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Defining informal caregivers by their characteristics safety roles and training needs in Europe

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This research re-examines and broadens the conceptualization of patient safety in home care setting through experts' perspective, and recent changes in the profiles of informal caregivers across Europe and explores their role in the dynamics of the evolving care economy. It assesses their contributions to home care, their impact on care quality, and their essential role in ensuring care recipient safety. A qualitative study using the consensus conference technique involving sixty-one experts from diverse healthcare and academic institutions across multiple European countries who participated in a two-day conference. The discussions focused on highlighting the characteristics of informal caregivers and identifying critical challenges in home care, recognition and reducing human errors in home care. Eligibility for participation required membership in the BetterCare consortium and expertise in patient safety. This study emphasizes the critical role of informal caregivers in Europe, updates their definition, and examines their contribution to care recipient safety in the home care setting. This finding underscores the urgent need for policymakers and healthcare institutions to support caregivers by providing education and resources to prevent errors and enhance care quality, ultimately improving outcomes for care recipients.

Keywords Informal caregivers, Care recipient safety, Home care, Care economy, Risk management, Qualitative research

As of 1 January 2023, the European Union (EU) population is estimated at 448.8 million people, with over one-fifth (21.3%) aged 65 years or older. This marks an increase from previous years, for example, in 2013, the share of those aged 65 or over was around 18% demonstrating the demographic ageing within the EU[1], a trend of major significance in the coming decades, as it strains social and healthcare systems, increasing the demand for chronic disease management and long-term care and prompting governments to seek solutions that alleviate system pressure, such as expanding home care options[2]. To address these challenges, European countries are experiencing shifts in the caregiving landscape, with a growing reliance on immigrants as informal caregivers. In particular, the care of older people in Europe increasingly depends on migrant carers, both in formal institutions and informal care arrangements[3]. As the demand for both childcare and elder care has increased across all regions[4], many caregivers are now supporting multiple generations, including caring for older relatives as well as children. This includes parents providing care for children with chronic conditions, reflecting the expanding role of informal caregiving in pediatric settings[5].

Recent research on the new care economy highlights that caregiving, particularly informal caregiving (often by family members), has a longstanding tradition[6].

In light of these developments, researchers and policymakers have shown growing interest in the role of informal caregivers, particularly in the context of health policy development[7]. This trend aligns with a social shift toward aging in place, new policies to help dependent individuals remain at home, and a notable rise in the number of immigrants filling informal caregiver roles[8]. To manage escalating demands and healthcare costs, many Western governments are moving away from formal care systems, while not adequately supporting

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informal caregivers[9]. In the EU, estimates indicate that informal caregivers provide as much as 60% of all long-term care, with their numbers representing between 10% and 25% of the total population in Europe[10].

As home care becomes more complex, training informal caregivers and understanding the impact of caregiving on families with chronically ill members have emerged as pressing public health issues[11]. Informal caregiving has significant psychological and relational consequences for caregivers[6]. However, a lack of consensus on the definition of informal caregiving challenges accurate caregiver counts and the development of policies that ensure quality care at home[12,13]. In response to these challenges, healthcare systems must adapt to meet individual needs cost-effectively while maintaining quality and safety standards[14]. Home care, especially near the end of life, often depends on the availability of informal caregivers who provide substantial care[15].

Homecare settings differ significantly from institutional environments such as hospitals and require specialized approaches and training to ensure care recipient's safety[16]. Informal caregivers often lack training or experience in care recipients' safety and receive minimal supervision, which can increase the risks for both care receivers and informal caregivers[17]. These caregivers encounter diverse challenges, including managing unfamiliar medical equipment, family communication issues, and medication management without appropriate training. These factors, combined with home care complexities, contribute to common safety risks such as falls, burns, poisonings and infections[18,19]. Particularly concerning are medication errors that can cause severe harm, such as infections, respiratory depression, anaphylaxis, or cardiac arrhythmias[19,20]. In this context, it is essential to consider the ethical dimension of caregiving, particularly the concept of dignity of risk. Informal caregivers are frequently faced with complex decisions that require balancing the protection of vulnerable individuals with respect for their autonomy and personal preferences. For older adults nearing the end of life, the opportunity to engage in everyday routines even when these involve inherent risks can significantly reinforce their sense of dignity, identity, and self-agency. Recognizing the dignity of risk involves accepting that absolute safety is not always the most ethical or person-centered objective. Within home care environments, which are deeply personal and emotionally significant, supporting the care recipient's autonomy not only contributes to their overall well-being but also upholds the ethical foundation of caregiving relationships[21]. Nonetheless, these ethical considerations do not diminish the very real safety challenges present in home care. Studies underscore caregivers' critical role in maintaining safety at home care, due to the tendency of care recipients with multiple medical conditions to face safety issues[22]. While this paper focuses primarily on safety challenges in home care such as harm minimization and caregivers' skills, this is not to suggest that other dimensions of home care, such as person-centred care, or quality of life, are less important. Rather, safety was selected as a focal point of this study due to its direct implications for preventable harm and the current lack of training and support for informal caregivers in managing health-related risks at home. This emphasizes aligns with the broader shift in healthcare, as an increasing number of patients are receiving complex care in the domestic environment. Despite their essential role, informal caregivers often lack adequate preparation to ensure care quality comparable to institutional setting. This focus recognizes the critical influence of informal caregivers on the safety and health outcomes of dependent care receivers. Terms such as "human error"[23], "system failure", and "adverse event"[24], which are commonly used in healthcare, need adaptation for home care settings, especially when care is provided by informal caregivers[25]. Typical errors include commission errors, such as incorrect dosing, repeated doses, and improper medication use (e.g., using expired medications, mixing up medications or storing them improperly)[26]. Errors of omission may arise from incomplete information, misunderstanding instructions, or failure to follow professional recommendations[20]. Medication errors are particularly harmful types of human error in the home care context[27]. Reflecting on whether the terms we commonly use in healthcare institutions apply in the same way or need to be adapted to the context of home care provided by informal caregivers is a task that has not yet been fully addressed. This is because care recipient safety in home care has not been clearly recognized until now as a shared responsibility between formal and informal caregivers.

