# The informational privacy of patients in prehospital emergency care - Integrative literature review

Running title: Informational privacy in emergency care

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CONFLICT OF INTEREST

The authors state there is no conflict of interest.

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What does this paper contribute to the wider global clinical community?

- The review points out that in the field of prehospital emergency care, the concept of informational privacy is still poorly recognised and, therefore requires more research in the future
- The realisation of patients' informational privacy in prehospital emergency care varies and is dependent on multiple factors.
- The need of paramedics for more education concerning informational privacy and its protection should be addressed in order to enhance the realisation of patients' informational privacy.

**Abstract**

**Aims and objectives:** To explore the informational privacy of patients in prehospital emergency care based on the existing literature.

**Background:** Informational privacy, a central value in healthcare is strongly connected to patients' safety and quality of care. However, its realisation faces challenges in the unique context of prehospital emergency care.

**Design:** Integrative literature review.

**Methods:** Systematic searches of the CINAHL, MEDLINE and Cochrane library databases (n=1588), and a manual search of the reference lists of the included articles (n=0), were conducted in August 2019. In the article selection, specified inclusion and exclusion criteria were used. Two Joanna Briggs Institute quality appraisal tools were used. Ultimately, 11 studies were included. Analysis was conducted by using content analysis. Overall, process of the review was guided by PRISMA checklist.

**Results:** The number of primary research studies related to informational privacy in prehospital emergency care is limited and mainly focused on privacy and confidentiality. The informational privacy was described from three aspects 1) information control by patients, 2) information protection by healthcare professional and 3) concepts related to informational privacy. The realisation of patients' informational privacy varied. Factors related to the realisation were related to the paramedics, the prehospital emergency care work and the patients.

**Conclusion:** More research specifically focused on informational privacy in prehospital emergency care is needed. Paramedics' understanding of informational privacy and its protection is essential to enhance the realisation of patients' informational privacy. Therefore, a response is required to their need for more education concerning informational privacy.

**Relevance to clinical practice:** Paramedics' attention should be drawn to the identified factors related to the realisation of informational privacy and its use in clinical practice in order to continue to provide high quality prehospital emergency care.

**KEYWORDS:** Informational privacy, privacy, confidentiality, prehospital emergency work, emergency medical services, paramedic

## 1. INTRODUCTION

Informational privacy (IP) is a part of a multidimensional privacy concept (Burgoon, 1982) and is often used interchangeably with the concept of confidentiality (Burgoon, 1982; Parrot, Burgoon, Burgoon, & LePoire, 1989; Allen, 2004). It is defined as a control over personal information and refers to one of the patient's basic rights (Woogara, 2001). The control over personal information allows individuals to determine the information they are willing to share and with whom, how their information is used, when and under what circumstances their information may be disclosed to other individuals or organisations, and to be assured that their information is being stored appropriately (Parrot et al., 1989; Geiderman, Moskop, & Derse, 2006; Britto, Tivorsak, & Slap, 2010).

The importance on research concerning IP and privacy in general is emphasised due to the fact that for patients' perceptions of privacy predict patient satisfaction with the health services and is thus related to the quality of care (Lin & Lin, 2011; Nayeri & Aghajani, 2010). In addition, for the well-being of patients, the respect for IP is essential to ensure the confidential relationship between the patient and medical professionals (Beltran-Aroca, Girela-Lopez, Collazo-Chao, Montero-Pérez-Barquero, & Muñoz-Villanueva, 2016). The increased implementation of electronic patient records and other eHealth services worldwide, however, makes the patient's IP a particularly topical issue (Entzeridou, Markopouloua, & Mollaki, 2018). This digitalization of healthcare provides various benefits in the field of emergency care such as immediate access to patient records especially in lifesaving situations (Ayatollahi, Bath, & Goodacre, 2009). However, the development has rightfully raised new concerns related to privacy issues and especially to data protection (Anderson, 2007;

Entzeridou, et al., 2018) which has resulted in the imposition of new national regulations (GDPR (EU) 2016) as well as to the increase in the number of studies conducted on the subject (Nayeri & Aghajani, 2010; Calleja & Forrest, 2011).

In previous research conducted, the research focus has been on the perceptions of the patients (Malcolm, 2005) or health care workers (Deshefy-Longhi, Dixon, Olsen, & Gery, 2004, Leino-Kilpi et al., 2003) concerning several issues: the realisation of privacy and confidentiality, factors influencing the realisation in hospital wards (Deshefy-Longhi et al., 2004; Malcom, 2005; Beltran-Aroca et al., 2016), nursing homes and other continuing care units (Leino-Kilpi et al., 2003), day surgery units (Renholm 2015) and emergency departments (Ayatollahi et al. 2009; Lin & Lin 2011; Beltran – Aroca et al., 2016). In addition, studies have been made from the aspect of security concerns in relation to electronic health records (Israel, Akinyele, Adisa, Ayo-Yusuf, & Conolly, 2014; Entzeridou et al., 2018; Kisekka & Giboney, 2018). The studies have revealed major IP problems especially concerning the custody of clinical records (Beltran – Acora et al., 2016), the disclosure of patient information (Leino-Kilpi et al., 2001) and the patients' possibility to control their own information (Deshefy-Longhi et al., 2004).

In prehospital emergency care (PEC), less is known about the patient's IP. However, it has been reported that in emergency care a patient's privacy, and IP, is at risk of being disclosed due to the acute nature of the work (Sohrabi & Alimohammadi, 2010; Nayeri & Aghajani, 2010; Lin & Lin, 2011). The acute nature of the work is also underlined in PEC. However, PEC differs in many respects from other sectors of health care (Erbay, 2014). In the PEC provided by emergency medical services (EMS), paramedics are dealing with individuals with sudden and life-threatening illnesses or injuries (Erbay, 2014; Zorab, Robinson, & Endacott, 2015), in challenging environments and often with limited patient information, and without immediate support from other professionals such as doctors (Sandman & Nordmark, 2006; Zorab et al., 2015). It may be the patient's first contact with health care and involves situations where help is most needed. Due to its acute nature, it overshadows matters that may not be seen as a priority when the situation is very critical. However, as elsewhere in health care (Olsen, Cutcliffe, & O' Brien, 2008), patients in PEC also deserve and expect that their IP is maintained, and therefore it is necessary to study this aspect.

