Patient- and relative-activated critical care outreach: a 7-year service review

Mandy Odell

ABSTRACT

Five years following the introduction of a whole-hospital, 24-hour critical care outreach (CCO) service, an additional service was introduced that enabled patients and their families to directly call the CCO team if they had concerns that were not being acknowledged by the patient's clinical team. The aim of this review was to report on 7 years of patient and family referrals using quantitative and free text data extracted from the CCO referral database. Information on demographics, frequency, nature and reason for the referrals have been reported that highlight the feasibility of such a service, and the potential to prevent patient deterioration. By tapping into the rich source of information from family concerns, future hospital services could be designed that could not only have an impact on patient outcome, but also positively influence the quality of the patient experience.

Key words: Critical care outreach ■ 24-hour care ■ Patient referrals ■ Rapid response systems

Various models of rapid response systems (RRSs) have been implemented across a number of countries (DeVita et al 2006; 2010). Using this model, a critical care outreach (CCO) service was implemented in one UK hospital in 2001, and has been operating 24 hours a day, 365 days a year since 2005. Clinical staff can refer patients to CCO if they breach early warning criteria, or if they are concerned about the patient. In 2009 the 'Call 4 Concern' (C4C©) service was introduced, which enables patients and their families to call the CCO team directly if they have concerns about the patient that were not being acknowledged by the patient's clinical teams (Odell et al, 2010). This is the first such service provided in the UK and the aim of this review was to report on 7 years of patient- and family- activated CCO to provide data on demographics, frequency and nature of C4C referrals, and report the reasons for the referrals. Demonstrating the feasibility of the service, the impact on prevention of deterioration and meaningful patient and family involvement could encourage other CCO teams to adopt C4C in order to promote better patient outcomes and experiences.

Background

RRSs were developed to address failures in recognition and escalation of deteriorating patients in hospital. While these

Mandy Odell, Nurse Consultant, Critical Care, Royal Berkshire NHS Foundation Trust, Reading, mandy.odell@royalberkshire.nhs.uk

Accepted for publication: December 2018

systems have made some impact on the recognition of the deteriorating patient and reduction of cardiac arrests, there still remains a considerable reluctance by ward staff to activate the RRSs (National Patient Safety Agency, 2007; Radeschi et al, 2015; Douglas et al, 2016). More recent research has highlighted that the reasons for this are complex and relate to cultural, professional and contextual factors (Shearer et al, 2012; Braaten, 2015; Odell, 2015). The involvement of patients and their families in deterioration recognition and escalation could address some of these professional barriers. As well as having an intimate knowledge of a patient's 'normal' demeanour, families and the patients have a unique and singular interest in their wellbeing (Miceli and Clark, 2005) that is unaffected by professional constraints.

Literature review

Systems to support patients and their relatives accessing hospital RRSs were first reported in the USA (Greenhouse et al, 2006). The motivation came from the cases of avoidable deaths of two children, Josie King (www.josieking.org) and Lewis Blackman (www.lewisblackman.net). Additional drivers have come from a number of international bodies and governments (Lawton and Armitage, 2012) and patient- and family-led campaigns for acute hospitals to actively encourage partnership and empowerment of patients and their families (Lawton and Armitage, 2012).

Paediatrics has led the way in the implementation of patient- and family-activated rapid response teams (RTTs) (Dean et al, 2008; Brady et al, 2015). More recently these services have been extended to adult patient facilities in the USA (Baird and Bobel Turbin, 2011; McCawley et al, 2013). A systematic literature review (Albutt et al, 2017) reported that 69% of 103 US institutions have a patient- and relative-led escalation service, and a literature review by Vorwerk and King (2016) concluded that consumer participation in early detection of deterioration is likely to improve outcomes for these patients. This innovation has made slower progress in the UK, with only one similar service reported in the literature (Odell et al, 2010), although others are being implemented.

Paediatric family-activated RRSs have reported that parents want an improvement in staff response to clinical concerns about their child (Miceli and Clark, 2005) and were unanimously in favour of such a service (Greenhouse et al, 2006). In adult family-activated RRSs there has been a positive response from patients and their families (Gerdik et al, 2010; Odell et al, 2010). The reluctance to implement these services in acute care hospitals in the UK may stem from concerns of overwhelming the system

with non-clinical calls (Zix et al, 2012), diverting attention from those in need and requiring additional resources (Roland, 2015). However, reports suggest there is a relatively low rate of calls (Bogert et al, 2010; Brady et al, 2015), with an average call rate of 23 over an 18-month period (Albutt et al, 2017).