Given the high risk of medication errors and other causes of adverse events in home care settings[28], involving informal caregivers in safe care practices and medication administration is essential. Enhancing their qualifications through targeted training and education is crucial for reducing errors and improving care recipients' outcomes[29].

Education is essential to improve home care. Providing caregivers with the necessary training on both safety and quality of care can significantly reduce harm risks. Safe care ultimately relies on evidence-based clinical decisions to optimize health outcomes and minimize risks[30].

Informal caregivers play a central role in supporting deinstitutionalization policies and European initiatives aimed at enhancing home care[31]. care recipient safety in home care requires the same level of attention as in institutional settings, such as hospitals and nursing homes. This demand underscores the need for programs designed to foster care recipient safety in home and other non-institutional settings.

The promotion of deinstitutionalization policies should not imply a shift in responsibility or a reduction in the obligation to ensure that care recipients receive appropriate care. Regardless of whether care is provided at home or delivered by healthcare professionals, family members, or other informal caregivers, it must meet safety and quality standards to protect the well-being of care recipients[32]. A transition toward home-based care should be accompanied by structured support, adequate training, and clear guidelines to empower informal caregivers and prevent gaps in care recipient safety[33]. Ensuring continuity and equity in care, regardless of the setting, must remain a priority for healthcare systems and policymakers.

This study aimed to re-examine and broaden the conceptualization of patient safety in home care setting through experts' perspective, acknowledging it as an essential yet underexplored aspect of healthcare. The emphasis on safety is driven by recent changes in caregiver profiles and the rise of a new care economy across Europe[34], where informal caregivers, typically lacking formal training, are taking on increasingly complex health-related tasks. These shifts demand rethinking of what constitutes safety in home care, beyond institutional

standards, and call for new approaches that reflect the realities, risks, and responsibilities of informal caregiving today.

Results

Sixty-one experts from diverse countries and professional backgrounds participated in the study, with a gender distribution of 37.7% (23/61) male and 62.3% (38/61) female experts. Thirty-six participants attended in person, and twenty-five joined via the Zoom application. Table 1 provides a breakdown of participants by country, profession, and attendance type.

Profiles of informal caregivers

Table 2 presents five themes related to caregiver characteristics, including: Nonprofessional, Role, Personal Relationship with the Care Recipient, Paid or Unpaid Nature of Care, Lack of Formal Training and Caregiver Burden. Defined by their nonprofessional status and lack of formal healthcare training, informal caregivers provide essential support focused on daily tasks and emotional care for individuals with chronic illnesses,

Country	*N*	Profession	Online	In-person
Albania	1	Nurse	✓	
	1	Physician		✓
Austria	2	Physician	✓	✓
Bosnia and Herzegovina	2	Physician		✓
Croatia	3	Physician	✓	✓
Czech Republic	1	Sociologist	✓	
Denmark	1	Nurse		✓
Estonia	1	Nurse	✓	
	1	Physician		✓
Finland	2	Nurse		✓
Germany	1	Physician		✓
	1	Economist		✓
Greece	1	Social Work	✓	
	1	Physician	✓	
	2	Nurse	✓	✓
Ireland	1	Nurse		✓
Israel	2	Nurse		✓
Italy	1	Nurse		✓
	3	Physician	✓	✓
Japan	1	Healthcare management	✓	
Lithuania	1	Physician		✓
Malta	1	Physician		✓
North Macedonia	2	Physician		✓
Norway	1	Business economics and management		✓
Poland	1	Physician		✓
Portugal	1	Physician	✓	
Serbia	1	Physician		✓
	2	Pharmacist	✓	✓
Slovakia	1	Psychologist		✓
Slovenia	1	Physician	✓	
	1	Lawyer		✓
Spain	2	Pharmacist	✓	✓
	3	Physician	✓	✓
	1	Nurse		✓
Tunisia	1	Engineer	✓	
Turkey	5	Nurse	✓	
	3	Physician	✓	✓
	1	Physiotherapist	✓	
	1	Engineer	✓	
Ukraine	1	Dentist		✓
Total summary	61		25	36

Table 1. Participant breakdown by country, profession, and attendance type.

Theme	Description	Verbatim Quote
Nonprofessional role	Informal caregivers are not employed as healthcare professionals but provide essential care.	"Informal caregiver is an individual responsible for providing care to a person with chronic illnesses, disabilities, or long-term health conditions outside of a professional medical. This role often involves assisting with daily tasks, emotional support, and other nonformal care responsibilities"
Personal relationship	Informal caregivers typically have a personal relationship with the care recipient, such as being a family member, friend, or neighbor.	"Informal caregivers are usually family member, they can be a mother, father, brother or neighbor. a person who has a personal relationship with the caregiver".
Paid or unpaid	Informal caregivers are mostly unpaid, although some may receive compensation under specific circumstances.	"Informal caregivers can be paid or unpaid, in most cases the informal caregiver do not receive any payment on the care they provide"
Lack of formal education	Informal caregivers generally lack formal healthcare training or certification.	"Informal caregivers are not trained or educated as professional healthcare providers."
Burden	Informal caregiving can be physically and emotionally demanding, with extended hours and long-term responsibilities.	"They often share a personal bond with the person they care for, which demands working long hours for a significant period of time and may lead to significant burdens".

Table 2. What are the characteristics of informal caregivers in your country?

Themes	Description	Verbatim Quote
Preventing potential harm	The primary aim of home care is to prevent potential harm and to ensure the wellbeing of the care-receiver.	"Ensuring that all caregivers are knowledgeable how to administer daily living care and how to prevent any potential harm"
Knowledge and awareness	Prevention plays an important role in ensuring safe home care, making it essential to raise awareness of signs of a life-threatening situation and adverse events.	"Educating both the care receiver and caregiver about the behavior in situations that can occur in the home care environment"
Risk management	Identifying in the surrounding possible threating factors and gathering a risk management plan	"Implementing fall prevention measures to protect older care recipients"
Safety and risk assessments	Safe home care involves conducting safety and risk assessments and ensuring that caregivers promptly seek assistance when necessary	"Regularly assessing the home environment for potential hazards and having emergency contact numbers readily available."
Quality and dignity	Safe care at home means providing high-quality medical care according to standards, while respecting the personality and dignity of the person receiving the care, without neglecting the well-being of the caregiver.	"Balancing medical care with respect for the care recipients personal preferences and the caregiver's mental health."