## 2. AIMS

The aim of this integrative literature review is to describe and synthesise the existing knowledge on the patient's IP and its realisation and the factors related to this realisation in PEC. The knowledge

produced may be used in future research, clinical practice, and in the education of paramedics in order to enhance the quality of prehospital emergency care. The research questions were as follows:

(1) What kind of research has been done regarding the patient's informational privacy in prehospital emergency care?

(2) How is informational privacy described in the field of prehospital emergency care?

(3) How is the patient's informational privacy realised in prehospital emergency care?

(4) What factors are related to the realisation of a patient's informational privacy in prehospital emergency care?

## 3. METHODS

### 3.1 Search strategy.

An integrative literature review was conducted by using the strategy of "five steps" by Whittemore and Knafl (2005) including (1) problem identification, (2) literature search, (3) data evaluation, (4) data extraction from primary sources and (5) data analysis and synthesis. This integrative review was guided by Preferred Reporting Items for Systematic Reviews and Meta‐Analyses (PRISMA; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) (Supplementary File 1), with a flow chart documenting the literature search conducted (Figure 1). The literature search was conducted in August 2019 using three databases including MEDLINE, Cochrane (library) and CINAHL. The search phrases were formed in co-operation with a library information specialist. Database-specific terms (MeSH-terms /keywords) were used where possible. The following search terms were used: "informational privacy", "information privacy", "privacy", "confidentiality", "data protection", "prehospital emergency care", "emergency medical services", "emergency medical care", "ambulance", "emergency care" and "emergency department". The limits for the search were peer-reviewed journals, the English language, and available abstracts. No time restriction was used. The emergency departments (ED) were included in the search as a separate search term because the activities of PEC care are often extended in the emergency departments.

### 3.2 Study selection

In the study selection process, the specified inclusion criteria were 1) the research was related to patients' IP in the context of PEC or in the context of the ED into which prehospital emergency care often extends, 2) an original, scientific, empirical article with no restriction on design and 3) in the English language. Articles were excluded: if they were related to patients' IP in other healthcare contexts, where informational privacy was discussed from the point of view of conducting the study, the IP was discussed from the aspect of research ethics, as well as all editorials, commentaries, guidelines, opinion pieces, conference papers and literature reviews. The reference lists of the included articles were screened but no additional articles were found. The citations (n=1588) from the search were first reviewed by titles and abstracts resulting in 74 references for full text examination (Figure 1). The study selection process was done by two researchers (E.K & S.K) and resulted in 11 studies.

### 3.3 Quality Appraisal

In this review, The Joanna Briggs Institute Critical Appraisal tools (Checklists for Analytical Cross Sectional Studies and for Qualitative Research) (https://joannabriggs.org/ebp/critical_appraisal_tools) were used. These tools included lists of criteria and a scoring option of four items: yes, no, unclear and not applicable. These options were further scored so that only the "yes" answers gained one point while the others remained zero. The maximum score on the checklist for Analytical Cross Sectional Studies was eight and ten for the checklist of Qualitative Research. Two evaluators (E.K & S.K) independently assessed the quality of the studies and any differences of assessments were resolved by discussion. The quality of the studies varied from three to seven out of eight and from six to nine out of ten. However, given the small number of studies and the content provided by these studies, the aim of the quality appraisal was more aimed on describing what the quality was like, rather than excluding the studies with poor quality. Therefore, based on the quality assessment, no studies were excluded from the data (Table 1).

### 3.4 Analysis

The 11 studies were tabulated according to author(s), publication year, country, purpose, design and findings of interest in this review (Table 2). The actual data analysis was undertaken using inductive content analysis (Elo & Kyngäs, 2008). First, expressions answering to the research questions were extracted from the data. These expressions were tabulated and allocated into sentences and simplified.

The analysis continued by finding similarities and differences and grouping the sentences with the same content into subcategories. This summarising and grouping continued until the main categories were formed. Analysis was conducted by the first author but ensured and verified by the whole research team.

## 4. RESULTS

### 4.1 Characteristics of the included studies

The selected 11 studies, from the years 1992-2020, represent eight countries; The United States of America (USA) (n=3), Iran (n=2), Finland, Australia, Belgium, China and United Kingdom (one in each country). One study was multi international since it was conducted in the USA and in South Africa. Six qualitative methods were used (Mlinek & Pierce, 1997; Bartlett, Xin, Zhang, & Huang, 2011; Kingswell, Shaban, & Crilly, 2015; Torabi, Borhani, Abbaszadeh, & Atashzadeh-Shoorideh, 2018; Torabi, Borhani, Abbaszadeh, & Atashzadeh-Shoorideh. 2019; Koskimies, Koskenniemi, & Leino-Kilpi, 2020) as well as four quantitative methods (Adams, Arnold, Siminoff, & Wolfson, 1992; Steele, Adcock, & Steel, 2016; Valenzuela Espinoza et al., 2016; Medford-Davis, Chang, & Rhodes, 2017) and one was a mixed method study (Tate, Hodkinson, Meehan-Coussee, & Cooperstein, 2016). The data collection methods used were interviews (Bartlett et al., 2011; Kingswell et al., 2015; Tate et al., 2016; Torabi et al., 2018 & Torabi et al., 2019), observations (Adams et al., 1992; Mlinek & Pierce, 1997; Steele et al., 2016) and surveys (Medford-Davis et al., 2017; Valenzuela Espinoza et al., 2016; Tate et al., 2016; Koskimies et al., 2020).

Only one study purely represented the topic of a patient's IP in PECs (Koskimies et al., 2020). In the rest of the studies informational privacy had a much smaller role. Otherwise, the topics were related to ethical conflicts and ethical decision making by EMS providers (Adams et al., 1992; Torabi et al., 2018; Torabi et al., 2019). The topics thus dealt with: language barriers occurring in EMS (Tate et al., 2016), solving risks, barriers related to and perceptions of the use of responders in overdose treatment (Bartlett et al., 2011), the use of Social Media (SoMe) in helicopter emergency medical services (HEMS) (Steele et al., 2016), privacy breaches in the emergency department (Mlinek & Pierce, 1997), sharing patient information through health information exchange or telemedicine (Valenzuela Espinoza et al., 2016; Medford-Davis et al., 2017) and ambulance ramping (Kingswell et al., 2015). Most of the studies used concepts of confidentiality or privacy similar to that implied by informational privacy when referring to the content

Informants in the studies were ED and EMS patients (adults), relatives, different level of EMS personnel with varying professional titles, EMS telecommunicators (working in dispatch centres), general public and health care professionals (not defined more precisely).

