shared decision making, and in the secondary outcomes; time nurses, identifying problems and involving family during discharge. However, all four outcomes show an increase in response option "yes" in PEM-2 compared to PEM-1. Demographic data of PEM-1 and PEM-2 seem to be equal, even though in both groups a substantial amount of missing data is present. The questions that were added to PEM-2 show that fourteen of the 30 participants received the right frequency of the intervention: one nursing visit per seven days of hospital admission. This was defined as the minimum frequency of nursing visits a patient should receive during hospitalization. These numbers show that the intervention is not carried out properly for the majority of patients. However, due to 44.4% missing data in this segment (n=54), and the participants who filled out the PEM questionnaire is a subset of the total population that received the intervention, it is difficult to make a definitive conclusion on how the intervention is carried out for the total population. These findings could have negatively

influenced the outcomes of this study. If the intervention was indeed not carried out properly, there is no difference between PEM-1 and PEM-2 participants meaning that the influence of the intervention could not be measured.

For the primary outcome, the hypothesis was that due to the intervention the response option "yes" would increase to 72%. In PEM-2 an increase of 4.4% was found for the outcome shared decision making, resulting in 44.4% "yes". Analyzing table 3 and 4, the question rises whether an increase to 72% is achievable when almost half of the participants use the response option "not necessary". The response options "not necessary" and "can't remember" were added to the Dutch PEM²⁸. The English PPE-15 version contained only three response options (Yes, definitely/Yes, to some extent/No)^{32,33}. Adding these "noncommittal" response options is debatable according to studies³⁵⁻³⁷. It could have a negative effect when treating it as missing data³⁵, or have a positive effect on data quality by not forcing a participant to provide a straight answer^{35,36}. If a large share of participants filled out a "non-committal" response, it could imply that the guestion is not understandable³⁷. The response option "not necessary" is stated as: It was not necessary to make a shared decision. This could imply that the participant was able to make a shared decision but didn't have to, or perhaps the participant didn't understand the meaning of SDM. Considering this, it is questionable if the PEM is the right questionnaire to measure SDM. For starters, the PEM uses only one question to capture patient experience to regards with SDM. Other measurements instruments, such as the SDM-Q³⁸ and the COMRADE³⁹ include more explicit questions to thoroughly analyze all elements of SDM. This could indicate that the one question included in the PEM is not sufficient to truly measure SDM⁴⁰.

To the best of our knowledge, this is the first study that integrates the Dutch PEM as a measurement instrument to analyze the impact of a PPC nurse intervention on patient experience. Comparing these results with similar studies is therefore difficult. One study used the English PPE-15 version to measure the impact of a set of specific PCC interventions. Findeklee et al.⁴¹ implemented PCC interventions tailored to patients with an endometriosis disease and focused on the role of physicians instead of nurses. When analyzing patient satisfaction with the PPE-15, results show that the intervention led to high satisfaction with medical treatment and dissatisfaction with nursing care⁴¹. This shows that the PPE-15 is suitable to filter certain variables when analyzing an intervention on a specific topic.

Certain aspects must be considered with respect to limitations of this study. The main limitation is the high percentage of missing data in both demographic data and intervention data. It is unknown if demographic characteristics such as age or gender are skewed for the overall population of hematological patients and if this might be a confounder when compared to the scores per outcome. Several studies^{42,43} show that female gender is a significant factor for higher levels of psychosocial problems such as anxiety and distress^{42,43}.