Table 3. What constitutes safe care at home provided by an informal caregiver?

disabilities, or long-term conditions with whom they typically have personal relationships, such as family, friends, or neighbors. While some may be compensated, many perform care-giving tasks without financial rewards.

The experts also acknowledged informal caregivers' crucial role in home care and the considerable challenges they faced, reaching a consensus on an updated definition for informal caregivers, as suggested below:

> Individuals who provide care at home to care recipients with chronic illnesses, disabilities, or other long-term health or care needs, without having formal qualifications or academic training as healthcare professionals. Caregivers can be family members or close friends offering support within the context of a personal relationship, but they can also include individuals who are not personally related to care recipients. This kind of care can be either paid or unpaid.

Safe care at home

The experts agreed that prioritizing care recipients' safety in home settings is essential, emphasizing the importance of establishing a framework to ensure safer home environments.

Expert discussions on safety in home care revealed five key themes: Preventing Potential Harm, Knowledge and Awareness, Risk Management, Safety and Risk Assessments, and Quality and Dignity. As outlined in Table 3, the main objective of home care is to prevent harm to those receiving home care.

The findings underscore the importance of conducting regular safety and risk evaluations within the home environment to identify potential hazards and ensure that emergency contacts are easily accessible. Additionally, raising awareness among caregivers and recipients about the risks of adverse events is crucial. A safe environment protects both care recipients and caregivers, who may face physical and emotional strain due to the demands of caregiving.

Potential factors contributing to human error at home

Expert discussions identified eight key themes related to safety risks commonly encountered in home care: Medication Errors, Communication Errors, Equipment Errors, Monitoring Failures, Environmental Hazards, Failure to Adhere to Procedures, Infection Control, and Dietary Mistakes. These themes represent the most frequent and preventable incidents that can compromise care recipients' safety, as detailed in Table 4. Medication errors such as incorrect dosages and improper administration were mentioned as particularly critical, along with communication issues highlighting the importance of clear and effective communication between caregivers and recipients. Additional concerns included misuse of medical equipment, insufficient monitoring of vital signs, environmental risks like falls, and inadequate infection control practices, all pointing to the need for improved caregiver training and safety protocols in the home care setting.

Themes	Description	Verbatim quote
Medication errors	Wrong dosage: administering incorrect doses.	"A caregiver gives a care recipient double the prescribed dose of pain medication, leading to an overdose".
	Administration errors: mistakes on how and when medications are given.	"A caregiver gives the care-receiver all the medication at the morning."
	Improper use of medical supply: incorrect use or handling of medical supplies.	"Using a contaminated syringe, leading to an infection".
Communication errors	Miscommunication: Inadequate information exchange between caregivers and family members or the health provider who ordered the prescription.	"A caregiver misunderstands a doctor's instructions, resulting in a missed dose of medication".
Equipment errors	Improper use/incorrect use or maintenance of medical equipment	"Misusing a home oxygen concentrator, causing it to malfunction."
Monitoring failures	Neglecting vital signs: failing to regularly check and monitor vital signs.	"Not noticing a care recipient declining blood pressure, resulting in delayed treatment"
Environmental hazards	Falls and burns: risks from the home environment, such as tripping hazards or insufficient lighting.	"An elderly care recipient trips over a loose rug and fractures their hip"
Failure to adhere to procedures	Non-compliance: deviation from standardized care procedures.	"A caregiver skips steps in a wound care procedure, leading to an infection"
Infection control	Poor hygiene practices lead to infection.	"Not properly cleaning wounds, causing an infection"
Dietary mistakes	Unhealthy eating habits: poor diet choices affecting health conditions.	"A care recipient with diabetes consuming high-sugar foods, causing blood sugar spikes"

Table 4. What could be classified as a human error or a general error in home care?

Themes	Description	Verbatim Quote
Education and training	Raising awareness of errors fosters a "just culture," encouraging open discussion and learning.	"To implement a no-blame approach and to diffuse their culture, to learn from errors"
	Care literacy: use training and simulations to enhance caregiver's skills before discharge.	"We want to create a hospital-based simulated apartment where caregivers learn home care before discharge."
	Clear procedures: develop and provide home care guidelines.	"Provisional guidelines and standards for home care will be one point."
	Customization & flexibility: tailor training and support to caregiver needs, considering culture, language, and diversity.	"Try to assess their needs. First, there are people who are less organized, more organized, people who need more training and support".
Communication	Facilitating clear communication between caregivers and care recipients to address significant issues.	"To improve care recipient caregiver communication so they can communicate effectively about something that maybe is not right"
Support systems	Institutional support: creating a legal framework and offer courses, lectures, and resources to enhance caregiver skills.	"In an institutional level, to provide a robust legal framework to support caregivers and to give institutional support to make them independent in providing care"
	Caregiver support: prevent burnout and errors with emotional and psychological aid.	"The caregiver burden could be a reason for medical errors, because they are tired, they are frustrated, they feel alone, support can prevent burnout and reduce errors"
Technology	Use of technology: support caregivers with reminders, dosing tools, and electronic records to prevent errors.	"Technology is an important tool in order to prevent errors and medication mistakes, those technologies can support the caregivers by giving them reminders"
Reporting systems	Adverse events: promote reporting and learning to prevent future incidents, ensuring a no-fear system for caregivers.	"Supporting caregivers who report adverse events."

Table 5. How can informal caregivers prevent errors and adverse events at home?

Enhancing safety in home care

During the discussion on amplifying safety in home care, key strategies to prevent adverse events were proposed, as detailed in Table 5. Here we focus on five key themes identified as necessary for improving safety in home care: Education and Training, Communication, Support Systems, Technology, and Reporting Systems. These themes represent fundamental components for a safer and more supportive environment for both informal caregivers and care recipients.