Owing to the infancy of patient- and relative-initiated RRSs, there is a dearth of robust outcome data. Studies have tended to involve a relatively low number of cases, mainly evaluating the feasibility and acceptability of such systems (Albutt et al, 2017). Fears that there would be inappropriate referrals and that essential services would be diverted from those in need have largely proved unfounded by studies, which report the following:

■ Relatives had picked up a noticeable change in the patients' condition that had not been addressed by the clinical team (Bogert et al, 2010; Brady et al, 2015)
■ An increase in admissions to higher levels of care (Gerdik et al, 2010; Zix et al, 2012; Brady et al, 2015)
■ A reduction in cardiac arrests (Ray et al, 2009; Gerdik et al, 2010)
■ A reduction in adverse incidents (Gerdik et al, 2010)
■ Calls were medically appropriate (Bogert et al, 2010; Odell et al, 2010; Hueckel et al, 2012)
■ An increase in staff calling RRTs based on family concerns (Zix et al, 2012).

Other findings include hospital and departmental improvements based on patient and family feedback (Greenhouse et al, 2006; Dean et al, 2008; Bogert et al, 2010) and an improvement in safety culture through patient and family empowerment (Miceli and Clark, 2005; Ray et al, 2009).

In a UK study, Rainey et al (2015) interviewed 13 patients and 7 relatives and found that patients had a limited ability to recognise the change in their clinical condition; if patients are clinically deteriorating they may not be able to raise concerns. Relatives are then relied upon to speak up on their behalf and vigilance becomes a key part of their role (Rainey et al, 2015). Studies also reported other factors that cause concern for patients and their relatives. Poor communication is the most common issue (Albutt et al, 2017), followed by dissatisfaction with staff (Baird and Bobel Turpin, 2011; Brady et al, 2015), concerns about plans of care and discharge planning (Greenhouse et al, 2006; Bogert et al, 2010; Baird and Bobel Turpin, 2011), and medication and pain concerns (Gerdik et al, 2010; Odell et al, 2010, Baird and Bobel Turpin, 2011). These secondary findings could be useful to help inform service development and reform.

Data to support organisations that are considering the implementation of a similar service are sparse, especially for UK hospitals. The aim of this service review is to share 7 years of experience of running a hospital-wide C4C service, describing the frequency and types of referral, sources of and reasons for the referral and the referral outcome. The information will be useful for others wanting to set up a similar service, as well as suggesting where further research may be useful in this emerging field.

Method
The survey took place in a 700-bed study hospital in the south east of England. The CCO service was set up in 2001 and responds to all referrals for patients (including obstetrics and paediatrics), as well as staff and visitors on site.

Banners advertising C4C were placed at the hospital entrances and main departments, information pamphlets were available in all wards and departments. C4C was also promoted by CCO staff, and intensive care unit (ICU) patients were given information when they were transferred out of ICU.

All referrals were recorded on a dedicated Microsoft Access database that included patient demographics, referral information and outcome. When the C4C service was fully implemented in 2010, additional data were collected on the nature of the C4C call— source and reason for referral.

Quantitative and free- text data on C4C referrals from the CCO database were transferred to an Excel spreadsheet for the 7-year period from 1 January 2010 to 31 December 2016. The reasons for the C4C referral were extracted from the free text and grouped into categories.

Ethical considerations
The hospital's research and development department agreed that formal ethical approval could be waived. All patient data was kept confidential and anonymised and database access was password protected.

Results
Number of referrals
During the study period the number of referrals to the CCO team totalled 70 041. These included all referrals from clinicians reporting early warning score breaches or concern about the patient, and were dealt with in the usual way by the CCO team. Of all the calls, 534 (0.8%) were C4C referrals, involving 312 patients; 41 patients had 2 calls, 15 patients had 3 calls, 11 patients had 4 calls, 3 patients had 5 calls and one patient had 6 calls concerning their care. One patient had 46 referrals over a number of years because of a complex, chronic condition.

The number of calls each month is shown in the *Figure 1*.

