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Ethical tensions surrounding resistance to care in older adults with neurocognitive disorders: a qualitative study of emergency department professionals' experiences

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Research Article

Keywords: dementia, emergency department, ethics, refusal of treatment, qualitative research, resistance to care

Posted Date: November 18th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11447023/v1

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Abstract

Purpose

Resistance to care (RTC) in older adults with neurocognitive disorders can be difficult to distinguish from refusal of care and may create ethical uncertainty in the emergency department (ED). The aim is to explore ED healthcare professionals' experiences of RTC among older adults with neurocognitive disorders.

Methods

We conducted a multicentre qualitative study inspired by grounded-theory methodology. Semi-structured individual interviews were conducted with physicians, junior doctors, registered nurses and advanced practice nurses working in three hospitals in the Île-de-France region. Interviews were analysed through experiential coding, category development, thematic analysis and integrative modelling.

Results

Twelve professionals were interviewed between 5 March and 17 April 2024. Five themes were identified: the variable and fluctuating nature of RTC; ED-specific contextual factors; staff experiences; ethical questions and ways of addressing them; and care strategies adapted to RTC. Participants described tension between providing necessary care and recognising possible expressions of the person's wishes. Relational care, family involvement, team discussion and reassessment of the benefit–risk balance supported individualised decisions.

Conclusion

RTC placed ED staff in situations where clinical urgency, decision-making capacity and respect for the person's wishes could conflict. Decision support should combine assessment of potentially reversible causes, capacity-sensitive communication and collegial adaptation of the care plan.

Key summary points

Aim : To explore the experiences of emergency department (ED) staff regarding situations where older adults with cognitive disorders and a need for urgent care have resistance to care (RTC).

Findigns : RTC was described as variable, fluctuating and context-dependent. ED staff experienced uncertainty about whether resistance represented a symptom, a refusal or both ; to address this, team discussion, relational care and family involvement supported individualised decisions.

Message : Clinical application: capacity-sensitive assessment and team-based care planning may help staff respond to RTC without presuming incapacity.

Introduction

Emergency departments (EDs) frequently care for older adults with acute illness. The reception and management of older adults with major neurocognitive disorders present distinctive challenges, and learned societies have published guidance for this population [1, 2]. Care may become more complex when resistance to care (RTC) occurs [3]. The term

is not used consistently in the literature; RTC may be understood as a symptom of an underlying and potentially treatable cause, particularly in an emergency [4].

In France, the right to refuse care is binding on healthcare professionals, and consent is required before procedures except in specified circumstances [5]. RTC may therefore also be understood as a possible expression of the wishes of a person whose neurocognitive disorders affect understanding, communication or the ability to provide informed consent [6]. Neurocognitive disorders alone, however, do not establish that a person lacks decision-making capacity; capacity must be considered in relation to the decision at hand.

Healthcare professionals' experiences of RTC have been explored in acute geriatric wards, cognitive and behavioural units and nursing homes [7–9], but the ED context has not been examined in this literature. The ED combines time pressure, diagnostic uncertainty, competing priorities and frequent transitions of care, all of which may shape how staff interpret and respond to RTC.

We explored ED healthcare professionals' experiences of RTC among older adults with neurocognitive disorders, focusing on how they distinguished RTC from refusal of care, understood decision-making capacity and adapted care in situations of ethical tension.

Methods

We conducted a multicentre, exploratory qualitative study inspired by grounded-theory methodology [10]. We used semi-structured individual interviews with healthcare professionals involved in decisions about the care of older adults in the ED. The interviews were conducted in person, on a single occasion. Participants were registered nurses, advanced practice nurses, physicians and junior doctors working in EDs at hospitals in the Île-de-France region.

We used purposive maximum-variation sampling. Eligibility required French fluency and consent to participate; there were no restrictions on age, sex or professional experience. We collected participants' sex, age and ED experience in five-year bands, hospital type (general or university hospital), experience in a French mobile intensive care unit (MICU) and perceived weekly frequency of RTC. All participants who were screened for the study agreed to participate.