Education and training are fundamental to enhancing caregiver awareness, fostering a "no-blame" culture. This culture encourages open discussions about mistakes, allowing caregivers to learn from them.

Care literacy and hands-on training, especially within simulated hospital environments, can be used to prepare care recipients for real-life situations. Providing clear procedures and guidelines also plays an important role, offering a structured approach to home care tasks. Effective communication between caregivers (formal and informal) and recipients, when possible, has emerged as crucial for identifying and addressing issues early. Strong support systems, including legal frameworks and resources, also help caregivers manage stress, thereby reducing the likelihood of errors. Technology further supports these safety initiatives by providing tools such as reminders, dosing aids, and electronic medical records, which can streamline care processes and alleviate caregiver burdens. Finally, establishing a reporting system allows caregivers to share and learn from their mistakes in a nonpunitive way, fostering continuous improvement in home care safety. A multifaceted approach that combines training, communication, support, and technology is instrumental in promoting safer home care for both caregivers and recipients.

Discussion

As care needs increasingly grow and society in Europe shifts toward home-based care, informal caregivers are likely to play a progressively significant role in healthcare delivery, which invites reflection on the profile and role of informal caregivers in the coming years.

Therefore, the safety of home care should be given the same level of importance as that of institutional health settings based on the results above, there is a clear need for adapted safety protocols that mitigate risks in home environments[35].

One of the key findings of this study is the lack of a European-wide definition for informal caregivers; instead, the current diversity of definitions across individual countries hinders the development of a cohesive and unified policy framework for informal caregiving in Europe. It also hinders efforts to provide adequate training, resources, and support. A standardized definition would facilitate the development of targeted training programs, safety protocols, and policy initiatives, supporting caregivers across different regions and enabling cross-national comparisons of care practices and outcomes[36]. This study addresses the concerns raised by numerous studies regarding the ambiguity surrounding the term "informal caregiver" and its implications for research and practice[37,38]. Although many studies have examined phenomena related to caregivers in home settings[39], the lack of an updated and widely accepted definition for informal caregivers persists. As the demand for home care services continues to grow in both complexity and scope, largely owing to an emerging care economy stemming from the aging global population[40,41], the need for a standardized definition becomes even more pressing. The experts made progress toward a consensus on a definition based on the characteristics of informal caregivers outlined during the discussions; this conceptualization unifies criteria across Europe and considers the changes in recent years.

The evolution of caregiver profiles over the past two decades, reflecting demographic and role changes, highlights the need for a supportive structure that acknowledges diverse backgrounds and experiences[42]. Furthermore, the current care recipient safety taxonomies in healthcare, which focus on facility-based care, require adaptation to address the complexities of home safety effectively[43]. Therefore, a new framework is essential for improving our understanding of safety challenges in home environments.

Research indicates that comprehensive education and training programs are essential for equipping caregivers with the skills and knowledge required for safe home care [44]. The experts emphasized the need for training adapted to Europe´s diverse cultural, social, and healthcare contexts, enhancing caregiver confidence and competence. Studies show that caregivers are facing growing responsibilities and increasing complexity in their roles, therefore, providing appropriate training should be considered an urgent need[44]. Essential skills for caregivers include medication management, recognition of safety hazards, and effective communication with healthcare professionals[45]. Support networks for caregivers involving platforms, organizations, and family members are also vital for building confidence and ensuring effective, appropriate care[46]. The home environment poses unique challenges for caregivers, as it is typically not designed for professional care delivery. Risk factors such as medication errors, falls, burns, and infections are more prevalent in home settings because of limited professional supervision. These safety concerns necessitate the implementation of tailored safety protocols and risk assessment tools specific to the home care context, which can help mitigate these risks[47]. Additionally, the frequency of medication and caregiving errors in home care settings is often attributed to caregivers lacking formal training, leading to increased risk for both care recipients and caregivers[45]. The experts expressed concern regarding the emotional and psychological burdens that informal caregivers face, which can significantly impact their ability to provide safe care. Caregiving is often physically demanding and emotionally taxing, leading to burnout, stress, and fatigue among caregivers[48]. These burdens contribute to increased levels of anxiety and depression among informal caregivers, impacting their overall well-being and caregiving efficacy[49]. Therefore, providing caregivers with access to psychological support, peer networks, and respite services is critical for sustaining the quality of care provided and enhancing caregiver well-being[50].

In addition, the potential benefits of integrating technology into caregiver training and support systems have been recognized. Digital platforms, mobile applications, and telemedicine can provide real-time guidance, educational resources, and access to support networks. Research shows that the use of technology in caregiving can help reduce caregiver burden while improving their ability to deliver effective care[51]. Moreover, these tools facilitate timely communication between caregivers and healthcare professionals, enabling earlier interventions and promoting better care coordination. A systematic review revealed that internet-based supportive interventions for caregivers of care recipients with dementia can significantly improve caregivers' well-being by reducing stress, anxiety, and depression while enhancing self-efficacy and confidence[49].

Research indicates that integrating informal caregivers into healthcare systems has a positive impact by significantly reducing the burden on formal healthcare services and improving overall health outcomes[36]. The development of comprehensive strategies to equip, support, and integrate informal caregivers into healthcare planning is crucial for ensuring sustainable, high-quality care[38,52].

To explore how best to achieve this integration, this study draws on diverse perspectives from international experts, who have contributed valuable insights from various health and care systems across Europe. The inclusion of an external expert from Japan, a country grappling with the challenges of an aging population, further enriched the discussion. This diversity enabled a more comprehensive understanding of informal caregiving, highlighting its characteristics and challenges across different cultural and systemic contexts. The consensus conference methodology facilitated in-depth collaborative discussions, enhancing the credibility and validity of the findings through collective expertise.

This approach also provides a strong foundation for future research and policy development related to informal caregiving, human errors, and adverse events in home care. However, as a qualitative study, the findings are inherently shaped by subjective interpretations and expert opinions, introducing potential bias. Additionally, the study's geographical representation was limited, as not all EU member states were included, which may

restrict the transferability of the findings into informal caregiving practices across the region's diverse healthcare contexts. Despite these limitations, this study provides a valuable basis for advancing the understanding of informal caregiving and informing future initiatives in this field.

