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Patient experience of cardiac surgery and nursing care, a Narrative Review

Introduction

Caring for patients is central to the National Health Service (NHS). The provision of excellent care to all is what the NHS aspires to achieve (Department of Health (DoH) 2012a). Therefore, it is highly relevant that those experiencing the service should be consulted to push continual improvements (Dr Foster Intelligence 2010; Tollyfield 2014). Since the publication of 'The NHS Plan' (DoH 2000) and 'Transforming Participation in Health and Care' (NHS England 2013) there has been an emphasis on patient, carer and public involvement in care provision, treatment choices and understanding their experience. Therefore, patient experience is gaining higher priority on the NHS agenda.

Care and treatment of patients with cardiac conditions has developed significantly over the past 20 years with the introduction of the National Service Framework for Coronary Heart Disease identifying quantifiable clinical outcomes for patients (DoH 2009). Additionally, several National Institute for Health and Care Excellence (NICE) guidelines are grounded in the best available evidence, guiding issues such as; Interventional procedures (NICE 2014a), quality standards (NICE 2011) and management guidelines (NICE 2014b) for patients with cardiac conditions, resulting in advances in diagnosis, treatment, medications and service improvements (Matthews and Cornwell 2012). The emphasis on clinical outcomes (DoH 2013) and patient safety (Commissioning for Quality and Innovation 2014) have also been acknowledged in recent policy (Darzi 2008), which identifies the patient experience as an important marker for quality. However, patient experience has received little research scrutiny (Darzi 2008; Maben, Morrow et al. 2012).

Publication of the NHS Patient Experience Framework (National Health Service National Quality Board 2011) and NICE guidance for Patient Experience in Adult Services (NICE 2013) is a step towards measuring patient experience and improving quality in healthcare. This guidance identifies indicators which contribute to a positive patient experience. However, whilst the guidance recognises the inherent difficulty in measuring patient experience, acknowledging its complex nature, it fails to offer solutions to these difficulties. This is in stark contrast to other NICE guidelines which provide audit tools for monitoring and evaluation. Similarly, 'Compassion in Practice',

the three year vision and strategy for Nursing, Midwifery and Care staff outlined implementation plans which prioritise patient experience and focuses on how people perceived the standards of care they received (DoH 2012b). However, there is currently no framework or formative feedback method for patient experience of nursing care delivery (Maben, Morrow et al. 2012).

Previous studies have explored the experience of cardiac patients. However, these have been disease specific (Dunckley, Quinn et al. 2007; Almond, Salisbury et al. 2012), family focussed (Wrigley and Lathlean 2010; Linden 2012), and intervention specific (Perkins 2008; Radcliffe, Harding et al. 2009). Additionally a qualitative synthesis (Leegard and Fagermoen 2008) aimed to reflect key themes and experiences in qualitative literature following Coronary Artery Bypass Graft (CABG) surgery, which did not reflect nursing specific outcomes. No study has attempted to capture the patient experience of nursing care following cardiac surgery, nor has a study synthesised different types of evidence to capture a multi-dimensional view of patient experience following cardiac surgery, nursing care or patient experience measurement.

Aims

The purpose of this Narrative Review was to consider:

- 1) What is the patient experience of cardiac surgery?
- 2) What is the experience of receiving nursing care following cardiac surgery?
- 3) What is the current evidence for measuring patient experience of cardiac surgery and nursing care?

Definitions of key terms used throughout the review are located in figure 1.

[Insert figure 1 here]

Research Design

A Narrative Review approach was adopted thereby allowing for the inclusion of quantitative and qualitative evidence (Dixon-Woods, Agarwal et al. 2004). The review adopted a systematic search strategy, critical appraisal of included studies and a transparent review process, to overcome the inherent limitations and criticism

in the absence of a standardised process for Narrative Reviews (Pope, Mays et al. 2009).

Methods

The review and synthesis was undertaken in four phases (Figure 2). Formulation of the search terms was supported by a combination of background reading and the PICO (Population, Intervention, Comparison and Outcome) acronym as a framework (Cooke, Smith et al. 2012).