### 4.2 Description of informational privacy

IP was described by the following three aspects 1) information control by patients, 2) information protection by healthcare professionals and 3) concepts related to IP (Table 3).

*Information control by patients.* IP was described as information control by patients. This control refers to the patient's rights to control the disclosure of personal information, to receive information and to know the content of personal patient records. Patients have the right to keep their personal information private or not by choosing what information they are willing to share and to whom (Kingswell et al., 2015; Tate et al., 2016; Medford-Davis et al., 2017; Koskimies et al., 2020) and the right to receive information concerning their care and condition if they wish to do so (Koskimies et al., 2020). Patients are entitled to know what has been documented in their records and to expect a high privacy standard in patient records (Koskimies et al., 2020). IP was described as a legal right (Koskimies et al., 2020) which is confirmed by the fact that consent by the patient is required when patient's information is disclosed to others not involved in the patient's care. Requiring patient consent ensures that patient's control over his/her patient records is maintained (Medford-Davis et al., 2017; Koskimies et al., 2020).

*Information protection by healthcare professionals.* IP, described as information protection by healthcare professionals, was used to refer to the duty of all healthcare professionals involved in patient's care to protect patients' information and to respect their privacy and confidentiality. The protection of patient records, containing patient information, was described as a legal duty and an obligation of all healthcare professionals (Adams et al., 1992; Mlinek & Pierce, 1997; Koskimies et al., 2020). Patients share their sensitive and personal information on the assumption that it will be protected. Therefore, the maintenance of confidentiality is required in the protection of patient records (Adams et al., 1992; Mlinek & Pierce, 1997; Bartlett et al., 2011; Koskimies et al., 2020). The respect of healthcare professionals for confidentiality and privacy is reflected in the information protection. In general, a respect for privacy and confidentiality is essential for the development of good and reliable patient relationships and highlights the will to preserve patients' dignity (Mlinek & Price, 1997; Torabi et al., 2018; Koskimies et al., 2020). A lack of respect has an influence on the patient's willingness to disclose sensitive medical information (Mlinek & Pierce, 1997) and even on the patient's willingness to receive help and care from the EMS (Bartlett et al., 2011). Therefore, the

respect for privacy and confidentiality should be maintained despite the nature of the situation (Koskimies et al., 2020).

*Concepts related to IP*. The concepts of confidentiality and privacy were related or used in relation to the concept of IP (Mlinek & Price, 1997; Medford-Davis et al., 2017; Torabi et al., 2018; Koskimies et al., 2020). In general, the concept of IP itself was less used and identified. Often it was not separated into its own domain but was described and discussed as an integral part of the privacy concept (Kingswell et al., 2015; Koskimies et al., 2020) or by the concept of confidentiality (Adams et al., 1992; Mlinek & Pierce, 1997; Bartlett et al., 2011; Torabi et al., 2018). Confidentiality was also especially used as being interchangeable with IP. A common pair of concepts presented in the studies were "privacy and confidentiality"; here privacy referred to any other dimension of privacy, but not to information and confidentiality describing the opposite of physical privacy (Torabi et al., 2018). In addition, an individual's understanding of privacy and confidentiality can vary due to different cultural and religious backgrounds and this needs to be considered (Torabi et al., 2018; Koskimies et al., 2020).

4.3 Realisation of patient's informational privacy

The realisation of a patient's IP varied between the following categories: 1) IP was realised and 2) IP was compromised (Table 3).

*Realisation of the Patient's IP.* The patient's IP was realised in the area of the protection of patient records, which concerned the handling of patient records, storing of patient records as well as reporting and conducting consultations (Valenzuela Espinoza et al., 2011; Torabi et al., 2018; Koskimies et al., 2020). Much attention was paid by paramedics to the protection of patient records and maintaining confidentiality. Patient records were handled appropriately, and patient information was not disclosed or reported to persons not involved in the patient's care (Koskimies et al., 2020). A Report was given straight to the persons taking care of the patient (Koskimies et al., 2020). Storing was good due to the electronic patient record system, although temporary storing of patient records required improvement (Koskimies et al., 2020). In addition, the patient's sensitive information was protected during consultations (Valenzuela Espinoza et al., 2011; Torabi et al., 2018). Patient's IP being realised in the area of protecting patient records, and especially during consultations, reflected to patients' trust on healthcare workers. Patients did not experience privacy issues as problematic during teleconsultations but trusted that their data and/or identity was protected by healthcare professionals (Valenzuela Espinoza et al., 2011).

*IP was compromised.* The realisation of IP was identified as being easily compromised. The realisation was compromised during ambulance ramping (Kingswell et al., 2015), in situations where language barriers occurred (Tate et al., 2016) and during challenging care situations (Adams et al., 1992; Torabi et al., 2018; Koskimies et al., 2020). Ambulance ramping had a negative effect on the patient's experience of privacy. During ambulance ramping there is a lack of private space which is why private information cannot be conveyed without the fear that some outsider might hear (Kingswell et al., 2015). Patients also waived their right to privacy during ambulance ramping because they had no expectations that their privacy would be maintained (Kingswell et al., 2015). Confidentiality breaches occurred in situations where EMS field providers and patients lack a common language. This was due to the use of bystanders or multilingual coworkers as interpreters or the use of nonverbal communication which meant necessary disclosing of patient information to persons not involved in the patient's care. (Tate et al., 2016.)

The challenging care situations included the patient's critical state and the nature of the public care environment (Adams et al., 1992; Torabi et al., 2018; Koskimies et al., 2020). Maintaining confidentiality often conflicted with medical obligations (Adams et al., 1992). In situations where the patient's state is critical and requires fast action and especially where the care environment is public, the realisation of IP must come second to saving patients' lives. (Torabi et al., 2018; Koskimies et al., 2020.) This is consistent with the paramedics' descriptions where they felt the realisation was not always in their hands (Koskimies et al., 2020).