This could imply that female patients could benefit more from the intervention, thereby signaling biopsychosocial problems early on during hospitalization. Another limitation is related to implementation phase of the intervention on the hematological ward. Before the official launch of the intervention in 2020, the research group conducted several studies^{25,44-45} in order to develop the nursing visits with the ICF framework and analyzing if nurses could work with the intervention. Thus, nurses were already acquainted with the need of the intervention and could have provided care already based on the biopsychosocial model of health. This could have led to contamination bias in the PEM-1 group. A limitation and a strength of this study is the response rate for the PEM. On average, 172 patients are admitted to the hematological ward in a six-month period. The response rate for the PEM is on average 43.6% for the hematological ward⁴⁶. The low response rate has to do with the fact that a patient cannot participate if they already participated in the last six months. Therefore, on average 65% of discharged patients are not able to participate⁴⁶. The total number of participants in PEM-2 (n=54) is therefore a strength, because it is close to the expected number of participants who were invited to take part of the PEM. A probable cause of the higher response rate is that nurses offered information about the study and the PEM during discharge produces.

This study can perhaps be repeated with a tailor-made measurement instrument with focus on the intervention. However, to truly measure the impact of the intervention *Functioning as focus of care* on patient experience, a qualitative study design will provide more in depth and detailed insights.

Conclusion

This study analyzed the nurse intervention *Functioning as focus of care* with regards to patient experience. No significant difference was found for the primary and secondary outcomes. The results of this study therefore do not provide a conclusive answer on how the intervention influenced patient experience. The intervention does however contribute to the overall trend of focusing on the biopsychosocial model of health and future research could provide insights to determine the impact of the intervention on patient experience.

Reference

- 1. Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: A systematic review of the literature. Med Care Res Rev. 2013;70(4):351–79.
- Epstein RM, Fiscella K, Lesser CS, Stange KC. Analysis & commentary: Why the nation needs a policy push on patient-centered health care. Health Aff. 2010;29(8):1489–95.
- Robinson JH, Callister LC, Berry JA, Dearing KA. Patient-centered care and adherence: Definitions and applications to improve outcomes. J Am Acad Nurse Pract. 2008;20(12):600–7.
- 4. National Research Council. Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academies Press, 2001.
- 5. Barry MJ, Edgman-Levitan S. Shared Decision Making The Pinnacle of Patient-Centered Care. N Engl J Med. 2012;366(9):780–1.
- 6. Légaré F, Witteman HO. Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. Health Aff. 2013;32(2):276–84.
- 7. Rigby D. Shared decision making. Aust J Pharm. 2015;96(1144):64–7.
- 8. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. Patient Educ Couns. 2006;60(3):301–12.
- Harnas S, Kraan J van der, Knops A, De Groot J. Samen Beslissen met de zorgverlener. Patientenfederatie Ned [Internet]. 2017;1–35. Available from: https://www.patientenfederatie.nl/images/Rapport_meldactie_Samen_Beslissen.pdf
- Wolf D, Lehman L, Quinlin R, Rosenzweig M, Friede S, Zullo T, et al. Can nurses impact patient outcomes using a patient-centered care model? J Nurs Adm. 2008;38(12):532–40.
- Robinson JH, Callister LC, Berry JA, Dearing KA. Patient-centered care and adherence: Definitions and applications to improve outcomes. J Am Acad Nurse Pract. 2008;20(12):600–7.
- Farre A, Rapley T. The New Old (and Old New) Medical Model: Four Decades Navigating the Biomedical and Psychosocial Understandings of Health and Illness. Healthcare. 2017;5(4):88.
- Leonardi F. The Definition of Health: Towards New Perspectives. Int J Health Serv. 2018 Oct;48(4):735-748.
- 14. The Lancet. What is health? :The ability to adapt. Lancet 2009;373(9666):781
- Stallinga G, Heerkens Y. (red) Functioneren als focus van zorg en welzijn. Met ICFvoorbeelden. 1^e druk. Houten: Bohn Stafleu Van Loghum; 2021.

