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Review

An integrative review of patient safety in studies on the care and safety of patients with communication disabilities in hospital

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ABSTRACT

Objective: To review the research literature on the experiences of patients with communication disabilities in hospital according to the Generic Model of patient safety.
Methods: In 2014 and 2015, we searched four scientific databases for studies with an aim or result relevant to safety of hospital patients with communication disabilities. The review included 27 studies.
Results: A range of adverse event types were outlined in qualitative research. Little detail was provided about contributing or protective factors for safety incidents in hospital for these patients or the impact of the incidents on the patient or organisations involved.
Conclusion: Further research addressing the safety of patients with communication disabilities is needed. Sufficient detail is required to identify the nature, timing, and detection of incidents; factors that contribute to or prevent adverse events; and detail the impact of the adverse events.
Practice implications: In order to provide safe and effective care to people with communication disabilities in hospital, a priority for health and disability services must be the design and evaluation of ecologically appropriate and evidence-based interventions to improve patient care, communication, and reduce the risk of costly and harmful patient safety incidents.

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1. Introduction

Improving the safety of the most vulnerable patients in hospital is a high priority in any self-improving health system [1,2]. The majority of serious patient safety incidents in hospital are not well documented due to the difficulty measuring and identifying the many components that play a part in the incident [2]. In hospital, vulnerable patients with communication disabilities (i.e., impairments of body structure or function that impact upon speech, language, or communication function) face a three-fold increased risk of sustaining preventable and harmful patient safety incidents [3]. There is, however, inadequate evidence on both the causes of the increased risk and on ecologically appropriate interventions (i.e., interventions that are appropriate in the context of a busy hospital ward) to reduce risk for this patient group. Such information is needed to inform improvements to practice, develop effective policy to prevent these adverse events, and reduce the impact of any associated negative outcomes. Without evidence relating to factors influencing their safety in hospital, patients with communication disabilities will continue to experience significantly longer stays and re-admission rates as a result of harmful and preventable patient safety incidents [2]. Apart from the costs to the patient's health and wellbeing, patient safety incidents incur substantial financial and opportunity costs to governments, hospital services, and community-based disability services and family carers, particularly if these events are associated with increased length of stay or re-admission to hospital [3].

According to the World Alliance on Patient Safety Drafting Group (2009) [4], "a patient safety incident is an event or circumstance that could have resulted, or did result, in unnecessary harm to a patient. A patient safety incident can be a reportable circumstance, a 'near miss', a no harm incident or a harmful incident (adverse event)" (p. 4). In this paper we use the term 'patient safety incidents' to embrace all of these circumstances.

Table 1
Models of patient safety, elements, type of model and comments.

Model	Model elements	Type of model and comments
The Systems Engineering Initiative for Patient Safety (SEIPS) [20,47]	Model focuses on the work system component (i.e. "structure"), and includes elements derived from ergonomics and human factor disciplines. Consists of person; organisation; technologies and tools; tasks; environment	Descriptive/exploratory/the "individual" with the SEIPS is any individual at the center of the healthcare system (i.e. health professional and/or patient), as such this system is tailored to support the performance of each individual. SEIPS 2.0 [47] has been updated to include the concepts of configuration, engagement and adaption
The Generic Reference Model [1,2]	Model has three broad categories: contributing factors and hazards; the incident; and outcomes and consequences	Causal/uses a "generic framework" to model patient safety underpinned by a risk management structure
International Classification of Patient Safety (ICPS) [4,15,16]	Model has 10 higher level classes of patient safety, with each class further categorised into a hierarchical structure	Causal/initiative of the World Health Organisation and aims to encourage patient safety research to incorporate a standardised framework and terminology to aid in the systematic collection and analysis of data, and in turn, improve its synthesis and use. This model builds upon the previous work of [1,2] and comprises elements of risk identification, prevention, detection and reduction, incident recovery and system resilience
Systems Analysis of Clinical Incidents [17,18]	Model overlays seven factors (institution, organisation, work environment, team, individual staff, task and patient) over the organisational-accident model [19] which includes a hierarchy of causative factors leading to the adverse event (accident). Consists of Latent failures (system and organisation processes); current conditions of work; Active failures (including the purpose; barriers/defences; accidents	Causal/recognises that adverse events occurs due to elements at the task, team, work environment, and organisation. The framework aims to define how these factors influence practice
Model of role of the learning disability liaison nurse and effect on patient safety [32]	Model identified the core elements of the role of learning disability liaison nurses' role in patient care. Model has seven key elements at the centre of the role: advocating, collaborating, communicating, educating, facilitating, influencing, and mediating. An additional two elements influence the two key elements: Supporting infrastructure; and nurses' expert knowledge, skill and experience	Descriptive/the role of the liaison nurse is complex and multidimensional. Patient outcomes are linked to capacity and consent to treatment, fostering person-centred adjustments to care, augmenting communication, and advocating for patient care. The 9 components in the model combine to influence the clinical, educational and strategic dimension of the nurses' role in place within the setting, which in turn effect the outcomes
Influences on the health, safety and welfare of adults with learning disabilities in acute care settings [26]	Model has concentric circles represent layers of impact on the patient: the direct layer (health, safety and welfare) and the indirect layer (liaison services and training). The model shows six key areas affecting the health, safety and welfare of this group: care provision; communication; staff attitudes; staff knowledge; supporters and carers; physical environment	Descriptive/communication, in particular, the difficulty in being able to communicate. Accompanied by table with detail on components
Factors that affect the promoting of a safer environment for patients with learning disabilities [48]*	Conceptual research framework is presented as a first step for informing the analytical framework for the analysis of barriers and enablers to providing "reasonable adjustments"	Descriptive/paper presents on the barriers and enablers to providing reasonable adjustments in health care for individuals with intellectual disability. These are presented in figure 1 of [48] "empirical framework". Factors in the framework are presented in the context of national and inter-organisational agendas and include organisational context; staff: individual and teams; patients and their carers

*Supplementary materials of [48].

