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Person-centred decisions in emergency care for older people living with frailty: principles and practice

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The authors declare holding or having held voluntary leadership roles in geriatric emergency medicine special interest groups in Europe: European Society of Emergency Medicine (JvO, PH, JAL) and European Geriatric Medicine Society (SM, SC); North America: Geriatric Emergency Department Collaborative (DM) and Society for Academic Emergency Medicine (SWL, TR); and internationally: International Federation for Emergency Medicine (CH, RM, DM).

Abstract

Older people living with frailty are frequent users of emergency care and have multiple and complex problems. Typical evidence-based guidelines and protocols provide guidance for the management of single and simple acute issues. Meanwhile, person-centred care orientates interventions around the perspectives of the individual. Using a case vignette, we illustrate the potential pitfalls of applying exclusively either evidence-based or person-centred care in isolation, as this may trigger inappropriate clinical processes or place undue onus on patients and families. We instead advocate for delivering a combined evidence-based, person-centred approach to healthcare which considers the person's situation and values, apparent problem, and available options.

Keywords

Frailty, emergency care, person-centredness, shared-decision-making

Key points

- Decision-making in emergency care is often based on guidelines and protocols with limited relevance to older people.
- Basing decisions solely on patients' personal values and perspectives may be flawed when risks are complex and uncertain.
- We advocate for integrating evidence-based, person-centred approaches within an operationalised ethical framework for reaching all decisions.
- We present a framework to support complex emergency care decision-making for older people living with frailty.

Introduction

Emergency care systems must evolve to serve an older population living with frailty. In 2023, one in seven adults attending European emergency departments (EDs) were older people living with frailty [1]. Frailty is associated not only with poorer outcomes from emergency care but likely also with different goals and perspectives: older people living with frailty have greater risk of prolonged admissions and in-hospital mortality, however they may prioritise other healthcare outcomes including feeling safe and independent at home [2].

Older people living with frailty commonly present with non-specific complaints which clinicians cannot interpret using paradigms of single system based sort and sieve [3]. Frailty captures the unexplained integrated effect of simple ageing, multiple morbidities, and socioenvironmental and epigenetic factors as an emergent state in the person [4]. Frailty related to an accumulation of deficits over the life course predicts all-cause mortality in multiple populations [6].

Guidelines and professional recommendations for geriatric emergency care advocate for comprehensive geriatric assessment (CGA) with goal-oriented management [7]. Multi-disciplinary collaboration is required to ensure that assessment and treatment are holistic. Indeed, the competence to deliver holistic geriatric care is beyond the scope of postgraduate curricula for many healthcare professions working in isolation, with training requirements rarely including identification and management of frailty or its integration into treatment planning. Healthcare systems are themselves complex sociotechnical systems with current research endeavours aiming to understand system interactions, safety and quality, informatics and healthcare provider behaviour [8]. Such a system may react variably depending on clinician competencies in delivering CGA or its design and configuration with regards to structures and processes, for managing older people with frailty.

The dearth of research representing acutely unwell older people living with frailty means that available guidance may be at odds with patients' personal values and preferences for care, or indeed professionals' perspective of the most appropriate management. Specific individual challenges include lack of best approaches to frailty assessment in emergency departments, poor organisational support and inadequate communication skills including for shared decision-making, moral dilemmas in dealing with end-of-life issues in older people with dementia, perceived medicolegal repercussions blinding or constraining decisions in the presence of poor insight into "best interest decisions", and absence of operational ethical frameworks for older care in ED. These factors often contribute to inappropriate care for complex older people in complex systems.

Practising in a field where recommendations and reality often collide can therefore prompt professional unease, resulting in reliance on one paradigm and thereby risking suboptimal patient experience [9]. Despite these difficulties, pragmatic decisions can still be made using appraisal of available information and evaluation of individual situations. In this article, we use a vignette to illustrate the flaws of relying solely on evidence or person-centredness and advocate instead for an approach that integrates both these paradigms.

Limitations of guidelines and protocols

Emergency care professionals are trained to diagnose and treat people of all ages across the full spectrum of undifferentiated acute illness and injury [10]. The requirement to respond to any problem in any patient at any time has prompted the development of a comprehensive suite of guidelines, protocols, and care pathways to ease cognitive burden of clinicians. These provide an evidence-based framework for selecting assessments and interventions, which professionals rely upon to provide safe, effective, and efficient care.