- Nederlandse Federatie van Universitair Medisch Centra (NFU). Experiment ZIRE: Zinvolle Registratie. [Internet]. 2021 [cited 2021 May 12]; available from https://nfukwaliteit.nl/pdf/NFU_8x2_verbeterverhalen_8-UMCG-Zinvolle-registratie.pdf
- 17. Albrecht TA, Rosenzweig M. Management of cancer-related distress in patients with a hematologic malignancy. J Hosp Palliat Nurs. 2012;14(7):462–8.
- Linden W, Vodermaier A, MacKenzie R, Greig D. Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age. J Affect Disord [Internet]. 2012;141(2–3):343–51. Available from: http://dx.doi.org/10.1016/j.jad.2012.03.025
- Gil F, Costa G, Hilker I, Benito L. First anxiety, afterwards depression: Psychological distress in cancer patients at diagnosis and after medical treatment. Stress Heal. 2012;28(5):362–7.
- Ryan H, Schofield P, Cockburn J, Butow P, Tattersall M, Turner J, et al. How to recognize and manage psychological distress in cancer patients. Eur J Cancer Care (Engl). 2005;14(1):7–15.
- Stallinga HA. Human functioning in health care: Application of the International Classification of Functioning, Disability and Health (ICF). [Groningen]: University of Groningen, 2015. Pag.178.
- V&VN. Leren van de toekomst. Verpleegkundigen & Verzorgenden 2020. [Internet].
 [Cited 2021 Feb 19] Available from: http://www.venvn.nl/Portals/1/Nieuws/Ouder%20dan%202010/306254 1 NI.pdf
- World Health Organization (WHO). International Classification of Functioning, Disability and Health (ICF). [Internet]. [cited 2021 Feb 1] Available from https://www.who.int/classifications/icf/icf_more/en/
- Achterberg T van, Holleman G, Heijnen-Kaales Y, van der Brug Y, Roodbol G, Stallinga HA, et al. Using a multidisciplinary classification in nursing: The International Classification of Functioning Disability and Health. Journal of Advanced Nursing. 2005;49(4):432–41.
- 25. Arend, A.B. The impact of 'functioning as focus in care' on health status in terms of the International Classification of Functioning, Disability and Health in patients with a hematological-oncological disease. [Internet]. [Cited 2020 Dec 8]. Available at; https://dspace.library.uu.nl/handle/1874/384276
- 26. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness.*BMJ Open* 2013;**3**:e001570.

- 27. Boer de D, Bos N, Zuidgeest M. Ontwikkelingen in het meten en gebruiken van patiëntervaringen en patiënt gerapporteerde uitkomsten [Internet]. [Cited 2021 feb 25]. Available at: https://www.nivel.nl/nl/publicatie/ontwikkelingen-het-meten-en-gebruikenvan-patientervaringen-en-patientgerapporteerde
- Bastemeijer CM, Boosman H, Zandbelt L, Timman R, de Boer D, Hazelzet JA. Patient Experience Monitor (PEM): The Development of New Short-Form Picker Experience Questionnaires for Hospital Patients with a Wide Range of Literacy Levels. Patient Relat Outcome Meas. 2020: (11):221–230.
- Vandenbroucke JP, Von Elm E, Altman DG, Gøtzsche PC, Mulrow CD, Pocock SJ, et al. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE): Explanation and elaboration. Epidemiology. 2007:18(6):805–35.
- 30. Bettery Institute. Het GG/ZZ gespreksmodel [Internet]. [Cited 2021 Feb 25] Available from: https://bettery.nl/dienst/het-ggzz-gespreksmodel
- 31. Nederlandse Federatie van Universitair Medisch Centra (NFU). Nieuwe Patiëntervaring monitor helpt zorg verbeteren. [Internet]. [Cited 2021 Feb 24] Available from: https://www.nfu.nl/themas/kwaliteit-van-zorg/patientervaringen-meten
- Jenkinson C, Coulter A, Bruster S. The picker patient experience questionnaire: Development and validation using data from in-patient surveys in five countries. Int J Qual Heal Care. 2002;14(5):353–8.
- Jenkinson C, Coulter A, Reeves R, Bruster S, Richards N. Properties of the Picker Patient Experience questionnaire in a randomized controlled trial of long versus short form survey instruments. J Public Health Med. 2003;25(3):197–201.
- American Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. J Am Med Assoc. 2013;310(20):2191–4.
- Montagni I, Cariou T, Tzourio C, González-Caballero JL. "I don't know", "I'm not sure",
 "I don't want to answer": a latent class analysis explaining the informative value of nonresponse options in an online survey on youth health. Int J Soc Res Methodol. 2019;22(6):651–67.
- Durand RM, Lambert Z V. Don't know responses in surveys: Analyses and interpretational consequences. J Bus Res. 1988;16(2):169–88.
- Zorginstituut Nederland/ NIVEL. Tool evalueren en optimaliseren van patiëntervaringsvragenlijsten - versie 1.0. [Internet]. [Cited 2021 May 15] Available from: <u>https://www.nivel.nl/sites/default/files/bestanden/1003064.pdf</u>
- Doherr H, Christalle E, Kriston L, Haèrter M, Scholl I. Use of the 9-item Shared Decision Making Questionnaire (SDM-Q-9 and SDM-Q-Doc) in intervention studies; A systematic review. PLoS One. 2017;12(3):1–16.

