Evidence Check

Patients' experiences in Australian hospitals

An Evidence Check rapid review brokered by the Sax Institute for the Australian Commission on Safety and Quality in Health Care. December 2015.
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This report was prepared by:
Reema Harrison, Merrilyn Walton, Elizabeth Manias

December 2015
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Suggested Citation:

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Patients' experiences in Australian hospitals: a rapid review of evidence

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1 Abstract

Background

Patients are uniquely positioned to provide insightful comments about their care. Currently, a lack of comparable patient experience data prevents the emergence of a detailed picture of patients’ experiences in Australian hospitals. This review addresses this gap by identifying factors reported in primary research as relating to positive and negative experiences of patients in Australian hospitals.

Method

We conducted a synthesis of evidence from qualitative studies of patients’ reported experiences in hospital and day procedure centres. A range of text words, synonyms and subject headings were developed and used to undertake a systematic search of seven electronic databases dating from January 1995 to July 2015 and the grey literature. Two reviewers independently screened the titles, abstracts or executive summaries and applied the inclusion criteria. Data were synthesised in a meta-narrative.

Results

Thirty-nine publications were included; 33 articles from database searches and six from the grey literature. Quality improvement researchers produced the dominant narrative and there was a strong nursing perspective. Seven themes emerged: ‘The care environment’, ‘Reciprocal communication and information sharing’, ‘Correct treatment and physical outcomes’, ‘Emotional support’, ‘Comfort, pain and clinical care’, ‘Interpersonal skills and professionalism’, and ‘Discharge planning and process’.

Conclusion

Tangible opportunities to enhance the patient experience are apparent. Small changes to the way that the health system operates, is resourced, and the way that health professionals engage with patients could substantially improve care. Examples include inviting patients and carers to contribute to decision making and discussions about treatment options and care preferences.
2 Introduction

Acknowledging and utilising patients' experiences of their care is critical to providing and improving health care. Patient experience has been identified as a core component of an optimal health system, along with improving the health of populations and reducing the per capita costs of care. Patients are uniquely positioned to provide insightful comments about their care and healthcare management. Furthermore, they are the only common link between healthcare services and care processes by which to document the overall care experience. Patient experience data can therefore inform healthcare providers of problems in the care process, which could involve the coordination of care, the care environment or the provision of treatment. Patients’ “direct experience of [the] care process through clinical encounters or as an observer” (p. 2) has been associated with improved clinical effectiveness and patient safety. For example, a good patient experience has contributed to medication adherence, appropriate use of screening services and reduced use of healthcare resources.

Incorporation of the patient experience ensures that healthcare provision is responsive to the preferences, needs and values of each patient. In Australia, the National Safety and Quality Health Service Standards require “the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services”. The routine integration of patient experience data into health systems assessment and evaluations is one of the first steps towards patient-centred care. Patient experience data can be used to constantly adapt and refine services and processes to better meet patients' needs. These data can also provide insight into the extent to which patient-centred care is achieved from an individual patient's perspective.

Capturing patients' experiences is challenging. Patient satisfaction surveys are often used to provide an indication of patients' experiences. Yet, patient satisfaction surveys often contain questions that fail to portray accurately the nature of the care experience. Such surveys often ask patients about their feelings rather than about what actually happened to them during their care; thereby missing an opportunity to identify the factors that might contribute to a positive or negative care experience. Patient satisfaction is a judgement of whether patients' expectations were met, which can be influenced by a range of factors. These may vary widely between different patients in an identical set of circumstances. Patients are often forgiving of healthcare providers due to providers' competing responsibilities and the high-intensity work environment. They may therefore report high levels of satisfaction even in instances of a negative care experience and vice versa depending on their expectations and perceptions of the care process. In addition, patient satisfaction data have not been shown to lead to improvements in care quality. Service improvement activities are contingent upon specific data about the nature of events that identify areas for change. Such data are not captured through satisfaction ratings and can only be obtained via patient experience data.

Patient experience surveys are used across Australia, but the content and the ways in which these surveys are administered vary between different jurisdictions, and across various types of hospitals. Currently, a lack of comparable data from hospital and day procedure patients prevents a national picture of patients' experiences emerging. This review focuses only on qualitative primary research studies, as it is this type of research that facilitates freedom of patient expression of their experiences. As far as we are aware, it is the
first review to assess primary qualitative research with patients about their experiences in Australian health care.

Aim

To identify primary qualitative Australian studies of patients’ experiences in hospital and in day procedure services from published and grey literature.

Objectives

1. To determine the key characteristics of positive and negative patient experiences in hospital or day procedure services in Australia.

2. To identify the system or service related factors that patients have identified as contributing to their positive and/or negative experiences.

3. To establish whether the positive and/or negative experiences of patients are associated with particular backgrounds or patient characteristics.
3 Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses – PRISMA statement – was used to guide the reporting of this rapid review. The PRISMA statement is an evidence-based approach for reporting systematic reviews and meta-analyses.

Eligibility criteria

Inclusion criteria

• **Types of publication**: Publications available in English are eligible, which reported original primary data published from January 1995 when the ‘Quality in Australian Health Care Study’ was published in the Medical Journal of Australia, to July 2015.

• **Types of participants**: Patients who were hospitalised overnight or as a day admission in an Australian hospital or day procedure centre. Day procedures could include, but were not limited to: surgical procedures with same-day discharge, diagnostic procedures (e.g., biopsy, endoscopy, colonoscopy), cardiology/heart procedures (e.g., stent/cardiac catheterisation), oncology/cancer interventions (e.g., radiotherapy, chemotherapy), renal dialysis, blood products/blood transfusion, in vitro fertilisation (IVF), and gynaecological procedures.

• **Types of study design**: Qualitative studies using semi-structured interviews, focus groups or other discursive methods that used narrative data.

• **Outcomes**: Patient-reported qualitative data of their hospital experience. Patient experience was defined as what actually ‘happens’ during the care process.

Exclusion criteria

Articles were excluded if they did not meet the inclusion criteria. Literature assessing patients’ experiences using hypothetical vignettes or scenarios rather than actual experience was also excluded. Studies that primarily focused on patients’ complaints were excluded because of their breadth and lack of sole focus on the care experience.

Study identification

Electronic databases

A range of text words, synonyms and subject headings were developed for the three major concepts in this review of ‘patient experience’, ‘qualitative studies’ and ‘Australian hospital settings’. These phrases were used to undertake a systematic search of seven electronic databases from January 1995 to July 2015 (see Supplementary file 1). Databases searched were: MEDLINE, JSTOR, PsycINFO, CINAHL, PubMed, Informit and Joanna Briggs Database of Systematic Reviews and Implementation Reports. Hand searching of relevant journals (BMJ Quality and Safety, Health Expectations, International Journal of Quality in Health Care, Patient Experience Journal) and reference lists of published papers ensured that all relevant published material was captured. Results were merged using reference-management software (Endnote) and duplicates removed.
Grey material

Qualitative studies reported in the grey literature (e.g. reports and papers published by government departments, public or private health service providers, non-government agencies, consumer organisations, professional bodies, advocacy groups etc.) were identified by searching the websites of relevant organisations (see Supplementary file 2 for a list of the organisations included). Literature identified was assessed along with the papers from the database searches.

Study selection and data extraction

Two reviewers (SM, RH) independently screened the titles and abstracts (or executive summaries for grey literature). Copies of full articles were obtained for those that were potentially relevant. Inclusion criteria were then independently applied to the full text articles by the two reviewers. Disagreements were resolved by consensus or consultation with a third reviewer (MW or EM). The following data were extracted from eligible literature: author(s), publication year, sample, setting, design, primary focus and main findings.

