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Research Article

Thematic Analysis of Free-Text Comments Provided in a Compassionate Care Questionnaire

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Abstract

Objectives: To analyse patients' free-text comments provided in a Compassionate Care Questionnaire.

Methods: Thematic analysis was used to analyse 1,427 free-text comments from a questionnaire, which focuses on measuring patient experiences of compassionate care in Accident and Emergency departments and elderly care wards, but encouraged free-text comments on patient experiences a whole.

Results: Qualitative analysis yielded four categories, of which a total of 13 themes and 18 subthemes were derived. Four themes focused on compassionate care, five related to transactional aspects of care, one related to overall quality of care, and three were of miscellaneous context. Narrative regarding compassionate care reflected on communication, patient involvement in care decisions, time spent with care staff, and isolation.

Conclusion: Overall, while patients generally reported to be pleased with their experiences of care, there were instances where patients felt that care did not meet the standards or expectations that they deemed appropriate. Areas for improvement around compassionate care focussed on communication, the time spent with care staff, and feelings of isolation. Transactional aspects of care, such as hygiene and infection, waiting times, food and the general hospital environment were also highlighted as areas in need of improvement. Patient comments from this questionnaire provide unique insights into why compassionate care matters to patients and how care is experienced when this aspect is missing.

Keywords: Compassionate care; Communication; Free-text comments; Thematic analysis; Patient experiences; Questionnaire; Relational aspects of care

Introduction

One of the findings of the Francis Inquiry highlights insufficient provision of compassionate care in hospitals [1]. Aspects of compassionate care include patients being treated with dignity and respect, compassion, and being offered emotional support. It was found within the Francis Inquiry that a lack of compassionate care was especially prominent for older patients aged over 65 years and those visiting Accident and Emergency (A&E) departments. [1] All NHS organisations across the UK were expected to take quick and decisive action to improve patient's experiences of care by strengthening and innovating quality improvement within front-line care, and challenging current organisational culture.

Compassionate care can also be referred to as the 'relational' aspects of care. While at this time, an absolute description of compassionate care is not available due to varying available definitions, it's key concepts centre around good communication, empathy and kindness [2-4]. Research by Jeffrey (2016) argues that communication is the foundation of compassionate care, as it is central to conveying empathy and kindness to the patient. In turn, this can help clinicians gain insight into the patients concerns and feelings [5]. Patients consider these relational aspects of care to be very important, and evidence suggests that they can help determine the overall patient experience [6-9]. In turn, a greater positive experience of compassionate care is often associated with results such as improved patient safety, treatment effectiveness and outcomes, reductions in overall service use, and better staff experiences [10-13].

Surveys which measure patient experiences of care often include a free-text (open ended) question to compliment a predominantly closed ended questionnaire [14]. However, it is not often that these qualitative excerpts are systematically analysed to identify patterns and subsequently used to drive improvements in care [15-16]. The value of these open ended questions is often overlooked within research. Previous literature has shown that by giving

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patients the opportunity to provide qualitative data, they can provide additional context and increase understanding of experiences to closed survey questions. This can help frontline staff and policy makers to identify areas where action and quality improvement is needed [17-19].

The National Survey Programme, commissioned by the Care Quality Commission, and other healthcare surveys do - to some extent - measure compassionate care. However, they are predominantly tailored to measure transactional care, such as access to services, waiting times and cleanliness. As such, a questionnaire focused on compassionate care was developed to help NHS organisations specifically target areas of good and bad performance within compassionate care, and inform action plans and quality improvement goals.

The purpose of this paper is to analyse free-text comments given by patients on a Compassionate Care Questionnaire, developed as part of a wider study, and highlight key areas of patient experience considered of particular importance during their time in hospital. By examining a qualitative aspect, of an otherwise quantitative measure, we seek to offer insight to the perspectives of patients who recently experienced a hospital visit.