### 4.4 Factors related to the realisation of patient's informational privacy in prehospital emergency care

Factors related to the realisation of patient's IP in PEC are described through the following categories 1) paramedic related factors, 2) patient related factors and 3) PEC work related factors (Table 3).

*Paramedic related factors.* Handling of patient records, paramedics' knowledge concerning IP, paramedics' professional activity as well as their attitudes towards IP were identified as paramedic related factors. Handling of the patient's information in such a way that third parties cannot see or hear the content of sensitive information was described as promoting the realisation of the patient's IP. To whom the paramedics disclosed information and where the disclosed their report was especially highlighted. Patient information cannot be discussed with colleagues unless they were involved in the patient's care. Reports should be given directly to the person or team supposed to be taking care of the patient (Koskimies et al., 2020). Unnecessary disclosing of identifiable patient information should also be avoided via authorized radios (Adams et al., 1992) as well as in SoMe platforms (Steele et al., 2016). As regards SoMe publications, as well as other situations where patient

information was disclosed to people other than those involved in patient's care, the requirement of the patient's consent was needed (Steele et al., 2016; Medford-Davis et al., 2017). Using a lowered voice during reports and consultations, enhanced the realisation of the patient's IP (Koskimies et al., 2020). The handling of patient records also included correct storing and proper recording. More attention especially needs to be paid to the temporary storing of information and not to leaving papers visible to bystanders. Storing under lock and key was recommended (Koskimies et al., 2020).

Paramedics' knowledge concerning IP was highlighted. Lack of information and knowledge among paramedics was identified as preventing the realisation of patient's IP (Torabi et al., 2018; Koskimies et al., 2020). Lack of knowledge and information about the IP concept as well as the patients' rights led to privacy breaches such as disclosing patient information to collaborative authorities without the patient's consent (Koskimies et al., 2018; Torabi et al., 2019). The rights of minors to control their own patient records caused particular uncertainty for the paramedics (Koskimies et al., 2020). To enhance the realisation of patients' IP more education and clear guidelines concerning disclosure of patient information is urgently needed among paramedics. The education should be focused on legislation concerning patient IP, and especially the right of minors to IP as well as the obligation of paramedics to protect rights even in acute situations. More guidance is especially needed in situations where patient information is disclosed to collaborative authorities and when publishing information on the media about incidents. In addition to paramedics, information should be directed to the significant others of patients, and to the collaborating authorities involved in patient care (Steele et al., 2016; Koskimies et al., 2020).

Paramedics' attitudes and their professional activity towards patient's IP were recognised as factors related to the realisation of patient's IP. The positive attitude of paramedics, seen in their respect for privacy and will to maintain confidentiality even in challenging situations, is part of good patient care and leads to a more reliable patient - paramedic relationship. When trust has been established, patients are more confident in disclosing sensitive information (Mlinek & Pierce, 1997). In contrast, a poor attitude by the paramedics was easily reflected in their way of working which resulted in unethical acts such as careless and indifference when handling patient records (Koskimies et al., 2020) and unnecessary disclosure of patient information to authorities (Bartlett et al., 2011). Even conscious breaches of confidentiality were reported (Koskimies et al., 2020). In addition, wrong assumptions concerning the publics' understanding of the medical terms or jargon they heard being used by health care professionals could be made because of dismissive attitudes by paramedics, and thus cause a risk of IP breaches (Mlinek & Pierce, 1997). However, the poor attitudes observed were described as being mainly due to a lack of information and knowledge (Koskimies et al., 2020). Professional

activity by paramedics was described as requiring observation and a critical evaluation of the ways of working of both one's self and others; this requires honest discussions and an open atmosphere in the work community. This observation was seen to enhance the paramedics understanding of the effect of their actions related to the realisation of patients' IP, and so promoted their skill in anticipating situations where the IP of patients may be threatened (Koskimies et al., 2020).

*Patient related factors.* The patient's knowledge concerning IP and the patient's cultural backgrounds and lack of a common language were identified as factors related to the realisation of IP. Patients knowledge concerning their rights in relation to IP was described as limited (Koskimies et al., 2020). Due to this unawareness, they may not even expect IP to be maintained in PEC (Kingswell et el., 2015). This was mainly described as due to the patients being poorly informed (Koskimies et al., 2020). Patients' varying cultural backgrounds caused a risk of IP breaches. By taking into account the patients' cultural and religious background and its influence on their perception of IP enhanced the realisation (Torabi et al., 2019; Koskimies et al., 2020). This required sensitivity from the paramedics and the patience to listen the patient's beliefs and wishes (Torabi et al., 2018; Koskimies et al., 2020). The lack of a common language between the patient and paramedics caused challenges and easily prevented the realisation of patients' IP. These language barriers often led to the use of informal interpreters such as bystanders or a colleague outside the shift (Tate et al., 2016). This however, complicated patients' opportunity to decide for themselves who should be the recipient of their private information (Koskimies et al., 2020).

*PEC work related factors.* The characteristics typical of PEC work and PEC work specific tools were identified as factors related to the realisation of a patient's IP. Characteristics typical of PEC included the critical condition of the patient, the presence of bystanders, constant haste, and lack of EMS personnel of both genders. The patient's condition is often critical and this demands the full focus of the paramedics leaving less resources for considering the protection of IP (Adams et al., 1992; Kingswell et al., 2015; Koskimies et al., 2020). In addition, it critically influences the patient's ability and possibility to influence their own care (Adams et al., 1992). The presence of bystanders clearly prevented the realisation and was mostly associated with the nature of a public care environment. Public care environments include bystanders, curious to see and hear details concerning the incident. Moreover, people taking videos and pictures of the situation are becoming increasingly common. This was considered as a clear invasion of privacy. The curiosity of people increased when the patient was well-known or a celebrity (Adams et al., 1992; Koskimies et al., 2020). In addition, the presence of relatives and other patients caused challenges to the IP protection by impacting negatively on the patient's willingness to disclose sensitive information (Torabi et al., 2018). In multi-patient situations

the consultations, reporting and interviewing is difficult to perform without other patients hearing the confidential information (Koskimies et al., 2020; Kingswell et al., 2015). This challenge occurred especially in the ED due to the proximity of other patients thus offering a less private reporting environment for paramedics. Therefore, a more audibly secured environment is needed especially in EDs during triage and ambulance ramping (Kingswell et al., 2015; Koskimies et al., 2020).