- Edwards A, Elwyn G, Hood K, Robling M, Atwell C, Holmes-Rovner M, et al. The development of COMRADE - A patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns. 2003;50(3):311–22.
- Scholl I, Loon MK Van, Sepucha K, Elwyn G, Légaré F, Härter M, et al. Measurement of shared decision making - A review of instruments. Z Evid Fortbild Qual Gesundhwes. 2011;105(4):313–24.
- 41. Findeklee S, Radosa JC, Mothes A, Younes S, Schafhaupt S, Stotz L, et al. Patient satisfaction with personal patient care (PPC) in the inpatient treatment of endometriosis. Arch Gynecol Obstet. 2020;301(2):545–50.
- 42. Raphael D, Frey R, Gott M. Distress in post-treatment hematological cancer survivors: Prevalence and predictors. J Psychosoc Oncol. 2020;38(3):328–42.
- Bergerot CD, Clark KL, Nonino A, Waliany S, Buso MM, Loscalzo M. Course of distress, anxiety, and depression in hematological cancer patients: Association between gender and grade of neoplasm. Palliat Support Care. 2013;13(2):115–23.
- Bakker J. To evaluate the usability of the ICF core set for HSCT patients, from the perspective of nurses: a feasibility study, Faculty of Medicine Theses, Master thesis. 2017.
- 45. Haasjes J. Human functioning of patients after hematopoietic stem cell transplantation displayed with the International Classification of Functioning, Disability and Health: a Delphi study. 2016.
- 46. UMCG Intranet Patiënt Ervaring Monitor (PEM). Rapportage Benchmark NFU 2020.
 [Internet]. [Cited 2021 May 17] Available from: https://cms.umcg.nl/patientenzorg/patientenparticipatie/themas/1589729/1444488/?su
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Table 1

Demographic	data	Patient	Experience	Monitor	data	2020	vs 20	021
Donnographilo	uutu	i unom	CAPONIONIOU	Wierinter	uutu	2020	10 20	<i>, ,</i>

Variables	PEM-1 (total n= 30)	PEM-2 (total n= 54)
Gender	n= 10 ^a	n= 23ª
- Male (%)	8 (80)	14 (60.8)
Age in years	n= 10 ^a	n= 23 ^a
- Median (min – max)	61 - 70 (31 - 71>)	55 - 64 (35 – 79)
Hospital length in days	-	17
(mean)		
Intervention Received	-	n= 30 ^b
Yes		29
No		1
Intervention: number of	-	
times received		
1-2 times		10
3-4 times		7
5-6 times		1
7 or more		6
Can't remember		5

PEM= Patient Experience Monitor. PEM-1 = Patient Experience Monitor data of 2020. PEM-2 = Patient Experience Monitor data of 2021

^a in both PEM datasets missing data is present, in total 60.7% is missing for demographic data.

