

Towards automated risk prediction of persistent pain: Exploring psychosocial factors from electronic health records after breast cancer surgery

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Abstract

Aim: The aim of this study was to describe what psychosocial factors associated with postoperative persistent pain can be found in electronic health records of patients with breast cancer, and which of these factors that may be used in the development of a decision-support system algorithm to better support health professionals in their clinical work.

Design: A qualitative descriptive study.

Methods: A retrospective electronic health record review was done using manual semantic annotation. A set of 101 records of patients with breast cancer were selected by computerized random sampling. The data were analysed with deductive content analysis.

Results: A total of 337 different expressions describing psychosocial factors associated with postoperative persistent pain were identified from the documentation done in the electronic health records. These regarded psychological strength and resilience, social factors, emotional factors, anxiety, sleep-related factors and depression. No records were found dealing with pain catastrophizing. Although psychosocial factors associated with postoperative persistent pain were documented in the electronic health records, documentation about such factors was not found in all patient's records, nor was the documentation done in a systematic manner.

Conclusions: The findings show that there is potential to use electronic health records as information source in the development of decision-support system algorithms to better support nurses in the identification of patients at risk of developing postoperative persistent pain. However, the documentation quality needs to be acknowledged in the application of decision support systems, which are built on information extracted from electronic health records. Future work is needed to standardize documentation practices and assess the comprehensiveness of the documentation.

KEYWORDS

decision support system, electronic health record, people with breast cancer, postoperative persistent pain, psychosocial factors

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1 | BACKGROUND

Breast cancer is the second most common form of cancer in women. In 2018, it globally affected more than two million people (11.6% of all cancers), and there were about 600,000 deaths from the disease, which is 6.6% of all cancer deaths (Bray et al., 2018). Persistent postoperative pain is a common phenomenon after breast cancer treatment (Kehlet et al., 2006; Niraj & Rowbotham, 2011) affecting 25%–60% of all patients (Andersen & Kehlet, 2011; Schreiber et al., 2014). Risk factors for the development of persistent postoperative pain include genetic predisposition, demographic factors, clinical factors (e.g. pain history, type of surgery, form of anaesthesia and severity of acute pain) and psychosocial factors (e.g. anxiety, depression, pain catastrophizing, sleep disturbances and individual vulnerability vs. resilience overall) (Schreiber et al., 2014; Tait et al., 2018).

Psychosocial processes are associated with the development of postoperative persistent pain (Edwards et al., 2016; Tait et al., 2018). Psychological factors may play a major role in the recovery or prolongation of pain when the surgery is due to a malignant life-threatening illness (Gold et al., 2016). A diverse set of factors are associated with postoperative persistent pain including depression (Dereu et al., 2017), anxiety (Attal et al., 2014; Bruce et al., 2013; Voute et al., 2020), sleep disturbance (Miaskowski et al., 2014; Moloney et al., 2016), pain catastrophizing (Attal et al., 2014; Manfuku et al., 2019), social factors (Miaskowski et al., 2014; Peuckmann et al., 2009), preoperative psychological stress (Sherman et al., 2015) and weaker passive coping strategies (Attal et al., 2014). However, psychological resilience (high optimism, high positivity and low mental anxiety) has a protective association with postoperative persistent pain (Bruce et al., 2013; Liesto et al., 2020).

Electronic health records are a collection of systematically stored patient health information in digital format (Nguyen et al., 2014). Electronic health records enable the collection and storage of information about psychosocial factors associated with postoperative persistent pain of patients who have undergone breast cancer surgery. Nursing documentation, which adheres to the nursing process has been shown to increase patient safety, promote access to patient health information by healthcare professionals, allow rational use of resources and improve communication among all healthcare professionals (Secginli et al., 2014). In Finland, patient care is documented in accordance with the nursing process model using the Finnish Care Classification (FinCC) terminology. The nursing process includes assessment and nursing diagnoses, planning and implementation of nursing interventions, monitoring interventions and assessing nursing outcomes (Saranto et al., 2014). Most of the nursing documentation is in free-text form.

Electronic health records form a large body of key information in healthcare (big data). These big data are used to promote health and well-being in nursing (Zhu et al., 2019). Electronic health records information can also be used for secondary purposes such as data-based integration analysis, which supports decision-making in clinical work and leadership in nursing. Digital health information and

technological advancements create new possibilities to administer advanced computational methods such as machine learning and natural language processing to retrieve information from data embedded in free-text clinical notes (Szlosek & Ferretti, 2016). Natural language processing models do not depend on predefined set of rules. These algorithms learn patterns from labelled free-text notes and apply these self-learned rules to other unmarked free-text contributions (Skeppstedt et al., 2014).