[Please insert figure 2 here]

A rigorous scoping search was used (Arksey and O'Malley 2005) (Figure 3 and 4). This involved combing formulated search terms. For example 'cardiac surgery' was combined with 'patient experience' and / or 'nursing care' or 'measurement'. Each search term combination was inputted the same in all databases. Limits were placed on database searches to focus the aims of the review. All titles were scrutinised and rejected based upon the inclusion criteria identified in Figure 5, a summary of the paper extraction process is located in Figure 4.

[Please insert Figure 3 and 4 here]

Some authors advise not to consider raw data or direct citations as findings (Sandelowski and Barroso 2002). However, following Weed (2005) raw data were sometimes used as part of the interpretations and reporting to ensure findings were as close to study participants' accounts as possible.

To ensure thematic analysis was systematic and rigorous in its approach it was conducted using published principles (Pope, Mays et al. 2009)

- 1. Direct citations from the abstract and findings of the primary studies were transcribed in to a new document.
- 2. These new documents were analysed and annotated by the researcher with themes that reflected the patient experience. For example, the theme 'pain related to treatment was not an issue' would be coded as 'physical' for example. This became an iterative approach where themes in the first study reviewed would be adopted in the following studies, and vice versa. Papers were reviewed until no new themes were identified.

- 3. Following review of the papers themes were collected, considered and broken down in to sub themes where appropriate. For example; the theme 'physical' was broken down further into the sub-themes: 'pain' and 'mechanical ventilation'.
- 4. Themes and subthemes were then discussed with the project supervisor and finalised.

Quality Appraisal

Figure 6 summarises the studies meeting the inclusion criteria. A structured quality appraisal tool was adopted (Spencer, Ritchie et al. 2003; Centre for Reviews and Dissemination 2008). Quality of studies was assessed before synthesis in order to raise researchers' awareness of the quality of studies prior to presenting the findings. Many primary qualitative studies are poorly reported (Campbell, Pound et al. 2003). Therefore, each qualitative study was assessed using the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury et al. 2007). Quality assessment was assured by identifying a summary score calculated from each COREQ domain (i) research team, (ii) reflexivity, (iii) study design, and (iv) analysis and findings. The assessment highlighted that all studies had weaknesses in the reporting, particularly in Domain 1 'Research team and reflexivity'. This is an important consideration as all studies used in-depth interviews to collect data meaning that the researchers closely engage in the research and with participants and are unlikely to completely avoid introducing personal bias to the research (Streubert-Speziale and Carpenter 2003). It is recommended that researchers should identify and state their relationship with participants to allow the reader to scrutinise the impact of this on the study findings (Tong, Sainsbury et al. 2007). This approach would have increased the credibility of the included studies.

The CASP (Critical Appraisal Skills Programme) tool was used to review studies (Gardner, Elliott et al. 2005; Backstrom, Wynn et al. 2006; Perkins 2008; Schou and Egerod 2008). This tool is well recognised for identifying methodological issues systematically (Pound, Britten et al. 2005). The CASP tool identified that minimal demographics, context or information on patients details of stay, albeit one study (Gardner, Elliott et al. 2005) were reported. Similar difficulties were acknowledged in the qualitative review by Leegard and Fagermoen (2008) suggesting a weakness in

the current evidence base. Further details on complications and length of stay would have allowed comparison between patients experiencing complications/ increased length of stay and those who recovered routinely and the impact on patient experience.

Jackson, Cook et al., (2014) developed a complex intervention so was critiqued using Medical Research Council guidance (MRC 2008) and was therefore reported separately. They developed the Patient Reported Experience Measures (PREMs) framework that was underpinned by current Patient Experience Frameworks (Picker Institute 1987; Gerteis, Edgman-Levitan et al. 1993; DoH 2012b; DoH 2013; NICE 2013). However, on review the PREMs Framework is so closely aligned to the NICE Quality standard for Adult Patient Experience it cannot claim specificity to heart-valve surgery. Although this may increase the transferability of the PREMs Framework to other specialties, this would need further testing.

Each paper was read several times by the lead author to gain an overview of the study aims, methodology, participants, findings, conclusions and limitations. A second review of each paper used CASP or MRC guidance. Each paper was then re-read without the aid of the relevant tool and further annotations made.

