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# Recommendations on teaching medical and nursing tasks to patients and informal caregivers: a Delphi study

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**Research Article**

**Keywords:**

**Posted Date:** November 1st, 2026

**DOI:** https://doi.org/10.21203/rs.3.rs-10947417/v1

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**Additional Declarations:** Competing interest reported. MB works as an advisor at Stichting KOMPAZ Nederland, a not-for-profit organization facilitating the implementation of self-management support.

# Abstract

**Introduction**. Patients and informal caregivers are increasingly being approached as equal members of the healthcare team and are performing medical and nursing tasks independently. However, patients and informal caregivers feel under-equipped to independently execute medical and nursing tasks, leaving them underprepared and overburdened. Therefore, this study aims to formulate consensus-based recommendations on the organization, training, and transfer of medical and nursing tasks to patients and informal caregivers.

**Methods**. A Delphi study was conducted among experts with backgrounds as policymakers, healthcare professionals, and researchers in health and/or social care, or as patients and informal caregivers. An initial set of 54 statements was drafted, categorized into four categories: (1) on strategy for health and social care organizations, (2) on the logistical prerequisites, (3) on eligibility criteria for patients and informal caregivers, and (4) on training and transferring medical and nursing tasks.

**Results**. 43 experts participated, of whom 36 were professionals from health or social care: policymakers (26%), providers (30%), researchers (28%). Additionally, recipients of health or social care participated: 7 in a primary professional role and 5 in a secondary role alongside their professional role (N=12, 28%). Together, they reached consensus on 45 recommendations across three rounds. Most recommendations (n=26) focused on the process of training and transferring of medical and nursing tasks to patients and informal caregivers.

**Conclusions**. The recommendations emphasize the need for a health care organization's strategic vision on collaborative practice that facilitates equitable relationships among professionals, patients, and informal caregivers. Healthcare professionals were considered responsible for providing reliable, accessible, and understandable information and for delivering face-to-face training sessions. Simultaneously, patients and informal caregivers were considered responsible for the safe performance of the medical or nursing task at hand within the scope of their training and for consulting a healthcare professional when in doubt. Experts warn for the instrumentalization of patients and informal caregivers, and the subsequent burden on them, amid rising health staff shortages, underscoring the need for a balanced partnership among all actors.


# Introduction

An increasing demand for care and workforce shortages stress our contemporary healthcare systems (World Health Organization, 2016). In 25 years, the share of people aged 60 and over will exceed that of adolescents aged 10–24 (Rudnicka et al., 2020). Although the global nurse workforce grew between 2018 and 2023, a projected shortage of 5.8 million nurses remains (World Health Organization, 2025). These developments require us to rethink and redesign how we deliver care.

Concomitantly, the role of patients and informal caregivers has changed tremendously over the years; they have become equal members of the healthcare team (Reinhard & Young, 2017), characterized by

the introduction of patient- and family-centered care principles as well as shared decision-making (Institute for Patient- and Family-Centred Care; Légaré et al., 2018). It is well established that patients' self-management and active family involvement have positive effects on the quality of care, clinical outcomes, and their quality of life and well-being whilst simultaneously reducing caregiver burden and readmissions (Bloemberg et al., 2025; Boger et al., 2015; Bosveld, Smits, et al., 2024; Determeijer et al., 2023; Dineen-Griffin et al., 2019; Levoy et al., 2022; Li et al., 2021; Musters, Kreca, van Dieren, van der Wal-Huisman, Romijn, Chaboyer, Nieveen van Dijkum, Eskes, Besselink, et al., 2024; Musters, Kreca, van Dieren, van der Wal-Huisman, Romijn, Chaboyer, Nieveen van Dijkum, Eskes, & Consortium, 2024; Northouse et al., 2010; Panagioti et al., 2014). With emerging staff shortages and growing demand for care, it is conceivable that patients and informal caregivers will be involved on an even greater scale.

The barriers to and facilitators of informal caregivers' participation in the care of hospitalized patients have been described previously (Bélanger et al., 2018; Determeijer et al., 2024; Foster et al., 2010). Determeijer et al. (2024) postulated that barriers to informal caregivers' involvement can be addressed through personal support, increased resources, and educational interventions, all grounded in the recognition of informal caregivers as integral and equal members of the healthcare team. In practice, however, informal caregivers feel under-equipped in figuring out and implementing the equipment necessary for medical and nursing tasks (Hanley & Collett, 2025), experience a lack of training (Gillespie et al., 2014; Ullgren et al., 2018), and face counterproductive rules and regulations or a lack thereof regarding their involvement (Determeijer et al., 2024), putting them at risk of adverse outcomes.

Facilitating patient- and family-centered care practices is especially important for training and transferring medical and nursing tasks. Traditionally, these medical and nursing tasks are considered within the realm of professionals, requiring specialized knowledge and judgment (Lee et al., 2019). Nevertheless, a large share, of up to 45 to 60%, of informal caregivers reported performing medical and nursing tasks, such as injections, wound care, or ostomy care (Davis & Wyman, 2020; Reinhard et al., 2012; Reinhard et al., 2019; Spillman et al., 2014). However, there are currently no general recommendations or guidelines on the training and transfer of these medical and nursing tasks by patients and caregivers. A lack of it can hinder implementation through risk-averse decisions and limit the benefits of patient and family involvement. More importantly, it leaves informal caregivers underprepared and overburdened (Keeton et al., 2020).

Therefore, this Delphi study aims to formulate consensus-based recommendations for the organization, teaching, and transfer of medical and nursing tasks to patients and informal caregivers across multiple organizational levels, specifically at the strategic level, the (organizing) professionals, and the patients and informal caregivers.