At any one time, patients with communication disabilities comprise up to 15% of the hospital population. Communication disabilities affect patients' ability to speak with and/or understand the hospital staff who care for them [3,5]. In some hospital wards, the prevalence of communication disability may be higher—as many as 88% of adults on stroke wards have communication disabilities [6]. Adults with communication disabilities (e.g., associated with cerebral palsy, intellectual disability, stroke, motor neuron disease) have a significantly increased risk of multiple health conditions that result in them entering hospital more frequently than their non-disabled peers and remaining there longer [7,8]. Those with lifelong or developmental disability experience a life-course of declining function with increasing age [9], and are over-represented in hospital because of their complex health conditions [10]. Indeed, young adults with cerebral palsy enter hospital up to seven times more frequently and remain there up to ten times longer than age-matched peers [7]. Although the costs to community services providing care in hospital are not known, these are likely to be substantial due to family carers taking leave from work to care, community organisations funding paid carers to provide care in addition to that provided by hospital nurses, and the substantial costs that relate to the harmful events [2]. If costs are to be decreased and patient safety, wellbeing, and satisfaction increased, new information on (a) what contributes to the system's errors for patient safety incidents in this population, and (b) strategies to increase system resilience, is needed. Rigby et al. recommended using research methods that included interviews, chart reviews, and document analysis to gather the most comprehensive information in patient safety research [11]. Data collection for such studies needs to be guided by any evidence on the care of patients with communication disabilities that relates to patient safety. People with communication disabilities form a heterogeneous population and the research on safety issues faced by this group provides a diverse literature in terms of aims, methods and findings. Consequently, it is important to select a 'guiding framework' for analysis of findings across studies. Therefore, both generic and specific patient safety frameworks were compared first for their applicability to literature relevant to the safety of patients with communication disabilities in hospital.

1.1. Patient safety models: the importance of conceptualizing patient safety

Within the context of patient safety research, a number of conceptual models have been proposed. Conceptual models aim to show the relationship between the various concepts, factors or variables so as to explain, organise, represent or plan a certain situation or phenomenon [12]. We considered the well-supported generic patient safety models and models of patient safety located in recent literature on the care of adults with communication disabilities in hospital. Descriptions of these models and characteristics aligning with the International Classification of Patient Safety (ICPS) [15] are presented in Tables 1 and 2.

The two main types of model that exist are causal and descriptive, with some models including elements from both categories [13]. Causal models act to explain through the explicit linking of concepts, the direct path to an endpoint or outcome. In comparison, a descriptive model includes all components relating to the outcome. Therefore, a causal model can be used to generate and test a hypothesis relating to the outcome, whereas a descriptive model is more useful for organising the various components of the situation or phenomena [13]. It is also important to define the model's context as this can impact upon its interpretation [14]. Furthermore, patient safety incidents do not occur in isolation, but within health systems in which contributing factors and hazards cause failures that lead to the incident [2].

Accordingly, a number of conceptual models relating to patient safety have been proposed and these differ in their components and the associated relationships. Vincent et al. [17,18] described a framework to systematically evaluate the various system factors influencing patient safety. This model extends Reason's organisational-accident model [19] in being adapted for clinical settings with classification of factors and conditions relating to the organisation, staff, task and patient factors [17,18].

The Systems Engineering Initiative for Patient Safety (SEIPS) [20] is a model that extends the early work of Donabedian and the Structure-Process-Outcome model [21]. SEIPS focuses on the work system component (i.e. "Structure"), and includes elements derived from ergonomics and human factor disciplines. The "individual" at the centre of the SEIPS model can be any person involved in the care of the patient and/or the patient. As such, this model is tailored to support the performance of each individual.

In 2006, Runciman [1] introduced a "generic framework" to model patient safety that is underpinned by a risk management structure. The model is split into three broad categories: (1) *contributing factors and hazards*, (2) *the incident*, and (3) *outcomes and consequences*. The conceptual 'generic model' described by Runciman et al. [2], encapsulates: contributing factors and hazards (environmental, organisational, human, subject of incident, drugs-equipment-documentation). These lead to *the incident*(any incident that could have led or did lead to damage-loss-harm, a near miss or adverse event, with characteristics of demographics, person involved, timing of incident, timing of detection, method of detection, preventability included). This in turn leads to (3) factors minimising or aggravating outcomes or consequences, which lead to (4) outcomes and consequences: (a) Health Care Outcome for

Table 2
Alignment of models of patient safety considered in relation to elements within the International Classification of Patient Safety.

Model reference in year order	Incident type	Patient outcomes	Patient char.	Incident char.	Contribut. factors/ hazards	Org. outcomes	Detect.	Mitig. factors	Amel. actions	Actions taken to reduce risk
Vincent et al. (1998; 2000) [17,18]	No	No	Yes	No	Yes	No	Indirectly related to defences		Barriers/	No
Runciman et al. (2006) [1]	Yes	Yes	No*	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Carayon et al. (2006) [20]	No	Yes	Yes	No	Yes	Yes	No	No	No	No
Brown et al. (2012) [32]	No	Unclear, indirectly		No	Yes	No	No	No	No	No
Holden et al. (2013) [47]	No	Yes	Yes	No	Yes	Yes	No	Indirectly related to "Adaptation"		
Bradbury-Jones et al. (2013) [26]	No	Yes	No	No	Yes	Yes	No	Indirectly		
Tuffrey-Wijne et al. 2014) [48]*	No	Yes	Yes	No	Yes	Yes	No	Indirectly		Indirectly

Key: char., characteristics; contrib., contributing; org., organisational; detect., detection; mitig., mitigating; amel., ameliorating.
*Conceptual research framework is presented as a first step for informing the analytical framework for the analysis of barriers and enablers to providing "reasonable adjustments" (Supplementary materials).

Table 3
Characteristics of included studies: population, aim (health quality research), method, analysis, participants.