The range of calls per month is 0 to 18, with an average of 6. There is no discernible pattern to the number of calls and the patients with frequent calls were spread over months so were unlikely to have made an impact on the monthly rates.

Time of day
The time of day of C4C calls are shown in *Figure 2*. As can be expected, the greatest number of referrals occurs during the day between 8 am and 9 pm, with the highest being made between 7 pm to 8 pm. Friends and family have much greater access to the patient during the day and the common end of hospital visiting time may explain the evening peak as families leave patients without family members to 'watch over them' over night.

Sources of referrals
Locations
C4C referrals were made from a wide range of locations including 41 hospital wards and departments as well as the emergency department, ICU, paediatrics and maternity (*Figure 3*). Referrals also came from patients once discharged home and
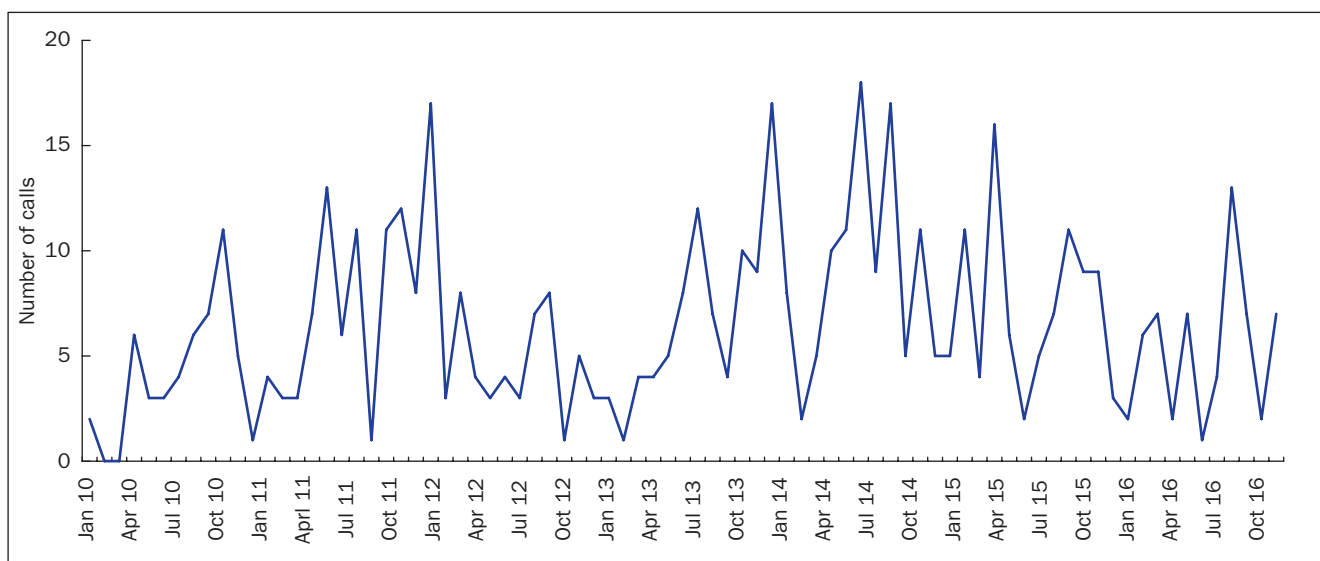
Figure 1. Number of Call 4 Concern referrals per month

other hospitals, as well as a small number made to the service because the individual did not know who else to call and had used the contact information found on the hospital website.

The majority of calls were from medical wards, which reflected the hospital demographic and CCO activity.

Family members

Of the 534 C4C calls, patients only activated the service 42 (7.8%) times. Of the remaining referrals, the most frequent family members to make a C4C referral were the daughter (n = 100), wife (n = 87) and mother (n = 53) of the patient. Eleven staff made C4C referrals; six for inpatient friends and family, four for ward patients, and one was a self-referral by an inpatient who was a member of staff. The range and number of referral relationships can be seen in *Figure 4*.

Reasons for making a C4C referral

Free-text data on the database were used to extract the reasons for a C4C referral. These were themed into six broad categories:

■ Concerns about clinical care: physiology, deterioration, pain,

Figure 2. The time of day of Call 4 Concern referrals

nasogastric (NG) feeding, infections, drugs, confusion, agitation
■ Information requirement or communication issues: lack of care planning, discharge planning, delays in care
■ Support, advice and reassurance: seeking advice, reassurance or clarity, or lack of information
■ Nursing/medical care concerns: care from nurses and doctors
■ Concerns about activities of daily living: hygiene, normal feeding, sleep or mood
■ Not a C4C or insufficient data.