This study lays the groundwork for significant advancements in recognizing, supporting, and advocating for the rights of informal caregivers by policymakers and stakeholders. By establishing a comprehensive framework that defines informal caregivers' role, characteristics, and training needs, this research offers a strong foundation for future EU-wide studies.

The harmonization of regulations across Europe to provide adequate support for informal caregivers at both the national and EU levels would benefit from a unified, evidence-based definition. Despite the advancements made in defining the "informal caregiver" at the Frankfurt conference, further research is suggested to better refine this concept.

Informal care plays a crucial role in long-term care systems[53] and is valued for its effectiveness in preventing institutionalization and promoting home-based care. Achieving high-quality informal caregiving and ensuring a caregiver's well-being requires a clear, shared definition of informal caregivers and the essential services available to support them. Without this foundation, informal care continues to pose significant financial and personal costs for both caregivers and the state.

Conclusion

These findings underscore the vital role of informal caregivers in Europe and the pressing need for a unified definition. The study advocates standardized guidelines and targeted training programs, calling on policymakers, healthcare institutions, and stakeholders to equip caregivers with the skills and resources necessary to prevent errors and improve care quality.

Methods and materials

Design

A qualitative study using the consensus conference technique, a structured method that assembles experts to discuss, debate, and reach an agreement on important key issues within their field, was conducted. The consensus process typically involves detailed discussions, evidence reviews, and commitments to reaching agreements that are acceptable to all participants[54]. This technique was chosen for its ability to facilitate effective interaction and the exchange of perspectives among experts. The Data collected through expert discussions underwent thematic analysis to identify key themes related to patient safety in home care[55].

Procedure

The two-day consensus conference, held in Frankfurt on February 22–23, 2024, brought together experts in a hybrid format. The event featured dynamic and structured discussions divided into two plenary sessions and working into three small groups where experts actively shared insights, exchanged ideas, and debated key issues, fostering a collaborative and inclusive environment.

On the first day, the facilitators, four researchers with extensive experience in healthcare quality, patient safety, and participatory research, introduced the objectives of the consensus conference topics and questions that had been shared with the experts in advance, presenting them once more to the plenary at the start of the consensus conference.

The facilitation team included senior academics and professionals affiliated with European universities, healthcare institutions, and the social care sector, all of whom held leadership roles within the BetterCare COST Action. Their collective expertise spanned public health, patient-centered care, occupational medicine, health systems improvement, and social care. While the facilitators were actively involved in the coordination of the project, they had no prior personal relationships with the participants.

The experts, working in small groups, identified the core issues and areas of agreement or disagreement. After open debates, each expert voted in favor of or against each key on every theme, providing their assessments and perspectives. The discussion points, ideas, conclusions, and areas of disagreement were subsequently shared in a plenary session to reach a consensus within the entire group. This process fostered debate, encouraged the exchange of ideas, and facilitated consensus on key concepts. Each group had two facilitators to facilitate discussions and focus on key aspects requiring participants' attention to achieve consensus.

On the second day, the facilitators reviewed and consolidated the key points from discussions held on the first day, incorporating input from each small group. These consolidated points were then presented to the plenary experts for further consideration and debate. Any unresolved issues were addressed through additional deliberation, and the iterative process ultimately led to a consensus on critical matters.

Participants

Experts were recruited through the BetterCare European consortium, which focuses on promoting patient safety in home care setting. A total of Eighty-six international experts, were invited via email to attend a hybrid meeting via the consensus technique. These experts were selected for their extensive experience in patient safety, risk management and quality of care. Many of these experts have carried out or are currently conducting patient safety studies and are involved in international projects.

The experts were divided into three small groups to facilitate focused discussions on effectively engaging informal caregivers in the safety of care recipients from diverse perspectives. Once a round of questions was completed, the experts had the option to rotate between the three groups if they wished, allowing for a richer exchange of ideas, opinions, and experiences. All the perspectives, experiences, and proposals were later

1. What are the characteristics of informal caregivers in your country?
Purpose: To capture diverse perspectives and develop a clear framework for understanding the defining characteristics, roles, and responsibilities of informal caregivers
Reasons: Informal caregiving involves a wide variety of tasks and responsibilities, which can differ significantly based on experts' experiences and cultural contexts
2. What constitutes safe care at home provided by an informal caregiver?
Purpose: To gather diverse perspectives on the defining aspects of safe care in a home environment. This question seeks to identify the fundamental elements that contribute to safety in home care
Reasons: Defining "safe care" helps address specific risks and challenges faced by informal caregivers in home settings
3. What could be classified as a human error or a general mistake in home care?
Purpose: To facilitate productive discourse, it is important that each expert in a discussion group delineates the concept of human error
Reason: Defining errors informs the development of effective interventions that improve home care safety and quality
4. How can informal caregivers prevent errors and adverse events at home?
Purpose: To explore strategies for preventing errors and adverse events and establish clear guidelines for safer home care
Reason: This conference seeks to suggest practical and actionable guidelines for informal caregivers through the identification of effective prevention strategies

Box 1. Elicitation questions.

presented during plenary sessions, ensuring the participation of all the meeting attendees, both in person and remote.

Invitees included members from various countries, including Albania, Austria, Bosnia and Herzegovina, Croatia, the Czech Republic, Denmark, Estonia, Finland, Germany, Greece, Ireland, Israel, Italy, Japan, Lithuania, Malta, North Macedonia, Norway, Poland, Portugal, Serbia, Slovakia, Slovenia, Spain, Tunisia, Turkey and Ukraine. Twenty-five invitees declined to participate.

