Pain measurement and documentation in patients visiting the outpatient clinic of the Department of Medical Oncology

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Abstract

Title: Pain measurement and documentation in patients visiting the outpatient clinic of the

Department of Medical Oncology.

Background: Pain is common in patients with cancer but is underreported and undertreated in one-third of patients with cancer-related pain. Because the treatment of cancer has shifted

more to the outpatient setting, it is important that health care professionals (HCPs) who

consult the patient pay attention to pain at the outpatient clinic.

Aim: The primary aim was to examine how HCPs conduct pain measurement and

documentation in patients with cancer at the outpatient clinic of the Department of Medical

Oncology. The secondary aim was to examine barriers and facilitators affecting HCPs in

using pain assessment instruments among patients with cancer at the outpatient clinic of the

Department of Medical Oncology.

Method: For this cross-sectional observational study, data was collected through a digital

survey. Analysis was performed using descriptive statistics and a Mann-Whitney test.

Results: Pain measurement is often or always executed by nurse practitioners (72%) or

oncologists (64%) during the consult (84%) and mostly reported in clinical notes (76%).

Barriers for using pain assessment instruments are not being motivated by management or

direct colleagues and the absence of reminders to use pain assessment instruments.

Facilitators are encouragement by direct colleagues, using pain assessment instruments

based on evidence and the presence of someone who actively takes charge in working with

such instruments. We could not detect any differences in barriers and facilitators in hospitals

that do (not) perform pain measurement was determined.

Conclusion: Pain assessment in patients with cancer visiting the outpatient clinic of the

Department of Medical Oncology is mostly performed in the traditional way by the HCP

asking the patient about pain and report this in clinical notes.

Recommendations: Investigate different (digital) ways to perform pain assessment and

explore patient's experiences and expectations on discussing this topic during the consult.

Keywords: pain measurement, pain assessment, cancer, outpatient clinic

Samenvatting

Titel: Pijnmeting en -registratie bij patiënten op de polikliniek Medische Oncologie.

Achtergrond: Pijn is een veel voorkomend symptoom bij patiënten met kanker en wordt te weinig gerapporteerd en behandeld bij een derde van de patiënten met kanker gerelateerde pijn. De behandeling van kanker vindt steeds meer plaats op de polikliniek en daarom is het belangrijk om als zorgverlener aandacht te hebben voor pijn bij patiënten op de polikliniek.

Doel: Het primaire doel is het onderzoeken hoe pijnmeting en registratie uitgevoerd wordt bij patiënten met kanker op de polikliniek Medische Oncologie. Het secundaire doel is het onderzoeken welke belemmerende en bevorderende factoren van invloed zijn op het gebruik van pijnscreeningsinstrumenten bij patiënten met kanker op de polikliniek Medische Oncologie.

Methode: In dit cross-sectionele onderzoek is data verzameld met een digitale vragenlijst. Data is geanalyseerd met behulp van beschrijvende statistiek en een Mann-Whitney test.

Resultaten: Pijnmeting wordt meestal verricht door een verpleegkundig specialist (72%) of oncoloog (64%) tijdens het consult (84%) en genoteerd in decursus (76%). Belemmerende factoren in het gebruik van pijnscreeningsinstrumenten zijn: geen motivatie door directe collega's of management en niet worden herinnerd aan het gebruik van pijnscreeningsinstrumenten. Bevorderende factoren zijn: aanmoediging door directe collega's, gebruik maken van een pijnscreeningsinstrument dat ontwikkeld is op basis van wetenschappelijk bewijs en de aanwezigheid van iemand die actief de leiding neemt in het gebruik van pijnscreeningsinstrumenten. Er is geen verschil vastgesteld in bevorderende en belemmerende factoren tussen ziekenhuizen die (geen) structurele pijnmeting uitvoeren.

Conclusie: Pijnmeting bij patiënten met kanker op de polikliniek Medische Oncologie wordt meestal uitgevoerd op de traditionele manier: de zorgverlener vraagt naar pijn bij de patiënt tijdens het consult en noteert dit in decursus.

Aanbevelingen: Het onderzoeken van verschillende (digitale) manieren om een pijnmeting af te nemen en exploreren van de ervaringen en verwachtingen van patiënten omtrent de bespreking van dit onderwerp tijdens een consult.

