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Clinical paper

Why are some ReSPECT conversations left incomplete? A qualitative case study analysis



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Abstract

Background: As an emergency care and treatment planning process (ECTP), a key feature of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is the engagement of patients and/or their representatives in conversations about treatment options including, but not limited to, cardiopulmonary resuscitation (CPR). However, qualitative research suggests that some ReSPECT conversations lead to partial or no decision-making about treatment recommendations. This paper explores why some ReSPECT conversations are left incomplete.

Methods: Drawing on observation and interview data collected in four National Health Service (NHS) hospital sites in England, this paper offers an in-depth exploration of six case studies in which ReSPECT conversations were incomplete. Using thematic analysis, we triangulate fieldnote data documenting these conversations with interview data in which the doctors who conducted these conversations shared their perceptions and reflected on their decision-making processes.

Results: We identified two themes, both focused on 'mismatch': (1) Mismatch between the doctor's clinical priorities and the patient's/family's immediate needs; and (2) mismatch between the doctor's conversation scripts, which included patient autonomy, the feasibility of CPR, and what medicine can and should do to prolong a patient's life, and the patient's/family's understandings of these concepts.

Conclusions: This case study analysis of six ReSPECT conversations found that mismatch between doctors' priorities and understandings and those of patients and/or their relatives led to incomplete ReSPECT conversations. Future research should explore methods to overcome these mismatches.

Keywords: Emergency care and treatment planning, Doctor-patient communication, Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

Introduction

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is an emergency care and treatment planning process (ECTP), implemented across National Health Service (NHS) trusts in the United Kingdom since 2016. A key feature of ReSPECT is engaging patients and/or their representatives in conversations about treatment options, including, but not limited to, cardiopulmonary resuscitation (CPR).¹ Through promoting conversations between clinicians and patients and/or their representatives, ReSPECT aims to facilitate shared understandings and shared treatment recommendations,² and thereby prevent harm to patients.^{3–10}

ReSPECT conversations are directed at eliciting patients' values and preferences and exploring treatment options, to formulate per-

sonalised treatment recommendations in a future emergency where the person cannot express their choices.² In our earlier analyses, we found that doctors tended to have rehearsed scripts for ReSPECT conversations, on which they drew when introducing the topic and making clinical recommendations. These scripts were aimed at mitigating the emotional load of ReSPECT conversations, and were premised on the assumption that patients/relatives would share the doctors' understandings.^{11–13}

Our recent qualitative evaluation of ReSPECT conversations observed in English hospitals found that about a quarter of the conversations we observed were left incomplete, leading to partial or no treatment recommendations.¹² Focusing on a subsample of these observed conversations, this study is the first to explore why some ReSPECT conversations are left incomplete, focusing on acute hospital settings.

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Methods

Design

As part of the ReSPECT Evaluation Study,¹³ participants from six acute NHS hospital sites in England took part in a qualitative investigation which included observation of ReSPECT conversations and interviews with clinicians, patients, relatives, and implementation leads. Observations took place in two rounds (August to December 2017 and April 2019 to January 2020). In the second round, we added ethnographic observations in wards and informal conversations with clinical staff. This analysis includes data collected from the four hospital sites that participated in the second round.

We employed a critical realist case study approach.¹⁴ Critical realist approaches are primarily concerned with understanding causes and outcomes; in this, they differ from other qualitative approaches, such as grounded theory, which is concerned with generating theories about processes or events, or phenomenology, which is concerned with understanding lived experience.¹⁵ Critical realism is underpinned by the assumption that language used by participants reflects reality, but that the interpretations of participants and researchers mediate this reality.¹⁶ We triangulated case study observation data with the doctors' interview-based reflections to develop an understanding of how conversation dynamics, communication styles, context, and values influenced the conversations' outcome.