# Methods

We conducted a Delphi study following the recommendations for Conducting and Reporting of Delphi Studies (CREDES; Jünger et al. (2017)). The Delphi technique is a widely used consensus method in

health services research (Hasson et al., 2000) that employs multiple rounds of questionnaires to reach consensus on a specific topic. In each successive round, the research team provides feedback on the results of the previous rounds, with at least two consecutive rounds required to reach consensus (Waggoner et al., 2016). Before the start of the study, we opted for three rounds to ensure feasibility and compliance while still allowing consensus to develop.

# Setting, participants, and recruitment

The study was conducted in the Netherlands. We adopted a purposive sampling method to invite stakeholders across four groups: (1) people working *on* healthcare, such as policy advisors and project managers, (2) people working *in* healthcare, such as nurses or social workers, (3) people receiving care, meaning both patients and informal caregivers, and (4) researchers in the field of family involvement and/or self-management support. Together with Dutch national organizations, such as the national center of expertise for long-term care, *Vilans*, the association for informal caregivers, *MantelzorgNL* (EN: Informal Care NL), the national informal care research platform, *Lectorenplatform Informele Zorg* (EN: Platform of professors on informal care), a locally-operating organization for patient involvement in education, *Stichting Mens Achter de Patiënt* (EN: Patient as a Person Foundation), and the personal network of the authors, people with (experiential) expertise on the topics of teaching and transferring of health tasks to patients and informal caregivers were identified and invited to participate. Prior to the start of the study, all participants received an information letter outlining the study's background, objectives, and other necessary details. Informed consent was obtained before the start of the study as part of the first online survey.

## Statement preparation

The authors drafted a set of statements based on available scientific and grey literature on the topic of study, encompassing perspectives of patients, informal caregivers and professionals, in Dutch and English (Bosveld, Lelij, et al., 2024; Bosveld, Smits, et al., 2024; de Jong & Nanninga, 2024; Determeijer et al., 2024; Hanley & Collett, 2025; Harvath et al., 2016; Inspectie Gezondheidszorg en Jeugd, 2024; Kirkland-Kyhn et al., 2018; Lindauer et al., 2017; MantelzorgNL, 2024; McDonald et al., 2016; Powell-Cope et al., 2017; Powell-Cope et al., 2018; Reinhard et al., 2012; Reinhard et al., 2019; Sexson et al., 2016, 2017), as well as experience from healthcare practice with a self-management support initiative (Bosveld et al., 2023). The initially drafted 54 statements were categorized into four categories according to organizational levels to optimize their uptake in daily practice: statements (1) on strategy for health and social care organizations, (2) on the logistical prerequisites, (3) regarding eligibility criteria for patients and informal caregivers, and (4) on training and transfer of medical and nursing tasks. The statements were developed for this study and the initial statements can be found in Supplementary material 1. At the end of the first round, participants were given an open-text box to add topics or statements they considered missing.

## Data collection

The surveys were conducted using Qualtrics survey software (Qualtrics, 2025). After pilot-testing the questionnaire within the research team, the survey was distributed. In the first survey, demographic information, such as age, gender, and role or occupation, was collected. Each participant was asked to rate the statements on a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). Before the start of the study, consensus was defined as ≥ 80% of participants (dis)agreeing with a statement using the first or last two options on the seven-point Likert scale. If at least 80% of the scores were ≥ 6, the statement was accepted as a recommendation. If ≥ 80% of respondents scored ≤ 2 on the seven-point Likert scale, the statement was discarded. In each round, each statement was accompanied by an open-text box for comments and feedback (e.g., clarifications of scores and suggestions for textual changes).

In each consecutive round, the rephrased statements on which the experts had not reached consensus in previous rounds, as well as an overview of the refined recommendations on which consensus had been reached in the earlier rounds, were presented. For the former, both the original and rephrased statements were presented, along with a summary of feedback from previous round(s). In Round 3, background information was added only to statements that had not yet reached consensus. For statements that had reached prior consensus but could do with refinement, the experts were asked to (re)confirm their agreement with the refined recommendations using a ‘yes’ or ‘no’ question.

# Data analysis

Quantitative data analysis was performed using descriptive statistics in Qualtrics (Qualtrics, 2025). All panel members’ inputs were weighted equally, regardless of experience or primary field of work. After each round, all qualitative feedback on each statement was subjected to thematic analysis, yielding overarching themes that served as the basis for discussions within the broader research team. Qualitative comments from each round were sent to members of the research team alongside the aggregated themes. The discussion focused on whether and how to rephrase statements, and whether to add or combine them.

## External review

To validate final outputs and ensure the final list of recommendations is valid, unbiased, and methodologically sound before dissemination, an external review was conducted. The Dutch Health and Youth Care Inspectorate, the supervisory body for health and social care in the Netherlands within the Ministry of Health, Welfare and Sport, was invited to review the outcomes but declined, as the request fell outside the Inspectorate's scientific remit. An independent professor in the field of organization of (informal) care and support for older adults and people with disability reviewed the manuscript. Their reflections and suggestions informed an iterative process of critical review and constant comparison of emerging interpretations and were included in the final version of this paper, strengthening the credibility and confirmability of the final set of recommendations.

# Results

In our Delphi study, the surveys were conducted between September 2025 and November 2025. A total of 46 experts were invited to participate. The first round was completed by 43 experts (a 93% response rate). Two experts provided reasons for not completing Round 1: one indicated that the survey was too extensive due to chronic stroke-related symptoms, and another participant withdrew participation because they had changed employers. All 43 enrolled experts were invited to participate in consecutive rounds. The second round was completed by 39 experts (91%), and the third round by 33 experts (77%). An overview of the participants' backgrounds is presented in Table 1.