Risk factors and psychosocial factors known to be associated with postoperative persistent pain are diverse and it is challenging for healthcare professionals to identify these. The use of decision-support systems integrated into electronic health records has the potential to increase nursing professionals' understanding of the psychosocial factors associated with the development of postoperative persistent pain, and to develop care for patients with breast cancer. Research shows that computerized decision support systems (CDSs) can increase protocol-based care and adherence to guidelines for improving efficiency and quality of healthcare (Roshanov et al., 2013). However, electronic health records of patients with breast cancer have not yet been reviewed for psychosocial factors associated with postoperative persistent pain for such a purpose. Hence, the aim of this study was to describe what psychosocial factors associated with postoperative persistent pain can be found in electronic health records of patients with breast cancer, and which of these factors that may be used in the development of a decision-support system algorithm to better support health professionals in their clinical work.

2 | METHOD

This qualitative descriptive study explored through a retrospective record reviewed the opportunity of using information documented by healthcare professionals in electronic health records to gain knowledge of the occurrence, content and care related to psychosocial factors associated with postoperative persistent pain after breast cancer surgery. Collected data were analysed with deductive content analysis.

The population included patients with breast cancer who had undergone breast cancer treatment including breast cancer surgery and various adjuvant therapies. The sample was extracted from electronic health records of patients treated at one university hospital in Finland ($N = 67,753$). The sample was limited to those patients with a breast cancer diagnosis and a breast cancer surgery procedure code. The total number of patients undergoing breast cancer surgery in the data set was 1943. From this number, 300 patient records were selected by computerized random sampling. The sample size was determined by saturation. Finally, free-text narratives from 101 patients' electronic health records were analysed as data saturation was reached at that point.

An annotation manual for the identification of relevant expressions related to psychosocial factors associated with persistent pain was developed based on a literature review to guide the data extraction. This

manual helped map psychosocial factors documented by healthcare professionals in the electronic health records during the breast cancer treatment process. The annotation manual contained instructions and information about the words, phrases and sentences that should be annotated and which specific expressions that should be used to label each of the identified expressions. Only narrative free text in the electronic health records was included in the analysis. The annotations were done with a web-based text annotation tool called the BRAT (Brat Rapid Annotation Tool). This tool is developed for structured annotation with labels predefined in the annotation manual. The tool enables text classification through the option of (1) adding notes to annotate the text and (2) adding relationships between the annotations done (Stenetorp et al., 2012). The BRAT was used in this study to label and classify all expressions related to psychosocial factors associated with persistent pain in the electronic health records.

Deductive content analysis was used in the analysis of the annotations collected. The data were first coded into meaningful variable categories based on the literature review and the annotation manual. Thereafter, codes were given to all original expressions, which were further grouped into subcategories and main categories. The original expressions were also quantified, i.e., the number of expressions annotated in the electronic health records was also calculated.

Data management adhered to the EU General Data Protection Regulation 2016/679, the Data Protection Act 2018/1050 and the Publicity Act on the protection of individuals when processing personal data. All data management was done through secure remote access to a computing environment on the server of the hospital district. Access to this secure environment required personal usernames and passwords. Access to the secure environment was granted to the researchers after signing licence and confidentiality agreements.

2.1 | Ethical considerations

The study was approved by the local Ethics Committee of the local University (3/2020) "University information REDACTED for blinded

review purposes". Administrative approval for the study was granted by the Hospital District (5/2020).

3 | RESULTS

The number of identified expressions related to psychosocial factors associated with persistent pain varied in the electronic health records (Figure 1). Multiple expressions were identified in some records, while no expressions were found in other records. The identified psychosocial factors formed six main categories (Table 1). These included psychological strength and resilience 39%, social factors 23%, emotional factors 11%, anxiety 11%, sleep-related factors 9% and depression 7%. The most often documented expressions regarded psychological strength and resilience. These were associated with survival and adaptability. The main psychosocial factors and subcategories including the number of identified expressions divided by occurrences in electronic health records are listed in Table 1.

The identified expressions related to the *psychological strength and resilience* category ($n = 131$) were associated with survival and adaptability. The patients trusted the treatments to be effective in general and they adapted their lives to manage with the diagnosed cancer and to find meaning in their lives in new ways, which gave them the strength to move forward. Expressions were found stating that the cancer did not limit life and that life progresses despite the cancer. The expressions about attitudes towards cancer were realistic and the future was seen as positive. Stress tolerance was associated with expressions of an emotional state described as "calm appearance" before surgery or treatments ($n = 22$) and being in a good and bright mood ($n = 19$). Documentation of social relations and support networks comprised family ($n = 29$) and the help of spouses, children, children's families and relatives. The size of the circle of friends ($n = 14$) varied from one to several and expressions about good supportive networks ($n = 14$) to help if needed were also found.