Data collection

ReSPECT conversation observations aimed to include orthopaedic, medical, and surgical wards in each hospital site, with specific ward areas selected by the principal investigator at each site. As described in our earlier publication,¹² KE observed ReSPECT conversations after being informed by clinical staff that a conversation was about to take place on a selected ward.¹⁷ Conversations took place at patients' bedsides or private meeting rooms, across various times of day – during or after ward rounds, following multi-disciplinary team meetings, and during visiting hours – and were observed with the agreement of patients and/or their relatives, if present.¹² KE conducted semi-structured interviews with the doctors who conducted these conversations, using a topic guide developed by the study team which explored their perceptions of the conversations, reflections on their practice, and experiences of the ReSPECT process.

The observed conversations were documented in handwritten fieldnotes, which KE later expanded and typed up. Interviews were audio recorded and transcribed. Written informed consent was obtained from the participating doctors. The data presented in this paper have been anonymised. The study was approved by the NRES Committee, West Midlands – Coventry and Warwickshire (REC reference: 17/WM/0134).

Data analysis

Of the 28 conversations observed, six incomplete conversations were identified. Conversations were defined as incomplete if no ReSPECT recommendations were agreed, or if only some of the recommendations on the doctor's agenda were agreed, but others had to be left for future discussions (see also¹²). These we considered our case studies. The typed fieldnotes and clinician interview extracts pertaining to each of these conversations were indepen-

dently analysed by KE and CJH (a medical anthropologist and a research psychologist, respectively) using inductive thematic analysis.¹⁸ KE and CJH were familiar with the data and had undertaken previous analysis.^{11,12,17,19} In this analysis they employed a new focus – understanding incomplete conversations – and were alert to new themes.

Data were coded using semantic and latent codes to explore both the explicit content of the data and the underlying assumptions and understandings.¹⁸ After coding all observation and interview data, these authors independently developed candidate themes. They then read through each other's codes and analysis notes, compared their candidate themes, discussed potential disagreements, reflected on the process of analysis, and agreed on the themes to be developed further.

After agreeing on the themes, the authors returned to the observation notes and interview transcripts, extracted the sections that pertained to each theme, and created a summary document with data extracts for all themes. This process added rigour, ensuring that all themes were supported by substantial and diverse case study evidence.

Findings

Sample description

Six incomplete conversations were observed in three hospital sites, in geriatrics, stroke, critical care, orthopaedics, general medicine, and surgical wards. They were led by doctors (three women and three men) of varying seniority (four consultant-level doctors, one middle-grade doctor, and one foundation trainee). The patients (four men and two women) ranged widely in age, with the youngest in their 20 s and the oldest in their 90 s, though most were over 70 years old. Two conversations involved only the patient, three involved the patient and their relatives, and one involved only the patient's family, as the patient lacked capacity. One conversation took place during a ward round and the rest took place after the ward round or during visiting hours. Four conversations took place at the patient's bedside and two in a private room. Two conversations were about resuscitation and treatment escalation (Cases 04, 05); three conversations conveyed bad news,¹² including discussion of a poor prognosis alongside emergency care and treatment planning (Cases 02, 03, 06); and one conversation was about planning for palliative care (Case 01).

Thematic analysis results

We identified two themes: (1) Mismatch between the doctor's priorities and the patient's/family's immediate needs, and (2) mismatch between the doctor's conversation scripts and the patient's/family's understandings. Some cases featured both mismatches and others only one.

1. Mismatch between the doctor's priorities and the patient's/family's immediate needs

In five conversations, while the doctors perceived the ReSPECT conversation as urgent, the patients/families had other needs that our analysis suggests had to be addressed before they could fully engage with the conversation. These included receiving more diagnostic and prognostic information, having time to integrate and cope with bad news, and receiving effective pain relief.

In one case, a patient and her family were waiting for a detailed conversation with a consultant about the patient's prognosis. The doctor who initiated the ReSPECT conversation knew this; however, he proceeded with the ReSPECT conversation, having been pressured by a more senior clinician. After the conversation ended inconclusively, with both the patient's family and the doctor agreeing that decision-making will become clearer after the scheduled conversation with the consultant, the doctor reflected that the patient had not yet 'fully grasped' that she had an end-stage disease (Case 04).