Constant haste, caused by rigorous timelines when carrying out patient examinations and treatment in order to be ready to take on the next task, contends with the protection of patients' IP (Kingswell et al., 2015; Koskimies et al., 2020). A less reported characteristics typical of PEC work was the lack of EMS personnel of both genders which may place patients in a situation where they do not wish to give or discuss sensitive information with a member of the opposite sex (Torabi et al., 2018).

As work specific tools, the electronic patient record system and ear headphones were identified as affecting the realisation of IP. Using ear headphones was recommended because it prevents bystanders from hearing confidential information spoken into radios used by authorities. However, perceptions of the electronic patient record system varied. Its use was mostly described as enhancing the protection of patient records because it enables the patient records to be stored electronically. However, the system has its weaknesses since it enables others, not involved in the patient's care, to handle the patient's records. (Koskimies et al., 2020)

## 5. DISCUSSION

Relatively few rigorous studies specifically on patients' IP in PEC have been conducted. Instead, the studies conducted have focused on confidentiality which, however, is closely related to IP. In addition, although IP was not the main purpose of research in several studies, it often appears in the results of studies. This shows that IP and privacy, in general, is a theme that strongly affects and has many connections with varying situations in healthcare.

IP was described from the aspects of information control by patients, information protection by healthcare professional and concepts related to IP. These aspects are closely in line with the definitions of IP in previous literature where the IP has been identified as a part of a multidimensional privacy concept related to patients' rights as a right to privacy (Burgoon, 1982; Demirsoy & Kirimlioglu, 2016) and especially to the patients' right to have control over their personal information (Parrot et al., 1989; Allen, 2004; Britto et al., 2010; Nayeri & Aghajani, 2010; Serenko & Fan, 2013). As our results show, the term IP itself is still less used or recognised and is often used as a synonym for the concept of confidentiality which may be due to the complexity of the concept (Beauchamp & Childress, 2001). For many of the individual patients their perceptions of privacy, including IP, was

affected by their cultural and religious backgrounds (Torabi et al., 2018; Koskimies et al., 2020). The influence of cultural backgrounds, demographics, and ethnicity on patients' experiences of privacy, and especially on the experiences of loss of privacy, has been identified before (Leino-Kilpi et al., 2003). However, according to Nayeri & Aghajani (2010) the influence of patient's cultural and religious backgrounds, and how it is considered in practice by healthcare professionals should be studied more in depth. In addition, attention should be paid to the differences between the education of nurses and physicians since it may have an impact on the way they perceive the privacy aspects of their practices (Burkhardt & Nathaniel, 2019).

According to our results, IP was realised in the area of protection of patient records (Valenzuela Espinoza, 2016; Torabi et al., 2018; Koskimies et al., 2020). However, in the Beltran-Acora et al. (2016) study, the breaches of confidentiality were especially related to the careless handling of clinical records and to the disclosure of patient information to nonmedical staff or third parties. Therefore, it is not surprising that patients are concerned that their personal information is not being protected well enough. Furthermore, 21% of the patients in the Lin and Lin (2011) study withheld information from healthcare providers in the ED due to the fear of inappropriate disclose of information by health care professionals. However, it is interesting that patients' concerns about confidentiality breaches during the use of telemedicine or using mobile phone images were low (Sikka, 2012; Lamas, Miguel, Muehlan, Schimdt, & Salinas, 2014) this is also supported by our findings. The realisation of patients' IP was identified as limited during ambulance ramping (Kingswell et al., 2015). This is in line with previous studies where breaches of privacy occurred because of the overcrowding of the ED. This situation causes a lack of inpatient beds and lengthened waiting times for everyone including ambulance ramping and thus increases breaches of confidentiality (Olsen et al., 2008).

From the identified factors in this study related to the realisation of patient's IP, it is possible for us to underline the paramedics' attitudes towards IP, the lack of knowledge concerning IP and the need for education on the subject. The poor attitude of paramedics is easily seen reflecting into their actions such as careless and indifferent handling of patient records and even conscious breaches of confidentiality. (Koskimies et al., 2020.) However, according to Beltran-Acora et al. (2016) the healthcare professionals' poor handling of patient records is due to lack of knowledge, and in many cases the breaches of privacy are unintentional. Overall, the healthcare professionals' low awareness and knowledge concerning the protection of confidentiality has been recognised previously (Ayatollahi et al., 2009; Calleja & Forrest, 2011). More education concerning patients' rights has been suggested for all health care workers, students in the field, as well as patients and their significant

others in order to enhance the realisation of patient's privacy. In addition to patient's' rights, our findings highlighted the need for education specifically covering the rights of minors to the control their patient records, and the disclosure of information in the context of collaboration with different authorities (Koskimies et al., 2020) as well as the publishing of information on media about incidents (Steele et al., 2016). However, less is reported on the education addressed to paramedics concerning IP and its protection in PEC despite the fact that the need for education has been recognized.

From the PEC work related factors, this study underlines the characteristics typical of PEC work, similarities to these have also been reported and highlighted in studies conducted in ED environments (Moskop, 2005; Olsen et al., 2008). As in PEC, maintaining patient's privacy in the ED is challenging due to a care environment that includes the presence of people not involved in the patient's care as well as the continuous need for haste and the patient's critical condition (Moskop, 2005; Olsen et al., 2008). However, in PEC the control of the bystanders in public care environments is more challenging. In addition, treatment is often carried out by two healthcare workers and they may be of the same gender. This may cause a challenge in certain cultures and religions by restricting the patient's ability to choose with whom to share / who to share /his or her sensitive information /with (Torabi et al., 2018; Koskimies et al., 2020.) Typical of the work in PEC and EDs is also the need for rapidly available patient information, which is provided by electronic patient information systems, especially in EDs (Ayatollahi et al., 2009). However, in PEC the information provided by these systems may still be scarce compared to the systems in the ED, and paramedics are forced to work with limited patient information (Zorab et al., 2015). According to Ayatollahi (2009), the staff working in the ED was not confident about the confidentiality of information in the system used. This supports our findings. Paramedics described the electronic patient record system as improving the storing of patient records, but at the same time it appeared to have flaws that jeopardize patients' IP such as easy access to patient information by persons not involved in patient care (Koskimies et al., 2020).