Data synthesis

Data were synthesised in a meta-narrative. This method was selected because of its relevance to the review objectives. Using a meta-narrative allows researchers to synthesise data from a range of disciplines to identify the key storylines in each area and to build up a rich data synthesis demonstrating the commonalities and differences between findings from each study and discipline. The meta-narrative analysis was undertaken in a series of six phases: planning, search, mapping, appraisal, synthesis and recommendations. Following these phases, eligible studies were reviewed and the research traditions and academic disciplines identified by one reviewer (RH), who also explored the conceptualisation of ‘patient experience’ by each tradition. Two members of the research team (MW, EM) identified key elements of the research and main findings and tabulated these elements. The studies were then subjected to an appraisal process before a narrative synthesis of the findings was produced.

Data appraisal

The fourth phase of the meta-narrative process involved an assessment using the Critical Appraisal Skills Programme’s (CASP’s) items for qualitative research to indicate the validity of each publication and relevance to the review questions. Studies were assessed against 10 items and scored ‘Yes’, ‘No’, or ‘Can’t tell’ for each item.
4 Results

Results of the search

After removing duplicates, 1124 records were identified. Title and abstract screening resulted in 76 references that fulfilled the inclusion criteria and copies of the full publications were obtained. A total of 39 publications were included in the review; 33 articles were identified as eligible from the full text review and six studies were identified from the grey literature (Figure 1).

Figure 1: Flow diagram of selection process
Excluded studies

Of the 22 papers retrieved from grey literature searching and contact made with 32 organisations, 12 were excluded; six because they did not report primary qualitative data and six because the data reported were about the needs or opinions of particular patients or patient groups about health care in general as opposed to their actual hospital experiences. A further paper was excluded due to a focus on primary care and another due to focus on patient experience data collection methods (see Figure 1 for reasons for exclusion of database articles).

Characteristics of included studies

Thirty-nine publications reported 34 unique datasets. Sample sizes ranged from one to 300 participants. Smaller sample sizes were typically used in interviews and focus group studies, and the largest studies used surveys that included open-ended items. Samples included hospital inpatients (27), hospital day case patients (4), or both hospital in- and day-patients (8). Samples were identified through the healthcare system (31), community networks (2) or were self-selected/volunteers (6). Thirty-eight studies were cross-sectional, with one taking place over a four-month period. Patient experience data were gathered using semi-structured interviews (19) surveys (3), focus groups (2), written narratives (2), or a combination of observations, interviews and/or focus groups (13). Papers focused on the following patient groups: inpatients (16), surgical patients (5), culturally and linguistically diverse patients (3), cancer patients (3), parents of child patients (2), patients with comorbidities (2), rural patients (2), adolescents (1), child patients (1), maternity (1), rehabilitation (1), brain injury (1) and chronic illness (1). See Table 1 for a summary of the included publications.
Table 1: Summary of included studies (n=39)

<table>
<thead>
<tr>
<th>First author</th>
<th>Date</th>
<th>Method</th>
<th>Analysis</th>
<th>Sample</th>
<th>Objective</th>
<th>Main findings</th>
<th>Search</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bradley, S</td>
<td>2013</td>
<td>Ethnographic interviewing</td>
<td>Taxonomic</td>
<td>9 self-selected patients</td>
<td>To empirically study the process and outcomes of the implementation of nurse-to-nurse bedside handover</td>
<td>Patients preferred bedside handovers rather than traditional closed-door office handovers. Bedside handovers incorporate social aspects for the patient and they subsequently feel more involved in their care.</td>
<td>Database</td>
</tr>
<tr>
<td>Brough, C</td>
<td>2006</td>
<td>Focus group and individual semi-structured interviews</td>
<td>Thematic</td>
<td>86 people from 4 non-English backgrounds recruited through formal and informal networks within each community</td>
<td>To determine consumer experiences on the effectiveness of language service provision, specifically interpreters, in health settings</td>
<td>Patients were often forced to communicate via family members or to get by without assistance. The current level and standard of language service provision appeared to compromise the effectiveness and quality of the care received. ‘Inappropriate’ use of interpreters of the opposite gender and the need for more access to interpreters noted.</td>
<td>Grey</td>
</tr>
<tr>
<td>De, S</td>
<td>2014</td>
<td>Semi structured face-to-face interviews</td>
<td>Thematic</td>
<td>36 parents of 27 children &lt; 3 months old</td>
<td>To describe the perspectives of parents of young infants presenting to hospital with fever</td>
<td>Parents of febrile infants expected reassurance and support from hospital staff but experienced a sense of relinquished control, inadequacy and guilt.</td>
<td>Database</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Methodology</td>
<td>Design</td>
<td>Sample</td>
<td>Purpose</td>
<td>Findings</td>
<td>Database</td>
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<tr>
<td>De Jesus, G</td>
<td>1996</td>
<td>Semi-structured survey</td>
<td>Thematic</td>
<td>148 completed surveys of same-day surgery patients</td>
<td>To determine if clinical outcomes are influenced by the specific information needs and expectations of same-day surgery patients</td>
<td>Information delivery was a principal factor influencing clinical outcomes and patient satisfaction. Accurate and timely information provision is crucial during the pre- and post-operative periods.</td>
<td>Database</td>
</tr>
<tr>
<td>Edwards, K</td>
<td>2014</td>
<td>Semi-structured interviews</td>
<td>Thematic</td>
<td>1 patient, 1 family member, 8 health staff</td>
<td>To explore the perceptions of one patient's hospital experience, identifying what mattered to the patient and family, and whether the healthcare providers were aware of what mattered</td>
<td>Medication management, physical comfort and emotional security mattered most to patients. Healthcare providers were not always aware of what mattered to the patient and family during their hospital admission.</td>
<td>Database</td>
</tr>
<tr>
<td>Ford, K</td>
<td>2011</td>
<td>Several data collection techniques including interviews, drawings and stories</td>
<td>Constructivist grounded theory</td>
<td>10 children between the ages of 6 and 12</td>
<td>To study views and experiences of admission to hospital for surgery among children</td>
<td>Therapeutic interventions such as humour, fun and play created an enjoyable care experience, and alleviated anxiety and fear often experienced by children admitted for surgery.</td>
<td>Database</td>
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<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Methodology</td>
<td>Sample Description</td>
<td>Research Aim</td>
<td>Findings</td>
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<tr>
<td>Garrett, P</td>
<td>2008</td>
<td>Grounded theory</td>
<td>49 patients and 10 carers from non-English speaking backgrounds</td>
<td>To better understand the experience and to identify critical factors leading to their constructions of care for non-English speaking patients</td>
<td>Recognition of patients’ powerlessness, rights, familial roles, language ability, religious and spiritual beliefs, socioeconomic status, and gender, contributed to experiences of care and the construction of illness among non-English speaking patients</td>
<td></td>
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<tr>
<td>Henderson, A</td>
<td>2009</td>
<td>Thematic</td>
<td>15 men and 24 women with a broad range of medical and surgical conditions</td>
<td>To identify potential threats to patient dignity and ascertain patients’ perceptions about, if and how, dignity was maintained</td>
<td>Patients’ dignity and privacy were maintained during care provision. Patients may be accepting of considerable deviations in care provision if they perceive the organisation is working in their best interests</td>
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<tr>
<td>Henderson, A</td>
<td>2004</td>
<td>Thematic</td>
<td>20 elective surgery, 14 males and 6 females, patients</td>
<td>To explore what hospitalised patients considered important for patient satisfaction to exist</td>
<td>Several factors were identified as important to patients to make their hospital stay satisfactory, demonstrated via 16 themes. The themes of ‘medical outcomes’, ‘clinical outcomes’, and ‘professionalism and competency of staff’ were the most consistently identified</td>
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</table>