Guidelines and protocols are typically specific to isolated problems, presentations, or situations. Examples include management checklists for femoral neck fractures, discharge procedures for asthma, referral protocols for chest pain, and life support algorithms for resuscitation. These are invaluable to clinicians caring for multiple people at the same time and navigating a complicated healthcare system. The guidelines and protocols help ensure that a person with any of a wide variety of acute problems receives all appropriate diagnostic and therapeutic interventions. Frailty in older people, though, is characterised by the accumulation over time of multiple problems. During acute health crises, these sub-acute or chronic problems also require consideration, and both diagnosis and intervention may be complicated by condition or treatment interactions. Current guidelines, protocols, and care pathways were not developed to accommodate such complexity. Managing only specific conditions risks losing oversight of the complexity of the person.

The evidence underpinning guidelines and protocols nearly always has limitations regarding its representativeness for older people living with frailty. These people are often excluded from research owing to cognitive impairment, multimorbidity, or even their age alone [11]. Furthermore, the available research often has limited meaningfulness, appraising service metric outcomes (such as waiting times and admission rates) rather than using person-centred measures. CGA is currently understood to be the most effective intervention for people living with frailty, and yet has rarely been evaluated in the acute care setting using patient-reported outcomes as endpoints [12]. As will become apparent, though, decisions based solely on person-centredness and personal goals can also be flawed, and a pragmatic, integrated decision-making process is necessary.

A person requiring geriatric emergency care

We consider now a common scenario requiring a clinician's consideration through which we will illustrate a process to reaching a pragmatic decision. We share this vignette with intentionally vague details to recognise the inherent uncertainty of such scenarios.

An older person living with severe frailty (CFS score 7 [13]) attends the ED by ambulance having been found on the floor, unable to get up. They have atrial fibrillation, cognitive impairment, and hypertension and usually take apixaban, amlodipine, and ramipril. They live alone with the support of carer who visits four times daily to assist with eating, dressing, toileting, and washing. They have a bruised forehead and tell you that they feel comfortable and well. Their wish now is to go home. They cannot recall what precipitated them falling to the floor.

Is this memory issue due to their cognitive impairment, a head injury, or perhaps syncope? There is uncertainty here over the person's background situation, recent events, and diagnostic impression. Can that uncertainty be resolved, or must it be tolerated?

Healthcare approached solely with guidelines

The person in the above vignette has multiple problems (or potential problems) which may be managed following multiple guidelines or protocols. Their cognitive impairment requires assessment, and delirium should be considered by evaluating for acute or fluctuating features [14]. Meanwhile, the presence of a head injury and use of anticoagulation medication requires that a CT examination be considered to investigate for intracranial bleeding [15]. Their unexplained fall should be treated as potential syncope, and, as they have neither high or low risk features prompting cardiovascular concern, they should likely be admitted for monitoring and referred to a syncope clinic [16]. Their blood pressure should be measured while standing, and titrated pharmacologically so as not to exceed 150/90 [17].

This person would require more interventions than can be reasonably achieved within the ED, making admission necessary. The potential harms from hospitalisation are extensive and may not outweigh the benefits. Prolonged stays and intra-hospital transfers increase the risk of delirium, and potential deconditioning makes discharge to residential care a real possibility [18, 19]. Increasing the intensity of hypertension management would contribute to polypharmacy, itself increasing the risk of further falls [20]. Even waiting for an admission bed is hazardous, with mortality risk observed due to delays [21]. Applying in isolation an evidence-based approach to healthcare may then be suboptimal for older people living with frailty. Instead, acute diagnostic and treatment decision-making for people living with frailty requires integrating a person-centred approach.

A flawed solely person-centred approach

Person-centred care orients medical decision-making as being shared between clinicians and patients, enabling patients to participate as equal partners in dictating the approach to diagnosing and managing the health issues [22]. In concept, this involves recognising people as active agents in improving health rather than passive recipients of care. Person-centred care engages patients as collaborators, whereas the medical model of care might direct actions for subjects. Personalisation requires appreciation not just of the health problem, but of how this is intersects with the individual's personality, character, culture, and identity [23]. This construct can be delivered in practice through conversations tailored to engage and understand a person and their values and beliefs, to provide enablement through knowledge and discussion, and to resolve tension between personal and professional perspectives [24]. Two patients, facing the same acute medical problem and surrounding circumstances, may choose different diagnostic and treatment approaches based on their goals and values.