^b In the PEM dataset 2021, 44.4% is missing for the intervention variables.

Table 2

Chi-square test for patient experience outcomes PEM-1 and PEM-2

Count of Yes ^a (%)							
PEM Variables	PEM-1 N= 30	PEM-2 N= 54	$\chi^{^{2} b}$	df	P-value ^c		
Shared decision making	12 (40.0)	24 (44.4)	0.156	1	0.693		
Time nurses	18 (60.0)	42 (77.8)	2.987	1	0.084		
Identifying problems	22 (73.3)	44 (81.5)	0.760	1	0.383		
Involving family during discharge	19 (63.3)	34 (63.0)	0.001	1	0.973		

Note This table shows the dichotomized value of the four PEM outcomes, in **Bold** the primary outcome is depicted

PEM= Patient Experience Monitor. df= Degrees of freedom PEM-1 = Patient Experience Monitor data of 2020 PEM-2 = Patient Experience Monitor data of 2021

^a Count of Yes; how many participants chose the answer option yes in comparison with the response option not yes.

^b Pearson Chi-square test.

^c P-value of 0.05< is considered significant.

Table 3

Detailed results presented in all the response options PEM-1 outcomes

	Response options PEM (n=30)						
Variables	Yes	Sort of	No	Can't remember	Not necessary		
Shared decision making (%)	12 (40.0)	1 (3.3)	5 (16.7)	1 (3.3)	11 (36.7)		
Time nurses (%)	18 (60.0)	11 (36.7)	1 (3.3)	0	-		
Identifying problems (%)	22 (73.3)	2 (6.7)	0 (3.3)	-	5 (16.7)		
Involving family during discharge (%)	19 (63.3)	1 (3.3)	3 (10.0)	0	7 (23.3)		

Note This table shows the five response options for the four PEM outcomes. The outcome time nurses and identifying problems have four response options. in **Bold** the primary outcome is depicted PEM= Patient Experience Monitor. PEM-1 = Patient Experience Monitor data of 2020.

Table 4

Detailed results presented in all the response options PEM-2 outcomes

	Response options PEM (n=54)						
Variables	Yes	Sort of	No	Can't	Not		
				remember	necessary		
Shared decision making	24 (44.4)	1 (1.9)	3 (5.6)	2 (3.7)	24 (44.4)		
(%)							
Time nurses	42 (77.8)	12 (22.2)	0	0	-		
(%)							
Identifying problems	44 (81.5)	1 (1.9)	1 (1.9)	-	8 (14.8)		
(%)							
Involving family during discharge	34 (63)	4 (7.4)	2 (3.7)	3 (5.6)	11 (20.4)		
(%)							

Note This table shows the five response options for the four PEM outcomes. The outcomes time nurses and identifying problems have four response options. in **Bold** the primary outcome is depicted