Database
<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Study Design</th>
<th>Methodology</th>
<th>Sample</th>
<th>Objective</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iedema, R</td>
<td>2008a</td>
<td>Semi-structured interviews</td>
<td>Discourse analysis identifying overarching themes</td>
<td>23 patients involved in adverse events and incident disclosure</td>
<td>To explore patients’ and family members’ perceptions of Open Disclosure of adverse events that occurred during their health care</td>
<td>Health service incident disclosure rarely met needs and expectations. A combination of formal Open Disclosure, a full apology, an offer of tangible support and evidence of practice improvement has a higher chance of gaining consumer satisfaction than if one or more of these components is absent.</td>
</tr>
<tr>
<td>Iedema, R</td>
<td>2008b</td>
<td>Semi-structured interviews</td>
<td>Discourse analysis identifying overarching themes</td>
<td>131 self-selected clinical staff and 23 patients and family members</td>
<td>To determine which aspects of Open Disclosure ‘work’ for patients and healthcare staff based on an evaluation of the National Open Disclosure Pilot</td>
<td>Patients and staff overwhelmingly supported the use of an Open Disclosure process as an information sharing strategy after an adverse event. The process was considered useful as a way to be briefed about the incident and its management in an ongoing process. Healthcare professionals must consider the patient or family perception of the severity of an event and not just the health system definition.</td>
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<tr>
<td>Reference</td>
<td>Year</td>
<td>Methodology</td>
<td>Data Collection</td>
<td>Analysis</td>
<td>Themes Identified</td>
<td>Findings</td>
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<tr>
<td>Iedema, R</td>
<td>2008c</td>
<td>Interviews with patients and carers, complaints data, root cause analysis data, staff stories and observation</td>
<td>Thematic</td>
<td>76 patients and 109 emergency staff across 3 sites</td>
<td>To engage frontline staff, patients and carers in identifying the best and worst aspects of their experience, and to co-design solutions</td>
<td>Consistent themes identified were: gratitude for the care provided, frustration with lack of parking and discomfort in the waiting room, lack of information and communication, patients being separated from carers and being treated with a lack of respect and courtesy</td>
</tr>
<tr>
<td>Iedema, R</td>
<td>2011</td>
<td>Semi-structured, in-depth interviews</td>
<td>Discourse analysis identifying overarching themes</td>
<td>39 patients and 80 family members who were involved in high severity healthcare incidents</td>
<td>To investigate patients’ and family members’ perceptions and experiences of disclosure of healthcare incidents and to derive principles of effective disclosure</td>
<td>Respondents expected better preparation for open disclosure, more two-way communication about what went wrong in their care, more follow-up support, to be consulted about the timing of a disclosure and more information about actions taken as a result of the incident</td>
</tr>
<tr>
<td>Johnson, A</td>
<td>2005</td>
<td>Semi-structured survey</td>
<td>Thematic</td>
<td>19 long stay patients with a length of stay between 14 and 30 days</td>
<td>To determine the perspectives of patients categorised as long-stay outliers about aspects of organisation of care and the perceived impact of their long-term hospitalisation</td>
<td>Long-stay patients required staff to be more family- and patient-centred when preparing for discharge</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Methodology</td>
<td>Data Collection</td>
<td>Design</td>
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<tr>
<td>Lobb, E</td>
<td>2011</td>
<td>Semi-structured interviews</td>
<td>Grounded theory</td>
<td>Purposive sampling was used to recruit 19 patients and 21 caregivers</td>
<td>To describe the experience of the initial communication for patients and caregivers of being diagnosed with high-grade glioma and subsequent prognosis</td>
<td>Themes identified by patients and carers: (a) shock at hearing the diagnosis; (b) trying to understand and process prognostic information when still in shock; (c) the perception of hope being taken away; (d) individualising prognostic information; and (e) clinicians’ lack of communication skills</td>
</tr>
<tr>
<td>Manias, E</td>
<td>2004</td>
<td>Semi-structured interviews</td>
<td>Framework analysis</td>
<td>10 chronically ill adult patients who had experienced multiple hospital admissions</td>
<td>To determine patients’ perspectives about self-medication in the acute care setting</td>
<td>Participants indicated that the opportunity to self-administer medication would leave nurses with more time to attend to their other clinical duties, while providing them greater autonomy&lt;br&gt; Nurses’ perception of medication management as their domain was identified as a key barrier to self-administration</td>
</tr>
<tr>
<td>Markovic, M</td>
<td>2004</td>
<td>Observations and semi-structured interviews</td>
<td>Thematic</td>
<td>10 women from different socio-economic backgrounds who had undergone a range of different surgical procedures</td>
<td>To explore anxiety in the context of day surgery and identify the issues pertinent to the experiences of day surgery patients</td>
<td>Day surgery-related anxiety was exacerbated by having to walk to the theatre and being separated from their carer</td>
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<tr>
<td>Author</td>
<td>Year</td>
<td>Methodology</td>
<td>Participants</td>
<td>Research Question</td>
<td>Findings</td>
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</table>
| Marshall, A      | 2004 | Semi-structured interviews | Thematic, phenomenological                                                    | 10 patients (8 women and 2 men) aged 18 and over and expected to be discharged within the next 2 days | To explore patients’ understanding and conceptualisation of patient-centred care
Patients equated the type and quality of care they received with the staff that provided it; themes of connectedness, involvement and attentiveness were prevalent in their descriptions of what they wanted from their care
Subthemes identified were: (1) resources (including workload and the physical environment); (2) culture; and (3) waiting |
| Montgomery, K    | 2012 | Semi-structured interviews | Interpretative phenomenological                                               | 10 patients undergoing aggressive inpatient cancer therapy (undergoing autologous stem-cell transplantation) and their caregivers | To gain deeper insights into patients’ experiences during aggressive cancer therapy and to suggest how these insights can be applied to models of patient-centred care
Patients understood that they could neither battle the cancer nor undertake the therapy on their own
Patients were frustrated by the limited opportunities to engage in their care |
<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Design</th>
<th>Quality</th>
<th>Participants</th>
<th>Research Question</th>
<th>Findings</th>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>O’Callaghan, A</td>
<td>2011</td>
<td>Semi-structured survey</td>
<td>Thematic</td>
<td>202 patients, of working age, admitted for acute care following a moderate to severe traumatic brain injury (TBI)</td>
<td>To investigate the continuum of care experienced by adults and their significant others following a moderate to severe TBI</td>
<td>Very few participants report receiving services in line with recommendations made in clinical care guidelines. Access to services varied according to individual’s healthcare funding and a lack of services were available on discharge.</td>
<td>Database</td>
</tr>
<tr>
<td>Olver, I</td>
<td>2010</td>
<td>Unstructured journal writing</td>
<td>Thematic</td>
<td>38 patients (22 women, 16 men)</td>
<td>To obtain patients’ experiences of the cancer treatment pathway to enable healthcare professionals to be educated on how to improve patient care</td>
<td>Patients experienced a wide range of emotional reactions to their care and felt more positive when given opportunities to be involved. The treatment environment, including personnel was considered important to the care experience.</td>
<td>Database</td>
</tr>
<tr>
<td>Peiris, W</td>
<td>2012</td>
<td>Semi-structured interviews</td>
<td>Thematic</td>
<td>19 adults undergoing inpatient rehabilitation for neurological and musculoskeletal impairments</td>
<td>How do patients receiving inpatient rehabilitation experience physiotherapy and does their experience differ if they receive extra Saturday physiotherapy?</td>
<td>Patients valued interacting with physiotherapists and other patients. The patient-therapist interaction was more important to the patient than the amount or content of their physiotherapy.</td>
<td>Database</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Methodology</td>
<td>Analysis Type</td>
<td>Sample Details</td>
<td>Research Questions</td>
<td>Findings</td>
<td>Publication Type</td>
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<tr>
<td>Penney, W&lt;sup&gt;20&lt;/sup&gt;</td>
<td>2007</td>
<td>Participant observation and semi-structured interviews</td>
<td>Thematic</td>
<td>36 patients aged 70 and over and 31 nurses caring for them</td>
<td>To explore the participation of older people in their care in acute hospital settings and to explore their views of participation</td>
<td>Older people equated participation in their own care with being independent. The difficulties in communicating with health professionals and an inability to administer their own medications in inpatient settings were described as barriers to participation.</td>
<td>Database</td>
</tr>
<tr>
<td>Piper, D&lt;sup&gt;32&lt;/sup&gt;</td>
<td>2010</td>