Sources	Population	Aim to determine	Methods	Analysis	Participants
Avis et al. [31]	Children with LD	Parents' views of the care provided by hospital nursing staff	Qualitative/interviews	Content themes	12 parents of children with special needs
Balandin et al. [49]	Adults with CCN	Experiences of people with CCN on communication with nurses in hospital	Qualitative/semi-structured interviews	Categorical data and content themes	10 individuals with acquired CCN
Balandin et al. [44]	Adults with CP and CCN	Experiences of adults with CP and CCN in hospital; communication barriers and facilitators	Qualitative/semi-structured interview	Categorical data and content themes	10 adults who had been hospitalised
Bartlett et al. [3]	Adults with communication difficulties	Extent to which preventable adverse events could be predicted by conditions that affect a patient's ability to communicate	Quantitative/medical record chart review	16 adverse event types; categorical data	Review of 2355 charts
Brown et al. [32]	Adults with ID	Impact and outcomes of four LD Liaison Nursing Services in South East Scotland on the healthcare experiences of people with ID in hospital	Mixed/referrals interviews and focus groups	Categorical data and content themes	5 people with disability, 16 carers, 39 primary HP, 19 secondary HP, 6 liaison nurses
Buzio et al. [50]	Adults with CP	Experiences of adults with CP during inpatient admission to a number of public hospitals	Quantitative/survey	Categorical data and content in comments	31 adults with CP
Cumella et al. [41]	Adults with LD	Strengths and weaknesses of the current provision of secondary healthcare for people with LD in England	Qualitative/consensus conferences	Consensus development, categories of meaning.	2 consensus development conferences, each with 40 people
Dinsmore [51]	Adults with LD	General hospital experiences of people with LD in hospitals	Qualitative/interviews	Content analysis	12 interviews with people with LD and with carers
Ford et al. [35]	Children with special needs	Paediatric nurses' experiences of caring for hospitalised children with special needs	Qualitative/interviews	Content themes	4 nurses working with children with special needs
Gibbs et al. [52]	Adults with ID	Experiences of adults with ID and their carers in a general hospital setting	Qualitative/focus groups	Grounded theory/ content themes	11 adults with ID, 9 parents, 5 paid carers
Hart [53]	Adults with LD	Learning disabled people views of their hospital experiences	Qualitative/interviews	Grounded theory/ content themes	13 people with LD
Hemsley et al. [54]	Adults with CP and CCN	Unpaid carers experienced caring for adults with CP and CCN in hospital	Qualitative/interviews	Narrative analysis	6 unpaid carers
Hemsley et al. [55]	Adults with CP and CCN	Experiences of parents who provide care to an adult son or daughter with CP and CCN in hospital	Qualitative/interviews	Narrative analysis	8 parents of 7 adults with CP and CCN
Hemsley et al. [56]	Adults with CP and CCN	Views of family carers on what supports are needed for family carers in the hospital setting	Qualitative/focus group	Content themes	6 family caregivers, including 5 parents and 1 sibling
Hemsley et al. [57]	Adults with CP and CCN	Views of hospital and disability staff on their roles and needs of carers of adults with CP and CCN	Qualitative/focus group	Content themes	6 hospital and disability staff
Hemsley et al. [58]	Adults with CP and CCN	Views of adults with cerebral palsy and CCN perceive on the role of the family carer in hospital	Qualitative/focus group	Content themes	6 adults with CP and CCN
Hemsley et al. [45]	Adults with DD and CCN	Views of paid carers, adults with CCN, and hospital nurses view paid carers' roles in supporting adults with CCN in hospital	Qualitative/interviews	Narrative inquiry	15 adults with DD and CCN, 15 paid carers, 15 hospital nurses
Hemsley et al. [46]	Adults with DD and CCN	Views of patients, paid carers and nurses on the communication needs of patients with DD and CCN in hospital	Qualitative/interviews	Narrative inquiry	15 adults with DD and CCN, 15 paid carers, 15 hospital nurses
Hemsley et al. [36]	Children with DD and CCN	Views of community and hospital based allied health professionals and hospital nurses on communication needs of children with CP and CCN	Qualitative/focus group	Content themes	18 allied health professionals, 14 hospital nurses, 16 community based allied health workers
Hemsley et al. [37]	Children with DD and CCN	Views of parents and children with CP and CCN on the children's communication needs and experiences	Qualitative/interviews, focus groups	Narrative inquiry, content themes	10 parents of children with CP and CCN, 7 children with CP and CCN
Hemsley et al. [40]	Adults with aphasia	Views of people with aphasia (PWA) and their spouses on their experiences of adverse events in hospital.	Qualitative	Narrative inquiry	10 people with aphasia, 10 spouses
Iacono et al. [59]	Adults with DD	How widespread were problems in receiving adequate care in hospital	Mixed/survey and interviews	Categorical data and content themes	328 survey respondents with 119 admitted to hospital in past year, 11 interviewees
Phua et al. [38]	Children with CP	Level of satisfaction with inpatient hospital care as perceived by parents of children with CP	Quantitative/survey and scale	Statistical analysis	40 cases (40 parents of children with CP) and 90 controls
Smeltzer et al. [60]	Adults with disabilities	Experiences of people with disabilities in their interactions with nurses and other assistive personnel	Qualitative/interviews, focus groups	Content themes	35 people with disability
Tuffrey-Wijne et al. [48]	Adults with ID	Cross-organisational, organisational and individual factors that facilitate or compromise the safety of pts with ID in hospitals	Mixed/interviews, surveys, expert panel discussions.	Descriptive statistics and conceptual framework analysis	1251 participants including staff, carers and people with ID

Tuffrey-Wijne et al. [43]	Adults with ID	Challenges in monitoring and preventing patient safety incidents/ describing patient safety incidents for people with ID	Mixed/interviews, questionnaires, observations and safety incident database reports	Descriptive statistics and qualitative analysis	1251 participants including staff, carers and people with ID
Webber et al. [39]	Adults with ID	Perspectives of group home staff and family members concerning hospital experiences of group home residents in hospital	Qualitative/interviews	Content themes/ grounded theory principles	55 participants: 17 family members, 16 home supervisors, 11 accommodation managers, 11 staff in aged care facilities

Note: HP, health professional; CCN, complex communication needs; CP, cerebral palsy; DD, developmental disability; LD, learning disability; ID, intellectual disability.

the subject, or (b) Consequences for the Organisation; leading to (5) Overall Outcome (Actual or Potential) and Resource Impact and Risk Rating. Within this model, patient safety incidents are followed by factors to minimise or aggravate outcomes, including both health outcomes and consequences for the patient and the organisation [2]. Attention to the possible causes of risk along with strategies to deal with problems can help with developing system resilience for the prevention of future incidents [4,15]. Finally the International Classification for Patient Safety (ICPS) [4,15,16] is a classification framework that comprises 10 higher-level classes of patient safety, with each class further categorised into a hierarchical structure. This model builds upon the previous work of Runciman [1] and comprises elements of risk identification, prevention, detection and reduction, incident recovery and system resilience. The ICPS is an initiative of the World Health Organisation and aims to encourage patient safety research to incorporate a standardised framework and terminology to aid in the systematic collections and analysis of data, and in turn, improve its synthesis and use.