Trefwoorden: pijnmeting, pijnbeoordeling, kanker, polikliniek

Introduction

Worldwide the incidence of cancer was estimated over 18 million cases in 2018¹. With an estimate of 9,5 million deaths in 2018, cancer is in the top 10 causes of death¹⁻². Pain is a very common symptom in patients with cancer and reported by more than 50% of patients after curative treatment or during anticancer treatment³. Cancer-related pain is mostly a chronic pain and can be caused by the treatment or tumor⁴. Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage⁵.

Approximately one third of patients with cancer-related pain are undertreated⁶. Patients are reluctant to report pain to their health care professionals (HCPs) and have misconceptions about analgesics⁷. Some patients have fear of adverse effects of opioid analgesics and therefore prefer a level of pain over increasing doses of opioids⁸. Initial and continuous pain assessment is an essential aspect of cancer care⁹.

According to the Dutch guideline *Diagnostics and Treatment of Pain in Cancer Patients*, pain should be assessed and documented once a day when patients visit the outpatient clinic¹⁰. Pain measurement and documentation is only conducted on the day patients visit the outpatient clinic. Because the treatment of cancer has shifted more and more to the outpatient setting, it is important that HCPs who consult the patient pay attention to cancerrelated pain at the outpatient clinic¹¹. The study of Te Boveldt et al (2015) showed that pain (or its absence) was only documented in 23.2% of the patients visiting the outpatient clinic in the Netherlands¹².

Assessing pain by patients' self-report is essential, because pain is a subjective experience and estimates of pain by HCPs are often discordant¹³. Reporting the pain by the patient himself, is the most reliable indicator of the pain. Different instruments can be used to assess pain in adult patients. Widely used reliable and validated instruments are the Visual Analogue Scale (VAS), Verbal Rating Scale (VRS) and Numeric Rating Scale (NRS)¹⁴.

In the Netherlands, the quality of healthcare in hospitals is monitored by the Dutch Health and Youth Care Inspectorate (IGJ). To determine which aspects require attention, the IGJ publishes a set of quality indicators every year¹⁵. In the Netherlands, all hospitals are obligated to provide insight in their data concerning these quality indicators. In 2018 the quality indicator *Pain measurement* was adapted by the IGJ¹⁵. This quality indicator includes pain measurement and documentation in patients with cancer visiting the Department of Medical Oncology at the outpatient clinic. The quality indicator is owned by pain nurses in the Netherlands¹⁶.

Designing the quality indicator *Pain measurement* yielded various critical responses¹⁷. Different professional associations stated that pain measurement in patients visiting outpatient clinics was not useful, would disturb the consults and increase the administrative load during the consults¹⁷. Hospital data of 2018 showed that only 40% of the hospitals gave insight in their data according to the quality indicator *Pain measurement*¹⁸.

The study of Oldenmenger et al. (2016) found that structural pain measurement and documentation at the outpatient clinic could lead to a 30% decrease in patients with moderate-severe pain¹⁹. Considering the undertreatment of cancer-related pain, the available measurement instruments and the quality indicators stated by the IGJ, pain is an important topic in the care for patients with cancer visiting the outpatient clinic. Therefore, it is important to gain insight in the way HCPs conduct pain measurement and document findings at the outpatient clinic and which barriers and facilitators affect the use of reliable and validated instruments in order to improve the quality of care for patients with cancer.

Aim

The primary aim was to examine how health care professionals conduct pain measurement and documentation in patients with cancer at the outpatient clinic of the Department of Medical Oncology.

The secondary aim was to examine which barriers and facilitators affect health care professionals in using pain assessment instruments among patients with cancer at the outpatient clinic of the Department of Medical Oncology.

Method

Design

A cross-sectional observational study was conducted²⁰⁻²¹. This design was executed to get insight in the current practice regarding pain measurement and documentation of different hospitals. The report of the findings was based on the Strengthening of the Reporting of Observational Studies in Epidemiology (STROBE) guidelines²².

Population, domain and sample

The research population consisted of HCPs working at the outpatient clinic of the Department of Medical Oncology and HCPs specialized in pain management. HCPs working at the outpatient clinic of the Department of Medical Oncology usually are (specialized) nurses, nurse practitioners or oncologists. Inclusion criteria for participating in this study included HCPs working at the outpatient clinic of the Department of Medical Oncology or the outpatient clinic for patients with pain. Participants must be able to read and write Dutch fluently. It was preferred to receive data from all the hospitals in the Netherlands providing care for patients with cancer at the outpatient clinic to gain maximum variation and a representation of the research population²⁰. Therefore, a convenience sampling was conducted.

