



What indicators of Indigenous patient engagement can be identified in the patient record? A retrospective descriptive study

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Abstract

Aim: To assess the usefulness of patient records to identify indicators of patient engagement for Indigenous patients admitted to hospital for acute cardiac care.

Methods: A retrospective review of 84 patient records at two metropolitan public hospitals from December 2007 to December 2009.

Results: Three overarching themes of patient engagement were identified: communication, compliance and cultural competence. All clinician-patient communication was in English, although a quarter of patients' records identified language or communication problems. The involvement of families resulted in an improved

exchange of clinical information. Compliance appeared to be the responsibility of the patient. Only one measure of cultural competency was identified: the involvement of an Aboriginal Liaison Officer (ALO). Less than half (46%) of patients accessed the ALO, implying a lack of system wide protocols for utilising the ALO. In addition, it was the clinicians who determined access to the ALO.

Conclusion: This study provides an opportunity to examine how information about patient engagement can be included in the medical records to assist in the improvement of patient care for people with cardiac disease.

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Implications: The study results raised the question of whether clinician-patient engagement should be defined as an indicator of quality of care and an outcome measure of in-hospital care. A potential outcome measure of clinician-patient engagement would be to quantify the level of patient understanding of their condition and treatment regime, and its long-term implications.

Background

Cardiovascular disease contributes to almost a quarter of the 'gap' in Indigenous life expectancy, resulting in Indigenous Australians being three times more likely to have a heart attack and nearly twice as likely to die from heart disease. (1, 2) Cardiovascular disease is a precursor to Acute Coronary Syndrome (ACS) and recent studies have reported disparities in the treatment received by Indigenous Australians, compared with other Australians who are diagnosed with ACS. The reasons for this treatment differential have not been conclusively identified. (3-5) However, it has been suggested that it may be, to some degree, attributable to a lack of engagement of Indigenous patients with health care services. (3, 6)

In the health care sector, the term 'engagement' refers to 'a deliberate effort and commitment [by the health consumer] to working toward [the goals] with treatment providers.' (7 p.753) This definition has been further expanded to encompass a number of aspects that influence the ability of the consumer to work effectively with health providers to achieve treatment and management goals. (8) These include access to health care providers, information sharing, involvement of the patient in decision making and self-care activities, respect and support of the provider for the patient's choices, and management of patient concerns. (7, 8)

Research on interactions and engagement between clinicians and Indigenous patients usually involves interviews, focus groups, questionnaires, hospital administrative data and observational methods. (6, 9-12) The patient medical record however, is potentially an additional and currently under-utilised data source for measuring patient engagement. A primary purpose of the medical record is to assist in the continuity of patient care by communicating clinical information and care planning among treating clinicians. (13) It is also a tool for evaluating the adequacy and appropriateness of patient care in order to assess quality and safety. (13, 14) Importantly, it is a statutory requirement of all health providers to record this information, making them the most commonly documented record of clinician patient interactions. (13, 15) However, little is known about how useful medical records may actually be in assessing or evaluating patient engagement.

Given the importance of patient engagement to achieving improved health outcomes, this study aimed to assess the usefulness of patient records as a means to identify indicators of patient engagement for Indigenous patients admitted to hospital for ACS.

The study was approved by the University of South Australia's Human Research Ethics Committee, the Queen Elizabeth Hospital Human Research Ethics Committee, the Royal Adelaide Hospital Ethics Committee and the Aboriginal Health Council of South Australia Research Ethics Committee.

Researcher standpoint

A common limitation in research undertaken by non-Indigenous researchers is a lack of adequate understanding or incorporation of Indigenous social realities, histories and experiences. (16) As an Aboriginal woman, the primary researcher and first author (YR) applied an Indigenous lens to this research. Indigenous researchers can bring Indigenous values and ways of knowing to the forefront in their research approach to strengthen analysis and contribute rigour to scientific processes. An Indigenous lens provides a counter narrative to Indigenous health research, which is often otherwise problematised and pathologised. (17, 18)

Methods

Study design and cohort selection

A retrospective medical file review of Indigenous patients who were admitted with high-risk non-ST-elevation acute ACS was undertaken from March-November 2013 at two major metropolitan hospitals in South Australia. Patients included in the review were identified from an earlier study that investigated the probability of Indigenous patients receiving recommended interventional and therapeutic care for the condition. (19)

Data source

Information extracted from the patient medical records included demographic data, patient history of cardiovascular disease, related clinical presentations, and in-hospital treatment. A 'Patient Engagement Audit Tool' was developed by the first author, derived from current literature describing Indigenous patients' experiences of engagement with health care services. (6, 10, 20, 21) Proxy indicators of effective engagement were identified and the final collection template contained eight variables that included quantitative measures and open ended text boxes (Table 1).