At the end of round 3, experts reached consensus on 45 recommendations. An overview of questionnaire content, participants, and outcomes, organized per round, is provided in Fig. 1. An overview of recommendations is provided in Table 2.

Table 1
Background information of participants (N = 43)

| **Characteristic** | **No.** |
|---|---|
| **Age in years, mean (SD)** | 51 (13) |
| **Gender (%)** | |
| *Female* | 38 (88) |
| *Male* | 4 (9) |
| *Other* | 1 (2) |
| **Primary role (%)** | |
| *Working* **on** *health or social care (policy makers, project leaders, managers, and/or employees of knowledge institutes)* | 11 (26) |
| *Working* **in** *health or social care (nurses, welfare professionals, case managers, informal care consultants)* | 13 (30) |
| *Recipient of health or social care (patients, informal caregivers, or patient or informal caregiver representatives)* | 7 (16) |
| *Researching health or social care (researchers or educators)* | 12 (28) |
| **Secondary role as a recipient of health or social care (%)** | 5 (12) |
| **Experience with performing medical or nursing tasks as a recipient of care (% of recipients of health or social care, primary and secondary roles)** | 6 (50) |

# Round 1

In the first round, 54 statements were presented. In total, 25 statements reached a consensus level of ≥ 80% in the first round. Three statements were accepted as recommendations, based on either 100% agreement or a high level of agreement, and no suggestions for refinement. Experts unanimously agreed on two of the three final eligibility criteria, stating that patients and/or informal caregivers must be physically and cognitively able to receive training in a medical or nursing task, as determined by a (trained) healthcare professional (no. 17 and no. 18, Table 2). Furthermore, experts almost unanimously agreed that during training sessions, healthcare professionals should be calm, reassuring, and nonjudgmental (no. 25, Table 2).

22 additional statements reached the predefined consensus threshold, but experts made valuable suggestions to refine or combine them. 20 statements were refined, including adaptations to eliminate ambiguity, unnecessary jargon, and overly specific wording, while preserving their initial intent. For example, one statement on providing patients and informal caregivers with the necessary resources required clarification, focusing primarily on specifying the resources deemed necessary. The other two accepted statements were combined with those that did not reach consensus to form more comprehensive, encompassing statements. These combined statements were presented in Round 2.

29 statements did not reach consensus in the first round. 19 of these statements were rephrased based on the experts' suggestions to increase precision or shift their scope. The other statements were combined to create more encompassing statements. In addition, experts suggested five new statements in the open-text box at the end of Round 1 (nos. 6, 33, 41, 45 and ID. C; these were added and presented in Round 2.

## Round 2

In Round 2, 49 statements were presented to the experts. All statements that reached consensus and were refined or combined in Round 1 were presented to the experts in Round 2, asking them whether they agreed to accept each statement as a recommendation with a 'yes' or 'no' response. All 22 statements were accepted as recommendations in Round 2. These included the recommendation for a vision for collaboration between formal and informal caregivers (no. 1, Table 2) and knowledge of the legal framework (no. 4, Table 2), and institutions are recommended to actively guide and support healthcare professionals toward a new reality in which a collaborative paradigm is increasingly dominant (no. 3, Table 2). Furthermore, experts recommend developing protocols across organizations to monitor the independent performance of medical and nursing tasks across the continuum of care (no. 7, Table 2). Assistive devices, such as those for administering eye drops and applying compression stockings, should be used in training to enable patients and informal caregivers to perform healthcare tasks independently (no. 10, Table 2). Additionally, organizations are recommended to ensure that patients and informal caregivers have the freedom to independently choose whether to perform medical and nursing tasks (no. 12, Table 2) and to provide them with the opportunity to obtain direct answers to urgent questions (no. 13, Table 2).

Moreover, healthcare professionals are recommended to assess the patient's and/or informal caregiver's eligibility, discuss personal boundaries, capacity, and expectations (no. 20 and no. 21, Table 2), and subsequently coordinate the timing of their face-to-face training (no. 24, Table 2) when the mental and physical condition permits (no. 22, Table 2). Experts recommend that informal caregivers be addressed individually and, when present, be involved in training (no. 23, Table 2). Each training session for a medical or nursing task should be tailored to the specific circumstances of the patient and/or informal caregiver (no. 26, Table 2), with attention to medical, cultural, and health literacy considerations (no. 27, Table 2). They should train on correct techniques, potential complications, warning signs of the medical or nursing task at hand, and necessary contact details (no. 29, Table 2). During the training sessions, healthcare professionals are recommended to allow the patient and/or informal caregiver to practice the task repeatedly under their supervision (no. 30, Table 2). Afterward, the healthcare professional is recommended to assess the patient's and/or informal caregiver's ability to perform the medical or nursing task, after which they jointly decide whether independent performance is feasible (no. 35 and no. 36, Table 2). Professionals are subsequently recommended to document the patient's competence and agreements in the patient's file (no. 37, Table 2).

When a medical or nursing task is performed incorrectly, healthcare professionals should intervene. Intervention consists of signaling, having an open conversation about it, adjusting the patient or informal caregiver, and, if necessary, organizing alternatives (no. 39, Table 2). Lastly, the patient and/or informal caregiver should know who to contact and how to do so, when necessary (no. 44, Table 2).

Of the 29 statements that did not reach consensus in Round 1 and were subsequently rephrased or combined, 23 statements were presented in Round 2. Of these 23 statements, two statements were accepted as recommendations based on a high level of agreement or lack of suggestions. This concerns the recommendation that healthcare professionals should use a didactic approach when training on medical and nursing tasks (no. 28, Table 2). At the same time, patients and/or informal caregivers should perform medical or nursing tasks safely, within the scope of their training, and consult a healthcare professional if necessary (no. 43, Table 2). Six other statements were accepted, but refined or combined for Round 3.