There are pitfalls in applying a solely person-based method however, as in this vignette, acceding to the person's wishes would require consideration as to whether pathway deviations were appropriate. This person has said they wish to go home, but are we sure they understand the risk of missed diagnoses or inadequate intervention given that they are living with cognitive impairment? These risks are significant, as they may have an intracranial haemorrhage or further syncopal events.

Asking all patients to make decisions for themselves seems unreasonable given the volume and complexity of information which must be understood to be fully informed. While always challenging, understanding health information can be particularly difficult while experiencing an acute injury or illness in a loud, unfamiliar ED environment. Also, when presented with medical information and asked to make a choice, older people may feel they must comply with professional advice [25]. If, indeed, the person has capacity to make such a decision, how comfortable is the clinician with taking the professional risk of facilitating discharge? This prompts us to ensure that decisions are truly being shared, but currently we lack a process through which to assure this in emergency care.

Ethical and legal considerations

The purpose of medical treatment is to preserve life, reduce suffering, and/or enhance well-being. The challenge arises when life is approaching its natural end and cannot be preserved. Approximately half of people with CFS 7, as in the vignette, will die within one year of attending emergency care and, as prognostication by clinicians is known to be imprecise, it is reasonable to consider possible mortality [26, 27]. Legal observers have commented that "the doctor's dilemma is best appreciated in terms of his or her objective; when the primary aim of the healthcare is to preserve life, futility has a role to play only when life can no longer be preserved" [28]. Medical futility was succinctly articulated by Jecker and Pearlmen as useless or ineffective treatment: "that which fails to offer a minimum quality of life on a modicum of medical benefit; treatment that cannot possibly achieve the patient's goals; or treatment which does not offer a reasonable chance of survival" [29]. The authors also commented on the importance of utilising scientific evidence to support a bedside quantitative analysis by the clinician alongside a logical and transparent qualitative framework that represents the patient's wishes and preferences.

These considerations assume particular importance in older individuals whose capacity for decision-making may be affected by age-related changes, including cognition, task-related factors and contextual factors in an ecological network [30]. The UK has a Mental Capacity Act (2005) which allows healthcare practitioners to adopt a best interest approach that uses corroborative history, wishes and preferences of the older person and places the responsibility on the decision-maker to weave these considerations into a management plan. This legal concept of "best interest" can however be conflated with "medical best interest" and undermines quality of care [31]. In countries without such legislation, clinicians should nonetheless be supported and, to some extent, informed in enacting ethical decision-making by professional and regulatory guidance.

There is a need for an approach to shared decision-making for older people who are incapacitated based on appreciating best interest without encroaching on autonomy. The Beauchamp and Childress principles-based approach offers an excellent balance between consequentialist and deontological approaches [32]. Healthcare has largely adopted these four principles of beneficence, non-maleficence, autonomy, and justice.

Uncertainty

Geriatric emergency care is perhaps uniquely characterised by the combination of acuity and uncertainty experienced by patients and professionals alike. Older people living with frailty who attend emergency care often seek to understand the severity of their condition and the likely trajectory, and to feel safe in their situation [2]. Meanwhile ED clinicians are required to care for people who are unwell with undifferentiated problems where there may be unclear guidance and uncertain outcomes.

Active recognition of the inherent uncertainties may aid professionals during evaluation and communication with patients. Sources of uncertainty are shown in Table 1. Uncertainty may relate to limitations in information available for informing decisions, or uncertain prognosis to aid determination of the appropriate paradigm or stance to take. Uncertainty about the clinical impression may prompt further investigations or tolerance of an unclear diagnosis, and uncertainty over the person's safety in their home situation may complicate discharge decisions. Such uncertainties can persist despite careful history gathering, intense investigation, and broad evaluation of the person's situation: lack of clarity may need to be expected and accepted.

Table 1: Sources of uncertainty in geriatric emergency care decision-making

Source of uncertainty	**Considerations**
Informational uncertainty	How much do you trust the information that you are being given? Does it all add up?
Prognostic uncertainty	What is the appropriate paradigm? Curative/restorative intent vs palliative stance (consider the Clinical Frailty Scale)
Diagnostic uncertainty	How clear are we (and do we need to be) about the diagnosis? Do we need to gather more tests/information?
Situational uncertainty	How confident do we need to be that the patient will be safe in the proposed setting?

