Adult Patients' Experience of Coercion in Intensive Care: A Scoping Review

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Abstract

Background

The use of coercion, which can be understood in a clinical context as imposing a measure against a patient's opposition or declared will, can occur in various forms in intensive care units (ICU). One prime example of a coercive measure in the ICU is the use of restraints, which are applied for patients` own safety and for the protection of caregivers. A scoping review was conducted to explore the empirical data available on the experiences of ICU patients with coercive measures.

Main text

For this scoping review, clinical databases (PubMED, EMBASE, PsychINFO, Web of Science Core Collection, CINAHL, Scopus and Cochrane Library) were searched for qualitative studies. Using the CASP criteria for qualitative studies, the review focused on empirical research that captured how ICU patients themselves experienced restraints or other forms of coercion and excluded research related to staff experiences. A total of nine studies could be retrieved that fulfilled the inclusion criteria.

The review describes common themes emerging from the scarce studies on patient experiences, including communication issues, delirium, memory, and emotional reactions. In spite of their serious clinical condition and fluctuating states of consciousness, a part of the patients did have memories of their ICU stay. Statements from patients revealed feelings of compromised autonomy and dignity that came with a loss of control. Physical restraints were only one concrete manifestation of coercion as perceived by patients in the ICU setting.

Conclusion

To date, there are few qualitative studies focusing on patient experiences of coercive measures in the ICU. In addition to the experience of restricted physical movement, the perception of loss of control, loss of dignity and loss of autonomy suggests that restraining measures are just one element in a setting that may be perceived as coercive. Health professionals may underestimate how deeply patients are affected by the perception of coercion. Good communication that clearly explains unavoidable measures to patients can reduce the negative impacts of coercive measures. More research on patient experiences is needed in order to reach a more comprehensive understanding of how patients perceive their ICU stay and to identify opportunities for further improvement of intensive care.

Introduction

Understanding the experiences of patients in the intensive care unit (ICU) is important in order to tailor interventions that minimize hardship and suffering. When a patient is faced with potentially fatal health conditions that require life sustaining therapies such as invasive machines and powerful medication, they often are inevitably exposed to physical pain, psychological distress, and delirium [1, 2]. Patients find

themselves in a situation of psychological and physical dependence on their caregivers, which can threaten their identity and dignity. Constraining the patient using an active or passive approach has been shown to increase the patient's sense of dependency and suffering [2]. When the ICU clinical teams support patients in understanding and adjusting to the situation, a sense of dignity and humanity can be restored [3, 4].

Coercion can be defined as "a mode of influence that operates by threats and force; aims at controlling the recipient's being, movement, or will; and leaves, at least initially, its recipient *disadvantaged*." [5]. In cases of coercion, a patient's liberty is restricted even if the patient is unable to actively recognize that he or she has been put under restraint [6]. "The transition to coercion occurs where support for the patient's self-determined formation of will ceases and the will of those treating the patient gains the upper hand without sufficient participation by the person concerned" [6].

Using this broad definition of coercion in a medical context, various situations in the ICU can be perceived by patients as coercion. In the ICU, restraints can take many forms; restraints are defined as, "something that limits an individual's freedom of movement" [7] and can include mechanical/physical [8], pharmacological, or psychological measures to actively or passively restrain the patient [7, 9].The need for continuous monitoring of a patient can also be perceived as a kind of environmental restraint [7, 10]. Examples of psychological restraints include threats, misinformation, manipulation, withholding privileges, and other influences [9, 11]. The various forms of restraint are often used in combination with one another [12].

The scientific literature mainly discusses the health professionals' point of view, especially on physical restraints. One common justification for the use of both mechanical and pharmacological restraints is to protect the patient, for example from injuries caused by unintentional removal of an endotracheal tube, cannula, catheter or other devices [13, 14]. However, studies suggest that the incidences of unintentionally removed devices is even higher in restrained patients [15, 16]. Some studies report the use of physical restraint being involved in severe injuries and even death [14, 17]. In addition, physical restraint may increase the need for sedation, magnifying the risk of possible consequences that are associated with deeper sedation. There is an ongoing debate regarding the association of restraints with post-traumatic stress disorder (PTSD) [18].