[Please insert figure 5 and 6 here]

Findings

For a summary of key themes/sub-themes see Figure 7.

[Please insert Figure 7 here].

Physical

Pain and physical discomfort

Findings suggest that patients undergoing heart surgery experience varying types and severity of pain and physical discomfort (Gardner, Elliott et al. 2005; Perkins 2008; Schou and Egerod 2008). This finding is consistent with previous qualitative (Holland, Cason et al. 1997; Doering, McGuire et al. 2002), and quantitative (Hunt 1999; Myles, Hunt et al. 2001; Bruce, Drury et al. 2003), studies from critical care and cardiac surgery. Contrary to these findings some patients reported not being in

any pain at all (Perkins 2008; Schou and Egerod 2008), and pain was manageable (Gardner, Elliott et al. 2005). Contrastingly, some patients' described their pain as 'absolute agony' (p376) (Perkins 2008). This is a significant finding, suggestive of variability in effective pain management following cardiac surgery.

Pain could be categorised into three main types; acute (related to surgery), chronic (pre-existing) and general (pain from invasive monitoring lines or lack of mobility). For example, patients reported physical discomfort from invasive monitoring lines, catheters, chest drains, nausea, thirst, numbness, immobility and the Endotracheal Tube (ET), with one patient developing a pressure sore, thus creating further pain and discomfort (Gardner, Elliott et al. 2005; Perkins 2008; Schou and Egerod 2008).

The review presents important findings for nurses who should recognise that pain manifests in various ways. An awareness of risk factors for post-operative pain including; <60 years of age, surgery lasting > 2 hours, depression, psychological vulnerability, high stress levels and surgeon (Breivik and Stubhaug 2008; Sommer, Rijke et al. 2008; Tan, Lim et al. 2008; Hinrichs-Rocker, Schulz et al. 2009) are also important considerations for nurses managing pain post-operatively, and may contribute towards a positive patient experience. This is supported by PREMs Framework (Jackson, Cook et al. 2014) that emphasises pain management as an important domain for patient experience. An understanding of the profound impact poor pain management has on all body systems such as; pulmonary, cardiovascular, gastro-intestinal, muscoskeletal, endocrine, psychological, muscle weakness and depression may enhance patient outcomes (Cogan 2010). Nurses should gather information relating to risk factors to identify patients that are at a greater risk of acute and chronic pain post-operatively to enable effective pain management strategies to be implemented. Effective pain management should reduce pain and physical discomfort which has been identified by Jackson, Cook et al., (2014) as a contributory factor to patient experience. The ability of patients to recall detailed accounts of the experience of pain indicates its significance in patient experience and the quality of care received.

Mechanical Ventilation

Schou and Egerod (2008), aimed to specifically describe the patient experience of weaning from mechanical ventilation following cardiac surgery. Physical experiences

of mechanical ventilation were uncomfortable and strange, sensations of choking, overheating, pressure and discomfort, including swollen vocal chords, swallowing difficulties and a sore throat (Gardner, Elliott et al. 2005; Perkins 2008; Schou and Egerod 2008). One patient described using a coping strategy to help tolerate the ET which they had learned from pre-operative information (Perkins 2008). These findings indicate that mechanical ventilation is not a pleasant experience for patients. However, relevant and effective information given prior to cardiac surgery could equip patients with strategies to effectively cope with weaning from mechanical ventilation.

Psychological and Emotional

Psychological

The psychological experience of cardiac surgery in the immediate post-operative period was mostly associated with negative emotions of distress, anxiety, embarrassment, insecurity, loss of control and reduced self-confidence (Schou and Egerod 2008). Others experienced emotions of agonising, hopelessness, depression, apprehension and regret (Gardner, Elliott et al. 2005). These negative emotions were commonly associated with weaning from mechanical ventilation (Schou and Egerod 2008). This is consistent with others' findings that highlighted depression (Blumenthal, Lett et al. 2003), and post-traumatic stress disorder (Schelling, Richter et al. 2003), also being associated with mortality following cardiac surgery (Blumenthal, Lett et al. 2003). In addition, patients reported emotional disturbance and depression years after cardiac surgery (Rymaszewska, Kiejna et al. 2003; Tolmie, Lindsay et al. 2006). The findings suggest a correlation between patients experiencing negative emotions post-operatively and an increased likelihood of psychological issues following discharge. Consideration of psychological screening of inpatients after cardiac surgery to identify these negative emotions would allow for early assessment and intervention to reduce the long term risk of psychological disturbance and thus potentially decrease the risk of mortality. Jackson, Cook et al., (2014), identified emotional support, alleviation of fear and anxiety about issues, clinical status/prognosis, impact of illness on patient, family and finances as important measures of patient experience, which is consistent with the other studies in the review.