<td>Patient and family interviews, surveys and observation</td>
<td>Thematic</td>
<td>219 patients and 378 staff across 4 sites</td>
<td>To engage patients, their families and staff in identifying the positive and negative aspects of their experience of two hospital departments</td>
<td>Aspects of the experience were consistently identified as problematic: inadequate communication between staff, patients and carers, uncomfortable waiting facilities, lack of provision of information, lack of privacy and poor communication between departments.</td>
<td>Grey</td>
</tr>
<tr>
<td>Piper, D&lt;sup&gt;32&lt;/sup&gt;</td>
<td>2014</td>
<td>Semi-structured interviews</td>
<td>Discourse analysis identifying overarching themes</td>
<td>13 participants from the ‘100 Patient Stories’ study</td>
<td>To analyse rural patients’ and their families’ experiences of Open Disclosure and offer recommendations to improve disclosure in rural areas</td>
<td>Rural patients expected better preparation for disclosure, more shared dialogue about what went wrong, more follow-up support, input into when the time was right for disclosure and more information about subsequent improvement processes. A formal open disclosure meeting following an adverse event was desired. Patients reported the impact of social familiarity on the Open Disclosure process in rural areas.</td>
<td>Database</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Year</td>
<td>Study Design</td>
<td>Analysis</td>
<td>Sample Size</td>
<td>Research Questions</td>
<td>Findings</td>
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<tr>
<td>Roden, J</td>
<td>2005</td>
<td>Semi-structured interviews</td>
<td>Thematic</td>
<td>14 parents of ill children</td>
<td>To understand perceptions of parent participation in their child's care</td>
<td>Good communication was identified as key to effective relationships between parents and staff</td>
<td></td>
</tr>
<tr>
<td>Schembri, S</td>
<td>2013</td>
<td>Written patient stories</td>
<td>Thematic</td>
<td>300 self-selected patients</td>
<td>To provide a perspective of healthcare experience through the patients' eyes</td>
<td>Three themes of positive experiences were: (1) attentive and considerate service; (2) effective treatment; and (3) timely service Three themes of negative experiences were: (1) ongoing problems; (2) service failure stories; and (3) slow and unresponsive service</td>
<td></td>
</tr>
<tr>
<td>Sharp, R</td>
<td>2014</td>
<td>Semi-structured telephone interviews</td>
<td>Thematic</td>
<td>10 patients selected while they waited for Peripherally Inserted Central Catheter (PICC) insertion</td>
<td>To investigate the patient experience of PICC insertion, the significance of arm choice and the impact of the device on activities of daily living</td>
<td>Those with no previous experience of a PICC described the information given by medical staff as minimal, technical and difficult to understand, leading to a poorer care experience</td>
<td></td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Methodology</td>
<td>Design</td>
<td>Participants</td>
<td>Study Aim</td>
<td>Findings</td>
<td></td>
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<tr>
<td>Stevens, J</td>
<td>2001</td>
<td>Semi-structured interviews</td>
<td>Thematic</td>
<td>16 women aged between 26 and 42 undergoing laparoscopic sterilisation</td>
<td>To build theory about the day surgery experience by examining the perceptions of a group of women undergoing the same procedure: laparoscopic sterilisation</td>
<td>Anxiety in the pre-operative period and lack of privacy in the pre- and post-operative periods were considerable concerns. Pre-operatively this led to patients not discussing their concerns or condition with nursing staff. Post-operatively this meant that patients were uncomfortable whilst they were experiencing pain, nausea and vomiting.</td>
<td></td>
</tr>
<tr>
<td>VIC Health</td>
<td>2005</td>
<td>Focus groups</td>
<td>Thematic</td>
<td>38 women and 5 men from the local community</td>
<td>To gain an understanding of the cultural aspects of childbearing that are important to Bangladeshi women and their families</td>
<td>Adaptations to make a more culturally appropriate care environment were considered important such as a space for daily prayers and space for family gatherings if required. The lack of availability of translators was also noted.</td>
<td></td>
</tr>
<tr>
<td>WA health</td>
<td>2015</td>
<td>Semi-structured interviews and focus groups</td>
<td>None</td>
<td>6 patients</td>
<td>None provided</td>
<td>Patients valued being treated as an individual in addition to good interpersonal skills and communication from staff. Some experienced long waiting times, uncomfortable waiting areas, a lack of privacy and anxiety due to being left alone for long periods of time in the Emergency Department (ED).</td>
<td></td>
</tr>
</tbody>
</table>
| Watson, J  
2002 | Semi-structured interviews | Thematic | 12 Indigenous women | To explore issues and experiences that existed for Indigenous women during and after their birthing experiences in an acute care setting | Inadequate communication and lack of understanding of cultural and spiritual traditions by healthcare professionals were issues even for those reporting a positive experience generally | Database |
| Williams, A  
2004a | Semi-structured interviews | Thematic | 12 patients within 14 days of being discharged home after an acute illness episode | To investigate perceptions of quality of care by patients experiencing comorbidities who required an acute hospital stay | Patients experienced poor continuity of care for comorbidities  
Discharge planning did not consider comorbidities  
The management of the acute problem took precedence  
As frequent hospital patients they perceived that they got ‘a bad deal’ | Database |
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Research Method</th>
<th>Data Collection</th>
<th>Participants</th>
<th>Methods</th>
<th>Findings</th>
<th>Database</th>
</tr>
</thead>
<tbody>
<tr>
<td>Williams, A</td>
<td>2004b</td>
<td>Semi-structured interviews, observation, document analysis of nursing care plans and patient notes</td>
<td>Grounded theory</td>
<td>40 patients who were, or who recently had been, hospitalised</td>
<td>32 nurses</td>
<td>To explore and describe, from the perspective of hospitalised patients, the perceived therapeutic effect of interpersonal interactions that were experienced during hospitalisation</td>
<td>Emotional comfort was identified as therapeutic in enhancing patient’s recovery. Factors influencing emotional comfort are: level of security; level of knowing; and level of perceived personal value. These factors were influenced by the interpersonal interactions that patients experienced.</td>
</tr>
<tr>
<td>Williams, A</td>
<td>2005</td>
<td>Semi-structured interviews and observation</td>
<td>Thematic</td>
<td>40 patients who were, or who recently had been, hospitalised</td>
<td>32 nurses</td>
<td>To investigate the impact of the hospital environment on patients’ experiences of personal control and the influence on health status. All of the patients in the study experienced feelings of reduced personal control that negatively affected their care experience.</td>
<td></td>
</tr>
<tr>
<td>Williams, A</td>
<td>2006</td>
<td>Semi-structured interviews and observation</td>
<td>Thematic</td>
<td>40 patients who were, or who recently had been, hospitalised</td>
<td>32 nurses</td>
<td>To explain the perceived therapeutic effects of interpersonal interactions experienced by patients during hospitalisation. Patients’ degree of emotional comfort was important for a positive care experience. The interpersonal skills of the healthcare staff influenced the emotional comfort of patients.</td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Methodology</td>
<td>Design</td>
<td>Sample Description</td>
<td>Research Question</td>
<td>Findings</td>
<td></td>
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<td>---------</td>
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<td>-----------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Williams, A</td>
<td>2008</td>
<td>Semi-structured interviews and observation</td>
<td>Thematic</td>
<td>56 patients who were, or who recently had been, hospitalised</td>
<td>To further develop the theory of optimising personal control to facilitate emotional comfort, in relation to therapeutic and non-therapeutic aspects of the hospital environment</td>
<td>Patients’ experience of feeling secure, their level of knowing and their level of personal value in terms of aspects of the hospital environment either contributed to feelings of reduced personal control or facilitated patients’ ability to optimise their personal control and emotional comfort</td>
<td></td>
</tr>
<tr>
<td>Zeitz, K</td>
<td>2011</td>
<td>Focus groups Co-operative inquiry approach</td>
<td>Thematic</td>
<td>4 volunteers 70 years or older who had either been patients at the hospital or cared for an older person, 4 clinicians, 3 facilitators</td>
<td>To identify the care issues experienced by older people in the acute setting that could be improved through a collaborative approach to action</td>
<td>Aspects of a negative experience included unsuitable food, lack of involvement and chaotic discharge processes. Participants identified the opportunity to work together with health providers as key to a positive experience</td>
<td></td>
</tr>
<tr>
<td>Zugai, J</td>
<td>2013</td>
<td>Semi-structured interview</td>
<td>Thematic</td>
<td>8 adolescent recovered-anorexic patients</td>
<td>To establish how nurses ensure weight gain and a positive inpatient experience for the treatment of adolescents with anorexia nervosa by considering consumer perspectives</td>
<td>Patients’ motivation to adhere to care was derived from strong relationships with nurses and they valued nurses who created a comfortable and productive environment</td>
<td></td>
</tr>
</tbody>
</table>
Study quality