The interview guide (Online ressource 1) comprised open-ended questions. It was developed *a priori*, piloted and reviewed by three independent experts (two ED physicians and one ED nurse). To minimise ambiguity, the guide defined "resistance to care", "refusal of care" and "appropriate ED visit" before the interviews.

With participants' agreement, interviews were conducted by the researcher and were audio-recorded and transcribed verbatim using word-processing software. Potentially identifying information was anonymised. Audio files were then deleted, and only the written transcripts were retained. The researcher kept a journal to support reflexivity throughout the study.

Analysis was conducted on the anonymised transcripts. Experiential codes were generated first; related codes were then grouped into properties and categories. Categories were compared and linked to identify key themes, followed by an integrative analysis that produced an explanatory model. The analytic process was triangulated through discussion between the researcher and the research supervisor.

Interviews continued until no new experiential codes emerged in a subsequent interview. Saturation was assessed after 10 interviews and confirmed by two additional interviews.

Each participant received an information sheet and consented to participation and audio-recording. During a pre-consent interview, participants were informed of the researcher's position and the objectives of the research being conducted as

part of a master's program in ethics. At the end of each interview, participants were asked about their experience. Psychological support was offered if an interview raised difficulties.

The protocol was approved by the research ethics committee of Paris Centre University (IRB No. IORG0010044). The study was reported against COREQ criteria [11] (Online ressource 2). Transcript review and participant feedback on the findings were not undertaken because of time constraints and concern about social desirability bias. To support credibility, the interviewer restated and summarised participants' ideas during each interview.

Results

The interviews were conducted between March 5 and April 17, 2024. A total of 10 interviews were sufficient to achieve data saturation, which was confirmed by two additional interviews, bringing the total number of participants to 12 individuals working in three hospitals in the Île-de-France region.

The final sample consisted of one junior doctor, five physicians, four registered nurses, and two advanced practice nurses. No participant requested psychological support after the interview. Participant characteristics are shown in Table 1.

Table 1
Sample characteristics

Interview	Duration (minute)	Gender	Professional category	Age range (year)	ED experience (year)	Practice MICU	Hospital type	Perceived frequency of resistance to care per week
I01	60	F	advanced practice nurse	36–40	1–5	No	UH	1
I02	70	M	physician	31–35	1–5	Yes	UH	2
I03	75	F	state-registered nurse	26–30	6–10	No	UH	1
I04	54	F	physician	41–45	11–15	No	UH	5–6
I05	90	F	physician	31–35	1–5	Yes	UH	rarely
I06	100	F	advanced practice nurse	46–50	1–5	No	UH	1–2
I07	90	M	state-registered nurse	41–45	1–5	No	GH	2
I08	110	F	junior doctor	26–30	1–5	Yes	UH	1–2
I09	110	M	physician	51–55	20–25	Yes	UH	1
I10	90	F	physician	36–40	1–5	Yes	UH	< 5
I11	70	F	state-registered nurse	26–30	6–10	Yes	GH	3
I12	80	F	state-registered nurse	31–35	6–10	No	UH	~ 30

I : interview, F : female, M : male, MICU : mobile intensive care unit, GH : general hospital, UH : university hospital

The interviews lasted an average of 82 minutes, with a range of 54 to 105 minutes.

The analysis identified five themes, each comprising several categories:

Patient RTC was characterized by considerable variability in how it was expressed and by fluctuations over time, depending on the nature of the care proposed. Moreover, from the healthcare professionals' perspective, RTC appeared more nuanced than a straightforward situation of refusal of care.

"While refusal of care can be more straightforward, clearer— like 'no, I don't want this,' *—resistance from the patient can be more like, we just can't manage it right now, [...] then suddenly it's fine, but two hours later when I try to restart the infusion*: 'no, don't touch me!'" (I07, registered nurse)

Participants identified ED-specific features, including the perceived frequency of RTC and contextual factors related to the ED environment and the reason for attendance. RTC was described as an obstacle to the patient's care pathway.