In another case, a doctor attempted to hold a ReSPECT conversation with a patient who had an end-stage disease and was struggling with severe pain. When the doctor asked the patient about his priorities, the patient kept referring to his pain. The doctor validated the patient's concerns, reassured him that he would be given stronger analgesics, and attempted to comfort him by offering water, crouching next to the bed, and touching his hand. However, when she returned to the ReSPECT conversation questions, the patient, overwhelmed by pain, could not engage. Reflecting on this, the doctor said the conversation would need to be held 'in chunks'. She explained that ReSPECT conversations were often a balancing act between the patient's needs and her clinical duties, performed under considerable time pressure:

...it's difficult because, you know, when I'm doing a long ward round and I've got a lot of patients to see, I, I try to be very patient-focussed and follow their agenda, but sometimes, I've gotta, I've gotta do what I've gotta do as well, and I've gotta be able to find a balance between that, those two, two different approaches. (Case 01)

The balancing act between patient/family needs and clinical urgency was particularly acute in 'bad news' conversations, where doctors attempted to combine poor prognostic information and ReSPECT decision-making. In these conversations, patients and/or families were presented with large amounts of information about the patient's condition and treatment options. One case involved a patient with an end-stage disease, with whom the doctor initiated a ReSPECT conversation following a lengthy discussion of her diagnosis, prognosis, and treatment options. This case was unusual in that the doctor acknowledged the patient's need for additional time, despite this competing with the clinical need to record a recommendation. After listing her emergency treatment options the doctor added, 'If you need time to think about it it's fine. It's all up to you'. The patient then requested more time to discuss her options with her family, and the doctor invited her to approach him the next day with her decisions. Reflecting on this, the doctor explained,

I just wanted me to sound like I'm giving her options and she's free at her will to decide which option she wants and we'll respect it. (Case 06)

By contrast, in the two other 'bad news' conversations, the patients' relatives were overwhelmed by the prognostic news and by the doctors' emergency treatment recommendations. In both cases, the patients had deteriorated rapidly and the doctors pressed the relatives toward a particular decision. As one doctor explained, when reflecting on her decision to hold the ReSPECT conversation:

...I noticed that there was no record of any kind of, of a conversation like this in the notes. And he became more poorly, and it

looked like the family was not aware that it can actually go in the wrong direction. (Case 02)

However, combining poor prognostic information and emergency treatment planning proved counterproductive. Without sufficient time to integrate the news, the relatives resisted both the doctor's assessments and the ReSPECT conversation.

Another urgent conversation involved a patient receiving poor prognostic news following investigative tests. This contrasted markedly with the more optimistic outlook the doctor had shared with the patient's relatives a day earlier. The relatives reacted with confusion, distress, and distrust, eventually requesting a second opinion. The doctor recorded a DNACPR recommendation, despite the family's disagreement, but did not complete a ReSPECT form. She later said the outcome might have been better had the conversation been held in two stages, allowing the family time to integrate the patient's prognosis:

I was not happy that I did not have two separate conversations [...] I should have spoken to the family before and then come with them, after they understood, to... the patient bedside. (Case 03)

2. Mismatch between the doctor's conversation scripts and the patient's/family's understandings

Doctors scripted the observed ReSPECT conversations with the assumption that patients/relatives would share the doctors' understandings of key concepts¹³, including patient autonomy, the feasibility of CPR, and what medicine can and should do to prolong life. However, in most of the incomplete conversations observed, the doctors' scripts were challenged by patients'/relatives' diverging understandings.