Assessment of the studies using the CASP suggested that all studies used qualitative methods appropriately, used appropriate research designs and 22 of the articles described rigorous analytic processes. However, the appraisal also revealed areas of weakness. The recruitment strategies relied on the healthcare services to invite their patients in four studies. The purposive selection process may have introduced bias; patients with better experiences or an ongoing relationship with the healthcare service may have been selected. In addition, a sample size of fewer than 10 was used in seven studies and 15 studies were conducted at a single hospital/day centre site, resulting in limited applicability of findings across settings. Information about the recruitment process was insufficient to make a judgement about its quality in five studies. Despite the use of strategies to provide a rigorous analysis, most studies (27) did not describe the researcher-participant relationship and consider how this relationship may have shaped the data. Ten studies did not report receipt of ethical approval to conduct the work and in one study it was unclear whether ethical approval had been granted.

Five of the six articles retrieved from the grey literature were assessed using the CASP appraisal questions. The patient stories identified on the Western Australia Health website were not appraised because they were simply transcripts and did not provide any detail regarding aims, data collection methods or analysis. Similar findings were identified in the five appraised articles as in the articles retrieved from the database searches. The aims were clearly stated with appropriate study designs and use of qualitative methods. None of the articles provided details of ethical approval for the work undertaken or adequate consideration of the relationship between researcher and participant in terms of the potential impact on the resulting data. Only one of the articles provided sufficient detail to determine the level of rigour in the analytic process. No papers were excluded following the appraisal.

Review findings

A meta-narrative is “the unfolding ‘storyline’ of research in a particular scientific tradition.” The 12 meta-narratives that contributed to the review are shown in Table 2; each had a particular conceptualisation of ‘patient experience’. Quality improvement researchers produced the dominant narrative (18 of the 39 studies). The nursing perspective was strong; 13 of the quality improvement studies came from nursing, with the discipline producing or contributing to 19 studies overall. Public health and health services researchers also had a key role in producing the literature; contributing to six studies across several health-related research traditions including paediatric health, cancer care, and ethnicity and health. Notably, only two studies were grounded in the medical discipline.

The conceptualisation of patient experience varied but often included patients’ perspectives of clinical processes, the engagement of patients in care and the notion of patient-centredness. None of the studies provided an explicit theoretical basis. Health professionals mostly conducted this work; the unifying principle was therefore the desire to make an improvement to practice rather than establish a theoretical principle. The literature was pragmatic and often focused on patients’ experiences in a particular healthcare setting rather than producing more widely applicable evidence. Seven overarching themes relating to characteristics of positive and negative care experiences emerged (see Table 3).
Table 2: Research traditions that have covered the Australian patient experience qualitatively

<table>
<thead>
<tr>
<th>Research tradition</th>
<th>Academic discipline</th>
<th>Definition and scope</th>
<th>Conceptualisation of patient experience</th>
<th>No. of studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Quality Improvement</td>
<td>Multi-disciplinary:</td>
<td>The analysis of a system’s or organisation’s performance and identification of systematic strategies to improve it</td>
<td>Satisfaction with clinical outcomes; a way of assessing patient-centredness; feedback on expectations; consumer participation</td>
<td>18</td>
</tr>
<tr>
<td>2. Communication studies</td>
<td>Interdisciplinary:</td>
<td>The study of communication, including interpersonal and mass media</td>
<td>Patient engagement via ongoing, interactive communication between patients, carers and professionals before during and after a care experience</td>
<td>5</td>
</tr>
<tr>
<td>3. Paediatric health</td>
<td>Multi-disciplinary:</td>
<td>The study of the medical care of infants, children and adolescents from birth up to 18 years of age</td>
<td>Carer participation; active involvement; satisfaction with medical management of care</td>
<td>3</td>
</tr>
<tr>
<td>4. Ethnicity and health</td>
<td>Health services research</td>
<td>The study of health and healthcare delivery for ethnically diverse consumers</td>
<td>Patient-based perspective of the care environment and processes</td>
<td>3</td>
</tr>
<tr>
<td>5. Rural health</td>
<td>Nursing</td>
<td>The study of health and healthcare delivery in rural environments</td>
<td>A patient-centred approach; stories of needs and expectations</td>
<td>2</td>
</tr>
<tr>
<td>6. Cancer care</td>
<td>Public health</td>
<td>The study of health and healthcare delivery for those with cancer</td>
<td>Insight to apply to treatment policies and staff education</td>
<td>2</td>
</tr>
<tr>
<td>7. Palliative care</td>
<td>Medicine</td>
<td>The study of health and healthcare delivery for consumers with terminal health care issues</td>
<td>Understand and identify patient needs</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Area</td>
<td>Discipline</td>
<td>Description</td>
<td>Themes</td>
</tr>
<tr>
<td>---</td>
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<td>------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>8</td>
<td>Women’s health</td>
<td>Sociology</td>
<td>The study of health and healthcare delivery for women</td>
<td>Patients’ ideas, perspectives and interpretations of processes and the environment</td>
</tr>
<tr>
<td>9</td>
<td>Community health</td>
<td>Health services research</td>
<td>The study and of the health characteristics of biological communities, generally geographically based</td>
<td>Consumer preferences and evaluations of care processes</td>
</tr>
<tr>
<td>10</td>
<td>Rehabilitation</td>
<td>Allied health</td>
<td>Studies that aim to enhance and restore functional ability and/or quality of life to those with physical impairments or disabilities</td>
<td>Perceptions and attitudes about the amount of care received</td>
</tr>
<tr>
<td>11</td>
<td>Indigenous health</td>
<td>Nursing</td>
<td>The study of health and healthcare delivery for Indigenous consumers</td>
<td>Identifying sociocultural needs, with a focus on communication</td>
</tr>
<tr>
<td>12</td>
<td>Adolescent health</td>
<td>Nursing</td>
<td>The study of health and healthcare delivery for adolescent consumers</td>
<td>Consumer contribution for therapeutic alliance</td>
</tr>
</tbody>
</table>
Findings, in relation to the review questions, were organised into themes. Rather than distinct characteristics of a positive care experience and a negative care experience, a continuum emerged. The full list of themes and related subthemes are shown in Table 3.