Analysis

Descriptive analysis

Baseline patient characteristics are reported using frequencies and percentages for categorical variables, and mean and standard deviations (SD) for continuous variables. Comparisons of the characteristics according to gender were made using χ^2 tests or t-test or the corresponding non-parametric tests. All analyses were performed with Stata software, version 11 (College Station, TX, USA).

Table 1 Patient engagement items, definition and proxy measures

Grouping	Definition	Categorisation
Patient escort	A person who accompanies the patient to the study hospital. The escort may include a spouse, sibling, adult child, family member or advocate. (10)	communication, cultural competence
Aboriginal Liaison Officer (ALO) Contact	ALOs provide a liaison service to Indigenous patients admitted to the study hospital. This may include emotional, social and cultural support to patients and their families; advocacy and liaison on behalf of patient and families; providing information about hospital services and assisting with referrals to Indigenous and non-Indigenous organisations. (22)	communication, compliance, support, cultural competence
Multi-disciplinary health team Interaction	Clinicians from a multi-professional health team comprising of, but not limited to, a dietician, a physiotherapist, a social worker, a cardiac nurse, an occupational therapist and a pharmacist.	communication, compliance
Medication Compliance	The extent to which the patient continues the agreed-upon mode of treatment. (23)	communication, compliance
Management Action Plan	Evidence the patient had been provided with one of three care plans: Chest Pain Action Plan, (8) Rehabilitation Plan, (8) Angina Management/Action Plan. (24)	communication compliance
Discharge letter	A communication document used to summarise a hospital stay that is usually addressed to the patient's primary care physician. (24)	communication, compliance
Hospital arranged post-discharge appointment	Post-discharge cardiac care appointment with a consulting cardiologist or Specialist or rehabilitation service provider.	communication
Mental Health and Social and Emotional Wellbeing issues	Refers to an assessment, presentation and/or discussion of psychological distress, impact of psychological distress, positive wellbeing, anger, life stressors, discrimination, cultural identification and removal from natural family. (25)	communication, compliance, cultural competence

Qualitative descriptive content analysis

Analysis of the qualitative data was based on descriptive content analysis and categorisation of themes into the proxy indicators building on the data collected from the Patient Engagement Audit Tool. (22) Analysis involved checking, grouping and categorising the data by two researchers, who negotiated a consensus on the final coding.

Results

Patient characteristics

There were 85 eligible participants identified from the baseline study (41 males and 44 females). While records for two female patients were not located, one of the male patients was found to have duplicate records. The medical records of 84 patients admitted with non-ST elevation were included in the retrospective medical record review.

There were no statistically significant differences in risk characteristics between males and females. The patients had a median length of stay of 3-3.5 days and 21% arrived at the hospital with an escort. Over three-quarters (79%) of the cohort had comorbid diabetes, 75% had hypertension and 50% self-reported current tobacco smoking on admission.

Almost half the patients (38/84) had contact with an Aboriginal Liaison Officer (ALO) during their admission. Over three-quarters (65/84) interacted with allied health team members, most commonly pharmacists, diabetic nurse educators or physiotherapists. Relatively few patients (11/84) had discharge action/management plans documented in their medical record and for those who did; the plans addressed management of ongoing chest pain or

rehabilitation. The review found that over 90% (77/84) of patients had a discharge letter filed in their medical record and 64/84 of patients had a post-discharge specialist appointment scheduled. Eleven patients were advised to make their own arrangements for follow-up with their general practitioner after discharge. Just over a third of the patients (36%) had a mental health diagnosis recorded in their medical record with the most common diagnoses being anxiety and/or depression (Table 2).

Table 2. Engagement proxy measures for Indigenous patients diagnosed with non-ST-elevation acute coronary syndrome

Engagement Proxy Measures (Audit Tool)	N=84 n (%)
Aboriginal Liaison Officer contact	38 (46)
Multi-disciplinary health team Interaction	65 (78)
Medication Compliance	51 (61)
Management Action Plan	11 (14)
Discharge letter	77 (92)
Hospital arranged post-discharge appointment prior to discharge	64 (76)
Patient to arrange post-discharge appointment	11 (14)
Mental health diagnosis and/or social and emotional wellbeing issues	30 (36)

Source: SA NSTEACS Retrospective Case Note Cohort Study – Patient Engagement

The study cohort is sourced from Indigenous patients who were admitted to two public tertiary metropolitan hospitals in South Australia. Indigenous participant refers to Aboriginal. Indigenous status was recorded if identified by the patient on admission. The results are presented as counts (percentages).