PEM= Patient Experience Monitor. PEM-2 = Patient Experience Monitor data of 2021

Appendix A

Bettery institute: conversation tool: GG/ZZ

Onderdeel	Wat doe je	Onderdeel	Wat doe je
fase 1 gezondheid en functioneren open en explorerend	 Leg in het eerste gesprek de opbouw van het gesprek uit. Vervolgens ben je volledig volgend en aanwezig bij de ander. Het is de bedoeling dat iemand zich uitspreekt over wat er voor hem/haar op dit moment toe doet. Wat speelt er in iemands leven? Start open, bijvoorbeeld: Vertel eens Wat vind je belangrijk, vandaag, in je leven, in je gezondheid Houd zoveel mogelijk je mond na de eerste vraag Je interviewt open, zonder oordeel of richting Herhaal de laatste woorden uit de laatste zin Vraag naar situaties: ik had gisteren pijn -'gisteren?', i.p.v. 'pijn'? Er is één manier om de stilte te verbreken: 'Waar denk je aan?' of 'Wat gebeurt er nu?' Vat het gesprek kort samen, laat bij voorkeur de patiënt dit doen Geen sturing, geen nieuwsgierigheid, geen analyse door jou Gebruik in 2^{de} en volgende gesprekken het registratieformulier EPIC van het vorige gesprek ter inleiding van fase 2 	fase 2 gedrag richting (doelen) en actie	 In tegenstelling tot fase 1 stel je je nu actief op en je doorloopt de vijf vragen: Wat vind je belangrijk? (samenvatting fase 1) Waar wil je iets mee? Wat wil je bereiken? Wat is de wenselijke situatie t.a.v. functioneren? Hoe is de huidige situatie t.o.v. de wenselijke situatie? Wat ga je doen om bij de wenselijke situatie te komen? Wat is de eerste stap? Heb je daar ondersteuning bij nodig? Van wie? Hoe groot is de kans dat dat lukt? Tips: Leg vooral kleine haalbare doelen vast Als patiënt niet tot een keuze kan komen vragen wat hij/zij nodig heeft om tot een besluit te komen Geen advisering, wel stimulering tot nieuwe perspectieven, bijv. 'Ik kan me voorstellen dat er voor u ook nog andere oplossingen zijn die wellicht beter bij u passen'
Fase 3 <i>zorg</i> zo nodig zorg bieden	 Leid de mogelijke overgang naar eventuele hulpverlening in: Heb je verder nog een hulpvraag, klachten? Voor de behandeling van je ziekte wil ik je nog wat aanvullend vragen/meten. Is dat oké? 	afsluiting besluitvorming en vervolg	Overeenstemming over oordeel en beleid Vastleggen van plan, acties, afspraken in het registratieformulier in EPIC. Laat bij voorkeur de patiënt de samenvatting geven Registreer samen met de patiënt in EPIC en maak afspraak voor de volgende verpleegkundige visite

Reference: Stallinga G, Heerkens Y. (red) Functioneren als focus van zorg en welzijn. Met ICF-voorbeelden. 1^e druk. Houten: Bohn Stafleu Van Loghum; 2021.

I

Appendix B

Vragen over het ziekenhuis

Dank u wel dat u onze vragen over uw opname voor het specialisme [specialisme] wilt beantwoorden. Met uw antwoorden kunnen wij de zorg in ons ziekenhuis blijven verbeteren.

De vragen gaan over wat er in het ziekenhuis met u is besproken. Maar ook hoe de ziekenhuisopname is gegaan en hoe de mensen op de afdeling met u omgingen.

OVER HET INVULLEN

De vragen gaan over uw ziekenhuisopname op/tot [ontslagdatum] voor het specialisme [specialisme].

- 1. Eerst ziet u een vraag
- 2. Klik op het antwoord dat u wilt geven
- 3. Klik op verder. Daarna ziet u de volgende vraag
- 4. U kunt ook uw eigen opmerkingen opschrijven
- 5. Als laatste klikt u op verzenden

Als het nodig is kunt u even stoppen met het invullen van de vragenlijst en later weer doorgaan. De vragenlijst kan worden afgemaakt tot 3 weken nadat u de e-mail heeft gekregen.

Uw deelname is vrijwillig en anoniem.

Bij vragen of opmerkingen kunt u contact met ons opnemen via [telefoonnummer patiëntenbureau] of via [e-mailadres patiëntenbureau]. Voor hulp bij het invullen van de vragenlijst kunt u contact opnemen met de helpdesk van Expoints door de uitnodigingsmail te beantwoorden.

De volgende vragen gaan over uw ziekenhuisopname voor het specialisme [specialisme], op/tot [ontslagdatum].

[Tijd op wachtlijst]

1 Het komt voor dat mensen een tijdje op de wachtlijst staan voor de opname in het ziekenhuis. Wat vindt u van de tijd die u op de wachtlijst stond?