Method

Setting and Protocol

A Compassionate Care Questionnaire (CCQ) was developed as part of a wider study, specifically to measure and improve the relational aspects of care delivered to inpatients and those using Accident and Emergency (A&E) services. Six case study sites were used to pilot the CCQ questionnaire. The sites were selected for geographic diversity, and their range of performance on the National Inpatient and Accident and Emergency surveys.

The questionnaire was piloted for 10 months across the six sites in A&E departments with patients of all age ranges, and on wards predominantly treating elderly patients. Data was collected by trained volunteers using tablets, allowing data to be reported in near real-time.

Exclusion criteria for completing the survey included patients who were not receiving treatment on the specified pilot wards/emergency departments, and those who had been identified by ward staff as unable/unfit to complete the survey e.g. due to lack of capacity to consent or not being well enough to participate.

The project was funded by the National Institute for Health Research Health Services and Delivery Research Programme (project number 13/07/39). Ethics approval was granted by the East of Scotland Research Ethics Service (EoSRES) REC 1 (approval number 14/ES/1065). Responses to the free-text comments, along with the demographic survey data, was used for the purposes of this analysis.

Analysis

Thematic analysis was used to analyse free-text comments, with a framework developed by two researchers. It is an approach considered to be well-suited and flexible to the varying needs of research projects [20,21]. It is used to identify patterns and highlight themes of importance of the subject matter being analysed [22-24].

Eighteen themes were identified within the initial framework, which were then subcategorised into either a positive, negative, or mixed code. One coder used the framework to code all 1,427 comments. To determine reliability of the coding, 10% of all comments from each trust were checked by a second coder. No comments were seen to be coded under an incorrect theme, however, 12 free-text comments were assigned to additional themes within the analysis.

Any discrepancies were discussed and resolved between the two coders. No additional themes were required, however, modifications were made to the framework. Comments that were found to not fit the framework were coded under the theme miscellaneous.

Results

Over the 10 month data collection period, 3,928 patients responded to the survey, of which 36.33 percent (n=1,427) provided free text comments.

Sample characteristics

The demographic characteristics of the sample (1,427 respondents providing a comment to the free-text question of the CCQ survey) are summarised in **Table 1**. It is important to note that the sample described only represents the percentage of respondents who completed the free-

Sample Characteristics	N (%)
Gender	
Male	590 (41.3)
Female	837 (58.7)
Age, years	
Range	3-108
Mean	70.62
Long-term condition	
Learning disability	18 (1.3)
Dementia	32 (2.2)
A mental health condition	54 (3.8)
Blindness or partially sighted	80 (6.0)
Deafness or severe hearing impairment	188 (13.2)
A long-standing physical condition	303 (21.2)
A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy	429 (30.1)
No Long-term condition	613 (43.0)
Ethnicity	
African	3 (0.2)
Bangladeshi	5 (0.4)
Caribbean	2 (0.1)
Chinese	3 (0.2)
English/Welsh/Scottish/Northern Irish/ British	1372 (96.1)
Gypsy/ Irish Traveller	4 (0.3)
Indian	5 (0.4)
Irish	6 (0.4)
Pakistani	1 (0.1)
White Asian	2 (0.1)
White and Black African	1 (0.1)
White and Black Caribbean	1 (0.1)
Other	19 (1.3)

Table 1: Sample characteristics.

text question of the CCQ. There was a near-even gender distribution, with females providing a higher percentage of comments. Most patients reported having no long-term conditions (LTC). Patients who reported having a LTC tended to have a long-term illness or physical condition. Specific examples of LTCs cannot be provided as respondents did not give this level of detail. Patients of English/Welsh/Scottish/Northern Irish/British origin predominantly provided free-text comments. The breakdown of number of responses by NHS Trust pilot site are presented in Table 2, alongside the proportion of comments that underwent reliability checking.