Proxy Indicators

Communication

Effective cross-cultural communication skills are critical. While two-way understanding can result in agreed strategies to manage a patient's health problems, communicating cross-culturally is not straightforward and associated complexities may impact on the quality of patient engagement.^(11, 23, 24) As evidenced from the medical records, all communication between the clinicians and patient in this study was in English, in spite of a number of patients coming from remote areas where English was not their first language. Other recorded barriers to communication included references to patients' hearing impairment, not being literate or numerate, limited English or having English as a second language. There was no record of an interpreter being used if the patient did not have a clear understanding of English. There was only one instance recorded where an Aboriginal Liaison Officer (ALO) was requested by nursing staff to assist in communicating with a patient. This nurse wrote that:

The Aboriginal Liaison Officer was requested to visit the patient when the patient refused to speak. [The ALO explained that] the patient [who had chronic kidney disease] was concerned about fasting prior to undergoing the procedure. (N15)

Patients were frequently described as being poor historians by virtue of being unable or inconsistently able to recall clinical information, or because they were shy and not communicative. For example:

... unsure of patient's understanding of English - appears good but patient not verbally communicating a lot. (N64)

... patient poor historian, very shy and difficult to gain a response from. (N18)

Families were reported as assisting with clinician-patient communication. For example, when documenting one patient's clinical history one pharmacist wrote that:

The daughter provided medical history [patient lives with daughter]. (P36)

In another example, family members were seen as an important factor in supporting complex patient decision-making and then communicating the request to the clinician. A specialist wrote that:

[The patient] did not want surgery until discussed with family, after discussing it with family the patient was happy to have the BKA [below the knee amputation]. (D10)

The importance of family being present to support the patient and assist with communication is also captured in the following notations:

Patient seemed very confused and disoriented when waking, daughter

come to stay with patient, more settled now [lives with daughter]. Daughter said her mother had also been confused the last couple of nights at [the regional hospital], daughter is supportive. (N24)

Daughter assisted with ADLs [Activities of Daily Living] and checking BSL [blood sugar level]. (N54)

Daughter in attendance most of the shift, [the] patient agitated, attempting to get out of bed, disorientated for time and place, daughter in residential wing stayed on the ward with patient, more settled. Daughter arranging for monitor and glasses to be sent to [hospital]. (N6)

Compliance

The World Health Organisation defines compliance as 'the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.'^(25 p3) Compliance is strongly associated with engagement as it seeks to achieve optimal health outcomes for the patient. ⁽⁷⁾ Compliance is facilitated through the nurturance of trust in the clinician-patient relationship while also providing an insight into the patient's knowledge and understanding of treatment strategies or pharmacological regimes. ⁽²⁶⁻²⁸⁾

Patients diagnosed with Type 2 Diabetes appeared to be commonly (61%) described as having poor compliance in relation to their medication. The reported reasons for poor compliance included: the patient had not regularly collected medication from local pharmacy; the patient had forgot to take medication; and, the patient had a low level of understanding of medications. One pharmacist wrote that:

Discussed T2DM [Type 2 Diabetes] control, dietary and lifestyle advice, [the patient] said 'that he has not taken medication in two weeks and asked for different medications', contacted [the patient's local] pharmacist [who] 'knew the patient and advised that [the patient] did not pick up his medication regularly and was known as non-compliant.' I cannot be sure patient will be compliant with medication since he did not take any medication for the fortnight. (P41)

Conversely, there were records that described 'good' compliance. These patients usually had an existing chronic illness, independently managed their medications and family members were included in the medication and treatment education. This is demonstrated in the following extract:

The patient [daughter present], was given dietary and lifestyle advice, was observed to be medication compliant and we [nurse, patient and daughter] discussed the changes to medication, patient showed good understanding of insulin therapy including the insulin pen, storage, dose and the needles ordered and provided to the patient. (N7)

An example of 'poor' compliance is captured in the following

notation by a nurse who described how a patient had discharged herself against medical advice and had remained engaged with her local health provider.