Specific patient safety frameworks have been developed for conditions including chronic kidney disease (see [29]) and mental health problems [30]. Such frameworks lead to prevention strategies and improvements in care [15]. Currently, there are no specific patient safety frameworks comprehensively outlining contributing factors, incidents, and consequences available for people with communication disabilities of any kind. Yet this group has a high risk of having a safety incident or adverse event in hospital [3].

1.2. Care experiences of people with communication disabilities

With an increased recognition of the health needs of people with a disability in hospital [see reviews 14–18] there is now an extant literature on the care experiences and needs of people with disabilities affecting communication [22]. Literature reviews to date have a focus upon various groups of patients with communication disabilities: older carers of adults with cerebral palsy and complex communication needs [23]; patients with severe communication impairment [24]; patients with aphasia on a stroke ward [25]; patients with intellectual disability [26–28]; and patients with severe communication disability [22,28].

In the context of (a) an extant literature on the care of adults with various types of communication disabilities in hospital, (b) knowledge that these patients face a three-fold increased risk for adverse events in hospital [3] and (c) evidence of extreme harms related to poor care for adults with disabilities, there is a substantial gap in the literature relating to the *safety* of adults with communication disabilities in hospital. Therefore, the aims of this study were to identify findings relating to patient safety in reports of original research investigating the *care* or *safety* of adults with communication disabilities in hospital, and to analyse these findings according to the 'generic model' of patient safety [2]. The results of this study can be used to inform (a) improvements to policy and practice in both hospital and disability services, and (b) future research investigating patient *safety* of adults with communication disabilities in hospital. This in turn that might serve to improve patient safety and reduce the incidence of preventable harmful patient safety incidents.

2. Methods

2.1. Search terms and search strategy

On 24th August 2014, and in a follow-up check on 27 April 2015, we searched four scientific databases (Embase, Web of Science, CINAHL, Medline) for studies relevant to safety in hospital for

patients with communication disabilities. The following search terms were used in various combinations and permutations: (i) *Safety* terms: patient safety incident, adverse event, safe/ty, unsafe, harm/ful event, critical incident, sentinel event, and variants; (ii) *Setting* terms: hospital, ward, secondary/acute care; (iii) *Population* terms: disability/disabled, handicap, stroke, cerebral palsy, intellectual disability, autism, traumatic brain injury (TBI), impairment, and (iv) *Communication* terms: aphasia, complex communication needs (CCN), communication disability, communication impairment, speech difficulty, unable to speak, nonverbal, non-vocal communication, augmentative and alternative communication (AAC), severe communication impairment (SCI), communication, dysarthria, anarthria, dysphasia, aphasia, communication impairment, speech impairment, language impairment, retardation (and variants). All potentially relevant references found were imported into Endnote X7 library for exclusion on title and abstract according to the inclusion/exclusion criteria.

2.2. Inclusion criteria

Only original research published in English in peer reviewed journals was considered for inclusion in this review. No limits were placed on the age of the patient. Studies with (a) a focus on care of hospital patients with a communication disability, secondary to any lifelong or acquired chronic disabling health condition, and (b) any finding related specifically to patient safety or patient safety incidents, were eligible for inclusion. Thus, authors of a study with a relevant aim and population needed to report findings directly related to patient safety incidents or adverse events, or to have related their findings to patient safety (e.g., adverse event described, risk of reduced safety, protection from safety risk, being safe or protected).

2.3. Exclusion criteria

Studies excluded from the review were those that (a) were not original research (i.e., systematic or literature reviews, commentary, reports), (b) were not published in English and in peer-reviewed journals; (c) did not have a primary focus on patients with a lifelong or acquired disabilities or their carers, nurses or other key stakeholders, (e.g., had a primary focus on patients with temporary communication impairments, such as those associated with intubation) or (d) did not report findings on adverse events or relate any finding to patient risk or safety.

Table 4
Types of adverse events reported.

Adverse event	Studies	Example quote
Admission problems	[36,37,45,55,61]	"When I had pneumonia, my friend saved my life, because the doctor was going to turn off my life support system. And my good friend came into the hospital, just in time. I think the hospital has got, they have to let people inside, because in my case if my friend wasn't there, I wouldn't be here." (p.1635) [61]
Discharge planning problems	[37,39,50,52,59]	"45% of respondents indicated that discharge planning was not discussed with them during their stay . . . this caused problems for the respondents at the time of discharge or after they had returned home." (p. 12) [50].
Medications errors/ Adverse drug reaction	[3,41] [59] (Medication Errors) [40,55] (Adverse drug reactions); [39] poor pain management	"There were examples of lack of attention to epilepsy, and a failure to prescribe appropriate medication". (p.35) [41] "These events were mainly drug related or caused by poor clinical management "(p.1559) [3]
Unplanned readmissions	[3,40]	"one-third of the patients who experienced preventable adverse events requiring readmission to hospital." (p.1559) [3]
Falls/positioning and falls risk	[37,40,46,50,54,55]	"difficulty physically accessing the hospital environment, mainly due to slippery floors or limited access in bathrooms and bedrooms. This made mobilization within the hospital environment dangerous or difficult." (p. 12) [50] Patients reported adverse events related to their inability to gain the attention of the nurse when a carer was not present (e.g., falls, head stuck in bedrails) (p.336) [22]
Mealtime/choking	[55] [45]; risk of - [38,39] (not fed)	"returning to the hospital ward to discover their son or daughter in distress or perceived to be in danger (e.g., untreated pain, medication error, choking, wet or dirty sheets)" (p. 247) [55]
Skin integrity risk/pressure areas	[41,54,61,39] (soiling not cleaned)	"Low expectations and unresponsiveness among ward staff resulted in failures to manage bedsores, failure to feed patients and dehydration." (p. 35) [41]. "We'd mainly need to communicate about hygiene—like toileting, showering, just making sure they're kept clean of urine, faeces that sort of thing, so regular toileting, turning as well you don't want them to get pressure area sores . . . " (p. e54) [46]
Complications as a result of treatment	[39,52,54]	"Of course when they cut the plaster open, we said look we really told you, she's been in pain like this for a long time now" (p. 247) [54] "Following my husband's heart surgery, he got an infection in the wound ... The hospital staff tried to explain to him that when he needed to cough, he should hug a rolled towel tightly to his chest, to prevent his wound from opening. However, he couldn't follow the instructions." (p. 713) [40]
Undesirable events	[31,41,49–52,54] [36–38,40**,45,55,58,59]	"Parents felt that they were left to give medicine, food and personal care." (p. 13). [31] . . . It also left them feeling unable to leave the bedside: "I am too frightened to leave the room because he's going to be ignored." (p. 13) [31]
Unplanned transfer from General to ICU	[40]**	Three participants (from 10) narrated unplanned transfer from general care to intensive care
Hospital acquired infection/sepsis	[40]**	Three participants reports hospital acquired infection/sepsis (one related this to difficulty of husband following instructions after cardiac surgery)