Trust name	Number of free text comments	Number of comments checked (10%)
Trust 1	238	24
Trust 2	171	17
Trust 3	323	32
Trust 4	152	15
Trust 5	244	24
Trust 6	299	30

Table 2: Breakdown of free text comments per trust, and the no. checked for reliability.

Qualitative analysis

The themes derived from the qualitative analysis are shown in Table 3. During discussion between the coders, it was found that eight themes could be merged into four overarching categories due to the context of the free-text comments. The themes of staff quality of care and overall quality of care were collapsed into one theme of quality of care, themes of communication and language barriers, were collapsed into one theme of communication, and finally, check-in, discharge, call bells, and waiting times were collapsed into one theme of waiting times.

The finalised framework consisted of four overarching categories of quality of care, compassionate care, transactional care, and miscellaneous. Each category contained subthemes.

Quality of care

The majority of patients reported a positive experience in the overall quality of care that they received. Feedback generally related to the care provided by staff, rather than their overall experiences of care. Staff were mostly found to be friendly, helpful, compassionate, kind and caring.

Some patients commented that the quality of care received was lower than expected. They felt that staff appeared unfriendly, and could often neglect patients. Agency, night staff, and reception were often perceived to provide a lower standard of care.

"Poor care. Left in your urine and left with no dignity… Nurses not caring enough and don't check on you enough."

On occasion, patients felt that their poor care stemmed from perceptions that care staff lacked the knowledge, confidence and ability required to perform their duties. This made patients feel uneasy and unsafe during their care.

"One nurse did not know what coeliac meant."

"Staff did not really understand mental health. [I was] made to feel uncomfortable."

Compassionate care

Patients often felt that they had too little contact with their care staff, especially the doctor in charge of their care. Despite this, patients recognised that the staff are often overworked, and so could not tend to their needs immediately.

"I have not met the consultant named on the board by my bed and I have been here 2 months."

Another observation by patients, found that it was often difficult to be seen by a consultant to determine the cause of their health problem. As a result, they don't receive the correct treatment for a substantial amount of time.

"They have passed me about a lot and still not come to

Initial coding framework	Mid-stage coding framework	Final coding framework
Staff quality of care	Quality of care	Quality of care
Overall quality of care		
Not enough time with care staff	Not enough time with care staff	Compassionate care
Involvement in care decisions	Involvement in care decisions	
Communication	Communication	
Language barriers		
Isolation	Isolation	
Hygiene & infection	Hygiene & infection	Transactional care
Staffing levels	Staffing levels	
Check-in	Waiting times	
Discharge		
Call bell		
Waiting time		
Food	Food	
Environment	Environment	
Survey/question comments	Survey/question comments	Miscellaneous
General thank you comments	General thank you comments	
Miscellaneous	Miscellaneous	

Table 3: Themes within thematic analysis.

a decision even though they warn its life threatening. [It] seems hard to get one doctor available for [a] specific need so left hanging for 3 days."

Patients felt that they weren't involved as much as they would like to be, if at all, in decisions regarding their care. In one case, a patient stated family and doctors had seemingly made decisions without his/her involvement.

"I don't feel that I have been consulted about my condition and treatment."

"Cross that family have apparently taken control of decisions about where [I] will live on discharge."

Only one patient reported that doctors had considered them to be an expert in their condition and complex health needs, and so always consulted him/her in care decisions.

"The doctors have been really good at treating me as an expert patient due to my complex health needs and have consulted me in regards to my treatment and what I would like to do."

Most patients considered that the communication they experienced was not acceptable, both in terms of staff-patient, and staff-staff communication. Patients felt that information they were given wasn't clear or substantial enough, leaving them confused and without the opportunity to ask questions to gain a better understanding of their situation. Patients also reported witnessing discussions between staff members, which came across as unprofessional and made the patients uneasy.

"Staff complain about being short-handed which is alarming for a patient."