"The nursing home sent her because she wasn't doing well, and we can't even figure out what's wrong with her—we don't understand anything, and she's not helping us at all because she's being oppositional. [...] And I thought to myself: 'she's just going to go back to her nursing home, and we won't have done anything for her.' *And who knows, things might just keep getting worse and worse."* (I03, registered nurse)

Participants described emotions and experiences ranging from resilience and empathy to reduced professional engagement. Experience, confidence in managing RTC and team cohesion supported more constructive responses, whereas performance pressures and medico-legal concerns added to the burden.

"I agreed with the woman, even though you're never comfortable with resistance to care. […] The fact of putting yourself in their shoes, of saying to yourself: '[…] I understand, I wouldn't want non-invasive ventilation (NIV) either, if I were in your place'." (I05, physician)

"That [RTC] limits my ability to develop forms of care other than technical care." (I12, registered nurse)

Accounts of refusal of care sometimes generated incomprehension among ED staff.

"Oh no, there's something I explained poorly; maybe I'm doing my job badly, or maybe I was a bit too blunt when explaining things. Because when you hit a wall straight away: either the person is closed off and you won't get anything out of them, or you've missed something in your role as a caregiver in how you explained things." (I05, physician)

"Refusal, in general, is always… worse, because they are aware of the severity of the situation and yet they don't care. When I come across it, I find it hard to conceive that this is possible." (I08, junior doctor)

RTC raised ethical questions about age-related stigma in the ED, decisions made under uncertainty and urgency, and doubts about capacity to consent. Participants also described the boundary between RTC and refusal as difficult to determine.

"His resistance didn't stop me […] from doing what I considered absolutely necessary. An informed refusal might have made me stop, leading me to think: Well, I think it's necessary, but the person categorically refuses, so I can't go against that.'" (I02, physician)

"It's not because someone has cognitive disorders that, in one situation, they may be in resistance, and in another in refusal. You need to be careful that what is refusal is not taken in general as resistance." (I09, physician)

Participants described tension between autonomy, beneficence and non-maleficence. They also described discussion with the person, relatives and colleagues as a way of working through uncertainty about capacity and the appropriate level of intervention.

"It's a little bit like the last remaining link of communication for a demented patient who can no longer say: 'You don't understand, I'm 95 years old, and I've had a good life, so thank you for leaving me alone.' *They can no longer say that, but they make big gestures to say*: 'Don't touch me.'" (I04, physician)

This account illustrates how staff may treat non-verbal behaviour as ethically relevant communication, even when they doubt the person's capacity to provide informed consent.

"There's a difference between access to care and the fact that a person doesn't want it, while being aware that giving consent when you have cognitive disorders seems completely mad to us. It's a bit like this ambivalence: I might be able to save their life with this, but at the same time I understand that the person doesn't want us to do it." (I05, physician)

Professionals adapted their strategies by using relational care, involving relatives and seeking specialist support. They also reassessed the benefit–risk balance, co-constructed the care plan where possible and, when they identified markers of refusal within RTC, sometimes refrained from providing the intervention.

"I think we should probably listen to this lady at some point, even if she doesn't seem able to tell us, um... We've had her here six times now, and six times she's told us she doesn't want the NIV. Well, there you go." (I05, physician)

The distribution of coded excerpts across interviews is shown in Table 2.