The number of referrals included in each category can be found in *Figure 5*. Some referrals generated more than one category when there were multiple issues perceived by the referrer.

The most common reason for making a C4C referral was for concern about the clinical care aspects of the patient (n = 210). This fits with the aims of the C4C service as it includes issues to do with the patients' physiology: deterioration; pain; NG feeding; infections; drugs; new confusion and agitation. In many cases the CCO team was able to address the issues by managing deterioration, facilitating further medical reviews and prescribing analgesia and antibiotics.

The second most common reason for referral was for communication issues (n = 147). Patients and their families were confused about ongoing care plans, investigations, diagnoses and discharge planning and wanted more clarity. Families often found it difficult to access more senior members of the medical team to get the information they needed. The CCO team was able to liaise with the different specialties and give the patients the information they needed, or clarify what they had already been told.

The third category was support, advice and reassurance (n = 87). The issues in this category were about families needing extra, 'third party' reassurance, where the patient was stable but the family members were stressed and needed more support. It also included instances where the referrer asked for advice about hospital procedure that could not easily be found anywhere else, such as how to make an appointment to see the consultant.
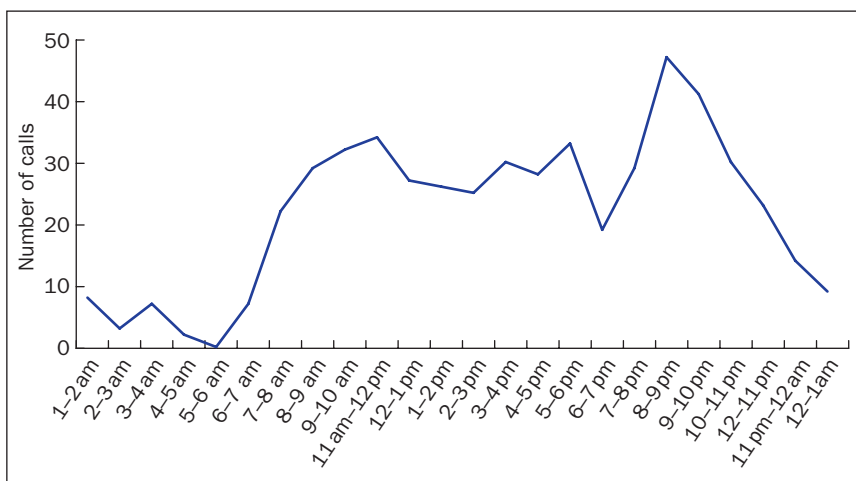
The fourth category covered concerns about general care (n = 47). These included medical and nursing care and were mainly related to negative staff attitudes, perceived shortness of staff, lack of medical reviews and lack of acknowledgement of concerns. The CCO team discussed these concerns with the ward teams and the matrons; families' concerns were acknowledged and action plans were put in place.

Lastly, concerns were raised regarding activities of daily living (n = 24). This category related to normal functions such as the patients' mobility, feeding and hydration.

In 88 cases, there was either insufficient text to determine the reason for the referral (n= 63) or it was not a C4C referral (n = 25).

Referral outcome

The majority of patients (401; 75%) seen by the CCO team following a C4C referral were discharged from the service with an appropriate plan in place. One hundred (18.7%) required further specialist review and 8 (1.4%) had treatment limitation plans made. Three patients died and 6 were transferred to a higher level of care.

Discussion

The objectives of the service review were to describe a patient- and relative-activated CCO service and provide information for those planning to develop a similar service in their hospital. Seven years of data on C4C referrals were reviewed and the number of calls, time of day, location source, referral source and referral outcome are discussed below. Free-text descriptions of the referral were reviewed and categories of reasons for referral were extracted and the areas of health care that are of most concern to patients and their families are also examined.