"Last night I was very upset by a female member of staff after my other [half] asked her at reception for a bottle for urine. She came to my bedside and said that I should be using the call button...She then told the nurse in charge of our care to look after her patients better in front of us. Very unprofessional."

Language barriers were also cited by patients as a challenge. Patients reported having difficulty understanding what was being said to them during conversations with foreign staff with accents.

Communication between departments was also erratic at times, causing problems and uncertainty for patients about their treatment, medication, dietary needs, or care after discharge.

"Meal times are quite erratic…there seemed to be a mix up and they did not know I was diabetic."

"The medicine I take at home wasn't given to me correctly at the hospital for the duration of my stay."

On the other hand, some patients found communication between members of staff, and between the staff and patient to be excellent. Patients felt well informed about their condition and care, family members were kept updated, and staff answered any patient questions.

In their feedback, patients also spoke of feeling isolated during their stay in hospital. Often they would be left alone, explaining that nurses were often too busy to spend time with them.

"They don't listen. No one talks to you. You sit all day. No one comes around."

However, this was not the case for all patients. Some felt that staff took time to get to know them and took an interest in them as people, not patients.

"We chat, we laugh. In a roundabout way you get to know them very well. I feel very relaxed about talking about 'personal' things without any blushing."

"They were there for me morning noon and night... never felt alone, always someone to talk to."

Transactional care

Patients frequently commented on staffing levels during their care. Patients experienced a visible lack of staff during their hospital stay, stating that staff often look "busy" or "rushed off their feet". In particular, they perceived that there were often not enough staff at night.

"Sometimes short staffed this is no problem to me but it does sometimes effect how much time they can spend with you."

Waiting times are a frequent occurrence in patient experience feedback. Some comments received in the CCQ stressed long waiting times in A&E, as well as waits for call bell responses on wards. This wait on wards frequently left patients in an undignified manner, due to being unable to attend the bathroom, whilst the wait in A&E – though understandably long – can cause patients distress.

"Having broken [my] foot to the extent where my foot was black, in pain and crying, I was left for 7 hours before having my cast on, my treatment was unpleasant and cost me almost losing my foot."

"This morning when I had to go for a scan, I was left alone in a wheelchair in severe pain and I felt that I was going to pass out in the scanning department."

Whilst waiting times were frequently commented on, some patients understood that the long waiting time related to staff being busy with other patients, and acknowledged that often they would be seen to when staff were able, given the current staffing pressures.

Discharge was also identified as unsatisfactory by patients, and caused unnecessary stress for them. Specifically, being discharged with little-to-no notice, or having to wait some time after notice to leave.

"I was told I could go home two days ago."

"Discharged with little notice which made [me] very anxious."

Generally, feedback regarding the food provided during the patients stay was regarded positively. Patients explained that it was always served warm, with suitable choices which catered to different dietary needs. However, some patients

reported that the food should be of a better quality. For instance, it was sometimes described as tasteless, cold and often "stuck to the plate". Similarly, patients described that they often did not receive regular meals, or were completely missed on food rounds.

"Only meal I got offered was breakfast this morning. I arrived via ambulance at 1400 yesterday."

Hygiene was briefly mentioned in some feedback provided by patients, as they observed that hygiene and infection control practices were not always adhered to by student nurses. Similarly, one patient stated that they had not received the personal hygiene care that they would have liked.

"Had feet washed [today] for first time since admission."

Feedback describing the hospital environment at each site was predominantly negative, with patients describing them as unclean and noisy. Also, some patients were not comfortable in being placed on a mixed gender ward and wanted to be moved, but unable to do so due to lack of beds. Concerns regarding lack of entertainment, such as radios, or that the TVs were broken or too expensive, were also raised. Simple requests were also made, such as air-fresheners, more wheelchairs and pillows, and for equipment to be installed, e.g. handrails in bathrooms.

Miscellaneous

In total, 45 comments contained a "thank you", to reflect the gratitude of a job well done, and their positive experience of care overall.