The *social factors* category included documentation of expressions associated with patient demographics ($n = 76$). This included

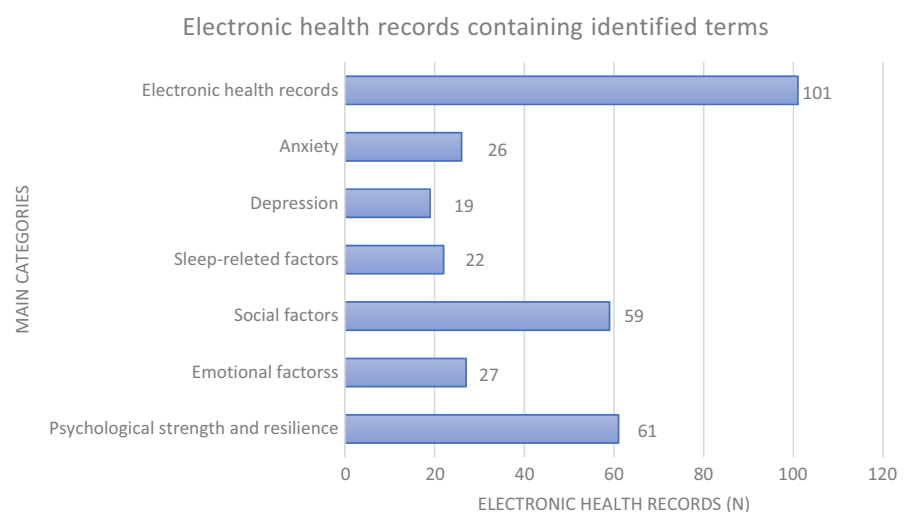


FIGURE 1 Number of electronic health records with expressions identified by main categories.

TABLE 1 Psychosocial factors and subcategories including number of identified expressions divided by occurrences in electronic health records

Psychosocial factors	Main categories	Subcategory and distribution of identified expressions	Number of identified expressions per subcategory (n)	Total number of identified expressions (n)	Total % of identified expressions
	Anxiety	• anxiety/distress	12	37	11%
		• other strong emotional state	19		
		• no anxiety	6		
	Depression	• depression	16	23	7%
		• no depression	7		
	Sleep-related factors	• sleep disorders	22	32	9%
		• sleeps well	10		
	Social factors	• single	17	76	23%
		• lives together	35		
		• employed	16		
		• unemployed	2		
		• pensioner	6		
	Emotional factors	• tension	18	38	11%
		• concern for relatives	4		
		• other feelings	16		
	Psychological strength and resilience	• recognition of empowerment	30	131	39%
		• stress tolerance	41		
		• positivity	13		
		• support network	47		
		Total		337	100%

employment, unemployed and retirement from work. Also, the type of housing was documented through how individuals lived together. Such expressions included spouse ($n = 15$), husband ($n = 14$), family ($n = 3$) and friend ($n = 1$).

The documentation in the *emotional factors* category ($n = 38$) was mainly related to stress and milder emotional states, such as tension, concern for relatives and other feelings. Tension was associated with the initiation of the treatment ($n = 12$) and was documented from mild to severe. Expressions related to tension were associated with fear of nausea ($n = 1$) and medication ($n = 1$). Also, a positive mood ($n = 3$) was mentioned in association with tension. However, sometimes no documented reason could be found in the electronic health record for an expressed tension ($n = 4$). Patients were also concerned about their relatives ($n = 4$). The records included also other expressions of strong emotions of patients, such as feeling bad ($n = 19$). Further emotions evoked by the illness and treatment included annoyance, confusion, fear, restlessness, worry and disappointment.

With respect to the *anxiety* category, the identified expressions covered all documentation entries that mentioned or assessed a patient's anxiety and all entries that described the emotional state suggestive of the patient's anxiety in other ways ($n = 37$). Anxiety was associated with fear ($n = 1$) and a need to increase anxiety medication ($n = 1$). A patient's anxiety was also expressed as very anxious or severely anxious in some cases in the documentation ($n = 4$). The amount of anxiety was measured using the Edmonton Symptom Assessment System (ESAS), which is a questionnaire developed for assessing the intensity of nine common symptoms experienced by people with cancer, including pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath ($n = 4$).