Table 3: Themes and subthemes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
<th>Subthemes</th>
</tr>
</thead>
</table>
| 1. Reciprocal communication and information sharing | Effective or ineffective communication between patients, carer and staff or between staff members | • Facilitating patient and/or family engagement  
• Negotiated patient autonomy  
• Setting expectations  
• Denying patient and family involvement  
• Gaps in information provision  
• Unclear information  
• Openness |
| 2. Interpersonal skills and professionalism | The level of friendliness, professionalism and competence of staff | • The social environment  
• Connected staff  
• Absence of empathy  
• Cultural competence |
| 3. The care environment | The availability, cleanliness and experience of the hospital surroundings and equipment | • Resource deficiency  
• Attentiveness to the physical environment |
| 4. Correct treatment and physical outcomes | Problems in the treatment process and whether the treatment led to the desired outcome | • Holistic care |
| 5. Emotional support | The level of emotional and psychological support provided by the healthcare team | • Emotional security |
| 6. Comfort, pain and clinical care | Ongoing day-to-day patient care beyond the main treatment | • Responsive, compassionate care |
| 7. Discharge planning and process | The organisation and implementation of the discharge process | • Chaos and confusion |
**Key characteristics of positive or negative patient experiences in hospital or day procedure services in Australia**

Patients often reported being happy or satisfied with their care, but only 15 papers explicitly identified specific features of a positive patient experience. A further four papers identified patient preferences and needs that, if addressed, may contribute to a positive experience. Factors identified in relation to positive experiences were generally related to communication and the interpersonal skills of staff. Twenty-nine papers identified factors leading to a negative patient experience.

1. **Reciprocal communication and information sharing**

The most substantial factor associated with both a positive and a negative patient experience was the existence and degree of effective communication between staff and patients. Seven subthemes emerged under ‘Reciprocal communication and information sharing’. The first subtheme was ‘Facilitating patient and/or family engagement’. Parents expressed a sense of partnership and involvement with medical teams when they were provided with a clear management plan, timely updates and given the opportunity to ask questions and discuss treatment options.31 Conversely, the subtheme ‘Denying patient and family involvement’ described negative care experiences (identified in nine studies) in which healthcare providers did not allow patients and/or their family members to engage in the care process.19,31,45-47,50,53 For example, parents of child inpatients often felt disempowered due to being excluded from decision-making associated with the medical management of their child.31 ‘Gaps in information provision’ described patients in seven studies who expressed dissatisfaction with the information they received pre-, during and post-hospitalisation.31,44,48,52,55,56,59 For example, inadequate information during the consent process was identified as leading to negative care experiences as patients did not understand the procedure.55 Lack of contact and communications with obstetricians/surgeons prior to an operation and a lack of debriefing from them after the operation also marked poor care.44 ‘Unclear information’ was a subtheme in six studies.32,41,44,48,50,59 Long-stay patients expressed a lack of knowledge about the expected duration of their stay; this issue links with inadequate patient involvement in care.41 Indigenous women reported not understanding the information provided by nurses about their maternity care and not having the opportunity to ask questions.59 They identified a need for nurses to recognise and adapt to varying levels of English language use in these communities.

‘Openness’ described a lack of openness among healthcare staff. Three studies of incident disclosure highlighted patient distress when they were not listened to, a feeling that staff were hiding mistakes made in their care and patients feeling as though they were not being included in an open discussion about problems occurring in their care.37,38,40 Particular concerns in the open disclosure process were inadequate patient preparation, inappropriate approaches to disclosing adverse events, and a lack of follow-up support and communication.40

‘Negotiated patient autonomy’ relates to the experiences of patients with chronic conditions. The opportunity to negotiate with staff about the arrangements for managing their medications, including self-administration of medications if requested, was favoured.43 In the subtheme ‘Setting expectations’, patients reported emotional comfort in the relief of anxiety when provided with clear information about what to expect from the overall treatment process prior to their procedure.56,59
2. Interpersonal skills and professionalism

'Interpersonal skills and professionalism' was a second important theme, with four sub-themes. Lack of 'Interpersonal skills and professionalism' among health professionals were key characteristics of negative experiences, generally highlighted by vulnerable patient groups. 'The social environment' described the importance of friendly nursing staff and a welcoming care setting. Positive and enjoyable care experiences were enhanced by friendly interactions with nurses in five studies. In a further subtheme where two studies identified the value of attentive and considerate staff members who responded to them in a timely way and were available when needed. In relation to the subtheme 'Absence of empathy', parents of paediatric patients described feeling distressed and angry when health professionals were not able to empathise with the stress and worry they faced about their child's care, and did not provide adequate emotional support to them as a result. 'Cultural competence' was highlighted in the negative care experiences of culturally and linguistically diverse patients (CALD) and Indigenous patients due to staff who were neglectful, lacked caring qualities, lacked understanding of their perspective or were perceived as racist.

3. The care environment

Two subthemes emerged in relation to 'The care environment.' The first subtheme, 'Resource deficiency,' was evident in four studies. Patients identified a lack of, or faulty equipment, bad, insufficient or unsuitable food and the lack of a clean and comfortable bed as contributing to negative experiences. Where equipment was available, negative experiences were noted if staff lacked the necessary training and skills to use it. Lack of transportation resources were blamed for delays in the transfer of patients to larger hospitals when needed. The second subtheme was 'Attentiveness to the physical environment'. Older patients' dignity was compromised when nurses did not ensure that curtains were drawn, patients were not suitably clothed when being escorted to the bathroom and when patients' beds and surrounding areas were not kept clean.

4. Correct treatment and physical outcomes

Negative care experiences associated with 'Correct treatment and physical outcomes' were only discussed in relation to patients with comorbidities. The only subtheme was 'Holistic care.' Patients described staff who only addressed their acute condition and failed to attend to their broader set of clinical needs. This lack of attentiveness to broader needs meant that being cared for in hospital was often less comfortable than staying at home.

5. Emotional support

The subtheme of 'Emotional security' was identified in relation to both positive and negative experiences. Three studies identified feeling safe and secure as critical contributors to a positive experience for children and for adults. Good communication with healthcare staff, combined with a trusting and close relationship, were important determinants of feeling secure in the care environment. Studies exploring emotion focused on anxiety. Child and adult patients described feelings of anxiety that were not recognised or alleviated by healthcare staff prior to or immediately after their treatment, causing them distress. Emotions were often discussed in relation to the outcomes of having a positive or negative care experience rather than as an aspect of the experience itself.
6. Comfort, pain and clinical care

‘Responsive, compassionate care’ was the only subtheme and described the lack of awareness among health professionals, and particularly nursing staff, of patients’ day-to-day needs. These needs included the provision of analgesia, the need to plan meals around individual patients’ health requirements and planning for interpreters throughout the care process to ensure patients’ concerns are known and met.34,43

7. Discharge planning and processes

Inadequacies in ‘Discharge planning and processes’ were identified in the negative experiences of patients in three studies.47,50,65 ‘Chaos and confusion’ in the discharge process was a common problem, with repetition, duplication and conflicting information often identified.65 Patients who were not consulted in the planning of their discharge said the process was poor. In one study, poor planning resulted in patients being re-admitted within 24 hours of their discharge and hospitalised for a further week.50 Patients described a lack of follow-up care after discharge and a general lack of support from health professionals beyond their immediate procedure.47

System- or service-related factors that contribute to positive or negative experiences.