Materials

To prepare for the consensus conference, the research team comprising four experienced members (NA, BK, PS, JM) with expertise in consensus building developed a set of open-ended elicitation questions [see Box 1]. The questions were designed to facilitate experts' discussion on the evolving roles of informal caregivers within the care economy and to support the broader objectives of the two-day meeting and to ensure that key aspects of informal caregiving and home care safety were meaningfully explored. Each small group was presented with a selection of these elicitation questions by the session facilitator to initiate open dialogue around many topics such as the characteristics of informal caregivers, the definition of safe home care, caregiving related errors, prevention of adverse events, stakeholders awareness, the legal framework, and the caregiver roles in mitigating risk. These broad topic areas, outlined in Supplementary Material 1, were intended to promote in-depth, experience-based discussion around key aspects of patient safety in home care. Experts were divided into groups, each focusing on a different set of topics to maximum coverage and diversity of perspectives. While discussions within the groups addressed specific prompts, plenary sessions provided space for sharing insights, debating key issues, and building consensus across all participant contributions. The group discussions included reflections on the changing profiles of informal caregivers, their influence on home care safety, and their broader impact on care quality. The full list of elicitation questions is presented in Box 1.

Data extraction

The data extraction process was meticulously designed to capture detailed and meaningful insights, guided by the study's elicitation questions. In each session comprehensive notes were taken and as supplements and to ensure every opinion was heard and noted, all sessions were audio-recorded for maximum precision and depth in documenting expert responses. These standard practices in qualitative research ensure transparency, enabling a thorough review and analysis of the collected information and establishing a strong foundation for reliable findings[56]. Following the initial data collection, the experts participated in group discussions to elaborate on their perspectives and exchange ideas with others. This iterative approach enriched the data, fostering diverse perspectives and deepening the understanding of critical issues. Iterative methods are widely recognized in consensus-building research for their ability to facilitate meaningful dialog and ensure inclusive engagement[57]. The research team collaboratively prepared the synthesis, identified points requiring clarification, and highlighted disagreements for the next session and plenary discussions. By identifying recurring patterns and trends, thematic analysis enables the research team to extract actionable insights and structure the data for further exploration and practical application[58].

Data analysis

Thematic analysis was used to identify patterns and ideas within the data, enabling the systematic coding and categorization of information into meaningful themes. This process ensured transparency and an organized approach to the analysis[55]. The research team conducted a preliminary review of the notes and early transcripts overnight to identify emerging ideas that could help guide and refine the discussions on day two of the conference. However, the full thematic analysis was undertaken after the conclusion of the two-day event, using the data from both group and plenary sessions. A framework matrix was applied to organize the findings, facilitating comparisons across expert responses and maintaining rigor in identifying recurring patterns[58]. On the second day and to strengthen the validity and credibility of the findings, experts' validation, also referred to as member checking, was conducted. The synthesized themes were presented by the facilitators to the experts for review and feedback, ensuring that they accurately represented the experts' perspectives and added rigor to the findings[59]. Collaboration with a multidisciplinary research team further enriched the analysis by incorporating diverse perspectives, increasing analytical depth, and minimizing potential bias. Multidisciplinary approaches are critical in qualitative research because they ensure that findings are robust and inclusive[56].

Consensus on key themes was achieved through an iterative process involving discussion, refinement, and validation. The research team re-examined the data, reassessed the themes, and refined the findings on the basis of expert feedback to ensure that they captured the depth and nuances of the data accurately. Only answers with recurring patterns and broad support were included in the final analysis, ensuring that the results were representative and actionable. This transparent, collaborative approach enhanced the credibility and reliability of the findings, producing insights deeply rooted in the data and reflective of experts' shared experiences[55].

Data availability

The datasets generated during and/or analyzed during the current study are available from the corresponding author upon reasonable request.