[The nurse] *contacted the [remote] community clinic [where the patient resided] and [was] advised that [the patient] has contacted the clinic and has told them she will be coming by bus on Friday [Advised] clinic staff to advise [the patient] to do her health review at [the regional] hospital. (N78)*

Strategies to assist compliance post-discharge were recorded in the medical records. On discharge, patients were advised that their GP would coordinate clinical services such as monitoring blood sugar level, smoking cessation advice, and referrals. Many patients did not identify a named GP as their primary provider of healthcare. Fifty percent of the patient records recorded an Aboriginal Community Controlled Health Service or a Community Health Clinic as their primary health care provider. Three patients stated that they accessed health care from a specialist health service (i.e. dialysis centre or diabetes centre) and a further three patients were incarcerated and accessed health care from the Department of Correctional Services.

Two hospital pharmacists wrote that:

[The patient] *is non-compliant, explained all new medication, and [the patient] agreed that [the hospital pharmacist] will liaise with community pharmacy managing meds. The local pharmacy was contacted to update medication records and arranged for dispensing of medication and dose aids. (P33)*

T2DM poorly controlled, discussed with patient strategies to reduce weight, hypo [hypoglycaemia] management discussed with patient, [the pharmacist] will write discharge plan for correctional services, insulin education session. (P26)

Cultural Competence

Cultural competence acknowledges and respects the difference between people while facilitating a process for health professionals' work in a cross-cultural situation. Cultural competence has been defined as:

A set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals that enable them to work effectively in cross-cultural situations. (29 p.iv)

In practice, it requires the clinician to acknowledge the cultural differences between the Indigenous patient and themselves, and to integrate of attitudes, values, knowledge, understanding and skills to facilitate effective interventions with the client. (30) Health services aim to bridge this cultural divide by establishing Aboriginal Health Units that employ ALOs. (31, 32)

Almost half (46%) of the records included evidence of involvement of ALOs, who were requested to perform a variety of tasks with

the health staff and for patients. Aboriginal Liaison Officers documented a broad range of activities that they undertook, for example:

[The patient] *wanted to know what's going on, saying that 'the nurse isn't telling her'; [ALO] explained that medical staff are waiting for test results and encouraged the patient to ask the nurse and doctor questions if she had concerns. (A12)*

[ALO] *arranged patient accommodation at [a local Aboriginal hostel] and contacted community clinic regarding transport [for the patient to return home]. (A17)*

[During an ALO support visit] *the patient asked [the ALO] to contact family to inform how [the patient] is going and have [the family] ring [the patient]. [The patient] lives with daughter, who is coming to Adelaide. (A5)*

Discussion

This descriptive study aimed to assess whether patient records were an appropriate source for identifying indicators of patient engagement for Indigenous patients with ACS. The content analysis found some evidence of patient engagement for Indigenous patients and the findings were categorised into three overarching themes: communication, compliance and cultural competency.

Communication

Cass and colleagues (2002) reported that miscommunication between the patient-clinician was pervasive yet often went unrecognised, especially with regard to diagnosis, treatment and prevention.(33) Brown (2010) and Artuso and colleagues (2013) reported similar findings, which consequently resulted in a diminished level of trust in the clinician. Patients became frustrated that they were not able to understand the information often contributing to negative experiences.(3, 6) In this study, miscommunication between patient and clinician was evident, with a quarter of patient records identifying issues around problems with communication. Although the remaining charts did not record problems, one should not assume from this that, from the patients' perspective, they did not occur. Communication problems appeared to be identified through the lens of the clinicians understanding of the exchange, rather than through a shared understanding of the clinician-patient interaction.

This study found that all clinician-patient communication was in English only, in spite of a quarter of patient records identifying language or communication problems. Health care providers are commonly acknowledged for using medical terms and jargon, and it requires a skilled communicator to effectively relay complex information about such things as diagnosis, pathology, pharmacology and invasive interventions. (6) Indigenous people throughout Australia are linguistically and culturally diverse.

Patients may, for example, speak standard English, Aboriginal English, Kriol and/or their traditional languages. (34) The reliance on didactic exchange may obscure other more subtle forms of non-verbal cues, such as body language and silence. (23, 39) Our findings are consistent with Cass et al., (2002) suggesting that failing to acknowledge communication barriers contributes to an attitude of complacency. Identifying these barriers is important and proactively seeking a solution to overcome them is essential.