Patients’ experiences were predominantly influenced by the attitudes and behaviours of healthcare staff, which manifested as inviting opportunities for engagement, being respectful and being friendly. Nonetheless, six system- and service-related factors were identified as important and often lacking, contributing to negative experiences. These were: staff resources, equipment and transport resources, a process to ensure coordination of the care between services, interpreters/translation services, pre- and post-admission information and an adequate discharge process. The types of system and service factors that influenced positive and negative experiences are shown in Table 4.
<table>
<thead>
<tr>
<th>System or service factor</th>
<th>Examples of factors resulting in positive care experiences</th>
<th>Examples of factors resulting in negative care experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Staff resources</strong></td>
<td>• Sufficient staff numbers</td>
<td>• Qualified staff not available</td>
</tr>
<tr>
<td></td>
<td>• Appropriate skill mix of staff</td>
<td>• Staff are not trained in use of necessary equipment</td>
</tr>
<tr>
<td></td>
<td>• Well-trained staff</td>
<td>• Inappropriate staff skill mix</td>
</tr>
<tr>
<td></td>
<td>• Qualified staff not available</td>
<td>• Lack of staff</td>
</tr>
<tr>
<td><strong>Equipment and transport resources</strong></td>
<td>• Suitable equipment</td>
<td>• Lack of equipment</td>
</tr>
<tr>
<td></td>
<td>• Working equipment</td>
<td>• Lack of suitable transport</td>
</tr>
<tr>
<td></td>
<td>• Clean equipment</td>
<td>• Lack of available transport to hospital</td>
</tr>
<tr>
<td></td>
<td>• Appropriate transport available to take patient to hospital</td>
<td></td>
</tr>
<tr>
<td><strong>Coordination of care processes</strong></td>
<td>• Policy to ensure that staff involved in a patient’s care communicate with each other</td>
<td>• Different methods for recording patient information</td>
</tr>
<tr>
<td></td>
<td>• Accurate documentation processes to maintain patient records that are accessible to all involved in their care</td>
<td>• Different storage locations for patient information in each specialty</td>
</tr>
<tr>
<td><strong>Translation services</strong></td>
<td>• Available interpreter</td>
<td>• Lack of interpreter</td>
</tr>
<tr>
<td></td>
<td>• Interpreters in a range of languages</td>
<td>• Bilingual staff not required to use their other language</td>
</tr>
<tr>
<td></td>
<td>• Interpreters for all types of clinical situations</td>
<td></td>
</tr>
<tr>
<td><strong>Pre- and post-admission information services</strong></td>
<td>• Consistent pre-admission policy implemented in every area</td>
<td>• Lack of written information for patients pre- or post-admission</td>
</tr>
<tr>
<td></td>
<td>• Central contact point that is available to patients pre- and post-admission</td>
<td>• No point of contact for the patient pre- or post-admission</td>
</tr>
<tr>
<td><strong>Discharge processes</strong></td>
<td>• Consistent discharge planning policy that is implemented</td>
<td>• Different processes used by different team members</td>
</tr>
<tr>
<td></td>
<td>• Follow up service for discharged patients</td>
<td>• No follow up process for discharged patients</td>
</tr>
<tr>
<td></td>
<td>• Discharge process that includes the patient or carer</td>
<td>• Lack of a clear policy around discharge</td>
</tr>
</tbody>
</table>

Based on the emerging themes, the key features of a positive care experience are depicted in [Figure 2](#).
Health care services are designed and resourced adequately to enable health professionals to provide a positive care experience.

Health care professionals’ attitudes and interpersonal skills provide the atmosphere for a positive care experience.

Health care professionals and service enables the patient to have a positive care experience.

Figure 2: Concept map of contributors to a positive patient care experience
Positive or negative experiences associated with particular patient groups.

Particular aspects of a positive patient care experience were important to the following patient groups: a) culturally and linguistically diverse patients (CALD); b) child patients; c) parents of child patients; d) Indigenous patients; e) cancer patients; f) those with comorbidities; g) those with chronic conditions; and h) rural patients. Key findings relating to each of these patient groups are shown in Table 5.

Table 5: Patient experiences in specific patient groups

<table>
<thead>
<tr>
<th>Patient group</th>
<th>No. of studies</th>
<th>Key issues affecting patients’ experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>CALD patients</td>
<td>30,34,57</td>
<td>• Lack of cultural sensitivity among healthcare staff e.g. same sex wards, lack of consideration for modesty when bathing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Lack of involvement or consideration of religious figures important to the patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Provisions needed to support cultural and religious beliefs e.g. accommodating family gatherings and prayers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Not being able to directly communicate with health professionals means patients not being informed about or involved in decisions and feeling ignored or poorly treated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Over-reliance on family as interpreters and reluctance of bilingual staff to use the patients’ native language – presence of professional interpreter key to positive experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Active engagement of patients by staff despite language barriers highly valued</td>
</tr>
<tr>
<td>Child patients</td>
<td>33</td>
<td>• Children left alone and cared for in adult wards as stressful</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Being placed in clinical areas such as the ED was difficult</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social and emotional support in the healthcare environment particularly important. Provision of nursing support at the time of surgery, and health professionals who engage with children and make the experience fun contribute to enjoyable care</td>
</tr>
<tr>
<td>Parents of child patients</td>
<td>31,53</td>
<td>• Parental empowerment as a determinant of a positive or negative experience. Empowerment facilitated by attentiveness of healthcare team, engaging parents as partners in the care process, and validating the importance of parents’ roles</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Negative experiences associated with relinquishing parental control to the healthcare team, a serious atmosphere in assessment resulting in feelings of fear, a lack of information about the procedure or a lack of empathy and feeling dismissed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Parents have a more positive care experience if they understand the level of involvement expected</td>
</tr>
<tr>
<td>Indigenous patients</td>
<td>59</td>
<td>• Miscommunication and a lack of cultural and spiritual understanding among health professionals</td>
</tr>
</tbody>
</table>
|                     |                | • Lack of preparation about what to expect from hospital and challenges of
<table>
<thead>
<tr>
<th>Group</th>
<th>Number</th>
<th>Issues</th>
</tr>
</thead>
</table>
| Having to leave close communities to give birth |        | - The provision of hospital self-care accommodation valued as a way to feel safe when outside of the community  
- Lack of communication and information provision in hospital led to feelings of loneliness  
- Lack of clear communication with Indigenous women who speak little English threatens safety of care  
- Those that had a positive experience were proactive in asking questions and seeking information |
| Cancer patients                      | 3      | - The communication of diagnosis and prognosis as important  
- Lack of compassionate and empathetic communication  
- Limited opportunities to participate in the treatment process frustrating  
- Carers being allowed to address a patient’s non-medical needs while in hospital as important |
| Patients with comorbidities          | 2      | - Health professionals overly focus on the acute problem and a lack of consideration for patients’ other health issues  
- Changes to regular medications, lack of provision of necessary medications and lack of opportunity to self-administer  
- Feeling overlooked, treated with a lack of respect and support due to the regularity of hospital visits  
- Negative experiences of coordination of care due to seeing a different specialist for each health concern  
- Lack of holistic care exacerbated by the use of cover specialists unfamiliar with the patient’s case. A good handover important  
- Nurses that provided comfort created a positive experience |
| Patients with chronic conditions     | 1      | - The opportunity to self-administer medications important; enabling patients to remain engaged and in control of their care  
- Self-administration perceived to save nurses a substantial amount of time that could be directed at other clinical activities  
- Some patients do not wish to self-administer medications in hospital; engaging with patients to identify their preferences is necessary to provide a good care experience  
- Timing of meals important for patients with diabetes to maintain the routines they are used to at home |
| Rural patients                       | 2      | - Lack of resources and experienced clinicians in smaller rural hospitals results in delayed diagnosis, transfer and treatment  
- Lack of equipment and lack of adequate training among staff  
- Lack of communication and coordination between rural and larger hospitals creates challenges in the coordination of care  
- Patients and clinicians often know each other in the local community, inhibiting open disclosure |
5 Discussion

The review provides evidence of key characteristics of a positive or negative patient care experience among inpatients and day-procedure patients in Australian hospitals. Patients’ sense of communication between with healthcare staff pre-, during and post-admission; interpersonal relationships with staff; the hospital environment; engagement in their care and discharge planning were all important. Rather than distinct characteristics of a positive care experience and a negative care experience, a continuum emerged. For example, where having opportunities to engage in care led to a positive care experience, healthcare staff who denied patient engagement created a poor care experience.