In one case, the doctor and patient held different understandings of patient autonomy. Before the ReSPECT conversation, the doctor told KE he expected this elderly patient may have already obtained a community DNACPR. Yet, during the conversation, the patient expressed a preference for resuscitation, explaining that his relatives became distraught during a previous ReSPECT conversation, when he said he would not want resuscitation. Although the patient did not suggest he had been persuaded to change his decision, the doctor repeatedly told him, 'you should make decisions for yourself'. In response, the patient explained why his relatives' feelings were important to him. The doctor then explained that CPR was inappropriate for someone of this patient's age and medical condition. However, the patient countered the doctor's narrative by saying he had witnessed a successful CPR attempt in the past, thereby supporting his stance that he should remain for CPR for his relatives' sake. The conversation ended inconclusively, and the doctor later said:

I imagined there would, he, the, the conversation might be more pragmatic and he might be a little bit, he might, it might have ended up in a position where we're having a discussion regarding what he wanted, but he wasn't quite engaging in that process [...] overriding all of his, all of, all of these ideas about being pragmatic, overriding everything, is his ultimate need, and desire, and want to be there for his family. (Case 05)

Similarly, in another case, a patient contested the doctor's assertions about the feasibility of CPR. The doctor spoke about CPR as 'fairly undignified' with 'a lot of trauma to the chest', concluding that

'with your comorbidity... CPR won't be successful' (Case 04). The patient, however, said she would not forgo CPR attempts as she was not at the end of her life. When the doctors were interviewed, they said they were unsure whether to record these conversations in ReSPECT forms, as they had been inconclusive (Case 05) or unclear (Case 04).

In Case 02, the doctor based her ReSPECT conversation script on the untested premise that the patient's relatives would agree with her about what medicine can and should do to prolong life. During the conversation, this doctor told the family she predicted the patient would undergo cyclical improvement followed by deterioration, thereby experiencing extended suffering with no recovery in sight. This, the doctor said, begged the question whether the patient should be 'kept alive at this state'. The patient's relatives reacted with anger; they thought the doctor had suggested that treatment be withdrawn to end the patient's life prematurely, and repeatedly said the patient would 'keep fighting' until 'ready to go'. During the subsequent interview, the doctor admitted that her explanation 'probably didn't really go that well', and explained the conversation was difficult because

[t]hey didn't have any, none of them had any background in, in medicine. If people have it's, kind of, easier because they know what to expect more or less. They had absolutely no idea what to expect. (Case 02)

Faced with a patient's or family's interruptions to their ReSPECT conversation scripts, both Case 05 and Case 02 doctors attempted to adapt the conversations to their interlocutors' understandings, while respectively reinforcing their key narratives about patient autonomy and the futility of resuscitation, or cyclical deterioration and prolonged suffering. This allowed these doctors to create a context and structure to the treatment preferences they expected the patient or family to express. However, in both cases, this approach may have contributed to a decision-making impasse.

Discussion

In a case study analysis of six incomplete ReSPECT conversations, mismatches between the doctor's priorities and the patient's/family's immediate needs, and/or between the doctor's conversation scripts and the patient's/family's understandings resulted in partial or inconclusive ReSPECT decision-making. In the first mismatch, while doctors performed ReSPECT conversations urgently and under time constraints, patients/relatives could not engage fully with these conversations, as their needs – for additional information, pain relief, or time to integrate bad news – had not yet been met. In the second mismatch, while doctors structured ReSPECT conversations on the premise that patients/relatives would share key concepts with them – including patient autonomy, the feasibility of CPR, and what medicine can and should do to prolong life – patients/relatives challenged these scripts with diverging understandings.

As some doctors expressed, an incomplete ReSPECT conversation was not necessarily unproductive, and could catalyse future discussions. Similarly, we have previously reported that GPs view ReSPECT conversations as ongoing and processual.¹⁹ However, excepting one doctor who encouraged the patient to take her time, the participating doctors aimed at completing the decision-making process in one conversation, timing conversations according to clinical urgency. In our earlier work on the full range of ReSPECT con-

versations – from those planned but not conducted, to those carried out to completion – we described how time constraints, coupled with clinical prompts such as a patient's projected deterioration, influence doctors' decisions about which ReSPECT conversations to prioritise and which to forgo.^{11,12,17} This necessity to respond to clinical time, however, prevents doctors from being led by patients' own timing, which has been identified as key to end-of-life and future planning conversations.²⁰ Allowing a wider range of health professionals, including senior and specialist nurses, to conduct ReSPECT conversations may ease some of the time pressures associated with these conversations.