The ambiguity around when and how to appropriately apply restraints is evident in the variation of their use and regulation in different countries. One study comparing the frequency of use of physical restraints in different countries showed a range of 7% to 87% of patients reporting the use of physical restraints of any form during their ICU stay [19]. The PRICE study, conducted in 34 European ICUs in 9 countries, found that an average of 33% of all patients were restrained in some way during their ICU stay [12]. Some differences between countries were significant; in the United Kingdom and in Portugal, no patients were restrained, whereas, in Italy, every ventilated patient was restrained [12].

Faced with these different approaches to coercive measures, and the ambiguity of their justification by different ICU teams there, is a need to broaden the scope of research on coercion and include the

perspective of patients in order to hopefully support the creation of guidelines that center the patient's experience. The aim of this scoping review is to better understand how patients experience restraints and other potential forms of coercion in the ICU.

Methods

Using a research protocol (PRISMA checklist 2018 [20]), a search was run that included qualitative and mixed methods studies of patient experiences of restraints or other coercive measures in the ICU that were available up until August 2019. Reviews were assessed for qualitative statements. Studies in German and English were included.

Studies were excluded if they only relied on a quantitative approach because such studies do not allow patients to express their full range of experiences. As the aim was to gain insight into the patient's perspective, records dealing with the experiences of nurses, physicians and other clinical staff were excluded (Table 2).

The main search was run using subject heading/MeSH terms and a keyword search. The search strategy was adjusted for the individual interface of seven databases (PubMED, EMBASE, PsychINFO, Web of Science Core Collection, CINAHL, Scopus and Cochrane Library). A google search of grey literature was conducted, but no relevant studies were identified.

Most records were identified through the Scopus database (n=193). Search terms are displayed in Table 1. Two examples of the search strategies are presented in Appendix 1. On the first attempt, only four records were identified through PubMED. The terms were amended to include all patient experiences in the ICU and the search rerun. The search was conducted, including screening and abstract assessing, by two colleagues. Studies had to fit the inclusion criteria and full text had to be available. After the screening process, 17 studies remained. The quality of the included studies was assessed using the Critical Appraisal Skills Program for qualitative research (CASP) [21]. The STEPwise approach was used for data extraction [22]. First, all relevant articles were searched for mentioning "coercion" or "restraints". Secondly, in the text analysis, categories and themes were identified through discussion with the second researcher [23].

Results

After removing duplicates, abstract screening, and full text analysis, 9 qualitative studies remained (Figure 2 + Appendix 2: Table 1). One study (Minnick) dealt with the topic "physical restraint in intensive care units". Eight studies covered communication, delirium, memories and psychological experiences in intensive care units. In these eight studies, spare statements about coercion experiences were mainly related to physical restraint. Two of the studies were secondary analyses of previous study results [24, 25]. Themes and results on coercive measures/restraints regarding patient experiences can be found in Table 3.

The findings can be summarized into four main groups of patient experiences:

(Table 4)

1. Most patients have no recollection, incomplete recollection, or faulty recollection regarding the experience of having been restrained in the ICU.
2. The statements that do exist on measures of restraints range from memories based on reality to delusional recollections.
3. Perceptions of coercion can be accompanied by a sense of loss of dignity, dependence, and discomfort.
4. Constructive communication can have a positive effect on patients' experiences in the ICU.

1. Often patients have no, incomplete or faulty recollection regarding the experience of having been restrained in the ICU.