Our findings reflect those of other reviews of qualitative studies of patients’ experiences of hospital internationally (which often focused on a specialised clinical setting or specific patient group). Patient-professional communication, opportunities for patient/carer involvement and the attitudes and behaviour of health professionals were the most important features determining a positive or negative care experience in the Australian literature and in international literature reviews. For example, one international review reported a synthesis of 11 studies of patients’ experiences of patient-doctor relationships in the UK, US, Canada and Sweden, finding that positive care experiences were associated with doctors who listened well, explained issues clearly and provided opportunities for patients to be involved in discussions and decision-making about their care.

The extent to which experiences were positive or negative depended on staff attending to patients’ cultural and language needs, the quality of the care environment and the coordination of care and discharge. A synthesis of 10 qualitative studies from the UK, Ireland, Australia and Canada explored experiences of the discharge process from critical care environments to general wards. Similar to the Australian studies, the need to be supported through feelings of stress and anxiety in the discharge process was important, along with a need for information about their clinical progress and discharge. Specific features of the Australian healthcare environment, such as rural and Indigenous populations have not however been considered in the international qualitative literature.

Implications and further research

Tangible opportunities to enhance the patient experience are apparent from the review findings. Small changes to the way that the health system operates, is resourced, and the way that health professionals engage with patients could substantially improve care. Based on the reviewed studies, several actions pre-, during and post-admission are likely to enhance patients’ experiences. For example, prior to hospital admission, healthcare organisations and staff should consider routinely speaking with patients and their carers about what will happen before, during and after their hospital admission. During hospitalisation, patients’ stay experiences are likely to be enhanced by healthcare organisations and staff that are welcoming and friendly, and that invite patients and carers to contribute to decision making and discussions about their treatment options and care preferences. Upon leaving hospital, healthcare staff should engage with patients and their carers to ensure patients are ready to be discharged and provide clear information about what will happen during this process.
Data about patients’ experiences in Australian hospitals are sparse and more work is needed to address some significant gaps. Studies of the following groups are currently required: rural, Indigenous, child, parent, mental health, family and carers of adults and patients with chronic conditions. While these groups have been included in patient experience studies, reliance on structured survey methods has restricted the degree to which their nuanced experiences have been captured. Larger multi-site studies with qualitative components would be valuable in addressing this goal.

Limitations

The review had limitations in terms of the review methods and of the limitations of the included studies. Most of the studies in the meta-narrative were grounded in the quality improvement paradigm and presented from a nursing perspective. Having a dominant narrative shaped the evidence and led to a focus on aspects of care that are often provided by nursing staff as opposed to the broader healthcare system. Literature from healthcare management, medicine and allied health professional perspectives would be valuable to develop this evidence base further.

There is extensive debate around the distinction between patient experience and satisfaction in existing literature, but these concepts were not delineated by authors in the included studies. Studies often conceptualised patient experience as the processes and feelings that patients experienced in the care process, but there was a heavy focus on whether patients’ expectations were met, which links to the concept of patient satisfaction rather than experience. This conceptualisation is perhaps in part influenced by the Medical Subject Heading (MeSH) term of ‘Patient satisfaction’ which is often used for patient experience studies due to the absence of a ‘Patient experience’ subject heading.

The lack of weight currently given to patient experience research is evident from the small pockets of work identified; generally conducted by individuals and small groups with an interest in this area rather than as part of significant research programs. This gap is also evident in the opportunistic and generally small sample sizes, gathered from single sites in most of the studies. These disparate pieces of work with varied aims and focus contribute to a patchy knowledge base about patients’ experiences in Australian hospitals.
6 Conclusion

Patients’ sense of communication between with healthcare staff pre-, during and post-admission; interpersonal relationships with staff; the hospital environment; engagement in their care and discharge planning were all central to a positive or negative care experience. Rather than distinct characteristics of a positive care experience and a negative care experience, a continuum emerged. Thus, where a good experience was associated with receiving good communication, a bad experience may result from a lack of communication. Tangible opportunities to enhance the patient experience are apparent from the review findings. Small changes to the way that the health system operates and is resourced, and the way that health professionals engage with patients could substantially improve care.
References


Supplementary file 1: Database search strategy (Medline example)

1. ((Patient* adj2 (perspective* or opinion* or experience* or perception* or view*)) or health care consumer*).mp.
2. (consumer* adj2 (perspective* or opinion* or experience* or perception* or view*)).mp.
3. (client* adj2 (perspective* or opinion* or experience* or perception* or view*)).mp.
4. patient participation/
5. patient preference/
6. patient satisfaction/
7. patient involve*.mp.
9. exp Professional-Patient Relations/
10. Hospital patient relations/
11. or/1-10
12. inpatients/
13. patients.mp and (exp hospitals/ or exp hospital departments/ or exp hospitalisation/)
14. (Acute adj (service* or care or setting*)).mp.
15. tertiary care/ or secondary care/
16. or/12-15
17. 11 and 16
18. day procedure*.mp.
19. (same day adj3 procedure*).mp.
20. Ambulatory Surgical Procedures/
21. Elective surgical procedures/
22. Ambulatory care/ and (exp Hospitals/ or exp Hospital departments/)
23. surgicenters/ or surgicentre*.mp. or surgicenter*.mp.
24. day surger*.mp.
25. or/18-24
26. 11 and 25
27. 17 or 26
28. limit 27 to (abstracts and english language and yr="1995 -Current")
29. limit 28 to (case reports or comment or editorial or letter or news)
30. 28 not 29
31. exp Australia/ or Australia*.mp. or Australi*.in.
32. 30 and 31.
Supplementary file 2: Search strategy (grey material)

The following organisations working in the field of patient experience were contacted and their websites searched to identify relevant work. The number of articles retrieved from each is listed:

1. Patient Opinion Australia – 1
2. Australian Commission for Safety and Quality in Health Care – 2
3. Clinical Excellence Commission – 1
4. Agency for Clinical Innovation – 3
5. Consumers’ Health Forum of Australia – 5
6. State and territory health departments:
   a. NSW Health – 0 – survey based
   b. Queensland Health – 0 – survey based
   c. Western Australia DoH – 1
   d. South Australia Health – 0 – survey
   e. ACT Health – 0 – survey based
   f. Northern Territory Health – 0
   g. Victorian Health – 0 – survey based
   h. Tasmania Health – 0 – no data from patients
7. Federal Department of Health – 0 – all survey work
8. State and territory consumer associations (CHF site used in most):
   a. Health Consumers NSW – 0
   b. Health Consumers Queensland – 0
   c. ACT Health Consumers Association – 0
   d. Health Consumers Council – 0 – Patient Opinion used
   e. Health Consumers Alliance of South Australia – 0
   f. Health Issues Centre – 0 – journal on Informit
9. Centre for Ethnicity and Health – 2
10. National Association of County and City Health Officials (NACCHO) – 0
11. Centre for Health Communication and Participation (Latrobe) – 1
12. Health Consumers of Rural and Remote Australia – 1
13. Professional organisations:
   a. Royal Australian College of General Practitioners – 0 – survey based
   b. Royal Australian College of Physicians – 0
   c. Royal Australian College of Surgeons – 0
   d. Australian and New Zealand College of Anaesthetists – 0 – survey based
   e. Allied Health Professions Australia – 0
14. Australian Institute for Patient and Family Centred Care (AIPFCC) – 2
15. CHOICE (previously Australian Consumers Association) – 0 – survey based