The 15 remaining statements did not reach consensus in Round 2 and were rephrased or combined for Round 3. Of the five recommendations suggested by experts in Round 1, one met the acceptance threshold and was refined for Round 3. The four other recommendations did not reach consensus and were rephrased or combined for Round 3.

# Round 3

In Round 3, 22 statements were presented. Experts reached consensus on all but three, yielding 45 recommendations in total. Experts recommended operationalizing the institutional vision on the collaboration between formal and informal caregivers within a clear framework (no. 2, Table 2). Additionally, organizations should facilitate the involvement of patients and informal caregivers by

providing them with information, resources, and support (no. 5, Table 2). This support should be organized together with social care organizations (no. 6, Table 2).

Experts also recommended implementing training sessions on medical and nursing tasks as early as possible in the care process (no. 8, Table 2). The assistive devices used during training should also be readily accessible for use at home (no. 11, Table 2). Furthermore, organizations are recommended to periodically evaluate their processes (no. 15, Table 2); provide additional training for healthcare professionals who train patients and/or informal caregivers (no. 16, Table 2); and allocate sufficient time for such training (no. 9, Table 2). Moreover, organizations are recommended to organize replacement care when patients and/or informal caregivers have to (temporarily) stop providing care (no. 14, Table 2). As part of the eligibility criteria, psychosocial circumstances were also added; they should permit the sustainable and qualitative performance of medical and nursing tasks (no. 19, Table 2).

Additionally, experts recommend taking into account the surroundings in which the medical or nursing task will be performed independently, as much as possible (no. 31, Table 2). Healthcare professionals should provide the option to record the task for personal use (no. 32, Table 2) as well as accessible, reliable, and understandable information, including text, illustrations, and videos on both the task at hand, as well as legal information (no. 33 and no. 34, Table 2). Healthcare professionals ought to evaluate the independent execution of tasks when the setting permits (no. 38, Table 2) and communicate agreements regarding the independent performance of medical or nursing tasks when transferring care to another healthcare professional or healthcare organization (no. 40, Table 2).

Experts reached consensus on recommendations for patients and informal caregivers, which state that patients, and, in the event of incapacity, a legal representative, should authorize the informal caregiver to perform medical or nursing tasks (no. 41, Table 2). Before performing a medical or nursing task, the patient and/or informal caregiver should conduct a self-evaluation to determine whether they can safely perform the task in their current situation (no. 42, Table 2). Finally, patients and informal caregivers should not independently train others to perform complex medical or nursing tasks (no. 45, Table 2).

Three statements did not reach consensus. One of the three statements that experts did not reach consensus on was: *'The organization ensures that the evolving roles of the patient, informal caregiver, and/or volunteer, as equal members of the future care team, are shaped in collaboration with them.'* (Statement A, Table 2; 78% of experts agreed). Experts indicated that '*equal members*' was already part of recommendation 2 and that '*the future care team*' was too ambiguous a term.

Another statement that experts did not reach consensus on was: '*After receiving information from the healthcare professional, the patient and/or informal caregiver must be willing to learn how to perform the medical or nursing task.*' (Statement B, Table 2; 79% of experts agreed). Experts considered the word 'must' too strong and questioned the extent to which patients and informal caregivers 'just' want to receive formal care, and should therefore not be part of the eligibility criteria. Furthermore, experts noted that 'freedom of choice' was already included in recommendation 13 (Table 2).

The final statement that experts did not reach consensus on was: '*The healthcare professional uses positive reinforcement to encourage and reinforce the independent performance of care activities by the patient and/or informal caregiver'* (Statement C, Table 2; 76% agreement). Experts deemed it too instrumental (*'Sounds as if someone is quickly grabbing a tool from their toolbox'*) and generally found it too specific for it to be a (general) recommendation.

Table 2
Final list of recommendations on the organization, training, and transfer of medical and nursing tasks to patients and informal caregivers

| **Strategic aspects for health and/or social care organizations** | | |
|---|---|---|
| **No.** | **Recommendation** | **% agrees** |
| 1 | The organization establishes a vision for collaboration among formal care providers and the patient, informal caregiver, and/or volunteer. | 95 |
| 2 | The organization translates its vision into clear, equitable agreements on education and the transfer of medical and nursing tasks to patients, informal caregivers, and/or volunteers. | 94 |
| 3 | The organization guides and supports its employees as they transition into roles involving patients, informal caregivers, and/or volunteers. | 100 |
| 4 | The organization is familiar with the legal framework governing the organization, education, and transfer of medical and nursing tasks to patients, informal caregivers, and/or volunteers. | 92 |
| 5 | The organization ensures that the patient, informal caregiver, and/or volunteer have sufficient information, resources, and support to provide care alongside formal care providers. | 97 |
| 6 | Where applicable, the healthcare organization collaborates with social care organizations to provide additional informal care support, including psychosocial counseling, day care for patients, respite care, and monitoring of medical and nursing tasks. | 94 |
| **Logistical prerequisites** | | |
| **No.** | **Recommendation** | **% agrees** |
| 7 | The organization establishes (cross-domain) protocols for teaching and monitoring medical and nursing tasks, particularly high-risk procedures, and reviews these agreements regularly. | 90 |
| 8 | The organization strives to teach medical and nursing tasks to patients and/or informal caregivers as early as possible in the care process. | 94 |
| 9 | The organization ensures healthcare professionals have sufficient time to teach medical and nursing tasks to patients and/or informal caregivers. | 96 |
| 10 | The organization ensures that the necessary assistive devices are available to educate the patient and/or informal caregiver on how to perform the medical and nursing task. | 92 |
| 11 | The organization ensures that the patient and/or informal caregiver has access to the assistive devices necessary to perform medical and nursing tasks independently. | 94 |
| 12 | The organization ensures that the patient and/or informal caregiver can contact the organization directly with urgent questions. | 95 |