A number of studies reported that patients had incomplete, confusing or delirious memories [24-30]. Minnick et al. describe incomplete recollection in 60% of patients who underwent restraining measures during their stay in the ICU [31]. In a study conducted by Chahraoui et al., all of the participating patients initially reported having no memory of their ICU treatment [32]. This might be explained by the severe and in some cases critical condition of patients included in the study. Moreover, metabolic, physiological and psychological changes that affect memory can appear alongside multiorgan-related illnesses and can be worsened by sedative and/or analgesic drugs [26, 32].

2. The statements that do exist on measures of restraints range from memories based on reality to delusional recollections.

Stories of being held down, restrained and medicated are often embedded in findings on hallucination and distorted memories [26, 30, 31]. Receiving life sustaining therapies in the ICU and including restrictions of movement often result in the feeling of being "locked up," [27]. In a study by Chahraoui et al., patients also had some recall of physical restraint, "painful memories of being tied down", after memories were triggered by an external source [32]. Furthermore, restrictions by equipment often contributed to the perception of being restrained. Darbyshire et al. (2016) describe a wide range of perceptions and delusions that include abduction, imprisonment and "feelings of restraint" generated by "restriction of movement by the equipment" and "blurred reality" [25]. In the collection of patient experiences of acute mechanical ventilation reported by Roberts et al., the majority of patients had memory of mechanical ventilation. They associated restraining measures and mechanical ventilation with fear and helplessness [29]. When patients were able to recall their ICU stay and experience with restraints, they expressed a range of negative feelings, which could be related to some forms of restraint.

3. Perceptions of coercion can be accompanied by a sense of loss of dignity, dependence, and discomfort

Table 4 shows that negative experiences in the ICU were not only related to the use of physical restraints; other aspects commonly linked to negative perceptions included lack of control, helplessness, noise, anxiety, pain, ventilation, dependency, insomnia and delirium with or without accompanying hallucinations. Endotracheal tubes, which interfere with active communication during ventilation, were especially linked to the perception of helplessness and dependency [24-30, 32]. Many patients attributed a sense of loss of dignity to dependency and lack of control [25-27, 29]. Moreover, feelings like powerlessness, uncertainty, and 'feeling lost' were commonly described in combination with anxiety [27]. Dziadzko et al. reported that restraining measures worsened the emotional state of the patient. Indeed, in their study, "The inability to communicate (34%), environmental factors (noise, alarms, laughter) (30%), procedures and restraints (24%), and intubation (12%)" were listed as the primary factors leading to negative emotions and worsened the psychological stress that is already present in the ICU [30]. These difficult experiences suggest that patients in the ICU are especially vulnerable to feeling or being coerced in the midst of an experience defined by a sense of loss of autonomy, identity and dignity. These situations carry the risk that the will of those "treating the patient could gain the upper hand without sufficient participation by the person concerned" [6].

4. **Constructive communication can have a positive effect on patients' experiences in the ICU.**

In contrast to other reports, the studies by Clukey et al. and Minnick reported patients who recalled their stay in the ICU and restraining measures without negative associations. Some patients were able to understand the use of restraint as for '*their own good*' if communicated and explained appropriately [28, 31]. Likewise, Guttormson et al. described experiences by patients where information was helpful in the acceptance of procedures and restraints [24]. For some patients, the presence of family members ameliorated some of the challenging factors of their ICU stay [28, 30, 32]. All studies stated that information and good communication could reduce stress or fear and be beneficial for patients in the ICU, whether the source of information came from family or providers (Table 4). Patients and relatives both described positive memories of emotional and moral support from the care team that improved the overall experience [30]. Good communication and understanding the reasons for the restraints alongside family and staff emotional support seemed to play a critical role in the patient's acceptance and ability to process the restraints.

Discussion

There is a paucity of qualitative studies concerning restraints in the ICU. A major challenge with studying the issue of coercion or restraints from the patient's perspective is that patients often do not clearly recall their ICU stay. Most patients had limited or incomplete recollections of their time in the ICU. That said, when reflecting on the overall experience of being in the ICU, physical restraints were perceived as a part of a threatening situation and as going against the patient's free will.