Memory

There were conflicting findings for patients' ability to recall events following cardiac surgery. Perkins (2008), found that all participants had detailed and lengthy memories of the initial post-operative period following Fast-Track surgery. Similarly, Gardner, Elliott et al., (2005), reported that patients had vivid memories of the ICU environment, recalling it as 'busy' and 'crowded', 'sterile' and 'constantly moving'. In contrast one patient who required three admissions to ICU only remembered the third admission; this memory was associated with agonising emotions. This important finding suggests that patients may be more likely to recall negative experiences following cardiac surgery. Ability to recall these experiences may be associated with a Fast-Track protocol; a process aimed at earliest possible discharge, often receive less sedative and analgesic medications than with the conventional protocol, and consequently could provide more detailed accounts when recalling their experiences (Perkins 2008).

Confusion and Hallucinations

Confusion and agitation were reported across the studies, and is therefore a significant finding (Gardner, Elliott et al. 2005; Perkins 2008; Schou and Egerod 2008). It is expected that patients may experience a period of confusion and agitation after cardiac surgery due to the cerebral effects of cardiopulmonary bypass (Woods and Sivarajan-Froelicher 2000). Much confusion was linked by patients to a disturbed sense of time and orientation. The UK Intensive Care Society (1997) recommend that ICUs have clocks visible to patients; however despite this, patients still experienced disorientation with time (Perkins 2008). One patient recalled vivid hallucinations or hearing voices of people who had died, the same patient also experienced confusion in the ward area (Gardner, Elliott et al. 2005). The substantial reports of disorientation and confusion with time have important implications for nursing practice. Nurses should be mindful that patients following cardiac surgery experience disorientation with time and therefore, where possible should reassure and orientate patients to time and place. This may lead to a positive patient experience and a reduced incidence of confusion in the clinical area.

Support

Patients considered the presence of their own family to be the most important source of support post-surgery (Schou and Egerod 2008). However some reported lacking the energy to effectively interact with relatives (Perkins 2008). Despite this, patients wanted relatives present when professionals were giving information; for their own support, but to also relieve the relatives' anxiety (Backstrom, Wynn et al. 2006).

Patients valued the collegiality and companionship of other patients more than talking to professionals (Gardner, Elliott et al. 2005). Contact with other patients allowed them to exchange experiences and talk about feelings and problems with someone in a similar situation (Gardner, Elliott et al. 2005). This was also reflected in the findings with patients reporting feelings of isolation if nursed in a side room (Gardner, Elliott et al. 2005; Backstrom, Wynn et al. 2006). The sense of collegiality was demonstrated through patients helping other patients who were in pain or who ate poorly. This is an important consideration for professionals who manage bed allocations. Where possible, patients of similar procedures and post-operative time points could be nursed together, to encourage support and collegiality and thus may improve their experience.

Information Provision

Information provision is required at key points along the journey, including preoperatively, immediately post-operatively, and following discharge (Backstrom, Wynn et al. 2006). Pre-admission information about approximate surgery dates and general information helped patients prepare for surgery, and they were generally satisfied with this. Furthermore, the format of information, in this case a video, was very informative and helped patients prepare for the challenges of surgery and the hospital stay. Patients wanted information to be given pre and post-operatively by the operating surgeon, and individualised to their particular case (Backstrom, Wynn et al. 2006). These findings suggest that patients require information at key time points in the cardiac surgery journey.

