SACRED

EMPOWERING CARE, ENRICHING LIVES

Understanding Needs in Dementia and Multimorbidity

SACRED Project Findings from WP2 Needs Assessment

DOCUMENT INFORMATION

Project acronym:	**SACRED**
Work package number:	**WP_2**
Document title:	Needs assessment: Results
Document version:	V03-05/06/2025
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Co-funded by the European Union

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Education and Culture Executive Agency (EACEA). Neither the European Union nor EACEA can be held responsible for them.

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Background

Providing integrated care to older adults with dementia, disabilities, and multi-morbidity requires healthcare professionals to address several key needs. Care should be tailored to individual preferences, values, and needs, involving older adults and their families in decision-making processes to enhance satisfaction and adherence to care plans. Healthcare providers must be well-educated in geriatric care, geriatric psychiatry, dementia management, and the complexities of multiple chronic conditions, including understanding the progression of dementia, managing disabilities, basic psychotherapeutic skills, and coordinating treatments for multi-morbidity (Callahan et al., 2009, Bunn et al., 2017, Draper et al., 2018, Abdi et al., 2019, Frost et al., 2020, Verstraeten et al., 2022).

In addition, health care professionals often overestimate their adherence to evidence-based guidelines due to limited awareness of their own performance and the lack of use of an interdisciplinary method, which further underscores the need for continuous education and collaborative approaches in geriatric care (Bakker et al., 2023, Bakker, 2016).

*"**Integrated care for older adults** is envisioned by the consortium as a coordinated, person-centered system that brings together a wide range of disciplines—including primary, secondary, tertiary, specialized, paramedic, and social services—under a unified approach. This model emphasizes close collaboration and effective communication among professionals, who work together using a shared patient file to ensure continuity and consistency in care. The approach is designed to address the complex and interrelated physical, mental, and social needs of older individuals through personalized, comprehensive, and seamless care. It supports older adults in maintaining their independence and quality of life by delivering services in their homes or nearby, integrating care into their daily routines, and involving informal caregivers in the planning and delivery of care. By fostering strong partnerships between healthcare providers, social services, and community resources, integrated care aims to reduce unnecessary hospitalizations and institutionalizations, promote functional ability and dignity, and ensure that older adults receive the right support at the right time. Ultimately, it is a system of care that is not only efficient and responsive but also deeply respectful of the individual's preferences, rhythms, and life context."* (SACRED consortium)

Effective integrated care necessitates collaboration among a diverse team of professionals, amongst which primary care physicians, specialists, nurses, social workers and therapists, ensuring comprehensive care that addresses the multifaceted needs of older adults.

Professionals need to communicate effectively with patients, families and other team members to ensure that care plans are appropriate, understood and followed, which is particularly important when dealing with cognitive impairments and complex medical histories. Recognizing and addressing the needs of family informal caregivers is essential, as they play a critical role in the care continuum. Providing them with resources, education, systemic therapy and respite can improve overall care outcomes (Callahan et al., 2009, Bunn et al., 2017, Draper et al., 2018, Abdi et al., 2019, Frost et al., 2020, Verstraeten et al., 2022).

*"**Interdisciplinary or multidisciplinary care for older adults** is viewed by the consortium as a collaborative, integrated approach to healthcare, where professionals from diverse fields—such as medicine, nursing, psychology, social work, occupational and physical therapy, speech therapy, nutrition, and pharmacy—work together to address the complex and multifaceted needs of older individuals. This model emphasizes shared decision-making, mutual respect for each professional's expertise, and coordinated planning to ensure that care is holistic, person-centered, and responsive to the medical, emotional, cognitive, and social dimensions of aging. Unlike traditional models where professionals may work in parallel without coordination, interdisciplinary care is characterized by active communication, joint assessments, and unified goals aimed at improving the older adult's overall well-being, independence, and quality of life. Key elements include the use of shared digital records, designated care coordinators, and continuous evaluation, all of which support seamless collaboration and tailored care delivery.*
(SACRED consortium)

Introduction of this report

As populations across Europe continue to age, the proportion of older adults with dementia and multi-morbidities living independently in their own homes is steadily increasing. This demographic shift underscores the growing importance of supporting **ageing in place**, a concept that emphasizes enabling older individuals to remain in familiar environments for as long as possible.