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References

1. Eurostat. Demography of Europe—2023 edition. Publications Office of the European Union, Luxembourg. (2023). https://ec.europa.eu/eurostat/web/interactive-publications/demography-2023
2. Butler, S. M. The challenging future of long-term care for older adults. *JAMA Health Forum* **3**, e222133. https://doi.org/10.1001/jamahealthforum.2022.2133 (2022).
3. Trummer, U. Migrant workers in European informal health care settings. *Eur. J. Public. Health* **33**(Suppl 2). https://doi.org/10.1093/eurpub/ckad160.074 (2023).
4. International Labor Organization. The launch of ILO-KataData survey on knowledge, perception and behavior on care work. International Labor Organization, Jakarta, Indonesia. (2023). https://www.ilo.org/meetings-and-events/launch-ilo-katadata-survey-knowledge-perception-and-behaviour-care-work.
5. Yang, J., Lin, L., Gao, Y., Wang, W. & Yuan, L. Interventions and strategies to improve social support for caregivers of children with chronic diseases: An umbrella review. *Front. Psychiatry*. **13**, 973012. https://doi.org/10.3389/fpsyt.2022.973012 (2022).
6. Shrestha, S., Arora, S., Hunter, A. & Debesay, J. Changing dynamics of caregiving: a meta-ethnography study of informal caregivers' experiences with older immigrant family members in Europe. *BMC Health Serv. Res.* **23**, 43. https://doi.org/10.1186/s12913-023-09023-4 (2023).
7. Kolade, O. R., Porat-Dahlerbruch, J., Makhmutov, R., van Achterberg, T. & Ellen, M. E. Strategies for engaging older adults and informal caregivers in health policy development: A scoping review. *Health Res. Policy Syst.* **22**, 26. https://doi.org/10.1186/s12961-024-01107-9 (2024).
8. Crimmins, E. M. & Ailshire, J. A. Aging and place: The importance of place in aging. *Public. Policy Aging Rep.* **31**, 1–2. https://doi.org/10.1093/ppar/praa043 (2021).
9. Lindt, N., van Berkel, J. & Mulder, B. C. Determinants of overburdening among informal carers: A systematic review. *BMC Geriatr.* **20**, 304. https://doi.org/10.1093/ppar/praa043 (2020).
10. Charalambous, A. Caregiving and caregivers: Concepts, caregiving models, and systems. in *Informal Caregivers: From Hidden Heroes To Integral Part of Care* (ed Charalambous, A.) 1–12 (Springer, Cham, 2023). https://doi.org/10.1007/978-3-031-16745-4_1.
11. Grossman, B. R. & Webb, C. E. Family support in late life: A review of the literature on aging, disability, and family caregiving. *J. Fam Soc. Work* **19**, 348–395. https://doi.org/10.1080/10522158.2016.1233924 (2016).
12. Tur-Sinai, A., Teti, A., Rommel, A., Hlebec, V. & Lamura, G. How many older informal caregivers are there in Europe? Comparison of estimates of their prevalence from three Europe? An surveys. *Int. J. Environ. Res. Public. Health* **17**, 9531. https://doi.org/10.3390/ijerph17249531 (2020).
13. Organization for Economic Co-operation and Development. Who cares? Attracting and retaining cares? workers for the elderly. *OECD Health Policy Stud. OECD Publishing* https://doi.org/10.1787/92c0ef68-en (2020).
14. Barreira, L. F., Paiva, A., Araújo, B. & Campos, M. J. Challenges to systems of long-term care: Mapping of the central concepts from an umbrella review. *Int. J. Environ. Res. Public. Health* **20**, 1698. https://doi.org/10.3390/ijerph20031698 (2023).
15. Mogan, C., Harrison Dening, K., Dowrick, C. & Lloyd-Williams, M. Health and social care services for people with dementia at home at the end of life: A qualitative study of bereaved informal caregivers' experiences. *Palliat. Med.* **36**, 976–985. https://doi.org/10.1177/02692163221092624 (2022).
16. Hughes, R. G. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses* (Agency for Healthcare Research and Quality, Rockville, MD, 2008).
17. Henriksen, K., Battles, J. B., Keyes, M. A. & Grady, M. L. *Advances in Patient Safety: New Directions and Alternative Approaches. Vol. 3: Performance and Tools* (Agency for Healthcare Research and Quality, Rockville, MD, 2008).
18. Banerjee, N. et al. Are home environment injuries more fatal in children and the elderly? *Injury* **53**, 1987–1993. https://doi.org/10.1016/j.injury.2022.03.050 (2022).
19. Mira, J. J. Medication errors in the older people population. *Expert Rev. Clin. Pharmacol.* **12**, 491–494. https://doi.org/10.1080/17512433.2019.1615442 (2019).
20. Shang, J., Wang, J., Adams, V. & Ma, C. Risk factors for infection in home health care: Analysis of national outcome and assessment information set data. *Res. Nurs. Health*. **43**, 373–386. https://doi.org/10.1002/nur.22053 (2020).
21. Staats, K., Grov, E. K., Husebø, B. S. & Tranvåg, O. Dignity of older home-dwelling women nearing end-of-life. *Informal Caregivers' Percept. Nurs. Ethics* **28**(3), 444–456. https://doi.org/10.1177/0969733020956372 (2021).
22. Cao, S. et al. What influences informal caregivers' risk perceptions and responses to home care safety of older adults with disabilities: A qualitative study. *Front. Public. Health* **10**, 901457. https://doi.org/10.3389/fpubh.2022.901457 (2022).
23. La Pietra, L., Calligaris, L., Molendini, L., Quattrin, R. & Brusaferro, S. Medical errors and clinical risk management: State of the art. *Acta Otorhinolaryngol. Ital.* **25**(6), 339–346 (2005).
24. World Health Organization. *World alliance for patient safety: WHO draft guidelines for adverse event reporting and learning systems: from information to action.*Report No.: WHO/EIP/SPO/QPS/05.3 (World Health Organization, Geneva, 2005). Available at: https://iris.who.int/handle/10665/69797.
25. Johnson, S. et al. No place like home: A systematic review of home care for older adults in Canada. *Can. J. Aging* **37**(4), 400–419. https://doi.org/10.1017/S0714980818000375 (2018).
26. MacDowell, P., Cabri, A., Davis, M. & US Department of Health and Human Services. Medication administration errors. *PSNet* (Agency for Healthcare Research and Quality, Rockville, MD, 2021). Available at: https://psnet.ahrq.gov/primer/medication-administration-errors.
27. World Health Organization. Medication errors: technical series on safer primary care. (World Health Organization, Geneva, 2016). Available at: https://apps.who.int/iris/handle/10665/252274.