Table 2
Distribution of coded excerpts by interview and analytic category

Interviews		**I01**	**I02**	**I03**	**I04**	**I05**	**I06**	**E07**	**I08**	**I09**	**I10**	**I11**	**I12**
Characteristics of RTC	Variability (fluctuations over time, nature of the care, etc.)	6	4	6	7	8	10	18	10	2	13	3	5
	Ambivalence toward their own needs	3		1	1	1			2		2		
	Impact of socio-environmental factors	4			1	2	3			2	4		
	Differences regarding refusal	1	1	2	1	2		2	1	1			
	Apparently reassuring discourse									3	2		1
ED specific contextual factors	Frequency of RTC	3	1	1	2	3	3	2	4	2	2	1	2
	Availability (time, human and material resources, etc.)	4	3	3			8	6	1	6	1	3	7
	Contextual factors related to the ED environment		1			2	6	3		1	6		5
	Situations of acute confusion		1	2					1		2		
	Obstacles to the care pathway			3	2		2	6	4	1	5	2	
Staff experiences	Resilience	4	1	2	1	2	1	4	7	1	5		7
	Team cohesion	5	3	10	6	3	2	10	9	2	4	5	5
	Empathy		2	8	1	10		1	4	2	5	2	4
	Impact of RTC on professional commitment		5	12	3	1		1	5	1			2
	Experience		3	2	1	3		2	1	3	1		1
	Performance pressure		3		4			9	1	2		1	3
	Impact of care provided by ED staff		4	2	1	3	4	3	3	2	2	2	
	Medico-legal concerns			1		1			2		3	6	
	Confidence in managing RTC				1	2		11	2	1	7		

Interviews		I01	I02	I03	I04	I05	I06	E07	I08	I09	I10	I11	I12
	Lack of understanding in certain situations of refusal (role of psycho-adaptive mechanisms)					8		1	1		1		5
Ethical questions and ways of addressing them	Collegiality	2	2		5	8	4	2	2		1	2	4
	Principle of beneficence	2	2	2	1	2	1	5	3	7	5	3	1
	Principle of non-maleficence	1		6	6	5		1	6	1	2	6	1
	Seeking assent/agreement	2		1	2	7		9		3	2	1	1
	Subsidiarity (ED staff, relatives)	1	1	4	3	6	9	2	6	8	8	11	2
	Doubts about capacity to consent	1	3	4	3	7	12	2	6	8	10	3	1
	Ethic of care		1	4	1	10	1	4		1	1	1	
	Age-related stigma		1	1	2	5	1	1		7			1
	Principle of autonomy			1	6	11	8	3	2	2	5	4	3
	Prevention of abuse			5	3	4		3	2	3		2	2
	Principle of justice				2		1		1				2
	Prevention of futile care				2	1				3		2	
	Ethical tension between autonomy and beneficience/non-maleficience					2	2	1	2	2		2	1
	Decisions made under uncertainty and urgency						5	1	2	1	4		1
Care strategies adapted to RTC	Semiological and etiological analysis (assessment of neurocognitive disorders, identification of triggering factors, etc.)	11	7	3	2	5	10	4	6	1	7	3	2
	Relational care strategies (providing	2	3	7	2	6	19	19	14	3	15	3	5

Interviews		I01	I02	I03	I04	I05	I06	E07	I08	I09	I10	I11	I12
	information and explanations, reassurance, distraction, etc.)												
	Support from relatives	4	2	1	3	3	4		2	3	2		
	Support from specialist	5	8	2	1	1	10	2	7	2	4	2	
	Adapting the care plan to RTC		7	9	7	4	7	3	7	13	18	7	3
	Use of restrictive interventions (chemical or physical) as a final option		3	2		1	1		8	4	2	1	
	Duty of best efforts		1	2			4		1	1	3	1	
	Signs of refusal during resistance to care					6	2					2	
	Refrain from providing care					5		1	2		5	1	3
	Ensuring that resources match needs (number of caregivers, coordination among caregivers)							6	5	1	3	2	1

The relationships among the five themes are presented in Fig. 1.

Discussion

This multicentre qualitative study explored how ED professionals experience RTC among older adults with neurocognitive disorders. Five themes described the phenomenon, characteristics of RTC, its ED context, staff responses, ethical questions and adapted care strategies. The findings show that RTC was not treated as a stable or self-explanatory behaviour: participants described changes over time, variation according to the proposed care and uncertainty about whether a person was expressing a symptom, a preference, a refusal or several of these at once.

The findings can be understood across three interacting levels. At the patient level, participants described clinical variability, ambivalence and resistance to particular procedures. At the professional level, experience, empathy, confidence, emotional burden and team cohesion shaped responses. At the institutional level, time pressure, performance expectations, limited resources and the organisation of emergency care influenced what staff considered possible. This model helps explain why the same behaviour could be interpreted differently by different professionals or at different points in the same ED stay.