The observed mismatches between doctors' scripts and patients'/relatives' understandings suggest gaps in these doctors' structuring of the clinical encounter. In previous analyses, we found that concerns over effective communication, trust-building, and rapport with patients and relatives are central to doctors' experiences of ReSPECT conversations.^{11,13,17} Narrative medicine scholars have theorised the clinical encounter as a mutual performance in which patient and practitioner co-construct a story of illness, healing, and at times, dying.²¹ Key to bridging the chasm between clinicians' and patients' scripts is a focus on dialogue, understanding the patient's values, and the conversational emplotting of the patient's trajectory.^{22,23} Applying narrative medicine insights, we suggest that ReSPECT trainings may benefit from emphasising dialogic practices, such as elements of Motivational Interviewing (MI).^{24,25} MI emphasises patient autonomy, self-efficacy, and techniques for dealing with patient ambivalence and resistance, and may be useful in advance care planning.^{26–28} According to MI, patient resistance indicates dissonance in the patient-doctor relationship. Describing practices to bridge this dissonance, MI suggests that clinicians should roll with patient resistance by letting the patient talk, avoid counter-arguments, summarise and reflect back what the patient has said, validate their point of view, and reframe the discussion by adding new perspectives.²⁶

This study has several strengths. To our knowledge, it is the only study exploring incomplete emergency care and treatment planning conversations, and is among the few that use ethnographic methods. ReSPECT conversations were observed in three hospital sites and six ward areas, with patients of different ages, thereby bringing considerable diversity to the analysis. The study is limited by its focus on doctors' interviews, and the analysis would have been richer had we been able to include the perspectives of patients, relatives, and other clinical professionals. As we did not ask the participating doctors about their previous training in ethics or communication, we cannot draw conclusions about whether training may have influenced their approaches to ReSPECT conversations, or if it could have made a difference to conversation outcomes. Additionally, while we aimed to observe as many ReSPECT conversations as possible, observations depended on the researcher being in the right place at the right time, or being notified by clinical staff that a conversation was about to take place. This means that not all the ReSPECT conversations that took place at the designated ward areas during our study period could be observed.¹⁷ As this analysis is based on six case studies, the data are unlikely to have captured all factors that underlie incomplete conversations. Furthermore, given the study's cross-sectional design, we could not follow up on incomplete ReSPECT conversations to ascertain whether they had led to further conversations. However, we aimed to offer a novel and exploratory analysis, rather than provide generalizable or longitudinal findings.

Conclusion and implications

In ReSPECT conversations with inconclusive or partial outcomes, mismatches were observed between doctors' priorities and patients'/relatives' immediate needs and/or between doctors' conversation scripts and patients'/relatives' understandings. Structural barriers, particularly time constraints in the acute hospital setting, underpinned some of these mismatches. Our findings suggest that future research should examine strategies to facilitate ReSPECT conversations in time-constrained clinical environments, as well as explore different processes and dialogical models to bridge gaps between doctors' and patients'/relatives' priorities and understandings.

Authorship

All authors have made substantial contributions to: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

CRedit authorship contribution statement

Karin Eli: Methodology, Formal analysis, Investigation, Writing – original draft. **Caroline J. Huxley:** Formal analysis, Writing – original draft. **Claire A. Hawkes:** Conceptualization, Writing – review & editing. **Gavin D. Perkins:** Conceptualization, Writing – review & editing, Funding acquisition. **Anne-Marie Slowther:** Conceptualization, Methodology, Writing – review & editing, Supervision. **Frances Griffiths:** Conceptualization, Methodology, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: GDP and CAH are members of the ReSPECT national working group. A-MS, FG, CAH, and GDP received grants from the UK National Institute of Health Research during the study.

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