Number of calls

It has been suggested that hospitals may be reluctant to implement a patient- and family-activated CCO service because of concerns of being overwhelmed with calls (Zix et al, 2012). The 7-year review reports a relatively low level of activation with 534 C4C calls. This is in keeping with other studies (Bogert et al, 2010; Brady et al, 2015). In a literature review concerning patient and relative escalation of clinical deterioration, Albutt et al (2017) found that, on average, RRTs were activated 15 times a year. While our data show a CCO activation rate of 76 a year on average, this still represent less than 1% of all CCO activity. Our higher activation rate may be due to a 24-hour CCO service and the maturity of the system.

Time of day

Visiting times may have an impact on referral rates. As family members and friends made up 92% of all referral sources, it makes sense that the majority of concerns would come to light during the day when they can visit. At these times patients and visitors are in contact and subtle changes in the patient's behaviour and demeanour may become more noticeable. The peak at 8 pm to 9 pm may represent an end to conventional visiting times and a heightened awareness for families to raise concerns before nightfall. No other evidence has been found
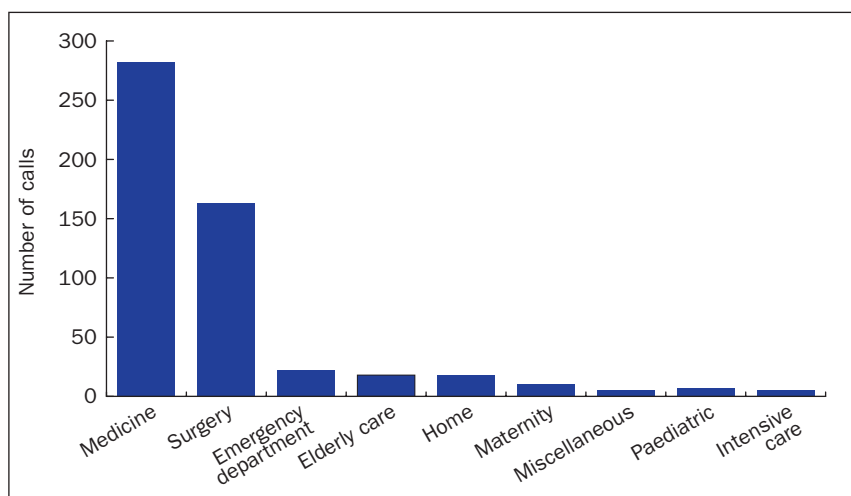

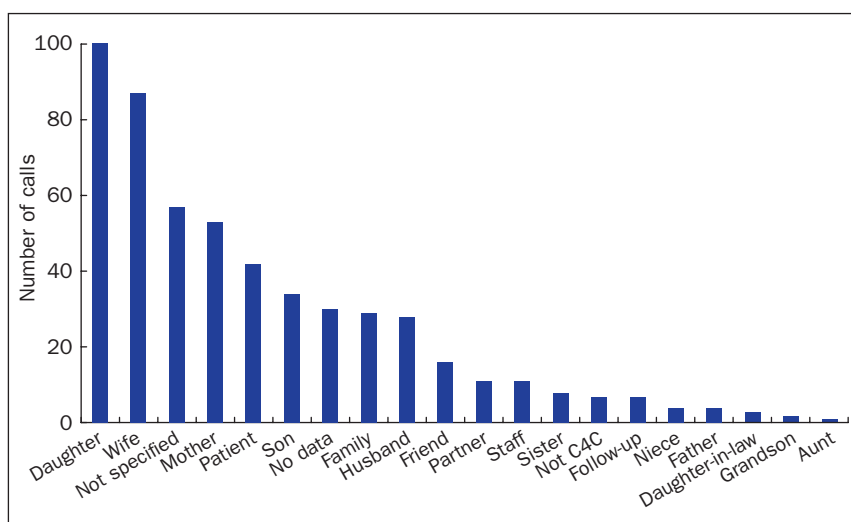Figure 3. Location referral sources for Call 4 Concern calls