Participants described two competing interpretations of RTC. One framed it primarily as a behavioural or psychological symptom requiring assessment and treatment, thereby supporting a duty to provide necessary care. The other treated it

as a possible expression of the person's wishes and therefore as ethically relevant to the care decision. These interpretations should not be reduced to a presumption that neurocognitive disorders mean incapacity. Rather, the interviews show how uncertainty about decision-making capacity can bring beneficence, non-maleficence and autonomy into tension [12]. The study's contribution is to show that staff may move between these interpretations during the same episode and adapt the care plan as new information becomes available.

Discussion with the person, relatives and colleagues was a recurring way of managing this uncertainty. Participants sought to preserve communication and dignity even when they doubted the person's ability to provide informed consent. Relational care, clear explanations, reassurance and non-pharmacological strategies were used alongside clinical assessment. This is consistent with an ethic of discussion, in which the person's expressed wishes remain relevant, and with an ethic of care, in which emotional and relational well-being are part of the clinical response [13, 14]. The data also suggest that an apparently direct refusal may be harder for staff to accommodate than fluctuating resistance, perhaps because it challenges the professional expectation to act [15]. This interpretation should remain tentative because it is based on participants' accounts rather than direct observation.

The study has several strengths. It addresses an underexplored ED context, includes four professional groups and draws on participants from three hospitals. Saturation was assessed after 10 interviews and examined in two further interviews. Analysis was triangulated between the researcher and supervisor. These features support the credibility and contextual transferability of the findings, but they do not establish statistical generalisability.

Several limitations should be considered. The sample was small and drawn from one French region, and the professional distribution was not balanced across the three hospitals. Interviews captured staff accounts rather than patients' or relatives' experiences and may have been affected by recall and social-desirability bias. Transcript review and participant feedback on the findings were not undertaken. The researcher's prior assumptions and professional position may also have influenced the interviews and analysis; the reflexive journal and supervisory discussion reduced but could not eliminate this possibility. The frequency counts in Table 2 should not be interpreted as measures of prevalence or importance.

The findings support a practical sequence for responding to RTC. First, staff should assess potentially reversible contributors, including delirium, pain, distress and environmental triggers, rather than treating RTC as a diagnosis in itself. The 4AT and Confusion Assessment Method are available tools for delirium assessment [16, 17]. Second, staff should examine decision-making capacity for the specific decision, using information from the person, relatives, referring professionals and advance care planning where available [18, 19]. Third, the team should adapt the care plan, prioritising relational and non-pharmacological strategies, seeking specialist support and reassessing benefit and harm as the situation evolves [4, 20, 21]. Restrictive interventions should not substitute for this assessment and discussion. Age-sensitive and anti-ageist approaches are also relevant because emergency professionals' interpretations of older patients' needs may contain ageist assumptions [22–24].

Conclusion

RTC among older adults with neurocognitive disorders placed ED staff in ethical conflicts involving urgency, benefit, harm, capacity and respect for the person's wishes. The findings do not show that neurocognitive disorders remove decision-making autonomy; they show how uncertainty about capacity can shape interpretation and care. Capacity-sensitive communication, assessment of reversible causes, team discussion and flexible care planning may help staff provide care that is proportionate and tailored to the person.

Declarations

This work was supported by a 'Année de Recherche' grant from the Regional Health Agency of Île-de-France (ARS Île-de-France) and Assistance Publique - Hôpitaux de Paris (AP-HP).

The protocol was approved by the research ethics committee of Paris Centre University (IRB No. IORG0010044).

Participants received an information sheet about the research project, oral consent was obtained. Written consent for audio recording was obtained from each participant.

Authors contributions :

L.A., M.L., and M.P. conceived the idea presented and developed the protocol.

C. Acknowledgements

• Thank you for participating in the interview.

• Offer to keep the participant informed of the results.