*Bartlett et al. (2008). "These events were mainly drug related or caused by poor clinical management. Almost half of the events were associated with some level of disability or multiple hospital admissions, with one-third of the patients who experienced preventable adverse events requiring readmission to hospital. These results emphasize the importance of providing additional resources for these patients to improve patient safety." (p. 1559).

**Hemsley et al. (2013c). "In their stories about adverse events, participants also narrated problems with (i) unplanned admission (including readmission) as a result of health care management within twelve months prior to the admission ($n = 3$), (ii) adverse drug reaction ($n = 3$), (iii) unplanned transfer from general care to intensive care ($n = 3$), and (iv) hospital acquired infection or sepsis ($n = 3$). PS5 viewed that a communication breakdown between her husband and the hospital staff had contributed in part to the event, as PA5 was unable to understand instructions relating to his follow-up care after heart surgery: "Following my husband's heart surgery, he got an infection in the wound . . . The hospital staff tried to explain to him that when he needed to cough, he should hug a rolled towel tightly to his chest, to prevent his wound from opening. However, he couldn't follow the instructions". (page 8).

2.4. Applying the inclusion/exclusion criteria

From a total of 1280 potentially relevant studies found, 1225 studies were excluded on reading of title and abstract, and the full texts of 55 potentially relevant studies were retrieved for further consideration. The first author and a research assistant (JS) separately judged the 55 full text articles. Applying the inclusion and exclusion criteria separately, the two raters agreed on all but three studies [31–33], and discrepancies for these studies were resolved through consensus. This procedure resulted in 27 studies being included in the review. The full texts of included studies were then subject to four stages of data extraction:

1) Characteristics of included studies: bibliometric data (record number, year, author, title); and study design features (aim, method, analysis, participants) (see Table 3)
2) Types of adverse events reported in the study (see Table 4).
3) Findings relevant to patient safety with evidential quotes (see Table 5).
4) Complete or partial narratives explaining an adverse event in hospital (i.e., containing some or all of the following narrative elements: Orientation, Abstract, Event, Evaluation, Outcome, Resolution; [34]) (see Table 6).

The majority of studies that met the inclusion criteria were qualitative designs ($n = 20$). Three were quantitative and four mixed methodology research (see Table 1). We performed a content analysis of findings across the studies to identify the details surrounding the types of adverse events and people involved, the circumstances surrounding any patient safety incidents, and the protections reported for the patients with communication disabilities in hospital.

Table 5
Views of key stakeholders on contributing or protective factors.

Finding relevant to patient safety	Studies	Example quote
Increased risk by neglect/absence of interaction/isolation/being left alone	[39,46,49–51,54,56,58,59]	"She's shut in that room by herself, they might take her in now and then, I don't know, but if she's having seizures they don't know because they're not around." (p. 206) [51]
Lacking a means to raise the alarm (no access to call bell/unable to use/put out of reach)	[40,44,46,49,55,58,59]	"He could not communicate in the ward; he fell out of bed ... in a ward if you needed help you have to push a button. He couldn't yet do that. So when he needed to go to the toilet he just thought 'well they are never going to come' and of course he couldn't walk so he just fell down."(p. 711)[40]
Incorrect feeding equipment/problem	[38,39,59]	" . . . .we've had a man with a PEG feed go into hospital and the nurse tried to stuff a banana down his throat." (p.160) [39]
Poor basic care	[31,44–46,50–54,59,60]	"Some respondents stated that their care was often left until paid carers or friends arrived to take over, or that hospital staff only provided assistance if no visitors were present." (p. 12) [50]
Constant presence of carer/vigilance	[31,36,37,40,44–46,50–52,54,59]	"I just don't know what would happen to her if I left her. .. If you're vomiting, you can't sit up, you can't see, and you can't hear and you can't buzz a buzzer. .. what would happen – there's no nurses there to sit with her. .. How could you take the chance?" (p. 1068) [52] " . . . and we're sitting there [in hospital] all day. There was no way on god's earth, I could come home, and leave her on her own. No way. No. No." (p. 244) [55] "I'd always done a very great deal with friends, and that just stopped, for a while . . . I just stopped my life, for that length of time, I knew it was just going to be a finite length of time, that when he was up and running again, then I would just go back to my life. I honestly felt it was necessary, this is not just me being paranoid, I just felt I didn't have the choice." (Isabella) (p. 244) [55]
Monitoring safety/role of 'liaison nurse'	[32]	"risk management"; also role in information-consent.; Documentation/information exchange/consent. ""The Liaison Nurse can do quite a bit of getting the two ends of that spectrum to understand each other". [Speech and Language Therapist, Primary Care] (pp. 1166-1167) [32] "Because sometimes I feel that before [the liaison nurse] was involved you were just pulled aside and that was you. I feel that [the liaison nurse]being there has been a lot different, now you get more of everything". [Patient 1] (p. 1167) [32]
Self advocacy	[40,57,58]	"I went for three days without food or a shower after major surgery, because the staff just wouldn't listen. So I got on my high horse and told doctor and he made the staff take time to listen, and then it was much easier". (p1766) [58] "If my husband couldn't be there I would try and explain about my aphasia, when I go to hospital I say 'I have aphasia and ask them if they know what it is and ask them to explain it back to me' because otherwise I get upset and uptight, so, easy for me if you understand me." (p.11) [40] "It was a frustrating experience. You continually have to work and be patient and learn how to be ignored and learn how to tell people how you feel. The nurses walking past and not saying hello, not chatting. Lying there and staring at the ceiling." (p. 114) [49] Nine participants described strategies that they used when a nurse did not understand their initial communicative attempt. These strategies included repeating the message, slowing down the pace of the message, and using AAC or gestures. (p.114) [49]
Advocacy of a carer	[37,38,40,45,46,54,55,56,59,36]	"Sure, like you need to be the person's champion, you need to be there, and be the voice, and you need to definitely push your opinion across, and say, 'Look, look at the whole picture . . . this is my loved one and the important thing is that they get what they need not just what everybody gets'". (p. 264) [56] "I agree that I need to be present in hospital to help PA3 remember what the doctor has said and also to ask the doctors questions to gain important information about my husband's care. I also feel I need to be present in the hospital to ensure that he is given his medication". (p. 713) [40] "Rory commented that the carer's presence acted as a signal to hospital staff 'for the able people to be more nice to us.'"(p. 1763) [58]