This review has limitations to be considered. The data search was restricted to articles published in English and from three databases only. Even though a manual search was also conducted, some of the relevant articles may have been left unidentified due to this limitation. However, an integrative review was specifically chosen to include studies with no restrictions on methodology in order to gain as broad a view of the topic as possible (Whittemore & Knalf, 2005). Another limitation is also the varying quality of the chosen studies. Although weaknesses were identified no studies were excluded from the review because of the limited amount of research conducted. The diverse use of concepts similar to IP among the studies caused challenges. Therefore, special precision was required in the

article selection process to identify all the studies exploring IP. In addition, most of the studies included were not primarily focusing on IP in a PEC context and therefore the amount of knowledge provided by many of these studies was rather limited.

Given the importance of the topic, any article identified was of significance as regards recognising gaps in the knowledge for further research.

## 6. CONCLUSION

This review showed that the research on patients' IP in a PEC context is scarce. Due to the acute and challenging nature of the PEC work, IP can easily be overshadowed which may lead to violations of IP. Therefore, more research is needed that is focused more clearly on IP in PEC context. In addition, this review revealed that the varying realisation of patients' IP is influenced by multiple different factors related to paramedics, PEC work and patients. From these factors, however, we highlight the paramedic related factors and more specifically the paramedics' knowledge concerning IP as a key element when enhancing the realisation of patients' IP. Therefore, organizations providing EMS should react on to the paramedics' need for more education concerning IP. Increasing paramedics' knowledge by education as well as practical guidance on how to protect patient's IP especially in challenging situations occurring in PEC, it may be possible to reduce the risks of patients' IP breaches and thus continue to provide high quality PEC for all the patients.

## 7. RELEVANCE TO CLINICAL PRACTISE

Factors related to the realisation of patient's IP in PEC should be brought to the attention of paramedics as well as to the organisations providing EMS to ensure the realisation of patients' IP more effectively. Even though there are factors not as easy to influence such as patient's critical condition, some of the factors can be influenced and therefore, needs to be considered more closely. Thus, the electronic patient record system improves the storing of patient records in certain situations it enables others, not involved in the patient's care to access the patient's records. This weakness of the system should be observed and resolved by the organisations providing EMS. Also, the organisations providing EMS should emphasize the use of interpreting services by paramedics even in challenging situations occurring in PEC to reduce the use of bystanders or multilingual coworkers not involved in patient's care as interpreters. Special discretion should be taken by paramedics when reporting, making consultations or interviewing patients in public places or crowded emergency departments, especially during ambulance ramping, to prevent outsiders from hearing the patient's

personal information. Overall, more guidance should be offered to paramedics concerning the disclosure of patient information, and especially concerning the disclosure of patient information in situations where collaborative authorities or underage patients are involved. Therefore, as mentioned earlier, more education is urgently needed for paramedics concerning IP and its protection which advocates an educational intervention of IP for paramedics to be planned and tested.

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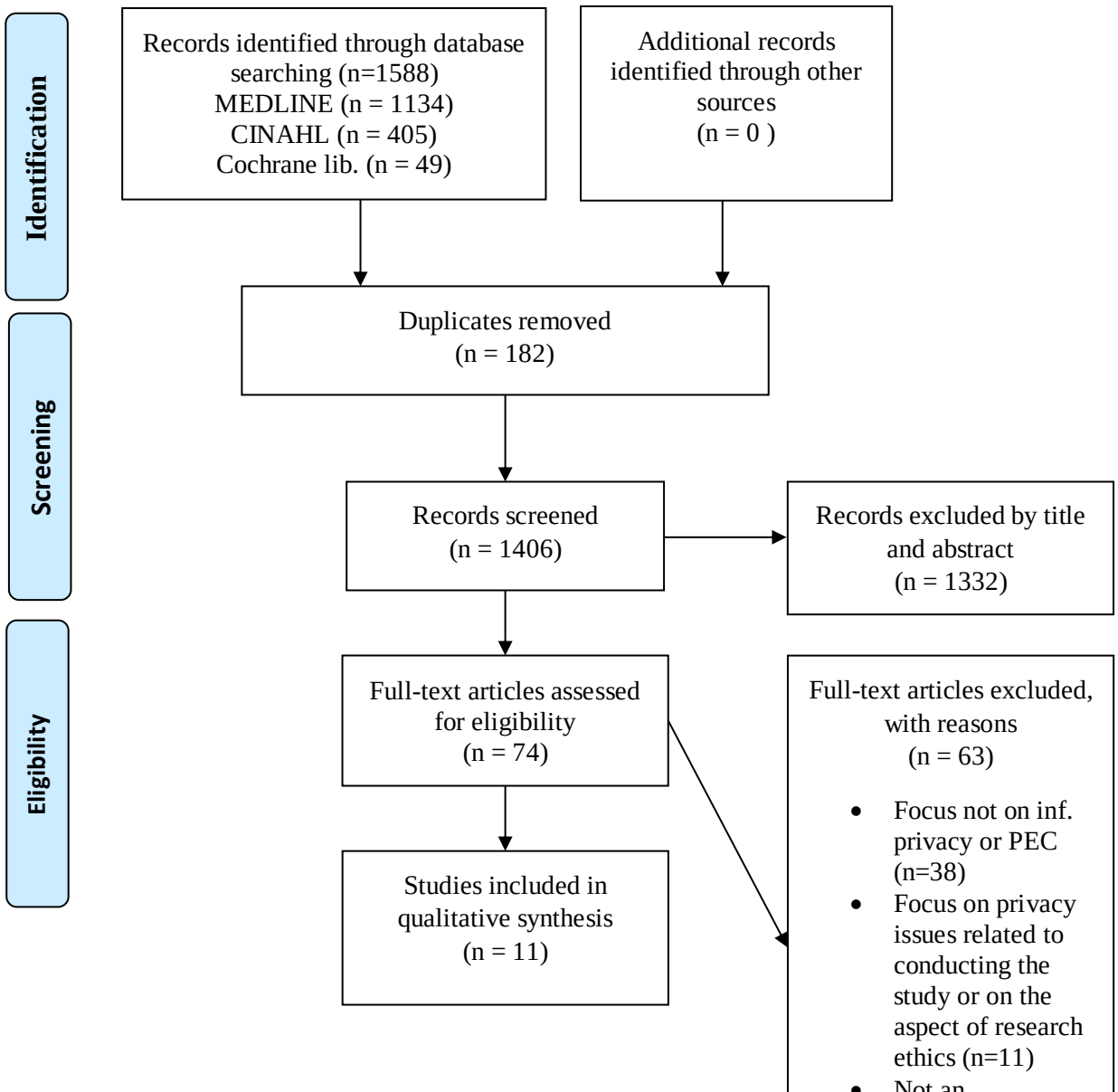
Identification
Screening
Eligibility
Records identified through database searching (n=1588)
MEDLINE (n = 1134)
CINAHL (n = 405)
Cochrane lib. (n = 49)
Additional records identified through other sources
(n = 0 )
Duplicates removed
(n = 182)
Records screened
(n = 1406)
Records excluded by title and abstract
(n = 1332)
Full-text articles assessed for eligibility
(n = 74)
Full-text articles excluded, with reasons
(n = 63)
Focus not on inf. privacy or PEC (n=38)
Focus on privacy issues related to conducting the study or on the aspect of research ethics (n=11)
Studies included in qualitative synthesis
(n = 11)