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Figures

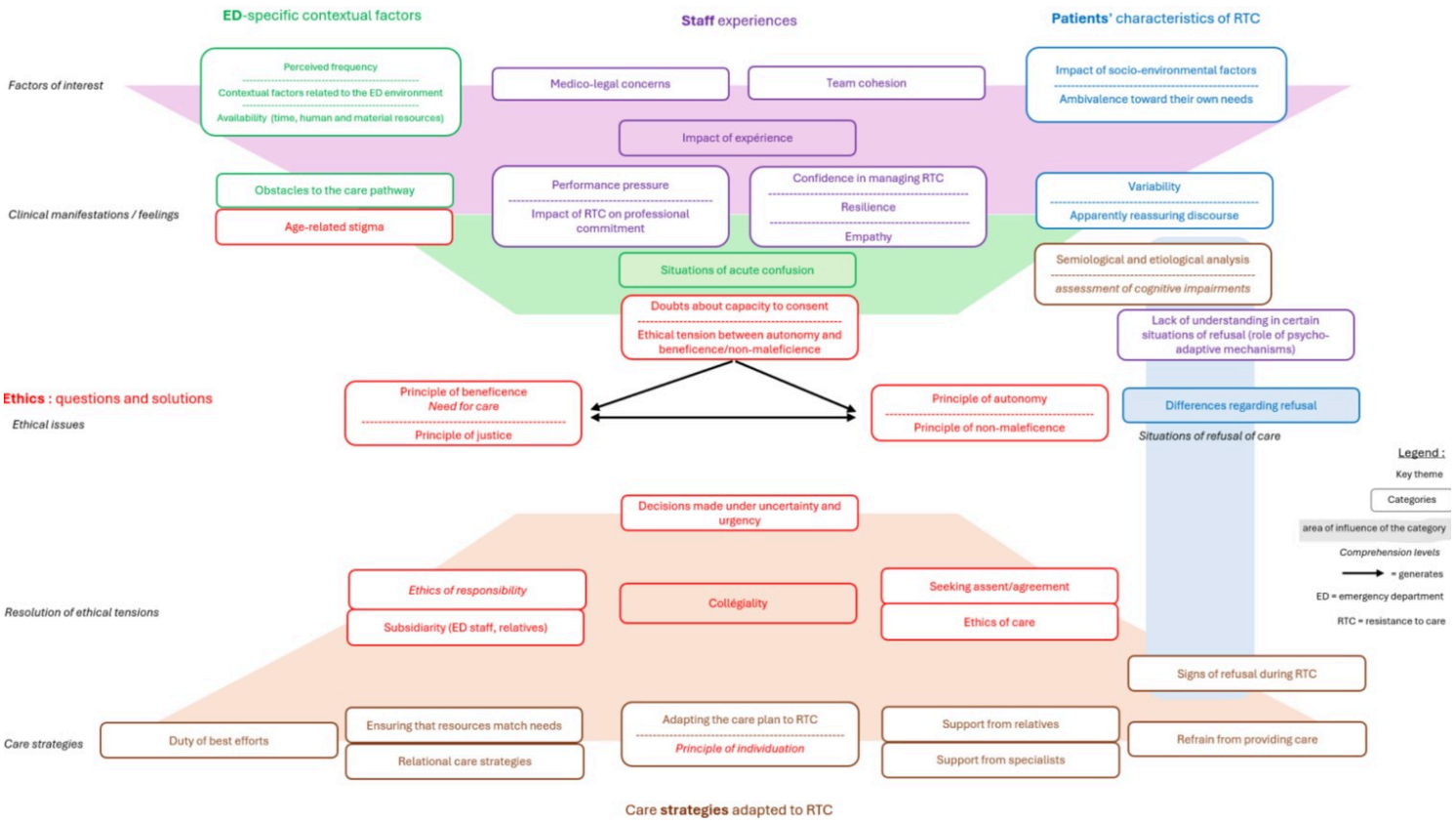


Figure 1

Explanatory model linking patient-, professional- and institutional-level factors with ethical responses and adapted care strategies

Supplementary Files

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