Table 6
Narratives and partial narratives reported in 18 studies relating to safety risk or adverse events.

Study	Story quote
Balandin et al. [44]	"I can't complain, but one night they woke me up and gave me a needle; it came out and there was a lot of blood [and] they never came back to clean me up - I couldn't reach the buzzer so I went back to sleep." (p. 59).
Hemsley and Balandin [54]	"Natalie was in plaster from the waist down . . . and she complained every day, and there was a problem with her back. And Natalie had no speech . . . we had difficulty explaining to the nursing staff that Natalie had a problem. And when the plaster came off the plaster had been put on incorrectly, and there was a piece of plaster that had . . . been boring a hole into Natalie's back. And the hole was very large, and very painful . . . of course when they cut the plaster open, we said look we really told you, she's been in pain like this for a long time now." (p. 247)
Hemsley et al. [55]	"Stories about returning to the hospital ward to discover their son or daughter in distress or perceived to be in danger (e.g., untreated pain, medication error, choking, wet or dirty sheets) were common across six of the interviews. In these stories, nursing staff had either neglected to notice or did not know how to respond to the patient. Parents were persistent and successful in their attempts to rectify the situation." (p. 247).
Hemsley et al. [55]	"At one stage Mel was on the ward, you see the thing is they can't even press the buzzer, and she was on Oxygen, and I could see she was in trouble. She couldn't . . . she still wasn't breathing right. So I went to the sister on the ward, and I said "I want a doctor". And she came and looked at her and she said; "Oh, I think she'll be alright, I'll let the doctor know". And I stood up and said "I want a doctor, now!" . . . the doctor came out of surgery . . . he took one look at her and he said "um . . . heart failure". She was having heart failure and they whisked her off straight into care." (p. 247).
Hemsley et al. [58]	"I went for three days without food or a shower after major surgery, because the staff just wouldn't listen. So I got on my high horse and told doctor and he made the staff take time to listen, and then it was much easier." (p. 1766).
Hemsley et al. [45]	"When I had pneumonia, my friend saved my life, because the doctor was going to turn off my life support system. And my good friend came into the hospital, just in time. I think the hospital has got, they have to let people inside, because in my case if my friend wasn't there, I wouldn't' be here." (p. 1635).
Hemsley et al. [46]	'They put me in my wheelchair but they forgot to tie me in, and I had a spasm, and I fell out on the floor, and I hurt my back . . . They were there when I fell out, and I couldn't say anything at all." (p. e54).
Hemsley et al. [46]	"PC7 highlighted the safety concerns about mealtime communication for people with DD and dysphagia: 'There were some things that she was aware that she couldn't have, she was trying to convey that to them, but they weren't really understanding . . . with having thickened fluids she's high aspiration risk and she found that very concerning to try and convey". (p. e55).
Hemsley et al. [46]	"PC3 said 'Communication problems can make it difficult for the person to let the hospital staff know that they need the toilet - I have seen one person not be understood and soil the bed." (p. e55).
Dinsmore et al. [51]	"an account of her son's 6-week hospitalization in summer 2009, initially for a broken ankle . . . experienced an increase in epileptic fits attributed to failure to ensure medication was followed." (p.207).
Hemsley et al. [36]	"One child . . . was able to eye gaze to say she was in pain; and she had a broken bone. And that took a long time before anyone actually paid attention to the fact that she was grimacing and she was really tense." (p. 160)
Hemsley et al. [37]	"There was a time that Mum wasn't there and I had to tell someone there was blood in my bed. I was quite lucky because a physio who knows me really well was there at the time, and I was able to show him." (p. 368) (near miss)
Hemsley et al. [40]	PS1 (spouse) recounted being notified by nurses that PA1 (patient with aphasia) had fallen while left alone in the toilet. She said: "He couldn't walk, they would have had to take him to the toilet, but they obviously left him there alone." (p. 714).
Iacono and Davis [59]	"The medication is a big problem because at the house we gave it to her at 11 o'clock at night and she was getting it at 10 o'clock at night, but in the morning it was an hour later, so the drugs were getting all mixed up which was causing her to have seizures and we couldn't tell the nursing staff because they had their policies and we had ours." (p. 258).
Phua et al. [38]	"He cannot swallow at all. Twice medication was brought in on a spoon for him to take . . . this could be fatal. Fortunately we were present" (p. 435).
Smeltzer et al. [60]	"Some participants reported that nursing staff feared them, ignored them, and at times abused them by, for example, removing the meal tray without helping them to eat when needed and by removing necessary assistive devices." (p. 34).
Tuffrey-Wijne et al. [43]	"A man with intellectual disabilities attended A&E on his own as he had noticed blood in his underwear . . . staff incorrectly believed the man was drunk. Later on, a carer noticed the blood and the man returned to A&E. He had a rectal prolapse which required emergency surgery." (p. 8).
Tuffrey-Wijne et al. [48]	"I told them he always has problems with diarrhea when he is on antibiotics (. . .) They didn't take any notice of what I said, and they gave him the antibiotics and he had diarrhoea for 12 days." (p. 7).
Webber et al. [39]	"I looked at her and I said, "What's the matter love?" and she said, "Oh, Denise it hurts, hurts." So I went to the staff and I said to them, 'Eileen's in pain. Can you please make sure that she gets her morphine' . . . I came back from the meeting two hours later; she's had no pain control . . . . And they said, "Oh, but she hasn't complained." (Aged care staff). Failure to identify pain also led to disruptive behavior, compounding the distress for everyone." (p. 158). "We've had a man with a peg feed go into hospital and the nurse tried to stuff a banana down his throat. (Disability Staff) (p. 160).