- 10 De tijd op de wachtlijst was geen probleem voor mij
- 5 De tijd op de wachtlijst was een beetje te lang
- 0 De tijd op de wachtlijst was veel te lang
- (97) 🛛 Ik heb niet op een wachtlijst gestaan
- (97) 🗆 lk kwam voor een dagopname

[Kennis dossier arts]

2 Hadden de arts of artsen die u sprak uw dossier goed gelezen?

- 10 Ja, het dossier was goed genoeg gelezen
- 5 Definition Het was gelezen, maar niet goed genoeg
- (97) 🛛 lk heb geen arts gesproken

[ga naar vraag 4]

(99) Uweet ik niet (meer)

[Vertrouwen arts]

3 Had u vertrouwen in de arts of artsen?

- 5 Meestal had ik vertrouwen in de arts(en), soms niet
- 0 Nee, ik had geen vertrouwen in de arts(en)

[Vertrouwen verpleegkundigen]

4 Had u vertrouwen in de verpleegkundigen?

- 10 Ja, ik had vertrouwen in de verpleegkundigen
- 5 Description Description 5 Description Description 5 Description Description 5 Descripti 5 Descripti 5 Descripti 5 Description 5 Descripti 5 Description 5

[Tijd verpleegkundigen]

- 5 Hadden verpleegkundigen genoeg tijd om voor u te zorgen?
- 10 Ja, er was altijd genoeg tijd voor mij
- 5 Er was meestal genoeg tijd voor mij
- (99) UWeet ik niet meer

[Tegenstrijdige informatie]

6 Soms spreken artsen of verpleegkundigen elkaar tegen. Gebeurde dat bij u?

- 10 Dee, ze spraken elkaar nooit tegen
- 5 Ze spraken elkaar soms tegen
- (97) 🛛 lk heb maar één arts of verpleegkundige gesproken
- (99) 🛛 Weet ik niet meer

De volgende vragen gaan over uw behandeling, bijvoorbeeld een operatie of een behandeling met medicijnen, of onderzoek.

[Samen beslissen]

7 Kon u meebeslissen over uw behandeling of onderzoek? 10...... Ja, dat kon zoveel als ik wilde

- 5 Dat kon minder dan ik wilde
- (98) Dat was niet nodig
- (99) UWeet ik niet meer

[Voor-/nadelen behandeling]

8 Heeft iemand u duidelijk uitgelegd wat de voordelen en nadelen van de behandeling of onderzoek zijn?

- 10 Ja, dat is duidelijk uitgelegd
- 6.7 Discrete Sommige dingen zijn niet duidelijk uitgelegd
- 3.3 Dee, dat is niet duidelijk uitgelegd
- (98) Dat was niet nodig

[Medicatie bijwerkingen]

9 Heeft iemand u verteld welke bijwerkingen u kon krijgen van uw nieuwe medicijnen?

- 0 Dee, er is niets verteld
- (97) 🛛 lk kreeg geen (nieuwe) medicijnen

De volgende vragen gaan over uw vertrek uit het ziekenhuis

[Betrekken bij ontslag]

10 Kon u meedenken en meepraten over uw vertrek uit het ziekenhuis?

- 10 Ja, dat kon zoveel als ik wilde
- 5 🛛 Dat kon minder dan ik wilde
- (97) 🛛 Ik kwam voor een dagopname
- (98) Dat was niet nodig
- (99) UWeet ik niet meer

[Nodige zorg bij vertrek]

11 Heeft iemand met u gesproken over de nodige zorg na uw vertrek? Bijvoorbeeld zorg van een huisarts, fysiotherapeut, thuiszorg, maatschappelijk werker, verpleeghuis, enzovoort?