| Strategic aspects for health and/or social care organizations | | |
|---|---|---|
| **No.** | **Recommendation** | **% agrees** |
| 13 | The organization guarantees the patient's and/or informal caregiver's individual freedom of choice in the independent performance of medical and nursing tasks. | 92 |
| 14 | The organization is responsible for organizing replacement care when patients and/or informal caregivers have to (temporarily) stop providing care. | 82 |
| 15 | The organization ensures the quality of education and the transfer of medical and nursing tasks by conducting periodic evaluations and paying equal attention to the experiences of patients, informal caregivers, and healthcare professionals. | 87 |
| 16 | The organization ensures that healthcare professionals have the additional knowledge and skills needed to educate patients and/or informal caregivers on medical and nursing tasks, and to transfer these tasks to them, including teaching principles and recognizing, discussing, and referring cases of informal caregiver burnout. | 91 |
| **Eligibility criteria for patients and informal caregivers** | | |
| **No.** | **Recommendation** | **% agrees** |
| 17 | The patient and/or informal caregiver must be physically able to learn and perform the medical or nursing task at hand. | 100 |
| 18 | The patient and/or informal caregiver must be cognitively able to learn and perform the medical or nursing task at hand. | 100 |
| 19 | The patient and/or informal caregiver and the care professional decide together whether the patient's and/or the informal caregiver's psychosocial situation permits the medical or nursing task at hand to be taught and transferred. | 91 |
| **Teaching and transfer of medical and nursing tasks** | | |
| **No.** | **Recommendation** | **% agrees** |
| 20 | The healthcare professional, individually if necessary, discusses with the patient and/or informal caregiver what they can and want to do regarding care, including personal boundaries, capacity, and expectations. | 92 |
| 21 | The healthcare professional regularly evaluates eligibility criteria for independent performance of medical and nursing tasks whilst educating the patient and/or informal caregiver on those tasks. | 90 |
| 22 | The healthcare professional, patient, and/or informal caregiver discuss whether their mental and physical condition permits training of a medical or nursing task. | 95 |
| 23 | Where applicable, the healthcare professional involves both the patient and the informal caregiver in educating the medical or nursing task. | 97 |
| 24 | The healthcare professional provides instruction on medical or nursing tasks during a face-to-face session, unless another format is more suitable for all parties involved. | 97 |

| Strategic aspects for health and/or social care organizations | | |
|---|---|---|
| **No.** | **Recommendation** | **% agrees** |
| 25 | The healthcare professional is calm, reassuring, and non-judgmental when educating about medical or nursing tasks. | 90 |
| 26 | The healthcare professional considers the specific circumstances of the patient and the informal caregiver and tailors instruction accordingly when teaching a medical or nursing task. | 100 |
| 27 | The healthcare professional considers the patient's and/or informal caregiver's cultural background, health literacy, language comprehension, and existing knowledge and skills when teaching a medical or nursing task. | 95 |
| 28 | The healthcare professional educates the patient and/or informal caregiver on medical and nursing tasks using didactic principles, such as activating prior knowledge, using a step-by-step approach, and incorporating reflection. | 91 |
| 29 | The healthcare professional informs the patient and/or informal caregiver, at a minimum, about the preparation, the correct technique for performing and completing the medical or nursing task, possible complications and warning signs, and the contact details for questions or problems. | 97 |
| 30 | The healthcare professional offers the patient and/or informal caregiver the opportunity to practice the medical or nursing task under their supervision repeatedly, tailored to the procedure's complexity and the individual's learning process. | 95 |
| 31 | The healthcare professional takes into account the environment in which the medical or nursing task will be performed as much as possible. | 97 |
| 32 | The healthcare professional offers the patient and/or informal caregiver the opportunity to film the medical or nursing task, after receiving instructions, for personal use, in line with the (digital) skills, preferences, and privacy regulations of all parties involved. | 85 |
| 33 | The healthcare professional provides the patient and/or informal caregiver with accessible, reliable, and understandable information, including text, illustrations, and videos, on how to perform the medical or nursing task. | 97 |
| 34 | The healthcare professional refers the patient and/or informal caregiver, before educating them, to sufficiently accessible, reliable, and understandable information about relevant legal frameworks and liability. | 94 |
| 35 | The healthcare professional, where applicable, regularly checks whether the patient and/or informal caregiver feels capable of performing the medical or nursing task independently. | 85 |
| 36 | The healthcare professional, where applicable, regularly assesses whether the patient and/or informal caregiver has the proper knowledge, skills, and attitude to perform the medical or nursing task independently. | 90 |
| 37 | The healthcare professional reports on the competence and agreements in the patient's file and keeps them up to date, where applicable. | 92 |
| 38 | The healthcare professional, the patient, and/or informal caregiver each evaluate the independent performance of the medical or nursing task separately and decide | 88 |