3. Results

3.1. Contextual information about the population, hospital settings and studies

Of the 27 included studies, 22 related to adults with communication disabilities, and 5 related to children with communication disabilities [31,35–38]. The populations included in the studies were: patients with cerebral palsy ($n = 9$); patients with intellectual/learning disability ($n = 9$); patients with developmental disability unspecified ($n = 5$); patients with acquired communication disabilities (progressive conditions, aphasia following stroke, or TBI) ($n = 2$), children with special needs (multiple disabilities) ($n = 1$). See Table 3 for characteristics of included studies data in terms of bibliometric data, design and methodology, and focus [2].

3.2. The incidents: near miss and adverse patient safety incident

While several of the studies included reports of 'fears' of patient safety incidents or accounts of near-miss incidents, not all included reports of actual incidents resulting in damage-harm-loss witnessed or experienced. An analysis of the type of incident represented revealed that many of the adverse incidents reported across 24 of the studies of hospital care or experience were categorised as 'undesirable events' [3]. Adverse events reported included falls, injuries, disease, complications, poor discharge planning, problems at admission, medication errors, adverse reaction to medications, causing complications, pain and suffering or extending the duration of hospital stay or resulting in inappropriate early discharge [e.g. 39]. The types of incidents outlined across the included studies are presented in Table 4.

Aside from descriptions of adult or child patients with different types of disabilities in hospital or parents, carers, or nurses for these patients; there was little demographic or other descriptive or categorical data available about the patient in the adverse events. Also, there was little information on the nurses or carers who featured in the stories of patient safety incidents or near miss events. Near-miss events implicated 'nurses' or 'carers', a cleaner [40], but did not provide details (e.g., role, level of training) about the people involved in the incidents. In terms of timing, in most studies, little if any temporal information was available. Examples of temporal information included the incident occurring 'at night' or 'when the patient attempted to use the toilet'.

Several studies demonstrated that the occurrence of an adverse event was overlooked or only detected when the carer returned to the hospital. Although adverse events were reported to researchers, often it was not clear whether the witness to the event had reported the incident to relevant hospital staff. The key stakeholders reporting near-miss incidents perceived that the events were preventable (e.g., if the patient had the means to gain attention, if experienced staff were present to recognise symptoms). Consequently, the included studies did not aid understanding about the timing or detection of incidents or the factors that contributed to the onset of the incidents reported. For the most part, the studies yielded information solely about the incident and the immediate nature of responses.

3.3. Factors minimising or aggravating outcomes or consequences

Successful advocacy (i.e., by either the parent, or the patient) mitigated the negative effects of undesirable circumstances (e.g., [55,56]), whereas advocacy failure aggravated the circumstances, resulting in serious negative health outcomes and distress for the patient (e.g., [54,58]). Once an incident occurred, failing to listen (e.g., to a child in pain), or to recognise complaints of pain or symptoms of distress, increased the negative outcomes of critical incidents for both children and adults [see Table 6]. Although parents and carers often described taking a strong advocacy position in protecting their son or daughter in hospital, in situations where they were ignored, outcomes were worse [see Table 6]. These findings suggest that where parents and carers express a concern with care, failure to *act* upon that concern may well result in more negative outcomes for the patient. These negative outcomes can result in suffering and increased healthcare costs associated with recovery (e.g., [3]). Thus, carers who raise a concern with care (i.e., care that results in pain, distress, or other undesirable events) may be raising 'red flags' that require more substantial system responses to remove the 'undesirable' event and investigate ways to improve care [3,43]. Successful advocacy will therefore rely on active listening and an appropriate response being made to the safety concerns expressed by patients or carers.

3.4. Narrative analysis of component stories of patient safety incidents

Across the 27 studies, several narratives of patient safety incidents were identified, with either story fragments or complete stories [34] (i.e., orientation or timing and place as a context, people involved, event, evaluation, resolution) (see Table 6). Stories of adverse events included stories with: 'suffering' being the primary consequence illuminated in the studies; the patient being endangered by the isolation arising from not having a method to communicate with nurses; a perilous care situation culminating in an adverse event; or protective carers discovering or forestalling an adverse event. Examples of both partial and complete stories of adverse events in the studies are included in Table 6.

The broad range of qualitative, descriptive, and mixed methods studies included in this review yielded similar qualitative findings across the studies. These included a common story of being in hospital with no way to gain the attention of or communicate with hospital staff (see Table 6). The stories also revealed that staff were not always attentive even when patients raised the alarm. Although previous research rightly recommends the provision of communication aids and further training for hospital staff in providing care to adults with communication disabilities, the results of this review also highlight other areas for further attention. Carers may also be implicated in patient safety incidents (e.g., [36,56]), other patients may be at risk, and care staff and nurses may be at Occupational Health and Safety (OHS) risk if patients cannot be cared for appropriately and safely on hospital wards (e.g., [45,52]). Carers may place patients at risk by using care methods that do not conform with OHS standards [45]. Nurses may avoid treatments that cause upset or discomfort in the patient [41]. There were also stories of patients with communication disability being a risk to other patients because of their challenging behaviour [41]. Often nurses must juggle competing demands and priorities which may mean patients are left minimally safe, even if uncomfortable, while other patients are attended to as a safety priority. Ford and Turner [35] reported:

> *"Sometimes when the nurse experienced more than one demand on their time, keeping the child safe was as much as they could do."*(p. 293). *"And minimizing long-term problems for us is usually not a priority. If . . . we don't lay them the way they're supposed to be, for this minute because I have to put you down and go and stop this child from choking on their lunch, then you will put them down . . . If I put you in your cot, lying on your back, yes, you're safe for this minute."*(p. 293) [35].

Sowney and Barr [42], in a study investigating the views of nurses on caring for adults with intellectual disability (ID) on emergency wards, described nurses' fears of caring for these patients and related the following relevant statement about safety:

> Concern was also voiced in the following conversation that poor understanding of the nature of intellectual disability can result in a patient's behavior being viewed as an aspect of intellectual disability and not a crucial indication that there is something wrong, which could lead to either over-investigation or diagnostic overshadowing. . . . Your fears always is (sic) that you are sending that person home and that you are missing something that is seriously wrong with them. (p. 40) [42].