Integrating evidence-based and person-centred paradigms with shared decision-making

Resorting to a solely evidence-based approach might have dictated that this person's care included investigations, interventions, and admission. Meanwhile, being led solely by the person's preferences may have caused them to feel unfair onus to appraise information and make decisions without full appreciation of risks associated with different choices. Clearly, neither in isolation is ideal. Evidence cannot be applied without appreciating and incorporating the personal context, and optimal person-centred care requires application of the relevant evidence [34]. We advocate, then, for explicitly integrating evidence-based and person-centred approaches throughout geriatric emergency care interactions. Indeed, while people living with frailty ubiquitously have multiple problems and will most often benefit from such specific attention to shared decision-making, combining the evidence-based and person-centred approaches could be considered for all emergency care users where complex and timely decision-making cannot be reduced to a single guideline or pathway.

Communication will necessarily involve eliciting the person's circumstances, preferences and goals for healthcare, as well as their likely long-term prognosis [35]. The clinician may then consider whether available guidelines and protocols are useful, appropriate, or meaningful. This need not be a time-consuming conversation and may indeed spare the time spent unnecessarily on unwanted investigations and admissions. In situations in which evidence is incomplete or lacking, principles of medical ethics may provide a basis for planning and decision-making. Shared decision-making requires the clinician to present and explain the available options, including the risks and benefits of each, and to recommend those most suited to the person's situation and goals [36, 37]. Sufficient information is communicated, in a manner which the person can understand and appraise, so that they are empowered to make an informed decision.

A framework for decision-making in geriatric emergency care

Conscious deviation from established guidelines may be necessary to deliver appropriate, goal-oriented care for an individual. Such decisions require a deep knowledge of the evidence, its limitations, and how to apply it as well as an appreciation of the person's unique circumstances. Discussing potential diagnostic and treatment approaches with a person requires advanced communication skills and an appreciation of potential risks.

Even after developing the skills to integrate evidence and person-centred care, experts in geriatric emergency medicine will still face cases in which this approach will feel uncomfortable and challenging [38]. To assist clinicians in finding reassurance that options have been appropriately considered and selected for the individual and that foreseeable risks are appreciated and mitigated or accepted, we recommend a supporting framework (Table 2). This framework is not a checklist or procedure for making decisions but rather an aid to assess and confirm that the decision-making process is robust, moral, ethical, and defensible for a particular person in a time and situation. The decision framework offers and supports a holistic approach to managing frailty that not only includes knowledge of traditional evidence-based medicine, but through exercising CGA principles tailors the management of multiple pathologies. Instead of maximising the treatment of every condition based on standards of care, we optimise the treatment of the older person with respect to their functioning and based on their goals of care.

The framework incorporates principles of comprehensive geriatric assessment and shared decision-making [36, 39]. It embeds core ethical principles in considerations regarding the acute problem, surrounding circumstances, available options, and best interest decision-making for the incapacitated older person. The framework guides the clinician to consider the person's particular circumstances including residence and support, acuity of presentation, baseline function and cognition, and goals of care. Appreciation and consideration of all of these informs identification of feasible endpoints [28, 32]. The framework then considers the nature of the current problem and its probable trajectories so that realistic communication strategies may be identified. Next, the available options are appraised for their beneficence and non-maleficence so that alternatives may be reviewed, and appropriate choices selected. Finally, the clinician is guided to consider how to implement the plan through engagement with relevant parties. The framework thereby supports the professional in arriving at defensible rather than defensive decisions.