Ethical issues

This study was conducted according to the principles of the Declaration of Helsinki²³. Handling and storage of personal data were in accordance with the Dutch Personal Data Protection Act²⁴. In this study, no behaviour was dictated and participants were not subject of a treatment²⁵. The study proposal was submitted and authorized by the medical research ethics committee. Digital informed consent was obtained before data was collected.

Procedures

Data was collected from February 14th through April 27th, 2020. The digital survey was distributed via various channels. The survey was published on the website of the Dutch Oncology Nursing Society and published in the newsletter of the Dutch Pain Nurses Society. Hospitals were contacted by phone for e-mail addresses to distribute the digital survey at the outpatient clinics. Also, the survey was shared on Facebook and LinkedIn.

Data collection

Data collection occurred through a digital survey using the program LimeSurvey²⁶. The digital survey consisted of a total of 59 questions: 16 multiple choice questions, 33 Likert-type questions and 10 open-ended questions²⁰. Depending on the answers given by the participant, some questions did or did not emerge because they were or were not relevant according to the previous given response. Hereby, more in-depth responses were generated. Questions were subdivided in sample characteristics, conducting pain measurement and documentation and barriers and facilitators of pain measurement and documentation.

The digital survey was pilot tested among nine nurses and nurse practitioners to test the feasibility and to support refinements of the survey²⁰. After pilot testing the digital survey, some questions were deleted, and some questions were reformulated. Face validity was established by experts in pain measurement and documentation. The primary aim of this study corresponded with the section on conducting pain measurement and documentation. This was measured through a 4-points Likert-type question consisting of the answer options never, sometimes, frequently and always. In addition, some open-ended questions were used to gain more detailed information on the way HCPs conduct pain measurement and documentation. The secondary aim of this study corresponded with the section on barriers and facilitators of pain measurement and documentation. The barriers and facilitators were measured through 5-points Likert-type questions (very obstructive, somewhat obstructive, neither obstructive nor promoting, slightly promoting, very promoting) stating facilitators and barriers of the use of measurement instruments based on literature and focus groups²⁷. Face validity was obtained by five experts in quality indicators or measurement instruments. This part of the digital survey was pilot tested and used in research by Cusveller and van Hell²⁷⁻²⁸. The digital survey of Cusveller and van Hell is suitable for this study because this study aimed to examine barriers and facilitators affecting HCPs in using pain assessment instruments²⁷. Cusveller and van Hell used the digital survey only in nurses²⁸. In this study the digital survey was distributed among different HCPs working at the outpatient clinic. Therefore, the terms 'as nurse' were changed to 'as health-care professional in the survey. In addition, the digital survey of Cusveller and van Hell is focused on the general use of measurement instruments and therefore the term 'measurement instruments' is always projected as plural. This study only investigates the use of a pain measurement instrument. For this reason, the plural form of the term 'measurement instruments' is changed in the singular form 'pain measurement instrument'.

Data analysis

Data analysis was performed using the Statistical Package for the Social Science (SPSS) version 26²⁹. The sample characteristics are presented in a frequency table consisting of categorical data³⁰. The analysis regarding the primary aim was based on complete case analysis of the first section²⁰. Questions in the first section needed to be answered before the participant was able to continue the survey. Therefore, there was no missing data in this section. An overview of the most frequent ways of conducting pain measurement and documentation were described. Data was presented in a frequency table to represent the variability and percentages were used to represent the central tendency^{20,31}. The answers of the open-ended questions were categorized and approached as quantitative data, supportive to the frequency tables.

The analysis regarding the secondary aim was based on available case analysis of the section about barriers and facilitators of pain measurement and documentation²⁰. Questions in this section were not obligated to be answered. This consideration was made because of the length of the digital survey and therefore not being able to use data from the previous section when a participant quits the survey in this section. The barriers and facilitators were presented and described to give an overview of the most common barriers and facilitators. A Mann-Whitney test was used to determine differences in barriers and facilitators between hospitals conducting pain measurement and documentation and not conducting pain measurement and documentation³⁰. A p-value <0.05 was considered as statistically significant.

Results

A total of twenty-eight HCPs submitted the digital survey, with a total response rate of 31.9% of the hospitals in the Netherlands. In four cases, there were multiple responses of HCPs working at the same hospital. Two HCPs did not meet the inclusion criteria, and were therefore excluded. Of the 26 remaining responses, 3 HCPs aborted the survey after the section on conducting pain measurement and documentation. In the section on barriers and facilitators of pain measurement and documentation not all HCPs completed all questions, resulting in 31 overall missing values (2.6%). HCPs were mostly 45 years or older (53.8%) and working in a general hospital (73.1%). More than 50% of the HCPs were working as a nurse practitioner. Only one man participated in this study (Table 1).