F I G U R E 1 PRISMA flow chart of article search and selection process

Table 1 The quality appraisal of the studies (n=11)

| Checklist for Qualitative Research, Joanna Briggs Institute | Bartlett et al. (2011) | Kingswell et al. (2015) | Koskimies et al. (2020) | Mlinek & Pierce (1997) | Tate et al. (2016) | Torabi et al. (2019) | Torabi et al. (2018) | Checklist for analytical cross sectional study, Joanna Briggs Institute | Adams et al. (1992) | Medford-Davis et al. (2017) | Tate et al. (2016) | Steele et al. (2016) | Espinoza et al. (2016) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Is there congruity between the stated philosophical perspective and the research methodology? | UN | Y | UN | Y | NA | UN | UN | 1. Were the criteria for inclusion in the sample clearly defined? | Y | Y | Y | Y | Y |
| 2. Is there congruity between the research methodology and the research question or objectives? | Y | Y | Y | Y | Y | Y | Y | 2. Were the study subjects and the setting described in detail? | Y | Y | Y | Y | Y |
| 3. Is there congruity between the research methodology and the methods used to collect data? | Y | Y | Y | Y | Y | Y | Y | 3. Was the exposure measured in a valid and reliable way? | NA | NA | NA | NA | Y |
| 4. Is there congruity between the research methodology and the representation and analysis of data? | Y | Y | Y | UN | Y | Y | Y | 4. Were objective, standard criteria used for measurement of the condition? | UN | Y | UN | Y | N |
| 5. Is there congruity between the research methodology and the interpretation of results? | Y | Y | Y | Y | Y | Y | Y | 5. Were confounding factors identified? | NA | Y | Y | NA | Y |
| 6. Is there a statement locating the researcher culturally or theoretically? | N | N | N | N | N | N | N | 6. Were strategies to deal with confounding factors stated? | NA | Y | Y | NA | Y |
| 7. Is the influence of the researcher on the research, and vice- versa, addressed? | Y | Y | UN | UN | N | UN | UN | 7. Were the outcomes measured in a valid and reliable way? | UN | Y | Y | UN | UN |
| 8. Are participants, and their voices, adequately represented? | Y | Y | Y | NA | Y | Y | Y | 8. Was appropriate statistical analysis used? | Y | Y | Y | Y | Y |
| 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? | Y | Y | Y | Y | Y | Y | Y | | | | | | |
| 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? | Y | Y | Y | Y | Y | Y | Y | | | | | | |

Y =yes, N =no, UN = unclear, NA = not applicable

TABLE 2 Summary of the studies (n=11)

| Study | Purpose | Design/sample | Findings of interest in this review |
|---|---|---|---|
| Adams et al. (1992) USA | To delineate and assess the range of ethical conflicts faced by prehospital care providers. | Quantitative, prospective, observational study.<br><br>Convenience sample of 607 paramedics during the four-month study period (October 1989 to January 1990) | Paramedics working in EMS face multiple ethical dilemmas regarding confidentiality issues.<br><br>The prehospital care providers' duty to maintain confidentiality sometimes conflicted with legal, operational, or public concerns. |
| Bartlett et al. (2011) China | To study the local understandings of risk factors related to overdose, evaluate the ongoing barriers to overdose response and enquire client's perspectives on how to further reduce opiate overdose mortality in Gejiu. | Qualitative, Descriptive,<br><br>Convenience sample of 30 individuals (15 people who had received a naloxone injection from a Huyangshu staff member to reverse an overdose and 15 individuals who called Huyangshu's hotline and were present during the administration of the naloxone injection). | Among "overdosers" there is an understanding that paramedics or EMTs would more likely breach the confidentiality of the patient (for example by calling the police) when compared to Huyangshu staff members. |
| Kingswell et al. (2015) Australia | To understand the ambulance ramping experience from the patients' perspective. | Qualitative, Interpretive phenomenology,<br><br>convenience sample of seven (7) patients who were presented at the ED by ambulance, and experienced an ambulance offload delay of more than 30 min. | Patients described breaches of privacy during ambulance ramping. Breaches of privacy had several elements such as: things that were seen, and things that were heard. |
| Koskimies et al. (2020) Finland | To describe patient's informational privacy, its realisation, and the factors influencing to the realisation in prehospital emergency care from the paramedics' perspective. | Qualitative, Descriptive,<br><br>discretionary sample of 26 paramedics working in one of the 22 rescue departments in Finland. | Patient's informational privacy was described and understood as patients' right to their own health records, as protection of the patient's health records as well as a comprehensive respect for the patient's privacy by individuals involved in the patient's care. Informational privacy was being realised as regards confidentiality, reporting, and maintaining the patient's health records. Multiple influencing factors related to the realisation were identified such as the nature of the work, environment, attitudes, lack of knowledge, training and guidelines. |