All documentation entries that referred to the *sleep-related factors* category were included in the identified expressions ($n = 32$). The Edmonton Symptom Assessment System (ESAS) ($n = 10$) was used to measure insomnia. Further sleep-related entries cited worrying ($n = 3$) as one reason for poor sleep. Sleep was also affected by upper limb symptoms ($n = 1$), decreased mood ($n = 2$) and an inability to cope with the situation at hand ($n = 1$). There were also general expressions about difficulties with sleeping ($n = 9$). The use of hypnotics was sometimes considered necessary to support a better sleep ($n = 3$). Expressions were also documented when a patient slept well and the disease had not affected sleep ($n = 10$).

The *depression* category included documentation about the difficulty in obtaining a cancer diagnosis psychologically ($n = 4$). Patients were described as crying ($n = 6$) and being in shock ($n = 3$). Depression was documented using "no sign of depression" and through changes in a patient's mood ($n = 23$). Mood changes included a mood decline ($n = 3$), a slight increase in the patient's mood ($n = 2$) and the expression of "feeling blue" ($n = 1$). Crying and general fatigue were also documented in connection with the expressions related to mood changes.

4 | DISCUSSION

The main finding of this study is that narrative free-text documentation made by nurses in electronic health records contains important information describing psychosocial risk factors and protective factors associated with persistent postoperative pain of patients with breast cancer. The psychosocial factors identified formed six main

categories including psychological strength and resilience, social factors, emotional factors, anxiety, sleep-related factors and depression. These findings may be used in the development of algorithms for decision-support systems that are able to help healthcare professionals identify patients at risk of developing persistent postoperative pain.

Details about patients' psychosocial factors were recorded in varying depth in the electronic health records. There was no clear and systematic documentation policy visible in the electronic health records about the documentation of psychosocial factors associated with postoperative pain after breast cancer surgery. It rather seemed that the content and style of documentation of these factors varied based on individual healthcare professionals. Documentation entries were made using similar phrases and expressions. The documentation of the psychosocial factors was widely scattered under different headings of the structured documentation system used (i.e. FinCC). The content and amount of the documentation had similar shortcomings in the process-based recording of nursing as reported elsewhere (Saranto et al., 2014). Hence, nursing managers need to give education in standardized documentation practices to increase the documentation quality and amount about treatment and care of patients with breast cancer.

Based on the results, the number of identified expressions varied in the electronic health records. The use of validated instruments for the assessment of psychosocial factors and symptoms was limited. The American Society of Clinical Oncology Breast Cancer Survivorship Care Guideline instructs to measure the patients' general distress, anxiety and depression (Runowicz et al., 2016). The use of different assessment instruments increases the consideration of the patients' psychosocial factors even when the patient does not report them. Systematic assessment of the patients' experiences ensures high-quality care for all the patients. Therefore, it is important to increase the use and documentation of systematic assessment of patient care. The prevalence of the aforementioned factors shows that healthcare professionals' documentation of psychosocial factors associated with persistent pain in patients with breast cancer should be improved. Hence, interventions are needed to increase healthcare professionals' understanding of the benefits of using and documenting systematic assessment instruments in patient care. Nursing managers need to acknowledge such needs in planning of professional development of staff nurses.

Emotional factors identified in our study included different emotional states due to the illness, e.g., tension, restlessness and agitation. These can be associated with stress experienced by the patient (Sherman et al., 2015). Psychological strength and resilience were the most documented expressions of the psychosocial factors (60%). Psychological resilience has been found to have a protective association with the occurrence of persistent pain (Bruce et al., 2013). No records related to pain catastrophizing were found in the data set, although it has been found to be associated with persistent pain (Attal et al., 2014; Manfuku et al., 2019). Patients did not necessarily tell healthcare professionals about their fears and negative thought patterns related to their pain experience. It is also possible that

discussions were held on this issue but these were not documented in the electronic health records.

Expressions related to anxiety were more common and they were documented in a quarter of the patient records, while expressions related to depression were found in one-fifth of the records. The actual number of individuals experiencing anxiety and depression remained unclear in the data set because these factors were not measured in all patients. Anxiety has been found to be a common phenomenon, with a prevalence of 41.9% in patients with breast cancer (Hashemi et al., 2020) and the prevalence of depression in this population was studied by Pilevarzadeh et al. in 2019 and their meta-analysis resulted in a prevalence of 32.2%.

Sleep-related factors were documented in one-fifth of the analysed electronic health records. Sleep disorders have been found to be common in patients with breast cancer (Tait et al., 2018). Identified sleep-related factors included both difficulty with sleeping and no sleeping problems at all. The use of instruments for the assessment of sleep was limited. The ESAS questionnaire was documented as the only instrument used to assess sleep disorders; this was found in 10% of the health records analysed. Further, social factors identified in our analysis included documentation of housing and how individuals lived, e.g., alone or together, with spouse, family or friend. Social factors are important to be acknowledged as loneliness has been found to be associated with more severe persistent pain in people with breast cancer (Peuckmann et al., 2009).