Conducting pain measurement and documentation

Fifty-four percent of the HCPs stated that they measured pain in patients with cancer visiting the outpatient clinic most of the time (always or often), 43% of the HCPs reported to do this sometimes. Only one HCP (3%) answered that pain measurement is never executed in patients with cancer visiting their outpatient clinic.

Pain measurement was mostly (often or always) performed by nurse practitioners (72%) and oncologists (64%). In 56% of the cases, HCPs answered that the patient himself initiates the topic pain often or always. In three cases (12%), the option 'other' was chosen. These HCPs specified that pain was measured by a research nurse or, when the patient arrived at the outpatient clinic, at the registration column (Table 2).

This way of pain measurement, at the outpatient clinic before the consult, was performed in 20% (n=5) of the cases. In two of these cases, HCPs specified that pain measurement was performed via the registration column as described earlier, the other three HCPs did not specify their answer. Eighty-four percent of the HCPs stated that pain is often or always measured during the consult (Table 2). In four cases (16%) pain measurement was often or always performed when the patient is at home. Of these four HCPs, three specified that pain measurement in this way was performed via a call from the HCP to the patient. The other HCP did not provide any details of the execution of this way of pain measurement. HCPs specified that if patients had pain, they asked additional questions or the anamnesis to get complete insight in the patient's pain. It was stated multiple times that pain measurement was not always part of the conversation. When HCPs were asked for reasons to pay attention to pain in patients with cancers visiting the outpatient clinic, it was stated frequently that pain is a common symptom in patients with cancer and that pain affects the quality of life.

In 24% of the cases, pain was never documented or only sometimes documented. Most of the time (76%), the pain measurement is often or always documented in clinical notes. Only in 36% of the cases, HCPs often or always used a specific checklist to report the patient's pain (Table 2). When a specific checklist was used, most HCPs (64%) used the NRS, 32% used the VAS and 4% used the VRS to assess patient's pain. Some HCPs (16%) answered not to use an assessment instrument to measure patient's pain. After pain measurement, HCPs specified to assess the pain in detail and start or modify the pain treatment if necessary.

Barriers and facilitators in using pain assessment instruments

Individual characteristics

The majority of the HCPs were positive (87%) and motivated (87%) about working with pain assessment instruments. The use of pain assessment instruments did not make them feel losing autonomy on their work (87%) but in 60.8% of the cases, it gave them additional control by using pain assessment instruments. Most HCPs (82.6%) agreed to have sufficient time to use pain assessment instruments in their daily work. They did understand the instruments (100%), were able to use it (95.6%) and were able to deploy interventions in response of the outcome (100%).

The majority of HCPs agreed that it is important to know what happens with the data collected by the pain assessment instruments (91.3%). Also, most of them were able to evaluate the patientcare by using pain assessment instrument (82.6%). On one topic the responses were more divided. Over half of the HCPs (52.2%) disagreed on being able to make their own choice of pain assessment instrument in relation to the patients' situation.

Barriers and facilitators

Figure 1 presents facilitators in using pain assessment instruments by HCPs working at the outpatient clinic of the Department of Medical Oncology. The three most frequent facilitators were encouragement in the use of pain assessment instruments by direct colleagues (83.3%), using a pain assessment instrument which is developed based on evidence (82.6%) and the presence of someone who actively takes charge in working with pain assessment instruments (80%).

Figure 2 presents barriers in using pain assessment instruments by HCPs working at the outpatient clinic of the Department of Medical Oncology. The three most frequent barriers were not being reminded to use a pain assessment instrument (58.8%) and no encouragement by management (50%) or direct colleagues (42.9%).

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There were no statistically significant differences in barriers and facilitators between hospitals that always or often execute pain measurement and hospitals that sometimes or never execute pain measurement.

Discussion

This study examined how health care professionals conduct pain measurement and documentation in patients with cancer visiting the outpatient clinic of the Department of Medical Oncology. Almost all HCPs performed pain measurement face-to-face during the consult at the outpatient clinic. Pain measurement was mostly executed by a nurse practitioner or oncologist. After measurement, three-quarter of the HCPs reported the pain often or always in clinical notes and only one-third reported the pain often or always at the specific checklist. When a specific checklist was used, two-third of the HCPs used the NRS.