| Strategic aspects for health and/or social care organizations | | |
|---|---|---|
| **No.** | **Recommendation** | **% agrees** |
| | together whether they can and want to continue performing it safely and independently, taking into account the task's complexity and the setting. | |
| 39 | The healthcare professional intervenes when medical or nursing tasks are not performed correctly. The intervention consists of identifying, discussing, adjusting, organizing alternatives as necessary, and reporting. | 97 |
| 40 | The healthcare professional communicates which medical or nursing tasks the patient and/or informal caregiver can perform independently and provides relevant details when transferring care to another healthcare professional or healthcare organization. | 91 |
| 41 | The patient, or, in the event of incapacity, their legal representative, explicitly authorizes the informal caregiver to perform the medical or nursing task. | 97 |
| 42 | The patient and/or informal caregiver checks before performing a medical or nursing task whether they can (still) perform the task safely in the current situation and consults a healthcare professional if necessary. | 97 |
| 43 | The patient and/or informal caregiver performs the medical or nursing task safely, within the scope of training, and consults a healthcare professional if necessary. | 90 |
| 44 | The patient and/or informal caregiver know who to contact and how to do so, when necessary. | 100 |
| 45 | The patient and/or informal caregiver should not independently train others to perform complex medical or nursing tasks; instead, they should consult a healthcare professional. | 81 |
| **Statements that did not reach consensus** | | |
| **ID.** | **Statement** | **% agrees** |
| A. | The organization ensures that the evolving roles of the patient, informal caregiver, and/or volunteer, as equal members of the future care team, are shaped in collaboration with them. | 78 |
| B. | After receiving information from the healthcare professional, the patient and/or informal caregiver must be willing to learn how to perform the care procedure. | 79 |
| C. | The healthcare professional uses positive reinforcement to encourage and support the patient's and/or the informal caregiver's independent performance of the medical or nursing task. | 76 |

# Discussion

In this Delphi study, 43 experts, with backgrounds in policymaking, healthcare, patient care, informal caregiving, and research, reached consensus on 45 recommendations for the organization, training, and transfer of medical and nursing tasks to patients and informal caregivers. To date and to our knowledge, it is the only comprehensive set of general recommendations globally on this topic, complementing

evidence-informed *'Do's and Don'ts'* for caregiver instructional videos (Levine & Reinhard, 2016), and specific medical device recommendations by Hanley and Collett (2025). The recommendations following from our study are divided into four categories: (1) on strategy for health and social care organizations, (2) on the logistical prerequisites, (3) regarding eligibility criteria for patients and informal caregivers, and (4) on training and transfer of medical and nursing tasks.

Across the consensus exercise, several central themes sparked discussion. First of all, the tension between the rising demand for care and the (projected) workforce shortages surfaced several times in discussions on, for example, ensuring freedom of choice (no. 13 and statement B, Table 2) and organizing replacement care when the patient and/or informal caregiver are unable to perform medical and/or nursing tasks (no. 14, Table 2). On the one hand, experts indicated that workforce shortages may limit their ability to arrange alternative formal care when necessary, as outlined in Recommendation 14. On the other hand, experts countered that the shortage of health care professionals should never fall on patients and informal caregivers and thus warned against using them as a *quick fix* for staff shortages. Increased collaboration among healthcare professionals, patients, and informal caregivers could lead to the instrumentalization of informal caregivers, whilst informal caregiving is inherently relational. According to Wittenberg (2025), caregivers emphasize the importance of being seen and establishing fair, equal, collaborative relationships with professionals. Recognizing this relational nature and organizing resources accordingly seems paramount for preventing informal caregiver burnout.

Concurrently, the recommendations regarding the responsibilities of patients and informal caregivers (nos. 41–45, Table 2) were also discussed. Although not explicitly mentioned in the experts' comments, they were generally combined more and reached consensus on these recommendations in later rounds, which may indicate a (subconscious) reluctance towards an increased responsibility. This reluctance might stem from a fear of overburdening patients and informal caregivers, who are already engaged in multidimensional processes when self-managing (Schulman-Green et al., 2021; Schulman-Green et al., 2012). In earlier work, informal caregivers noted that carrying out health tasks generally takes little time but can nonetheless have serious implications for their daily lives (Bosveld, Smits, et al., 2024), further substantiating burden as a source of the perceived reluctance. At the same time, our findings address concerns regarding burden, as experts reached consensus on several recommendations aimed at preventing the overburdening of patients and informal caregivers, including collaboration with social care organizations, the provision of replacement care when needed, and discussions about personal boundaries, capacities, and expectations (nos. 6, 14, and 20, Table 2). Additionally, the Informal Caregiving Integrative Model (ICIM), rooted in the Model of Carer, Stress and Burden (Sörensen et al., 2006) and the Job Demands-Resources Model (Demerouti et al., 2001), could help organizations to better understand the determinants of informal caregiver burnout and cater accordingly (Gérain & Zech, 2019).

# The recommendations in a global context

Although the recommendations from this study were formulated for a Dutch context, we think they may be applicable in contexts beyond the Netherlands. Following the report by Reinhard et al. (2012), the Caregiver Advise, Record, Enable (CARE) Act was enacted in 2017 and is now law in over 40 states and territories in the United States of America (USA). The CARE Act requires professionals in the USA to provide caregivers with instructions for medical/nursing tasks as part of discharge planning. In the USA, the CARE Act helps informal caregivers as their loved ones are admitted to the hospital and as they transition home. However, a live (in-person) demonstration is not required under the CARE Act, and instruction may be delivered via video, primarily to prevent delays in discharge. The Home Alone Alliance has since produced a series of evidence-informed instructional videos, readily available to informal caregivers across the USA (AARP Public Policy Institute). Interestingly, in our study, videos are recommended as a source of information (no. 33, Table 2). Still, a face-to-face session is strongly advised – unless all parties agree on another, more suitable format for learning a medical or nursing task (no. 24, Table 2). Additionally, Shaffer et al. (2018) concluded that computers and mobile devices offer practical means of disseminating caregiving-related information, such as educational videos. Nevertheless, these digital approaches may perhaps be less accessible to older caregivers, caregivers with lower educational attainment, and those experiencing poorer health.