Our study also showed that not all factors included in the annotation manual were found in the data, such as the experience of pain catastrophizing. Most of the identified expressions were documented related to the postoperative period of adjunctive therapies, which indicates a need for more focus on the initial interview with patients, with a more detailed explanation of the patient's psychosocial factors upon admission to the hospital. The informativeness of the content of the documented entries varied and the entries related to the psychosocial factors and treatment measures were not systematic. It is a big challenge for algorithm developers if documentation of care given is lacking in electronic health records. This requires nurse managers' interference and activities to improving professionals' documentation practices to improve the quality of documentation and care.

The number of patients with breast cancer is large and due to advanced treatment results, most patients survive (Nekhlyudov et al., 2019). Human health and well-being consist of a biopsychosocial entity (Gatchel, 2004) in which the consideration and identification of psychosocial factors in the early stages of breast cancer care enables comprehensive treatment of patients. Due to the risk of developing persistent pain, psychosocial factors should be considered and documented in the care processes of all patients with breast cancer. Patients need systematically programmed psychological assessment and, if necessary, access to appropriate psychological services during their cancer care (NICE, 2004).

Risk factors and associated factors are diverse and it is challenging for healthcare professionals to acknowledge all factors that are known to be associated with postoperative persistent pain. We

identified quite many expressions in our data set ($n = 337$) related to factors associated with persistent postoperative pain in patients with breast cancer. This is a promising result for the development of an algorithm that automatically identifies such factors from electronic health records. These findings support the idea that electronic health records can be used in the development of a decision-support system for healthcare professionals for better identification of patients at risk of developing persistent pain.

4.1 | Strengths and limitations

The development of an algorithm to automatically analyse narrative free-text information from electronic health records to support clinical decision-making requires theoretical content validation. This can be used as a basis for the technical implementation and to ensure clinical relevance and functionality. There is hardly any similar research on the use of narrative free-text in this context and therefore clear methodological approaches for such research do not yet exist. This study brings new knowledge and methods to support the development of clinically relevant decision support systems for practice. However, one weakness of the study relates to the secondary use of electronic health record data. The analysis may involve a shortfall in the content in relation to the subject of the study and research questions. Documentation is done by healthcare professionals and may not sufficiently represent the point of view and experiences of the patient. The documentation may be skewed by possible interpretations and misunderstandings done by professionals, in which case the content may be inaccurate.

5 | CONCLUSIONS

The use of decision-support systems integrated into electronic health records has the potential to increase healthcare professionals' understanding of psychosocial factors associated with persistent pain, and improve the care of people with breast cancer. High-quality narrative documentation of patient care enables the development of natural language processing-based decision support tools to better guide clinical decision-making for improved identification of individuals with an increased risk for developing persistent pain after surgery, and to support early nursing interventions for the prevention of the development of persistent pain. However, this study showed that their systematic documentation practices were lacking about the documentation of psychosocial factors in electronic health records. Differences in content quality and amount were seen across the electronic health records. Hence, the need for further development of electronic health records documentation practices of healthcare professionals remains a highly relevant issue still today.

The limitations in the quality of narratives, which are based on a lack of systematic documentation practices and differences in

documentation should be acknowledged when developing algorithms to support clinical decision-making. Future work is needed to improve documentation practices for a more standardized quality of documentation. Nurse leaders are in a key position for the assessment and development of documentation practices and culture within their organization. Nursing leaders are also needed as active participants in the development and implementation of novel technologies. Already well-proven practices could be further strengthened and new improvements could be done. More research is also needed for the development of continuous education of nursing professionals about documentation practices.

FUNDING INFORMATION

There was no funding for this work.

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

DATA AVAILABILITY STATEMENT

Data openly available in a public repository that issues datasets with DOIs.

ETHICAL APPROVAL

The study was approved by the Ethics Committee for Human Sciences at the University of Turku Finland (J14/20) at the date of 23.3.2020 and obtained a research permit from the local Hospital District (T95/2020, ML4CIA) at the date of 12.5.2020 which also covers the permission to do text mining research on the data.

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How to cite this article: Liukas, T., Rosio, R., & Peltonen, L.-M. (2023). Towards automated risk prediction of persistent pain: Exploring psychosocial factors from electronic health records after breast cancer surgery. *Nursing Open*, 00, 1–7. <https://doi.org/10.1002/nop2.1594>