Additionally, the most common barriers were lack of motivation by management or direct coworkers and not being alerted to use a pain assessment instrument. Using tools based on evidence, encouragement from direct colleagues and a key user who takes the lead in using pain assessment instruments were found to be strong facilitators. There were no differences in barriers and facilitators in hospitals that do perform and do not perform pain measurement and documentation.

Worldwide an increasing number of hospitals use electronic medical records and offer patients the opportunity to access their records or to incorporate data from eHealth applications in the electronic medical records³²⁻³⁴. Despite the improved use of patient portals, this study showed that HCPs hardly use these opportunities. Only a small percentage of HCPs performed pain measurement through digital assessment and none used a patient portal to assess patient's pain. The use of patient portals could lead to higher patient satisfaction, improved knowledge of the disease and care and improvement of safety³⁵. Therefore, patient portals could also be used to improve patient's knowledge on (for instance) misconceptions of adverse effects of opioids.

Data on the quality indicator *Pain measurement* of 2018 stated by the IGJ showed that less than half of the hospitals delivered data of pain measurement and documentation in patients with cancer visiting the outpatient clinic of the Department of Medical Oncology¹⁸. Comparing this data with the hospitals in this study, the majority of the hospitals improved the frequency of pain measurement and documentation from zero to ten percent in 2018 to often in this study. The hospitals that did not gave insight in their data concerning pain measurement and documentation in 2018, improved to sometimes or often in this study. Although the percentages of pain measurement and documentation in patients visiting the outpatient clinic of the Department of Medical Oncology does not represent the quality of these pain assessments, attention to pain and structural documentation could lead to a decrease in moderate-severe pain¹⁹. Only in a few hospitals a decrease with reference to the data of 2018 was observed. The data of 2018 showed that these hospitals perform pain measurement and documentation in almost 100% of the patients visiting the outpatient clinic¹⁸. This is not congruent with the results of this study, in which these hospitals stated to perform pain measurement and documentation sometimes or often.

In this study, support by direct colleagues in using pain assessment instruments turned out to be a strong facilitator and no encouragement by direct colleagues or management proved to be a strong barrier. These findings were similar to the study of Kjellström et al (2017), which stated that encouragement increases the work motivation of HCPs and therefore improves the quality of care³⁶.

Not being reminded to use pain assessment instruments also was identified as a strong barrier. This is congruent with the literature, which states that reminders are a successful approach for increasing care measures³⁷. Therefore, encouragement and reminders should be used to increase the motivation of HCPs in using pain assessment instruments and improve the quality of care.

In order to appreciate the results of this study, some limitations need to be considered. The first and most important limitation is the small sample size. Despite the use of different channels to distribute the survey to reach participants who were difficult to identify, barely one-third of all the hospitals in the Netherlands participated in this study²⁰. Therefore, the results must be interpreted with some caution and validity is a concern³⁸. As a result of the COVID-19 pandemic, the priority of HCPs was supporting the immediate care in hospitals and not to participate in studies³⁹. For this reason, it is possible that only HCPs with a positive and supportive attitude towards pain measurement and documentation participated in this study and sampling bias occurred⁴⁰. Therefore, it is possible that the results of this study are more positive than the actual clinical practice. A strength of this study was the use of open-ended questions in the digital survey. By using open-ended questions, more in-depth responses were generated and HCPs were given the opportunity to specify their answers. Generating more in-depth responses by using open-ended questions provides the researcher a more complete picture of the clinical practice²⁰. Another strength of this study was the use of a validated questionnaire. The section of the digital survey on barriers and facilitators in using pain assessment instruments was developed and used in previous studies and face-validity was obtained²⁷⁻²⁸. Finally, there were less than three percent of missing values in the section on barriers and facilitators of pain measurement and documentation. Therefore, the representativeness of the already small sample size was not affected41.

Based on the results of this study, it is recommended to investigate and implement the use of patient portals in the outpatient setting. Patient portals in the outpatient setting could be used to assess patient's pain before the consult at the outpatient clinic and to improve patient's knowledge on their disease and/or the importance of discussing the topic pain. Future research should also explore patient's experiences and expectations on discussing the topic cancer-related pain during the consult at the outpatient clinic. Another suggestion is to use encouragement and reminders to motivate HCPs in using pain assessment instruments at the outpatient clinic. This could be performed by a pop-up in the electronic medical record of the patient during the consult or by discussing the importance of pain assessment with direct colleagues or management.