Autonomy and dignity are universally recognized as ethical principles to respect, even though their specifications may vary in national laws [33, 34]. Coercion can arise by way of measures that restrict

freedom (restraints). There is widespread consensus that restraint should only be applied in exceptional circumstances and if communicated clearly [16, 35, 36]. Even though restraints are used to protect the patient from self-induced harm, there is limited evidence that physical and/or pharmacological restraints are related to better outcomes [14, 37]. The intensive care community is aware of the psychological and ethical risks of restraining measures [16]. To avoid restraint in the ICU, guidelines are suggested and training efforts have been established [38, 39]. It is valuable to have the patient's perspective on restraining measures when developing such guidelines and messaging [40].

Individual freedom may be limited by situations in which one cannot express oneself, cannot pursue one's individual goals, or cannot access opportunities to act [41]. There is also a perception in the literature of patients' experiences regarding lack or bad communication, lack of information, lack of control, helplessness, anxiety, pain, ventilation, dependency, insomnia and delirium that carry a risk of overriding the autonomy and dignity of the individual [42, 43].

Some authors argue that non-pharmacological strategies should be considered before using restraints [38]. Other studies have suggested that allowing the patient to remain awake; mobilizing them; administering sufficient therapy for pain, delirium, and anxiety; and including the family as much as possible in the process are all useful [38, 39]. Here, the challenge seems to be how best to keep patients awake and mobile during their stay in the ICU to improve quality of life [44]. Moreover, there remains an asymmetrical power dynamic between the clinical team and the patient.

When adequate and focused communication is provided, some patients are able to accept restraining measures for their own good. This is a challenge, though, as patients in the ICU are often incompetent or agitated. Communication in such situations is difficult. Patients do report feeling understood and supported when talk to [28, 31]. Patients want to be informed and updated and also want to discuss problems to be a partner in decision-making [45]. Allowing family members to be with the patient in the ICU helps to empower patients and has been shown to positively influence outcomes and decrease length of stay [46, 47]. To preserve a sense of reality and to provide the best possible support, patient diaries, a later visit to the ICU, or psychological support post-discharge may be useful [48, 49].

In this scoping review, the identified experiences of coercion in the ICU were not only related to the use of restraints. The perception of helplessness, dependency, powerlessness and the loss of dignity may additionally be considered as a risk of disadvantage and coercion.

Guidance and education on how to recognize the patient as a person and communicate with him/her as a partner may reduce the perception of coercion and related negative emotions. Following a care ethics approach, a patient's perspective and participation should be included in the therapeutic journey [40].

Limitations

A major limitation of the present study is the lack of recollection of ICU experiences by patients, as well as the delusional memories that might have impeded their perceptions. This has been widely reported by

previous studies and can be difficult to avoid as it is related to the actual clinical situations of ICU patients. Another limitation concerns language. The study only included studies available in English and in German, and may, therefore, have missed important contributions published in other languages.

Conclusions

The present scoping review revealed a significant lack of literature concerning coercion and restraints in the ICU from a patient perspective. Based on the findings, restraining measures cause a range of negative emotions, which reinforces the idea that they should only be used in exceptional circumstances. Furthermore, the perception of helplessness, dependency, powerlessness and loss of dignity may be considered psychological forms of coercion. It may be relevant to broaden the term coercion and coercive measures to encompass forms beyond just physical or chemical fixation to include these psychological vulnerabilities. Future research should investigate the long-term impacts of coercion on patients' outcomes and explore alternative measures.

Abbreviations

ICU – Intensive Care Unit

CASP - the Critical Appraisal Skills Program for qualitative research

Declarations

Ethical approval and Consent to participate:

Not applicable

Consent for publication:

Not applicable

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All data generated or analized during this study are included in this published article (and its supplementary information files).

Conflict of interest:

The authors declare no conflict of interest.