In a follow-up report by Reinhard et al. (2019) on the implementation of the CARE Act, two out of five informal caregivers reported not receiving instruction, and those who did reported needing more. This aligns with the findings of Lee et al. (2019), who raise concerns that CARE Act assistance is insufficiently thorough due to limited time spent reviewing the information together and insufficiently detailed explanations or demonstrations. Therefore, Reinhard et al. (2019) call for more substantial efforts to recognize informal caregivers and to provide them with training and support for complex care. The findings of this study might aid the implementation of supportive practices for caregivers in institutions that are establishing such practices, and at the same time serve as a quality or accreditation guide for institutions that wish to continuously develop their caregivers' supportive practices, whether under the CARE Act or not. Our findings explicitly highlight the need for sufficient time, face-to-face training, a comprehensive eligibility assessment, and recommend establishing safety nets for patients and informal caregivers. The categorization of our recommendations aligns with organizational dimensions of health and social care institutions, aiding the uptake in practice.

# Practical implications: the organizational dimension

The recommendations that follow from this study indicate that certain conditions need to be organized, but do not necessarily clarify how to do so. Hence, one could question how to optimally implement training to enable patients and informal caregivers to perform medical and nursing tasks independently. Dunn and Milheim (2017) state that patient instruction is often constrained by time pressure, which may lead to adverse outcomes, such as improper use of medical equipment at home or minimal adherence to discharge instructions. One of the recommendations from our study states that organizations should ensure *'healthcare professionals have sufficient time to teach medical and nursing tasks to patients and/or informal caregivers.'* (no. 9, Table 2). With the increasing complexity of patient care and the shortage of

nurses, implementing training within the current care process may strain scarce staff and result in suboptimal training for patients and informal caregivers. This holds especially true if health care professionals, in addition to their regular care tasks within current care processes, are asked to develop supporting training materials (no. 33 and 34, Table 2).

Furthermore, Keeton et al. (2020) call for approaches that extend into home and community settings to support individuals as they transition from inpatient settings, aligning with recommendation no. 7 to establish *'(transmural) protocols for teaching and monitoring medical and nursing tasks, particularly high-risk procedures'*. Furthermore, follow-up for informal caregivers should not solely focus on the *lege artis* performance of medical or nursing tasks. Additionally, social care professionals could assess and follow up on informal caregivers' perceived burden as they continue to perform medical and nursing tasks by providing psychosocial counseling, organizing day care for patients, or providing respite care for informal caregivers, as described in recommendation 6 (Table 2).

An initiative that has been successful in mitigating these challenges is the Academy for Selfcare (formerly known as the Academy for Patients and Informal Caregivers) of the Maastricht University Medical Centre + and the home care organization Envida (Bosveld, Smits, et al., 2024), constituting a comprehensive, supportive infrastructure across the continuum of care. Within this organizational division, so-called *training nurses* have dedicated time for supporting patients' and informal caregivers' self-management. Their dedicated time ensures the availability, consistency, quality, and continuity of training for patients and/or informal caregivers (Bosveld, Smits, et al., 2024). Furthermore, having dedicated *training nurses* embodies the organization's aim of person-centered care and increases its visibility both within and beyond the organization.

Appointing dedicated *training nurses* to support patients' and informal caregivers' self-management requires a strong strategic vision aligned with the increasingly collaborative paradigm of health and social care delivery, which often spans organizational boundaries. This is especially important because most healthcare delivery models focus primarily on individual patients, overlooking informal caregivers (Charalambous, 2023). In times of rising staff shortages, appointing dedicated *training nurses* could be challenging, both financially and in terms of availability of professionals.

# Strengths and limitations

Experts with a variety of backgrounds, including policy advisors, health care professionals, patients, informal caregivers, and researchers, participated in our study, with nearly equal representation among the 43 participants, that is, if one includes secondary roles. Having more than one role filling out the questionnaires warrants reflection. On the one hand, participants with dual roles can draw on both professional knowledge and lived experience, potentially leading to more balanced input. On the other hand, participants with double roles could be drawn between worlds or identities, forcing them to choose one perspective over the other. If only primary roles are included, the patient and informal caregiver perspectives are less represented than the professionals' perspective.

Recruitment took place in cooperation with national organizations, ensuring the invitation of nationally renowned experts across different stakeholder groups. This triangulation, including the external review, combined with a high predefined consensus criterion and the absence of response weighting, strengthens the trustworthiness of the outcomes. Although methodologically sound, the predefined consensus criterion may be arbitrary, as the three statements that did not reach consensus were only just short of it. Therefore, we have opted to present these statements so the reader can interpret these findings themselves. Furthermore, qualitative comments from each round were discussed with at least two members of the research team to reduce researcher bias.

All experts who participated in the study lived in the Netherlands. As the organization of care, and therefore the support of patients and informal caregivers, may differ across countries and regions, the transferability of our findings could be limited. This might be limited across health care systems in the Global North, and even more so in the Global South (Determeijer et al., 2023).

# Conclusions

This Delphi study yielded 45 recommendations on the organization, training, and transfer of medical and nursing tasks to patients and informal caregivers at the levels of the health care organization, the (organizing) professionals, and the patients and informal caregivers. Experts warn of the instrumentalization of patients and informal caregivers amid rising health staff shortages, underscoring the relational nature of informal caregiving and the need for a balanced partnership among all actors. The recommendations could serve as a guide for organizations and professionals to initiate and evaluate their efforts to collaborate with patients and informal caregivers in the independent performance of medical and nursing tasks. The current outcomes provide insight into *what* needs to be done, but not *how* to do so in increasingly demanding circumstances. Further research should focus on how the recommendations are translated to and ensured in practice.