28. World Health Organization. Medication errors (World Health Organization, Geneva, 2016). Available at: https://iris.who.int/handle/10665/252274.
29. Mollica, M. A. & Kent, E. E. Caregiver education and training: Learning preferences of informal caregivers of adult care recipients. *Clin. J. Oncol. Nurs.* **25**(4), 483–487. https://doi.org/10.1188/21.CJON.483-487 (2021).
30. World Health Organization. The conceptual framework for the international classification for patient safety: final technical report. (World Health Organization, Geneva, 2009). Available at: https://iris.who.int/bitstream/handle/10665/70882/WHO_IER_PSP_2010.2_eng.pdf?sequence=1.
31. Organization for Economic Co-operation and Development (OECD). Help wanted? Providing and paying for long-term care. OECD Publishing. (2011). Available at: https://www.oecd.org/en/publications/help-wanted_9789264097759-en.html.
32. Green, M. R. et al. Caregiver policies in the United States: a systematic review. *J. Public. Health Pol.* **46**, 22–37. https://doi.org/10.1057/s41271-024-00529-7 (2025).
33. Siew, A. L. et al. Mastering the art of caregiving: Instructional approaches to teaching healthcare-related procedural skills to informal caregivers-an integrative review. *J. Adv. Nurs.*. https://doi.org/10.1111/jan.16944 (2025).
34. Cohen, J. The values of the care economy comment on ensuring global health equity in a postpandemic economy. *Int. J. Health Policy Manag.* **12** https://doi.org/10.34172/ijhpm.2023.7762 (2023).
35. Dehnavi, M. et al. Investigating the effect of using a home safety training application by caregivers on accident risk management in elderly individuals. *Exp. Gerontol.* **199**, 112661. https://doi.org/10.1016/j.exger.2024.112661 (2025).
36. Wieczorek, E., Evers, S., Kocot, E., Sowada, C. & Pavlova, M. Assessing policy challenges and strategies supporting informal caregivers in the European union. *J. Aging Soc. Policy* **34**(1), 145–160. https://doi.org/10.1080/08959420.2021.1935144 (2021).
37. Roth, D. L., Fredman, L. & Haley, W. E. Informal caregiving and its impact on health: A reappraisal from population-based studies. *Gerontologist* **55**(2), 309–319. https://doi.org/10.1093/geront/gnu177 (2015).
38. Lacsa, J. E. M. Unveiling the unseen: Informal caregivers as pillars of healthcare systems. *J. Public. Health* **46**(3), e575–e576. https://doi.org/10.1093/pubmed/fdae028 (2024).
39. Bom, J., Bakx, P., Schut, F. & van Doorslaer, E. The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. *Gerontologist* **59**(5), e629–e642. https://doi.org/10.1093/geront/gny137 (2019).
40. World Health Organization. World report on aging and health. World Health Organization, Geneva. (2015). Available at: https://www.who.int/publications/i/item/9789241565042.
41. Sun, V. et al. The role of family caregivers in the care of older adults with cancer. *Semin Oncol. Nurs.* **37**(6), 151232. https://doi.org/10.1016/j.soncn.2021.151232 (2021).
42. Wolff, J. L. et al. Family caregivers of older adults, 1999–2015: Trends in characteristics, circumstances, and role-related appraisal. *Gerontologist* **58**(6), 1021–1032. https://doi.org/10.1093/geront/gnx093 (2018).
43. Zimbroff, R. M., Ornstein, K. A. & Sheehan, O. C. Home-based primary care: A systematic review of the literature, 2010–2020. *J. Am. Geriatr. Soc.* **69**(10), 2963–2972. https://doi.org/10.1111/jgs.17365 (2021).
44. Aksoydan, E. et al. Is training for informal caregivers and their older persons helpful? A systematic review. *Arch. Gerontol. Geriatr.* **83**, 66–74. https://doi.org/10.1016/j.archger.2019.02.006 (2019).
45. Mira, J. J. et al. Safe care and medication intake provided by caregivers at home: Reality care study protocol. *Healthc. (Basel)*. **11** (15), 2190. https://doi.org/10.3390/healthcare11152190 (2023).
46. Rodríguez-Madrid, M. N., del Río-Lozano, M., Fernández-Peña, R. & García-Calvente, M. Changes in caregiver personal support networks: gender differences and effects on health (CUIDAR-SE study). *Int. J. Environ. Res. Public. Health* **18**(21), 11723. https://doi.org/10.3390/ijerph182111723 (2021).
47. Shahrestanaki, S. K., Rafii, F., Ghezeljeh, N. & Ashghali Farahani, T. Patient safety in home health care: a grounded theory study. *BMC Health Serv. Res.* **23**, 467. https://doi.org/10.1186/s12913-023-09458-9 (2023).
48. Longacre, M. L., Valdmanis, V. G., Handorf, E. A. & Fang, C. Y. Work impact and emotional stress among informal caregivers for older adults. *J. Gerontol. B Psychol. Sci. Soc. Sci.* **72**(3), 522–531. https://doi.org/10.1093/geronb/gbw027 (2017).
49. Boots, L. M., de Vugt, M. E., van Knippenberg, R. J., Kempen, G. I. & Verhey, F. R. A systematic review of internet-based supportive interventions for caregivers of patients with dementia. *Int. J. Geriatr. Psychiatry*. **29** (4), 331–344. https://doi.org/10.1002/gps.4016 (2014).
50. Lopez-Hartmann, M., Wens, J., Verhoeven, V. & Remmen, R. The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: A systematic review. *Int. J. Integr. Care* **12**, e133. https://doi.org/10.5334/ijic.845 (2012).
51. Ruggiano, N., Brown, E., Li, J. & Scaccianoce, M. Rural dementia caregivers and technology: What is the evidence? *Res. Gerontol. Nurs.* **11**(4), 216–224. https://doi.org/10.3928/19404921-20180628-04 (2018).
52. Poco, L. C. & Malhotra, C. More competent informal caregivers reduce advanced cancer patients' unplanned healthcare use and costs. *Cancer Med.* **13** (11), e7366. https://doi.org/10.1002/cam4.7366 (2024).
53. Friedman, E. M. & Tong, P. K. A framework for integrating family caregivers into the health care team (RAND Corporation, Santa Monica, CA, 2020). Available at: https://www.rand.org/pubs/research_reports/RRA105-1.html.
54. Murphy, M. K. et al. Consensus development methods, and their use in clinical guideline development. *Health Technol. Assess.* **2**(3), i–88 (1998).
55. Nowell, L. S., Norris, J. M., White, D. E. & Moules, N. J. Thematic analysis: Striving to meet the trustworthiness criteria. *Int. J. Qual. Methods* **16**(1), 1–13. https://doi.org/10.1177/1609406917733847 (2017).
56. Miles, M. B., Huberman, A. M. & Saldaña, J. *Qualitative Data Analysis: A Methods Sourcebook* (SAGE Publications, Inc., 2014).
57. Gale, N. K., Heath, G., Cameron, E., Rashid, S. & Redwood, S. Using the framework method for the analysis of qualitative data in multidisciplinary health research. *BMC Med. Res. Methodol.* **13**, 117. https://doi.org/10.1186/1471-2288-13-117 (2013).
58. Braun, V. & Clarke, V. Reflecting on reflexive thematic analysis. *Qual. Res. Sport Exerc. Health* **11**(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806 (2019).
59. Birt, L., Scott, S., Cavers, D., Campbell, C. & Walter, F. Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qual. Health Res.* **26**(13), 1802–1811. https://doi.org/10.1177/1049732316654870 (2016).

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Author contributions

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Declarations

Competing interests
The authors declare no competing interests.

Ethical approval
All participants provided informed consent prior to the conference. Contributions were anonymized to ensure confidentiality. This study was approved by the Research Ethics Committee of Sant Joan d'Alacant University Hospital, Spain (24/028). All methods were carried out in accordance with relevant guidelines and regulations, including the Declaration of Helsinki.

Informed consent
All participants in this study provided informed consent.

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