A small proportion of patients commented on the quality of the questionnaire, often referring to some repetitive questions, and suggesting that questions should be split between nursing staff and doctors. However, positive feedback was also given on the survey, with patients praising that it was an excellent tool to improve healthcare.

Other miscellaneous comments included comments such as who completed the questionnaire on the patients' behalf, praise for the NHS from foreign patients, and other information given by the patient, such as a commenting that a volunteer was helpful. Some examples pertaining to the context of these comments are provided below.

"The patient got tired and had nothing more to say."

"Don't strike."

"Reduce senior management to save money to improve patient care"

"… Worried about flat/bungalow access and state of health of tortoise…"

Conclusion

By presenting a thematic analysis of patient free-text comments found in the CCQ, we seek to help highlight the aspects of care which patients consider to be important, and to understand why. We have chosen to highlight exclusively the themes within the free-text comments as these describe patients reasoning in their own words. The findings are consistent with those of the larger survey results, which are beyond the scope of this paper. The CCQ instrument is tailored to assessing patient experiences of compassionate care. Not surprisingly, the majority of free text comments were related to experiences of compassionate care, framed by earlier survey questions assessing these types of experiences. However, the volume of comments addressing transactional aspects of hospital care experiences shows that these are paramount to a positive hospital experience [25]. There were no obvious differences between respondents in A&E to those staying on the wards, as patients gave comments of similar context within both environments.

The large quantity of free-text comments relating to compassionate care highlight the importance of interpersonal relationships between patients and their care staff. This finding is consistent with previous research which suggests that elements of compassionate care, in particular communication, can contribute significantly to a patients' overall experience of care [6-10].

Free-text comments provided by the patients highlight deficiencies in communication of hospital staff with patients, as well as involving patients in decisions about their care. Some reported feelings of isolation or being overlooked when this communication and involvement was not provided sufficiently. Similarly, communication can ease patients by giving them the confidence that they are in the right place, and are being looked after by skilled and knowledgeable staff. The free-text comments given by patients suggested that insufficient communication could lead to the patient feeling unsafe and insecure in the care that they received.

Transactional aspects of hospital care described in patients' responses focussed on waiting times, discharge processes, food quality and the hospital environment itself. This suggests that while compassionate care is often a deciding factor in the patient's overall experience of care, transactional care is still a priority for patients as these address the fundamental needs for food, water, cleanliness and security.

In conclusion, the free text comments provide patients with a platform to express themselves, elaborate on responses provided to closed questions, and gives opportunity to voice new issues outside of the scope of the closed-ended survey questions [15]. Moreover, relationships between concepts of interest are described in the responses, which can form the basis of future exploration. It is of interest to highlight that, whilst during the pilot staff made use of weekly quantitative reports for quality improvement, their priority was on monitoring the free-text comments given by patients. Staff frequently reported that it was easier for them to check the progress of initiatives put in place via free text comments, and that it was much more valuable as a data source in terms of context of the patient experience.

While our work does provide valuable insight to the experiences of patients during a recent hospital stay or A&E visit, and aspects of care which they consider important, this study is not without its limitations. Specifically, the questionnaire was only available at six case study sites in

England, on particular wards and their A&E departments. Therefore, the findings outlined in this paper are only representative of a small population of patients, and may not be generalisable to a wider patient population.

The CCQ was developed as a measure to collect patient experiences of compassionate care in near real-time. This contrasts with the approach used in the national survey programme whereby questionnaires are completed by patients in the months following their hospital experience, and focusses more on transactional aspects of care. As such, it may be interesting for future research to compare the content of free-text comments given by patients regarding their experience of care in surveys which are administered during their hospital visit versus after their stay. Also, future research should explore the influence of framing effects on the content of free text comments. For example, the content and emphasis of free text comments may be different for questionnaires that primarily measure transactional aspects of care from those that examine relational aspects of care.

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