4. Discussion and conclusion

4.1. Discussion

As the vast majority of the studies included in this review relied on participant reports it is not possible to determine the extent to which the patients' communication disabilities were directly related to the adverse events reported. Consequently the results of this review must be viewed in the context of limited research. Nonetheless, the commonality in reported narratives across multiple studies (see Table 6) increases the plausibility of claims about the poor quality of care and risks to patient safety made by key stakeholders. Such perceptions could be used to inform future health services, care quality, and patient safety research in populations with communication disabilities. Although 19 of the studies included stories of a range of adverse events (see Tables 3 and 4), all relied on witness reports. No studies included description of the consequences of the events on the health organisation and only one study made use of medical record chart review as a data source [3]. One study also sourced data from a patient safety incident databases [43]. None of the studies investigating hospital care experiences used matched documentary or incident reporting database data to triangulate or corroborate the stories of adverse events to: (a) confirm contributing factors and consequences beyond pain and suffering, (b) discover follow-up actions taken by any party to prevent future adverse events for that patient, or (c) improve understanding of factors associated with reporting or complaints mechanisms (e.g., the patient safety incident database, patient complaints system). Where complaints in relation to threats to safety or adverse events did feature in the stories, they were in relation to people with communication disability or their carers being reticent or unable to complain (e.g., [44], p. 59, "I can't complain but ..."). Nonetheless, the studies, when considered together reveal a range of stakeholders' views on what might form contributing or protective factors in patient safety incidents for people with communication disabilities. These impressions and views could be used to inform future patient

safety research in populations with communication disabilities. Such research could encompass observational studies and investigations into the documentation of circumstances surrounding patient safety incidents, including for example the role of improved methods for handover of written health information.

Despite using a broad range of search terms in four scientific databases, only four studies were found with a specific focus on adverse events or patient safety in patients with communication disabilities [3,33,39,40]. For adults with aphasia [40] difficulties understanding healthcare instructions and discussions also led to problems with discharge planning, medications, and unplanned readmission. Spouses also reported forestalling adverse events but were not always able to remain at the bedside for extended periods. No observational studies of adverse events were reported. However, the 23 studies that aimed to investigate hospital care reflected concerns around 'health care quality' for patients with communication disabilities, and contributed some information relating to 'patient safety' issues for this group. Poor quality of care was reflected in relation to problems with providing adequate and safe mealtime assistance and appropriate mealtime equipment (e.g., [34,39,46]), providing access to a call bell (e.g., [44]), ensuring positioning was safe and comfortable (e.g., [39]), providing adequate supervision to prevent falls (e.g., [40]), and providing a safe physical environment for people with reduced mobility or who use wheelchairs (e.g., [46]). The findings of this review suggest that patients with functional limitations in communication resulting from aphasia have similar concerns regarding their safety as patients with developmental disabilities and comparable speech limitations (e.g., [40]).

Aside from reflecting concerns around poor quality of care, the studies reported several 'near-miss' events forestalled by vigilant parents or carers returning to the hospital. Carers' fears and expectations of adverse events were also notable across studies, along with the need for increased vigilance by family and paid carers during hospitalisation. However, even where carers were involved and engaged in supporting a person with communication disability in hospital, the risk was not ameliorated completely. Indeed, risks for early discharge and poor discharge planning still occurred, along with medication management difficulties resulting in adverse drug reactions and medication errors. The studies aiming to investigate the views and experiences of patients and carers or hospital staff yielded both 'human factors' and 'environmental factors' in the findings relevant to patient safety for patients with communication disabilities. The patient's communication needs and methods, roles of paid carers, and the impact of limited time to communicate has been shown to affect care quality and safety [45,46]. Safety incidents included choking, medication errors, and inappropriate early discharge with unplanned readmission within two days, and 'near miss' events forestalled by carers (e.g., falls, pressure sores) [45,46].

4.2. Conclusion

Across the included studies, a range of factors that contributed to or increased the risk of patient safety incidents in patients with communication disabilities were identified. Attention to these factors in hospital policies, practices, and hospital staff training is needed in an effort to improve patient safety for patients with communication disabilities. The studies suggest that despite additional care from paid carers or family, adverse events continued to occur for patients with communication disabilities. It is untenable to expect carers to remain at the hospital at all times, particularly when there are no policies or procedures guiding these carers in their roles. Many carers of older adults with disability, and spouses of older adults with communication disabilities, are themselves old and frail. Their own health issues associated with ageing mean that they will not be able to provide a high level of support in hospitals indefinitely [55]. Research in this area is urgently needed to provide information that will be used to reduce patient safety incidents in hospital for this vulnerable group, and to discover more of the factors conceptualised in the Generic Model of Patient Safety [1]. Rather than relying on patient reports, studies are needed to gather and analyse matched data from multiple sources, including observations, interviews with patients, carers, and hospital staff, medical records, and patient safety incident database reports.

4.3. Practice implications

Patients who have communication impairments being left alone and having no access the nurse call system not only suffer isolation but have no way to raise the alarm if needed. Therefore, the position of the patient and proximity to other patients or the nursing station is an important consideration at admission. The provision of an adapted call bell (e.g., by a large button switch) for patients who are unable to reach or use the nurse call system is frequently recommended in the studies but, to date, there is little evidence that it is ever implemented. In addition, the provision of good quality basic care is likely to prevent a range of undesirable events arising for patients with disabilities and communication impairment in hospital. When patients are unable to explain their specific requirements, such as feeding equipment or need for modified foods, fluids, or specific assistance techniques, care and safety can be threatened. Ensuring that the patient has a method to communicate with staff needs to be considered within the patient charter of rights, as patients have a right to communicate directly with hospital staff. Given the protective role of carers or spouses in the included studies, hospital staff need to consider and negotiate the roles of carers and to engage with them in considering the patient's safety in hospital. With little information on this found in included studies, the patient's own preparation and abilities in raising the alarm, self-advocacy for care needs, and framing reports of patient safety incidents in hospital complaints are important areas for future research. The role of a liaison nurse with specific skills in nursing patients with communication disabilities and the roles of speech language pathologists in advising hospital staff on the patient's communication could also be considered as prudent if aiming to reduce patient safety incidents relating to poor nurse-patient communication.

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