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Authors contribution:

SJ: conception, acquisition of data, analysis and interpretation of data, drafting and revising the article, final approval

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BR: revising the article, final approval

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Tables

Table 1: search terms

	concept	search terms
1	**coercion/restraints**	restraint
		constraint
		repress*
		coercive
		AND
2	**ICU**	intensive care
		critical care
		critically ill
		intensive care medicine
		AND
3	**experiences**	experienc*
		memor*
		patient`s attitude
		interview
		narrative
		qualitative trial
		qualitative study
		reviews
		mixed method
		NOT
4		child*
		psychiatr*
		geriatric
		experiences staff
		quantitative survey only

Table 2: inclusion/exclusion criteria

inclusion criteria	exclusion criteria
• > 18 years old • mentioning restraining or coercive measures • interviews conducted after stay in the ICU (patients) • qualitative studies and mixed-studies • reviews – with patient experiences in the ICU to find qualitative studies with coercive measures or restraint	• setting: psychiatric, geriatric, regular ward • experiences/case reports by clinical staff dealing with restraint patients • quantitative studies without qualitative component • questionnaire-only studies

Table 3: themes paper - scoping review coercion

Author	Themes	experiences on coercion and restraining measures in the ICU
Minnick [31] 2001/USA	physical restraint	patients do not remember great distress being restraint
Dziadzko [30] 2017/USA	acute psychological trauma in the critical ill	procedures/restraint (24%) = “Things that made patient feel worse”
Guttormson [24] 2014/USA	communication during mechanical ventilation	accepting restrain when informed
Darbyshire [25] 2016/Great Britain	delusion on intensive care	restraint, restriction of movement by environment à lack of control
Moser [27] 2018/Switzerland	fear on chronical ill patients on ICU	restraint (“wie eingeschlossen”), Angst durch Fixierung Angst andere Wirklichkeit: (“I felt trapped”)
Chahraoui [32] 2015/France	psychological experiences patients on ICU	negative memories: restraint,
Russell [26] 1999/Australia	experiences in intensive care unit	between delusion and reality: restrain: “feeling captive”
Clukey [28] 2014/USA	pain in intubated and sedated patients	some lack of memory restraint intubation worse than restraint
Roberts [29] 2019/USA	experiences of acute mechanical ventilation	restraint: “..frightened and disconcerted and really anxious…” “I had no control”

Table 4: negative/helpful experiences on ICU

Author	Negative experiences	Helpful experiences
Minnick	- delirium - intubation	- communication
Dziadzko	- inability to communicate - environmental factors - procedures and ***restraints*** - intubation	- communication - support by family - emotional support - moral support
Guttormson	-lack of information à *helpless* -perceived lack of information was associated with *not feeling in control and helplessness* -can`t communicate	-benefits of information/ communicationà relieve anxiety and 'settle the mind.' - information helped tolerate treatments including the ventilator and ***physical restraints***.
Darbyshire	- delusion **- *restraint*,** restriction of movement by equipment à lack of control - loss of autonomy - isolation	
Moser	-fear by delusions, ---nightmares helpless/ dependency without dignity (feeling like an object)	- information - trust in people
Chahraoui	- lack or false memory, - negative memories related to ***physical restraint***, sleep disorders difficulties arising from not being able to talk, pain, feelings of incomprehension about ICU stay, feelings of fear, sensation of impending death and a feeling of having been abandoned by their family/caregivers	-positive memories: support from the health care team and family
Russell	- lack of communication - delusion: stories of being held down, ***restrained*** and medicated `into oblivion'.	-presence of good communication

	- poor communication, - lack of privacy, fear, pain and noise - lack of dignity	
Clukey	-intubation worse than ***restraints***	- nurse provide information and anticipatory guidance helped relieve anxiety for both - good communication
Roberts	- lack of communication - lack of control - frightened and disconcerted, anxious - lack of control	- effective communication