In conclusion, this study shows an improvement in pain measurement and documentation in patients with cancer visiting the outpatient clinic of the Department of Medical Oncology. Pain measurement and documentation is mostly performed in the traditional way by the HCP asking the patient about pain and documenting in clinical notes. HCPs hardly use digital methods, like patient portals to assess patient's pain. Using patient portals for pain assessment could further improve the quality of care for patients with cancer and decrease the severity of pain. Encouragement and reminders positively contribute to use pain assessment instrument by HCPs.

References

- Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2018 Nov;68(6):394-424.
- 2. WHO. The top 10 causes of death. [Internet]. Available from: https://www.who.int/en/news-room/fact-sheets/detail/the-top-10-causes-of-death. [Accessed 7th September 2019].
- Van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, Tjan-Heijnen VC, Janssen DJ. Update on Prevalence of Pain in Patients With Cancer: Systematic Review and Meta-Analysis. J Pain Symptom Manage. 2016 Jun;51(6):1070-1090. doi:10.1016/j.jpainsymman.2015.12.340.
- 4. IASP. Cancer Pain. [Internet]. Available from: https://www.iasp-pain.org/globalyear/cancerpain. [Accessed 14th September 2019].
- 5. IASP. IASP Terminology. [Internet]. Available from: https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698#Pain. [Accessed 19th September 2019].
- Greco MT, Roberto A, Corli O, Deandrea S, Bandieri E, Cavuto S et al. Quality of cancer pain management: an update of a systematic review of undertreatment of patients with cancer. J Clin Oncol. 2014 Dec 20;32(36):4149-4154. doi:10.1200/JCO.2014.56.0383.
- 7. Paice JA, Von Roenn JH. Under- or overtreatment of pain in the patient with cancer: how to achieve proper balance. J Clin Oncol. 2014 Jun 1;32(16):1721-1726. doi:10.1200/JCO.2013.52.5196.
- 8. Cleeland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA et al. Pain and its treatment in outpatients with metastatic cancer. N Engl J Med. 1994 Mar 3;330(9):592-596.
- Fallon M, Giusti R, Aielli F, Hoskin P, Rolke R, Sharma M et al. Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines. Ann Oncol. 2018 Oct 1;29(Suppl 4):iv166-iv191. doi:10.10193/annonc/mdy152
- 10. Nederlandse Vereniging van Anesthesiologie. Richtlijn Diagnostiek en Behandeling van Pijn bij Patiënten met Kanker. [Internet]. Available from: https://www.oncoline.nl/pijn-bij-patienten-met-kanker. [Accessed 9th September 2019].
- 11. Dollinger M. Guidelines for Hospitalization for Chemotherapy. Oncologist. 1996;1(1&2):107-111.

- 12. te Boveldt ND, Vernooij-Dassen MJ, Jansen A, Vissers KC, Engels Y. Pain is not systematically registered in Dutch medical oncology outpatients. Pain Pract. 2015 Apr;15(4):364-370. doi:10.1111/papr.12180.
- 13. Shurgarman LR, Goebel JR, Lanto A, Asch SM, Sherbourne CD, Lee ML et al. Nursing staff, patient, and environmental factors associated with accurate pain assessement. J Pain Symptom Manage. 2010 Nov;40(5):723-733. doi: 10.1016/j.jpainsymman.2010.02.024.
- 14. Williamson A, Hoggart B. Pain: a review of three commonly used pain rating scales. J Clin Nurs. 2005 Aug;14(7):798-804.
- 15. Inspectie voor Gezondheidszorg. Basisset Medisch Specialistische Zorg Kwaliteitsindicatoren. [Internet]. Available from: https://www.igj.nl/documenten/indicatorensets/2017/08/08/basisset-medisch-specialistische-zorg-2018. [Accessed 9th September 2019].
- V&VN. SIG Pijn bij kanker. [Internet]. Available from: https://www.venvn.nl/afdelingen/pijnverpleegkundigen/deskundigheid/sig-pijn-bij-kanker/. [Accessed 9th May 2020].
- 17. van Boekel RLM, van Dijk JFM, Moons CAM. Samen werken aan betere pijnzorg: de ontwikkeling van de kwaliteitsindicator Ziekenhuisbreed pijnmanagement. [Internet]. Available from: http://pijn.venvn.nl/Portals/39/Indicator%20 Ziekenhuisbreed/VVNP%20Ziekenhuisbreed%20Document%20kwaliteitsindicatoren. pdf?ver=2018-03-30-085024-723. [Accessed 9th September 2019]
- 18. Zorg voor Data. Databestanden Basisset MSZ 2018. [Internet]. Available from: https://www.dhd.nl/producten-diensten/omniq/Paginas/Databestanden-Basisset-MSZ.aspx. [Accessed 14th September 2019].
- 19. Oldenmenger WH, Witkamp FE, Bromberg JE, Jongen JL, Lieverse PJ, Huygen FJ, et al. To be in pain (or not): a computer enables outpatients to inform their physician. Ann Oncol. 2016 Sep;27(9):1776-1781. doi:10.1093/annonc/mdw250.
- 20. Polit DF, Beck CT. Nursing Research Generating and Assessing Evidence for Nursing Practice. 10th ed. Philadelphia: Wolters Kluwer;2017.
- 21. Omair A. Selecting the appropriate study design for your research: Descriptive study designs. Journal of Health Specialties. 2015;3(3):153-156.
- 22. von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. Ann Intern Med. 2007;147(8):573-577.