# Declarations

### Ethical approval

The study was not subject to the Dutch Medical Research Involving Human Subjects Act (WMO). The *Faculty of Health, Medicine and Life Sciences research ethics committee* of *Maastricht University* granted permission for the study (FHML-REC/2024/092) and the study was conducted in accordance with relevant guidelines and regulations. All participants provided written informed consent to participate.

### Consent for publication

Not applicable.

### Data availability statement:

The data supporting this study's findings are available upon reasonable request.

**Competing interests:**

MB works as an advisor at Stichting KOMPAZ Nederland, a not-for-profit organization facilitating the implementation of self-management support.

**Funding:**

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

**Author contributions:**
MB – Conceptualization, data curation, formal analysis, investigation, methodology, project administration, software, visualization, writing – original draft

MvB – Conceptualization, methodology, formal analysis, supervision, writing – review and editing
MvZ – Conceptualization, Resources, supervision, writing – review and editing.
HM – Conceptualization, Resources, supervision, writing – review and editing.
WvM – Conceptualization, methodology, formal analysis, supervision, writing – review and editing

**Acknowledgements:**

We thank Vilans, MantelzorgNL, Stichting Mens Achter de Patiënt, and the Lectorenplatform Informele Zorg for consulting their networks to identify relevant experts as participants for this study. We extend our sincere gratitude to prof. dr. Hennie Boeije, professor of an endowed chair in Organization of (informal) care and support for older adults and people with disability at the Department of Organizational Sciences at the VU Amsterdam, and a senior researcher at Vilans, Utrecht, for her contributions to the external review of this study before publication.

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# Figures

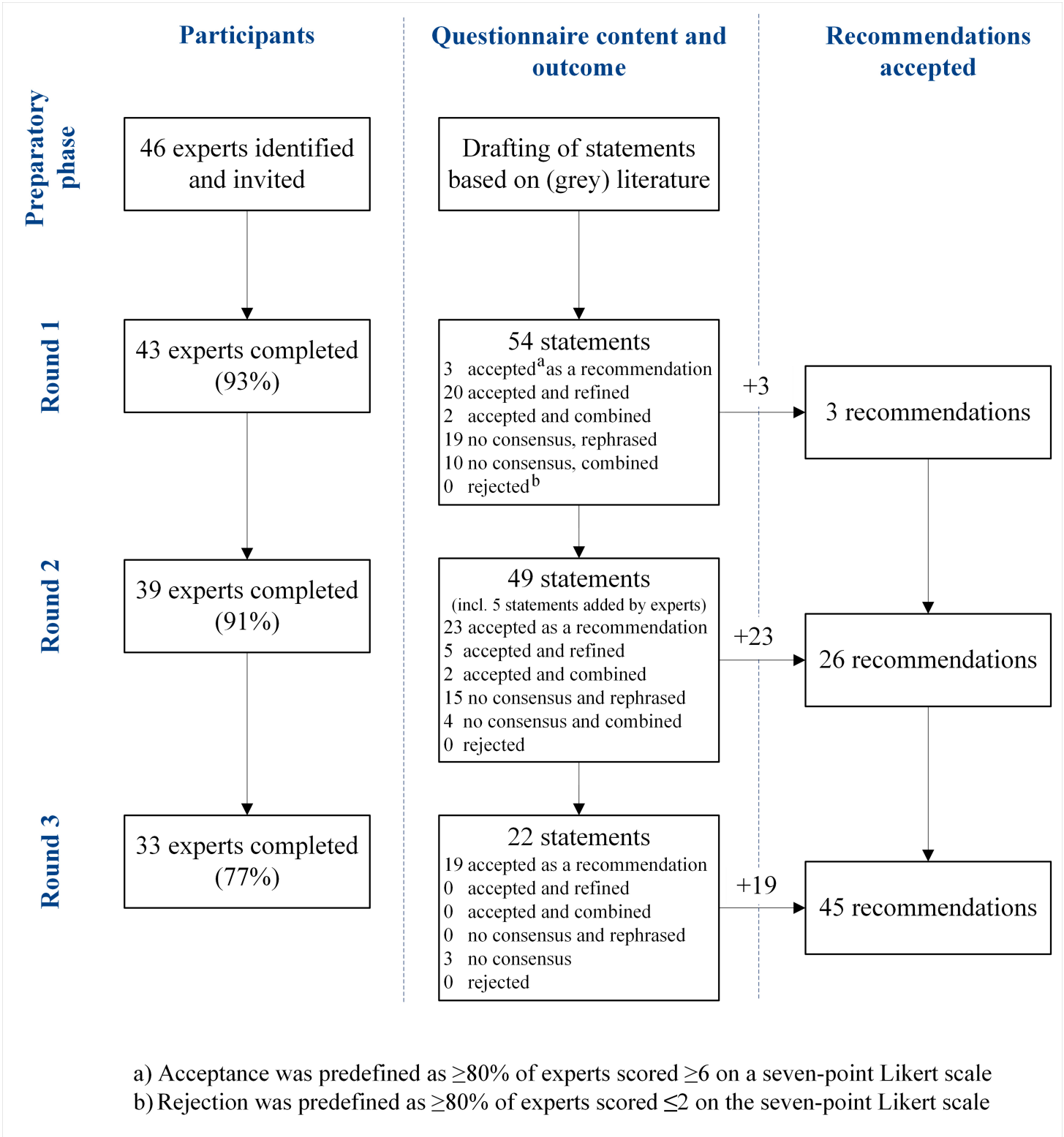



**Figure 1**

**An overview of participants, questionnaire content, outcomes, and recommendations**

# Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplQuestionnaireRound1AppropriateCollaborationTransferofCareActivitiesEN.docx