| | | | |
|---|---|---|---|
| Mlinek and Pierce (1997) USA | Aimed to determine the frequency of visual and auditory confidentiality and privacy breaches in a university ED. | Qualitative Prospective, observational study<br><br>32 patients who checked into the ED during the observation periods were observed. 100 patients and family members were interviewed at ED release. | In the waiting/triage area, breaches of privacy occurred due to poor auditory privacy. Confidentiality and privacy breaches committed by all members of the ED's healthcare team including paramedics. |
| Medford-Davis et al. (2017) USA | To study whether patients in emergency department are willing to share their medical records across health systems through Health Information Exchange and if so, whether they prefer to sign consent or share their records automatically. | Quantitative, Cross-sectional study,<br><br>982 adult patients presenting at / in tertiary hospital-based EDs in the United States between the hours of 7 a.m. and midnight between 28 April and 11 August 2015 | Most of the patients were willing to share their data in a Health Information Exchange but preferred to sign a consent form. However, in the case of emergencies, 90% of those would be prepared to waive the consent of inform. exchange. Reason for preferring to sign a consent form were privacy, awareness and control over who could access their information and the desire to restrict some doctors and hospitals from such information retrieval<br>The main concerns for the minority who were not willing to share their data were related to privacy and security issues. |
| Tate et al. (2016)<br><br>USA and (South) Africa | to identify and describe the communication strategies used by emergency medical services providers when confronted with language barriers as well as to describe the experienced limitations of the strategies used . | Mixed methods study Descriptive<br><br>Seven (7) dispatch centers (three in New Mexico and four in Western Cape) and 27 paramedics. | breaches in patient confidentiality was identified as a limitation of the strategies most commonly used by 33% of the interview participants.<br>The most commonly used communication strategies were using bystander interpreters, multilingual coworker interpreters, and non-verbal communication methods. These strategies are often effective however, they are limited by concerns of associated time delays, inaccuracies, and risks to patient confidentiality. |
| Steele et al. (2016)<br><br>UK | To Explore the use of SoMe by helicopter emergency medical services (HEMS). To identify SoMe platforms used, highlight the trends in SoMe use as well as sort out whether the existing guidance to SoMe use is sufficient. | Quantitative Cross-sectional, observational study<br><br>24 UK HEMS | SoMe is being widely used among HEMS. Its use was mainly pervasive and some of the SoMe posts contained extensive information about patient's treatment and location. The way SoMe is being used leads to questions of whether such practices may jeopardize patient privacy and confidentiality. |
| Torabi et al. (2019)<br><br>Iran | To describe the experiences of Iranian prehospital emergency personnel in the field of | Qualitative, Descriptive, | EMS personnel recognize and understand the cultural value of respecting patient privacy. The respect for patients' privacy and |

| | | | |
|---|---|---|---|
| | ethical decision-making and to identify strategies that are used to solve ethical conflicts. | 15 Iranian prehospital emergency personnel | confidentiality is reflected in the paramedics' way of work. |
| Torabi et al. (2018)<br><br>Iran | To identify and describe the Iranian pre-hospital emergency service personnels' experiences in the field of ethical decision making when they faced with ethical dilemmas. | Qualitative, Descriptive,<br><br>Puprosive sampling of 14 EMS personnel | From the ethical dilemmas described, some of the major issues EMS personnel were faced with related to the patient's privacy and confidentiality issues, such as, respecting the patient's privacy in private consultation as well as in general during prehospital emergency care.<br><br>Multiple limitations are probably involved in failing to protect patient's privacy and confidentiality such as: a lack of personnel of both genders, lack of knowledge of the patients' rights , priority to save the patient's life, the psychological stress caused by relatives' presence during patient's treatment. However, despite the limitations, the EMS personnel tried to maintain the privacy of patients. |
| Valenzuela-Espinoza et al. (2016)<br><br>Belgium | To characterize and compare the opinions of the general public, health care professionals, and stroke patients concerning the use of telemedicine in emergency treatment during ambulance transportation and for chronic care at home. | Quantitative, Cross-sectional study,<br><br>607 participants (of which 123 = professional caregivers who conducted the questionnaire online via UZB intranet, 234 = visitors whose survey was conducted via face-to-face interviews of visitors at the UZB on World Stroke Day and 250 = participants via social media). | Privacy issues were not seen as problematic, since only 7% of all respondents had no confidence that their privacy and identity would be protected during telemedicine consultations. Most respondents were ready to participate in future teleconsultations. |

TABLE 3 Results for research questions 2) How is informational privacy described in the field of prehospital emergency care, 3) How is the patient's informational privacy realised in prehospital emergency care and 4) What are the factors related to the realisation of patient's informational privacy in prehospital emergency care?

| Research question | Main categories | Subcategories |
|---|---|---|
| 2) How is informational privacy described in the field of prehospital emergency care? | Information control by patients | Patient's right to control the disclosure of personal information<br><br>Patient's right to receive information<br><br>The patient's right to know the content of his/her personal patient records |
| | Information protection by healthcare professionals | Duty to protect patient information<br><br>Respect for privacy & confidentiality |
| | Concepts related to informational privacy | Privacy<br><br>Confidentiality |
| 3) How is the patient's informational privacy realised in prehospital emergency care? | IP was realised | Protection of patient records |
| | IP was compromised | Ambulance ramping<br><br>Situations where language barriers occur<br><br>Challenging care situations |
| 4) What are the factors related to the realisation of patient's informational privacy in prehospital emergency care? | Paramedic related factors | Handling of patient records<br><br>Knowledge concerning IP<br><br>Professional activity<br><br>Attitude towards IP |
| | Patient related factors | Knowledge concerning IP<br><br>Cultural background<br><br>Lack of common language |
| | PEC work related factors | Characteristics of the PEC work<br><br>Work specific tools |

The data can be accessed via the corresponding author.