Table 2: Framework for clinical approach to assessment and management decisions in geriatric emergency medicine

Consideration	**Prompts**
Background setting	Care home (nursing, residential) or own home, and use of social care and/or family support
Physiological vital signs, e.g. National Early Warning Score (NEWS2)	Urgency: how life-threatening is the situation?
Clinical Frailty Scale	Level or degree of frailty at the person's baseline (two weeks ago)
Cognition and capacity	Ability to participate in shared decision-making. Assessment of baseline functional state and cognition
Goals of care	Care plan review, escalation threshold. Is this person's goal primarily to lengthen life, to optimize quality of life, or to improve comfort?
What is the problem: acute or decompensation of chronic?	Acute problems need to be managed with reference to the Clinical Frailty Scale two weeks ago and chances of reversibility in the degree of acute change in baseline brought on by the condition, and NOT based on reversibility of the condition (vast majority of conditions are reversible; moderate or severe frailty currently are not). Decompensation in chronic condition is also unlikely to be reversible
Can it be managed by the primary care clinician and community services?	Delirium and most of its precipitants can often be better managed in the community. Differentiate precipitating from existing predisposing factors, as the latter are unlikely to be amenable to acute intervention
What are the benefits and harms of community care?	For every intervention, consider beneficence versus non-maleficence
What are the benefits versus harms of hospitalisation?	Should the focus be longevity or quality of life? ("adding months to life or life to months?") Are you comforting yourself, the family, or the patient? Ensure care is aligned to the person's values and preferences
What options are compatible with this person's situation?	Beyond pathophysiology, what personal factors and values are contributing to the individual's preferred outcome? What interventions are appropriate in this context? Is there an option to do nothing?
Has it been discussed with patient and family?	This discussion can replace existing care plans. Existing plans do not need to be challenged, but instead can be reviewed and updated
Are staff and care workers happy with the plan?	Emergency and community professionals delivering the care need to be comfortable to carry out the plan. Include them in the decision-making
Follow up	Review by and for what. Safety netting – what to expect and what to do if condition changes.

	Information sharing between services including recommendations from current encounter

Using the decision-making framework

This framework was operationalised in Leicester, UK during Covid-19 pandemic restrictions in response to a requirement for physicians to remotely support prehospital decisions. The scheme provided paramedics with senior decision-making advice by telephone for all day-time consultations with older people, thereby enabling specialist supported frailty-attuned prehospital care. Hospital-based specialists in emergency and geriatric medicine used this framework to support and assure their decision-making and documentation. A reduction in conveyances was observed, suggesting that decisions were reached with consideration beyond existing protocols [40].

The framework can be readily applied to the person presented in the case vignette. This person has a head injury without concerning symptoms or signs, and the ED clinician may explain that a CT scan is unlikely to identify a clinically significant finding [41]. Their frailty is recognised, and the clinician further explains that, given these, intracranial bleeding on CT would most probably not prompt any neurosurgical intervention. The person's family members are also engaged, and it is agreed to avoid the investigation and instead observe for any new symptoms that may be related. The person's preference for discharge is balanced with the potential for low burden interventions to ensure that home continues to be a safe living environment. The clinician offers transfer to the same-day emergency care unit for continuation of CGA with an occupational therapist and pharmacist, and the patient and family accept this. This enables the loan of a transfer aid to reduce risk of falls and an agreement that a higher blood pressure target is acceptable. Finally, the person's anticipated long-term prognosis is sensitively discussed, given the severity of their frailty [26]. The individual agrees with the recommendation that cardiopulmonary resuscitation would not be effective and therefore that they should not receive it. While they do not currently have the capacity to formally delegate their ongoing decision-making to a legal proxy, their preferences are incorporated into the action plan presented in discharge letters copied to their primary care clinician and their home care company.

Facilitating such decision-making requires advanced experience in clinical evaluation, critical appraisal, and communication. There is an urgent need to develop competence and confidence among emergency care clinicians, owing to a growing population of older people living with frailty and increasing use of emergency care resources. As such, training in complex decision-making should not be restricted to subspecialty curricula and should be regarded as aspirational for all senior clinicians who see older people living with frailty, thus meriting inclusion in training programme learning outcomes. Measuring the effectiveness and outcomes of combined evidence-based and person-centred decision-making exceeds the constraints of current health service metrics and routinely recorded data, and therefore further research and implementation of person-reported measures are required. Senior clinicians facilitating complex decision-making should be supported through peer and specialist structures for continuing supervision and development.

Summary

Older people living with frailty will attend emergency care settings in increasing numbers and with multiple, often complex problems. Existing guidelines and protocols are often based on evidence which poorly represented older people living with frailty. Clinicians must consider personal preferences, however basing decisions solely on these may be inappropriate. The geriatric emergency care clinician must appraise the available evidence in the context of an individual's situation and values, integrating these paradigms to form a recommendation for truly person-centred care.

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