Figure 4. Patient, family member and staff referrals to Call 4 Concern
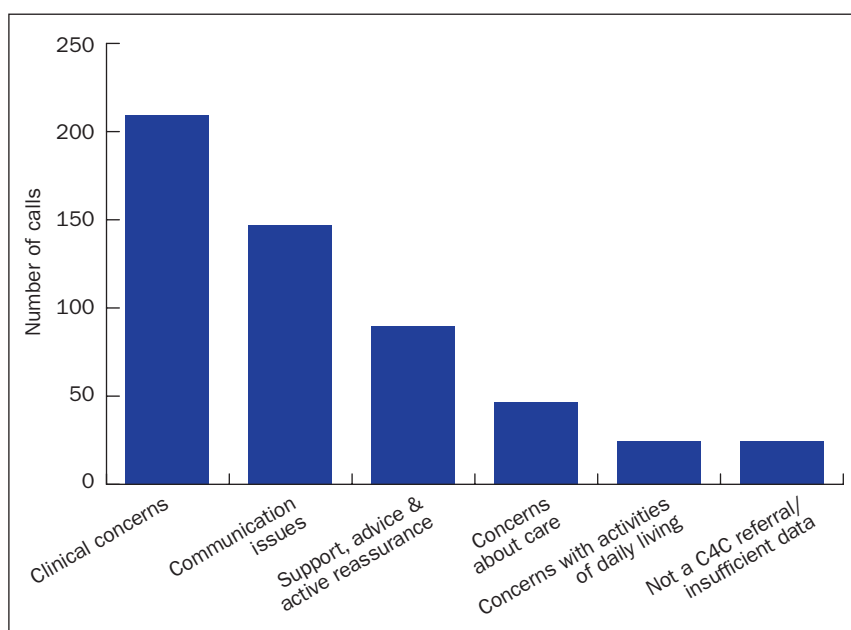

Figure 5. Categories of concerns for Call 4 Concern referrals

that describes daily patterns of family and patient activation of CCO, but a 24-hour C4C service is key to ensuring that any concerns are addressed in a timely manner.

Location source

The location source of C4C referrals is dependent on the scope of service deployment within the hospital and how well the service has been embedded. No other studies found have reported on the uptake of such a service and the review shows a wide spread of referral sources across all specialties. The ward and department volume of referrals reported reflects the activity of the CCO service as a whole, but may not necessarily reflect the areas where patients and their families have concerns. The large number of patients and their relatives/friends using the hospital on a daily basis can be a considerable challenge in ensuring awareness of the C4C service and how to use it. In spite of available C4C information, there may be considerable numbers of patients and relatives who are unaware of the service.

Referral source

Of all the people who made a referral, only 7.8% were patients. This resonates with the findings of Rainey et al (2015) who reported that patients had a limited ability to recognise changes in their clinical condition. This may be due to patients' frailty, confusion or illness and not having the physical resources to access C4C. There may also be concern regarding a negative response from staff taking care of them if they were to call in independent help. During the implementation phase, negative attitudes towards C4C from staff were addressed through reassurance and demonstration of improvements in care and patient-staff relationships (Odell et al, 2010). Over the years ,clinical staff's acceptance of C4C has become established, demonstrated by 11 referrals being made by staff.

Engaging ward staff in supporting the C4C service, and including them as an information source, might help as well as targeting advertising at families and friends. Interestingly, it was female relatives—daughters, wives and mothers who made up the largest relationship group, making up 45% of all referral sources.

Areas of health care that are most concerning for patients and their families

Reasons for making a C4C were recorded in the database and were extracted and categorised. There were many reasons for referrals, which made categorisation challenging. There were also missing data and some inconsistency and ambiguity in the data recording; however, six broad categories were extracted from the data. The categories were in line with reports from other studies that highlighted patient and families concerns: communication (Albutt et al, 2017); dissatisfaction with staff (Baird and Bobel Turpin, 2011; Brady et al, 2015); concerns about plans of care and discharge planning (Dean et al, 2008; Bogert et al, 2010; Baird and Bobel Turpin, 2011), and medication and pain concerns (Gerdik et al, 2010; Odell et al, 2010; Baird and Bobel Turpin, 2011).

Referral outcomes

The purpose of implementing a patient- and relative-activated CCO service was to enhance the surveillance opportunities for the patient and improve the detection of deterioration to enable more timely management. The service was being appropriately activated with the majority of referrals for physiological aspects of the patients' condition and only 5% of referrals deemed not to be a C4C. This is similar to the findings of Bogert et al (2010) and Brady et al (2015). One hundred and fourteen patients required significant interventions such as further specialist review, treatment limitation plans and admission to higher levels of care, which is consistent with the findings of Gerdik et al (2010), Zix et al (2012) and Brady et al (2015), and supports the view that C4C referrals were medically appropriate (Bogert et al, 2010; Odell et al, 2010; Hueckel et al, 2012), and so may have a positive effect on patient outcome (Vorwerk and King, 2016).