Figures

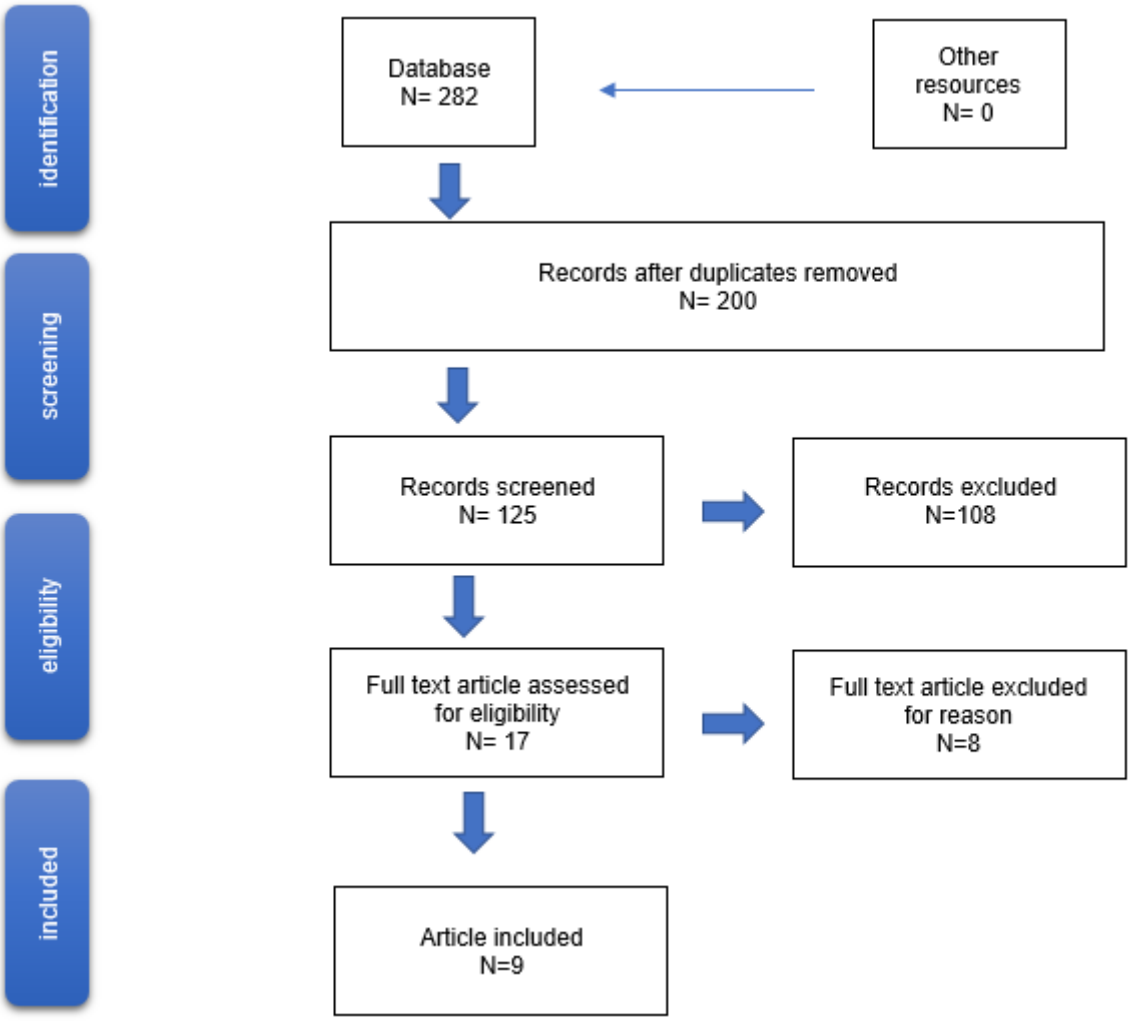

Figure 1

Flowchart (PRISMA)

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Appendix1.docx
- Appendix2.docx
- graphicalabstractfinal.pptx