- 5 Daar is wel wat over gesproken, maar niet genoeg
- 0 Dee, daar had ik graag over gesproken
- (98) Dat was niet nodig
- (99) Uweet ik niet meer

[Familie bij vertrek]

12 Heeft iemand genoeg aan uw familie of naasten verteld zodat zij na uw vertrek goed voor u kunnen zorgen?

- (98) Dat was voor mij niet nodig
- (99) UWeet ik niet meer

[Signaleren problemen]

13 Heeft iemand u verteld op welke problemen u moest letten na uw vertrek?

- (98) Dat was niet nodig

Algemene vragen over het ziekenhuis

[Respect]

14 Vond u dat de mensen in het ziekenhuis met respect met u omgingen?
10 □ Ja, ze gingen altijd met respect met mij om

- 5 De meesten gingen met respect met mij om, sommigen niet

[Veiligheid]

15 Voelde u zich veilig in het ziekenhuis?

- 5 Description Description 5 De

Welk cijfer geeft u het ziekenhuis voor **deze** (dag)opname? 1 betekent 'Heel slecht', 10 betekent 'Heel goed'.

Heel slec	ht							Hee	el goed
1	2	3	4	5	6	7	8	9	10

Wat deden we heel goed in het ziekenhuis? Schrijf het hieronder op (niet verplicht).

Noem geen persoonlijke gegevens, zoals namen of telefoonnummers.

Wat kunnen we **beter doen** in het ziekenhuis? Schrijf het hieronder op (niet verplicht). Noem geen persoonlijke gegevens, zoals namen of telefoonnummers.

De laatste 3 vragen gaan over u

Het is niet verplicht om deze vragen in te vullen.

Welke school of opleiding heeft u als laatste gedaan (met diploma). Klik 1 antwoord aan.

- Een paar jaar lagere school, of basisschool (geen diploma)
- Lagere school of basisschool
- LTS, LEAO, LHNO, Huishoudschool, VMBO basis, VMBO kader, VMBO GL, MBO niveau 1
- MAVO, (M)ULO, VMBO-t, MBO-kort, MBO niveau 2, MBO niveau 3 en MBO niveau 4
- MKBO-lang, MTS, MEAO, BOL, BBL, INAS
- HAVO, VWO, Atheneum, Gymnasium, HBS, MMS
- BBO, HTS, HEAO, kandidaats wetenschappelijk onderwijs
- Wetenschappelijk onderwijs (universiteit)
- Ik heb een andere opleiding gedaan

Hoe vindt u uw gezondheid meestal?

- Mijn gezondheid is uitstekend
- Mijn gezondheid is heel goed
- □ Mijn gezondheid is goed
- Mijn gezondheid is niet zo goed
- □ Mijn gezondheid is slecht

Als u deze keer meetelt, hoeveel keer lag u dan in een ziekenhuis de laatste 12 maanden?

- Ik lag 1 keer in een ziekenhuis
- □ Ik lag **2 of 3 keer** in een ziekenhuis
- Ik lag 4 of meer keer in een ziekenhuis

Dit was de laatste vraag

Druk nu op de knop verzenden

Hartelijk dank voor het meedoen.

Met uw antwoorden kunnen we onze zorg blijven verbeteren.

Uw gegevens worden anoniem verwerkt. We weten dus niet wie de lijst heeft ingevuld. Wij kunnen u daarom geen persoonlijke reactie teruggeven op de door u ingevulde vragenlijst.

Vragen?

Heeft u vragen over uw eigen gezondheid of behandeling in het [naam ziekenhuis]? Bespreek dit dan met uw vaste arts of verpleegkundige. U kunt ook contact opnemen met de afdeling [naam afdeling, bijv Patienteninformatie] van ons ziekenhuis: [contactgegevens].

Meer weten?

Wilt u meer weten over de uitkomst van de vragenlijst of bent u benieuwd wat wij met de resultaten doen? Kijk op onze website: [website UMC, met specifieke link naar de juiste pagina].

Deze vragenlijst is eigendom van Picker Institute Europe. De vragen zijn bedoeld om de kwaliteit van de zorg in het ziekenhuis te verbeteren met behulp van de ervaringen van patiënten.