The remaining referral categories relate to significant concerns for patients and their families, and resonate with the findings of Miceli and Clark (2005), Greenhouse et al (2006) and Ray et al (2009) in the promotion of improvement in safety culture through patient and family empowerment. This service review also found that staff were raising C4C referrals both for inpatients who were the family and friends of staff members, but also for their ward patients, also found by Zix et al (2012).

Limitations of the review

No other literature has been found that describes such a substantial number of referrals from patients and families to a CCO service over an extensive length of time. However, there are some limitations to the review in the methodology as well as the setting. This review was conducted in a single-site hospital, and even though the CCO team was a well established, 24/7 service, there could still be some local organisational, professional and cultural issues that could have influenced the results of the review. However, many of the findings were comparable with the findings from other studies and can play a useful contribution to the knowledge base in this emerging field.

The review was largely descriptive and lacked hospital outcome data. This meant that the effect of a C4C service could not be associated with patient mortality or morbidity. However, a greater understanding of the concerns of patients and their families can contribute to system changes and improvements in patient experience and satisfaction.

Categorisations of the free-text data was complex, subjective and undertaken by a single reviewer. The original data were subject to the situational interpretation by the individual members of the CCO team. This could have led to inconsistent data entry, and missing and inaccurate information. However, the large volume of C4C referrals meant that referral patterns were more easily extracted for categorisation of calls, which were found to be similar to the reports from other studies in the field.

Suggestions for further research

Due to the emerging nature of this field there is a scarcity of research that is neither descriptive nor small scale. The early work that has been published is important in laying the groundwork for establishing the feasibility and necessity of such service initiatives. Further research could explore a number of areas such as: patient and relative satisfaction, clinical staff attitudes,

patient and relative knowledge of services, referral drivers, who refers and the influence of gender, association with reduction in complaints and incidents, and effects on mortality and morbidity.

Conclusion

This service review reported on 7 years of hospital-wide C4C referrals from a patient- and relative-activated CCO service. Building on earlier publications in this emerging field, the review was able to establish that such a service is not only feasible but can have an impact on preventing patient deterioration. The reasons that cause patients and families concern have been highlighted and this information can inform the future design of hospital services. By involving patients and families in care, the patient experience and outcomes can be influenced. **BJN**

Declaration of interest: none

Albutt AK, O'Hara JK, Conner MT, Fletcher SJ, Lawton RJ. Is there a role for patients and their relatives in escalating clinical deterioration in hospital? A systematic review. Health Expect. 2017; 20(5):818–825. https://doi.org/10.1111/hex.12496

Baird SK, Bobel Turbin L. Condition concern: an innovative response system for enhancing hospitalized patient care and safety. J Nurs Care Qual. 2011; 26(3):199–207. https://doi.org/10.1097/ncq.0b013e31820b1f91

Bogert S, Ferrell C, Rutledge DN. Experience with family activation of rapid response teams. Medsurg Nurs. 2010; 19(4):215–222; quiz 223

Braaten JS. Hospital system barriers to rapid response team activation: a cognitive work analysis. Am J Nurs. 2015; 115(2):22–32; test 33; 47. https://doi.org/10.1097/01.naj.0000460672.74447.4a

Brady PW, Zix J, Brilli R et al. Developing and evaluating the success of a family activated medical emergency team: a quality improvement report. BMJ Qual Saf. 2015; 24(3):203–211. https://doi.org/10.1136/bmjqs-2014-003001

Dean BS, Decker MJ, Hupp D, Urbach AH, Lewis E, Benes-Stickle J. Condition HELP: a pediatric rapid response team triggered by patients and parents. J Healthc Qual. 2008; 30(3):28–31

DeVita MA, Bellomo R, Hillman K et al. Findings of the first consensus conference on medical emergency teams. Crit Care Med. 2006; 34(9):2463–2478. https://doi.org/10.1097/01.ccm.0000235743.38172.6e

DeVita MA, Smith GB, Adam SK et al. 'Identifying the hospitalised patient in crisis': a consensus conference on the afferent limb of rapid response systems. Resuscitation. 2010; 81(4):375–382. https://doi.org/10.1016/j.resuscitation.2009.12.008