- 23. World Medical Association, World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013 Nov 27;310(20):2191-2194. doi:10.1001/jama.2013.281053.
- 24. Autoriteit Persoonsgegevens. Algemene verordening gegevensbescherming (AVG) [Internet]. Available from:https://autoriteitpersoonsgegevens.nl/nl/overprivacy/wetten/algemeneverordening-gegevensbescherming-avg. [Accessed 10th May 2020].
- 25. Overheid. Wet medisch-wetenschappelijk onderzoek met mensen. [Internet]. Available from: wetten.overheid.nl/BWBR0009408/2020-01-01. [Accessed March 12th 20201
- 26. LimeSurvey. Professional online surveys with LimeSurvey. [Internet]. Available from: limesurvey.org. [Accessed March 12th 2020].
- 27. van Hell-Cromwijk MC, Hoekstra TS, Holwerda T, Cusveller BS. Naar verpleegkundig eigenaarschap van kwaliteit. Kwaliteit in zorg. 2014;4:24-26
- 28. Cusveller B, van Hell M. Screening van complicatierisico's: Welke factoren beïnvloeden het registreren van kwaliteitsindicatoren? TVZ. 2017;4:50-54
- 29. IBM Corp. Released 2018. IBM SPSS Statistics for Windows, Version 26.0. Armonk, NY: IBM Corp.
- 30. de Vocht. Basishandboek SPSS 24. Utrecht: Bijleveld Press;2016.
- 31. Boone HN, Boone D. Analyzing Likert Data. Journal of Extension. 2012 Apr;50(2).
- 32. Dendere R, Slade C, Burton-Jones A, Sullivan C, Staib A, Janda M. Patient Portals Facilitating Engagement With Inpatients Electronic Medical Records: A Systematic Review. J Med Internet Res. 2019 Apr 11;21(4):e12779. doi:10.2196/12779
- 33. Kruse CS, Bolton K, Freriks G. The Effect of Patient Portals on Quality Outcomes and Implications to Meaningful Use: A Systematic Review. J Med Internet Res. 2015 Feb. 2;17(2):e44. doi:10.2196/jmir.3171
- 34. Knegtmans MF, Wauben LSGL, Wagemans MFM, Oldenmenger WH. Home Telemonitoring Improved Pain Registration in Patients With Cancer. Pain Pract. 2020 Feb;20(2):122-128. doi:10.1111/papr.12830.
- 35. Woollen J, Prey J, Wilcox L, Sackeim A, Restaino S, Raza ST, et al. Patient Experience Using an Inpatient Personal Health Record. Appl Clin Inform. 2016 Jun 1;7(2):446-460. doi:10.4338/ACI-2015-10-RA-0130
- 36. Kjellström S, Avby G, Areskoug-Josefsson K, Andersson Gäre B, Andersson Bäck M. Work motivation among healthcare professionals. J Health Organ Manag. 2017 Jun 19;31(4):487-502. doi:10.1108/JHOM-04-2017-0074
- 37. Dexheimer JW, Talbot TR, Sanders DL, Rosenbloom ST, Aronsky D. Prompting clinicians about preventive care measures: a systematic review of randomized