Environment

The clinical environment was part of the patient experience following cardiac surgery. Some found the ICU to be calm and quiet (Perkins 2008), similarly, patients appreciated the light tone kept on the ward (Backstrom, Wynn et al. 2006). It is not clear what 'light tone' meant to patients as this was unexplored by the interviewer. Contrastingly, some patients found the clinical area to be busy, crowded and 'sterile' (Gardner, Elliott et al. 2005). In the same study, one patient found the environment particularly threatening and unsettling. It is important that these findings are considered within the dynamic and changing context of the ICU environment. Environmental considerations are also reflected in the PREMs Framework by Jackson, Cook et al., (2014).

The sound of equipment within the ICU environment may be significant to patient experience, but the type of noise reported varied. Patients reported the sound of humidified oxygen, the sound of suctioning, and alarms from hemodynamic monitors as significant noises (Perkins 2008).

Nursing Care

An aim of this review was to explore the experience of nursing care following cardiac surgery. However, no study specifically aimed to explore the experience of nursing care following cardiac surgery. Therefore, findings which explicitly related to nursing care were identified and included. It could be argued that patient experiences of interventions such as extubation for example; where the persons delivering the intervention were referred to as 'they' in the accounts could have been delivered by nurses, as this is common practice in ICU settings, but for the purpose of this review this assumption was not made.

Patients were generally satisfied with their experience of nursing care and recalled both 'transactional' and 'relational' aspects of nursing care delivery. Definitions of these terms can be found in Figure 1. Experiences of communication were reported across all studies, and are therefore significant to patient experience. The most vivid experience of communication between nurses and patients was associated with being mechanically ventilated (Perkins 2008; Schou and Egerod 2008). Patients reported that nurses used none-augmentative methods of communication such as

gestures, pen and paper and computers, this was valued (Schou and Egerod 2008). Contrastingly, one patient felt that communication could have been made easier for him, and expressed a preference for the use of closed questions which required only a nod or shake of the head (Perkins 2008). Similarly, one patient felt that nurses were not even trying to communicate with them. This is consistent with a classic study which found that critical care nurses focussed more on the technical aspects of care (Ashworth 1980). Further information, about the context in which the data were collected may have provided an interesting insight in to patients' communication expectations. However, new evidence now places great emphasis on the importance of relational aspects of care and patient experience (Robert, Cornwell et al. 2011). Therefore, nurses working with patients following cardiac surgery should be mindful of not only the technical aspects of care, but relational aspects of care, particularly communication and its impact on patient experience.

Patients experienced nursing presence in varying degrees. Some patients recalled an awareness of nurses 'being there' (Perkins 2008), others described more vividly hearing the voices of nurses (Gardner, Elliott et al. 2005; Perkins 2008). This is consistent with findings from (Zikorus 2007), a nurse's personal experience of critical illness which explores her experience of holistic care and appreciation of nurses 'being there' in ICU's. Patients would have liked nurses to spend more time talking, touching or just making eye contact with them (Schou and Egerod 2008). This contrasting finding suggests that nurses should individualise patients' contact and communication needs.

One study found differing perceptions in the patients' concepts of time and 'nurse's time'. Patients reported nurses using words such as 'soon' and 'now', particularly relating to extubation, when in fact hours or days would pass by (Schou and Egerod 2008). This was irritating for some patients, with one saying they would rather not be given an indication of time. Despite this disparity, patients did understand that there were other patients requiring care, and would excuse the nurse's behaviour. However, they appreciated being offered a reason for a delay and when an intervention would likely occur. An accurate or quantified communication of time may be more beneficial for patients at this time (Magnus and Turkington 2006). Further findings related to nursing time were found with patients highlighting a difference between nursing time on the ICU and a general ward area (Gardner, Elliott et al.

2005). The latter was associated with a lack of nursing time from patient perspectives (McKinney and Deeny 2002).

Patient Experience Measurement

The terms 'patient satisfaction' and 'patient experience' are used interchangeably in the literature yet have subtly different meanings (Shale 2012). For clarity they are defined in Figure 1 along with other key terms.