Douglas C, Osborne S, Windsor C et al. Nursing and medical perceptions of a hospital rapid response system: new process but same old game? J Nurs Care Qual. 2016; 31(2):E1–E10. https://doi.org/10.1097/ncq.0000000000000139

Gerdik C, Vallish RO, Miles K, Godwin SA, Wludyka PS, Panni MK. Successful implementation of a family and patient activated rapid response team in an adult level 1 trauma center. Resuscitation. 2010; 81(12):1676–1681. https://doi.org/10.1016/j.resuscitation.2010.06.020

Greenhouse PK, Kuzminsky B, Martin SC, Merryman T. Calling a condition H(elp). Am J Nurs. 2006; 106(11):63–66

Hueckel RM, Mericle JM, Frush K, Martin PL, Champagne MT. Implementation of condition help: family teaching and evaluation of family understanding. J Nurs Care Qual. 2012; 27(2):176–181. https://doi.org/10.1097/ncq.0b013e318235bdec

Lawton R, Armitage G for The Health Foundation. The role of the patient in clinical safety. Thought paper. 2012. https://tinyurl.com/yd25mt4m (accessed 11 January 2019)

McCawley BA, Gannotta RJ, Champagne MT, Wood KA. Calling a 'condition H'. Nurs Manage. 2013; 44(12):30–35. https://doi.org/10.1097/01.numa.0000437770.71392.8d

Miceli PJ, Clark PA. Your patient—my child: seven priorities for improving pediatric care from the parent's perspective. J Nurs Care Qual. 2005; 20(1):43–53; quiz 54–55

National Patient Safety Agency. Recognising and responding appropriately to early signs of deterioration in hospitalised patients. 2007. https://tinyurl.com/y83hogys (accessed 11 January 2019)

Odell M, Gerber K, Gager M. Call 4 concern: patient and relative activated critical care outreach. Br J Nurs. 2010; 19(22):1390–1395. https://doi.org/10.12968/bjon.2010.19.22.1390

Odell M. Detection and management of the deteriorating ward patient: an evaluation of nursing practice. J Clin Nurs. 2015; 24(1–2):173–182. https://doi.org/10.1111/jocn.12655

Radeschi G, Urso F, Campagna S et al. Factors affecting attitudes and barriers to a medical emergency team among nurses and medical doctors: a multi-centre survey. Resuscitation. 2015; 88:92–98. https://doi.org/10.1016/j.resuscitation.2014.12.027

Rainey H, Ehrich K, Mackintosh N, Sandall J. The role of patients and their relatives in 'speaking up' about their own safety: a qualitative study of acute illness. Health Expect. 2015; 18(3):392–405. https://doi.org/10.1111/hex.12044

Ray EM, Smith R, Massie S et al. Family alert: implementing direct family activation of a pediatric rapid response team. Jt Comm J Qual Patient Saf. 2009; 35(11):575–580

Roland D. But I told you she was ill! The role of families in preventing avoidable harm in children. BMJ Qual Saf. 2015; 24(3):186–187. https://doi.org/10.1136/bmjqs-2015-003950

Shearer B, Marshall S, Buist MD et al. What stops hospital clinical staff from following protocols? BMJ Qual Saf. 2012; 21(7):569–575. https://doi.org/10.1136/bmjqs-2011-000692

Vorwerk J, King L. Consumer participation in early detection of the deteriorating patient and call activation to rapid response systems: a literature review. J Clin Nurs. 2016; 25(1–2):38–52. https://doi.org/10.1111/jocn.12977

Zix J, Giaccone M, Wheeler D, Dressman K, Muetting S, Tegtmeyer K. Family activated rapid response team: what we know five years later. Crit Care Med Poster abstract. 2012; 40(12). https://doi.org/10.1097/01.ccm.0000425107.81133.dc

KEY POINTS

- This study found that implementing a Call 4 Concern service did not result in a considerable extra workload
- Patient and family involvement may support earlier recognition of the deteriorating patient
- There is potential to improve hospital systems and processes based on patient and family feedback

CPD reflective questions

- How do you enable patients and families to raise concerns about their care in your clinical setting?
- What do you think would be the barriers and enablers to setting up a Call 4 Concern service in your clinical setting?
- What type of service would you like to have available to you if you had a family member in hospital?