- controlled trails. J Am Med Inform Assoc. 2008 May-Jun;15(3):311-320. doi:10.1197/jamia.M2555
- 38. Patino CM, Ferreira JC. Internal and external validity: can you apply research study results to your patients? J Bras Pneumol. 2018 May-Jun;44(3):183. doi:10.1590/S1806-37562018000000164
- 39. World Health Organization. Strengthening the Health Systems Response to COVID-19. [Internet]. Available from: http://www.euro.who.int/__data/assets/pdf_file/0007/436354/strengthening-health-systems-response-COVID-19-technical-guidance-1.pdf. [Accessed 10th May 2020].
- Mann CJ. Observational research methods. Research design II: cohort, cross sectional, and case-control studies. Emerg Med J. 2003;20:54-60. doi:10.1136/emj.20.1.54
- 41. Kang H. The prevention and handling of the missing data. Korean J Anesthesiol. 2013 May;64(5):402-406. doi:10.4097/kjae.2013.64.5.402

Tables and figures

Table 1: Baseline characteristics

Variable		N (%)	
Age (years)	≤ 24	0 (0)	
	25 – 34	6 (23.1)	
	35 – 44	6 (23.1)	
	≥ 45	14 (53.8)	
Gender	Female	25 (96.2)	
Current function	Nurse	0 (0)	
	Oncology nurse	5 (19.2)	
	Nurse practitioner	14 (53.8)	
	Pain specialist	2 (7.7)	
	Oncologist	3 (11.5)	
	Other*	2 (7.7)	
Hospital	University hospital	7 (26.9)	
	General hospital	19 (73.1)	

^{*}function of the participant was not included in the answer options and not specified

Table 2: Ways to conduct pain measurement and documentation

		Never	Sometimes	Often	Always
		N (%)	N (%)	N (%)	N (%)
Who	Patient tells about pain	2 (8)	9 (36)	12 (48)	2 (8)
asked	Outpatient assistant	21 (84)	2 (8)	2 (8)	0 (0)
	(Oncology) nurse	4 (16)	8 (32)	8 (32)	5 (20)
	Nurse practitioner	4 (16)	3 (12)	11 (44)	7 (28)
	Oncologist	2 (8)	7 (28)	11 (44)	5 (20)
	Other*	22 (88)	0 (0)	0 (0)	3 (12)
When	At home	10 (40)	11 (44)	2 (8)	2 (8)
asked	At the outpatient clinic	14 (56)	6 (24)	0 (0)	5 (20)
	During the consult	1 (4)	3 (12)	12 (48)	9 (36)
	Other**	21 (84)	4 (16)	0 (0)	0 (0)
Where	Pain is not registered	14 (56)	5 (20)	4 (16)	2 (8)
noted	Clinical notes	1 (4)	5 (20)	10 (40)	9 (36)
	At a specific checklist	6 (24)	10 (40)	2 (8)	7 (28)
	Other***	24 (96)	1 (4)	0 (0)	0 (0)

^{*}registration column, research nurse

^{**}called by homecare, called by patient himself, at daycare

^{***}noted during consult by phone (not specified where)

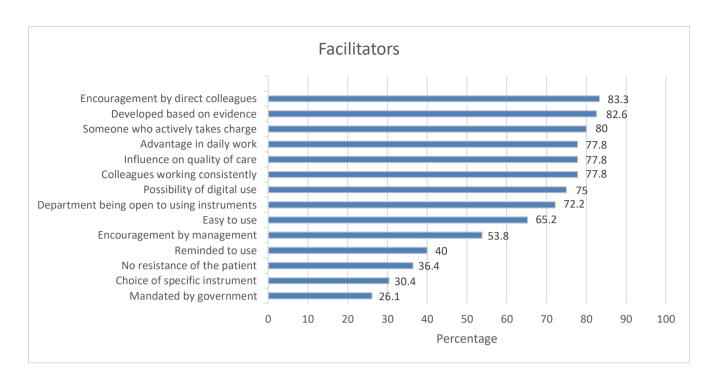


Figure 1: Facilitators in using pain assessment instruments

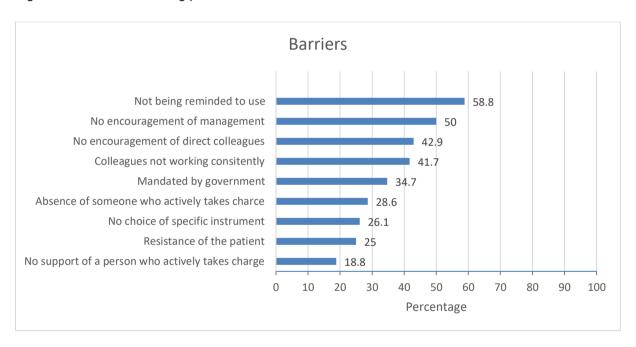


Figure 2: Barriers in using pain assessment instruments