No studies specifically aimed to measure patient experience of nursing care following cardiac surgery. Jackson, Cook et al., (2014) developed a PREMs framework and questionnaire for patient experience following heart valve surgery. A small-scale pilot study of the questionnaire was inconclusive in measuring patient experience, but instead found quantitative outcomes for patient satisfaction. It is therefore, difficult to assess the PREM's suitability for measuring patient experience. However, when findings of reviewed qualitative studies (Gardner, Elliott et al. 2005; Backstrom, Wynn et al. 2006; Perkins 2008; Schou and Egerod 2008) are considered against the PREMs Framework some consistencies are found (Figure 8).

[Please insert Figure 8 here]

This is an important finding which demonstrates that findings from the qualitative studies which included both heart valve surgery and CABG surgery can be correlated with the PREMs Framework. Therefore, the framework could be suitable for measuring patient experience following other types of cardiac surgery; however this would need further piloting in different patient populations. Furthermore, these correlations demonstrate that different types of feedback methods, in this case user involvement versus existing qualitative studies, highlight important similarities of patient experience across different surgical procedures and that using different feedback types may be a robust method for developing patient experience measures for cardiac surgery.

Conclusion

This narrative review of the qualitative and quantitative evidence provides a unique contribution to our understanding of the patient experience of cardiac surgery and of receiving nursing care following cardiac surgery. The review also updates the current

evidence for measuring patient experience of cardiac surgery and nursing care. Our findings indicate the importance of nurses considering the physical, psychological and emotional aspects of patients' experiences of cardiac surgery. However, as none of the studies considered patients' experiences of nursing care following cardiac surgery, findings which explicitly related to nursing care were identified and included. Patients' accounts suggest that they were generally satisfied with their experience of nursing care and they recalled both 'transactional' and 'relational' aspects of nursing care delivery. Nevertheless, the lack of studies that specifically investigated the patient experience of nursing care in cardiac surgery highlights the urgent need for future studies that begin addressing this important aspect of cardiac nursing.

Another gap in the literature is the lack of studies measuring patient experience of nursing care following cardiac surgery, although the PREMs framework and questionnaire for patient experience following heart valve surgery may be suitable for use following other types of cardiac surgery. In future studies, different feedback types may provide a robust method for developing patient experience measures for cardiac surgery and former patients could be included as advisors in these projects to ensure that they are user-led developments.

Limitations

There is no standardised procedure for conducting narrative reviews, and they have been criticised for this. Therefore, to demonstrate that this narrative review adopted a logical and transparent approach to searching, data extraction, quality appraisal, thematic analysis and synthesis output the COREQ guidelines were adopted (Tong, Sainsbury et al. 2007).

Due to the flexible nature of narrative reviews allowing for the inclusion of different research methods (qualitative and quantitative), it was difficult to appraise the studies using a single approach. Therefore, studies sharing the same methodology were critically appraised using the same appraisal tool, to allow consistency. It was also therefore difficult to weight the quality of the studies, particularly with a small number of studies.

The authors acknowledge the review is limited by the number of included papers. Whilst this is identified as a limitation, it is also a strength of the current review which paves the way for future rigorous research in this area as it presents important findings, and conclusions are drawn highlighting the urgent need for futures research into the topic.

No studies in the review purposely aimed to capture the experience of nursing care following cardiac surgery. Therefore, all conclusions that are specific to nursing care were interpreted by the first author/researcher. As a researcher having nursing experience of working with patients following cardiac surgery, personal bias may have affected the conclusions drawn. In an attempt to avoid this, only conclusions drawn which were explicit about nursing were included in the review.

Key Points

- 1) Cardiac surgery patients are able to recall a variety of physical, psychological, emotional, environmental and nursing care experiences.
- 2) Whilst none of the studies explicitly aimed to explore the patient experience of nursing care following cardiac surgery, our review contributes to our understanding of the patient experience of cardiac surgery and of receiving nursing care following cardiac surgery.
- 3) Patients' accounts suggest that they were generally satisfied with their experience of nursing care and they recalled both 'transactional' and 'relational' aspects of nursing care delivery
- 4) There is an urgent need for future studies to explicitly capture the patient experience of nursing care in cardiac surgery.
- 5) In future studies, different feedback types may provide a robust method for developing patient experience measures for cardiac surgery and former patients could be included as advisors in these projects to ensure that they are user-led developments.

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