Brown (2010) reported that when families were excluded from decision making processes around further investigation or treatment, patients were less likely to communicate with clinicians and subsequently were more likely to become withdrawn. (9) This study found that when families were present they provided emotional support during times of distress or fear, assisted the patient with decision making for treatment and care, assisted with activities of daily living, acted as cultural brokers and assisted with clinician-patient communication. Family involvement appeared to be an important factor in facilitating two-way communication between the clinician and patient.

Compliance

Compliance is a biomedical social construct that implicitly represents how the clinician evaluates the patient's ability to adhere to prescribed health care. (28, 35) This study found that poor diabetic control was often recorded as being the result of the patient not complying with the prescribed medical therapy. Compliance appeared to be reported as the sole responsibility of the patient, inadvertently inferring that if the patient only modified their psychosocial behaviour, compliance would improve. Rather than relying solely on an institution-centric approach, compliance needs to be reconceptualised to include a therapeutic relationship that is focused on a shared understanding, problem solving and goal setting.

A therapeutic relationship between clinician and patient provides an opportunity to negotiate healthcare that is more acceptable to the patient and will therefore potentially increase the effectiveness of health service delivery and health outcomes. (27, 36) For example, in this study compliance was described only as medication and treatment adherence. However, previous research has found that poor compliance may be symptomatic of a broader social discourse rather than individualised intervention. (3, 6) The medical records contained no reference to the structural macro-social factors (political landscape and institutions) or distal social connections (neighbour and community) that have a downstream effect on proximal social connections (family and friends) (37) and may impede patient agency to adhere to care. A therapeutic relationship could be a mechanism to negotiate agreed strategies that become shared responsibilities, rather than the onus being solely on the patient. For this form of relationship to occur, clinicians need to be self-reflective and focus more broadly on the practice of health care rather than focusing solely on the patient's

behaviour. (35)

Cultural competence

This study found that there was a sole measure of cultural competency recorded in the patient record: the involvement of ALO as a cultural broker. Both hospitals employed ALOs from Monday to Friday between the hours of 8 am to 4.30 pm and they undertook a multitude of tasks. However, there was little evidence that the ALO had a prominent role in the healthcare provided to Indigenous patients. Less than half (46%) of the charts indicated that Indigenous patients accessed the ALO, implying a lack of system wide protocols for utilising the ALO. The study findings imply that it was the clinicians who determined access to the ALO. This suggests that control rests with non-Indigenous clinicians, who may not value the importance of this cultural component of the health service. Further, the role of the ALO may have been underutilised. Opportunities to support and engage patients can therefore be lost and the potential value of this resource remain unrealized. Taylor and colleagues (2009) found that a dedicated Indigenous workforce reduced Indigenous patients' fears and anxiety. (6) Daws and colleagues (2014) reported that when patients had access to an ALO, they were more likely to attend rehabilitation and engage with other clinicians. (38)

Healthcare providers need to be more attentive to the unique context of Indigenous patients, especially where there is evidence of a disconnect between the clinician and patient that may hinder a therapeutic relationship. Establishing relationships should be done through system wide policy and protocols and not left to individual clinician decision making with no contribution from the patient or liaison with ALOs. The role of the ALO appears pivotal in brokering of relationships with clinicians and patients and may play a major role in facilitating increased engagement. To ensure those relationships can be forged; access to an ALO should be extended beyond the office hours currently provided.

Limitations

Study limitations may be the reliability of the patient engagement audit tool. Further work is required to assess whether the tool captures all factors relevant to adequately defining 'patient engagement' in the context of Indigenous health.

In addition most clinicians may not think to record aspects of engagement and therefore some level of engagement may have taken place that was not able to be captured. The relatively small sample of records came from two metropolitan hospitals that admit patients from the local jurisdiction, as well as regionally and from interstate. Therefore it cannot be assumed that these findings translate to a wider, heterogeneous Indigenous population across Australia.

Conclusion

This study investigated whether medical records were an appropriate source to identify indicators of patient engagement for Indigenous patients admitted to hospital for ACS. The research found that the records contained some evidence of communication, compliance and cultural competency that could be used to measure patient engagement. The research highlighted the need to more fully capture patient engagement data in patient notes. Importantly, healthcare providers may need to consider the opportunity of improving and recording clinician-patient engagement. This can be achieved by reconceptualising compliance, improving institutional cultural competency that fosters a therapeutic relationship and making more use of existing resources such as ALOs.

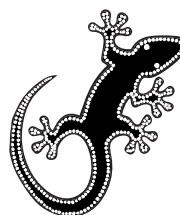
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