Ageing in place not only aligns with the preferences of many older adults but also contributes to their sense of autonomy, dignity and well-being. However, this trend also places greater demands on home care services and informal caregivers—often family members—who play a vital role in maintaining daily routines, managing health conditions and providing emotional support. In addition to home care, the demand for **residential care** for older adults with dementia and multi-morbidities is also increasing.

As the number of older adults with dementia and multi-morbidity continues to grow, the need for **both home-based and residential care** is increasing. While many older adults prefer to age in place, supported by informal and formal caregivers, others require more intensive support provided in residential settings.

Ensuring that caregivers across these environments are adequately supported and equipped is essential for maintaining high-quality care. In this context, understanding the needs of older adults and those who care for them is critical to shaping responsive, integrated care systems that can adapt to the diverse realities of ageing in the community and in care facilities.

The purpose of this report is to provide a comprehensive analysis of the needs assessment conducted across various pilot sites for older adults with dementia, disabilities and multi-morbidity. The assessment aimed to understand the perspectives of professionals, students and older adults regarding the delivery of integrated care. Integrated care is defined as a holistic approach that addresses the medical, psychological, social and emotional needs of older adults, ensuring that care is coordinated and performed among various healthcare professionals and tailored to the individual's preferences and priorities.

*"**Holistic care for older adults** is understood by the consortium as a comprehensive, person-centered approach that addresses the full spectrum of an individual's needs—physical, psychological, social, and spiritual. Rather than focusing solely on medical conditions, this model emphasizes treating older adults as complex individuals with unique life experiences, values, and goals. It involves consciously paying attention to the whole person, integrating aspects such as mental well-being, meaningful relationships, social participation, and personal beliefs. While some view the term "holistic" as potentially vague or associated with alternative therapies, the shared vision centers on promoting dignity, autonomy, and quality of life. Holistic care is not only a method but also an attitude—one that respects the individuality of older adults and supports their well-being in a way that is both compassionate and contextually aware of their environment, lifestyle, and support systems."* (SACRED consortium)

This report is part of the **SACRED project** (Sharing And Caring for at-Risk Elderly with Dementia or Disabilities), which focuses on improving the quality of life for older adults through innovative and integrated care solutions. The SACRED project leverages digital tools to provide accessible, comprehensive education, preparing (future-)informal caregivers across Europe with best practices and evidence-based knowledge for immediate and long-term improvements in elderly care. This report presents findings from surveys, focus groups, and interviews conducted with professionals, students, and older adults within the SACRED project. Its aim is to inform the development of the e-learning program, rather than to generalize the results.

This project is co-funded by the **Erasmus+ program (EU)** and is coordinated by the City of Rotterdam (Netherlands). The SACRED consortium consists of 9 partners: AFEdemy, Academy on Age-Friendly Environments in Europe BV (Netherlands), Hogeschool Rotterdam University of Applied Sciences (Netherlands), Istituto per Servizi di Ricovero e Assistenza agli Anziani, I.S.R.A.A. (Italy), Odisee University of Applied Sciences (Belgium), Social Cooperative Altera Vita of Cyclades, Altera Vita (Greece), Universitat de Valencia (Spain), ANRIMAC (Tenerife, Spain) and ELISAN, Réseau Européen pour l'Inclusion et l'Action Sociale Locale (France).

The needs assessment utilized both **quantitative and qualitative methods**, including surveys, focus groups and individual interviews. These methods provided a comprehensive understanding of the needs and experiences of **professionals, students and older adults**. Quantitative data offered a broad overview of demographic information and background details, while qualitative data provided deeper insights into the perceptions, beliefs and experiences of the participants.

The report is structured to highlight the key findings and differences in the experiences and perceptions of integrated care among the **six pilot sites** in Rotterdam (Netherlands), Syros (Greece), Flanders (Belgium), Treviso (Italy), Tenerife (Spain) and Valencia (Spain). Each section delves into the specific challenges, strengths and areas for improvement identified by professionals, students and older adults in these pilot sites.

By examining the insights gathered from these diverse groups, the report aims to provide valuable recommendations for enhancing the delivery of integrated care. The ultimate goal is to improve the quality of life for older adults by ensuring that their care is comprehensive, personalized, effectively coordinated and performed by professionals. This report serves as a crucial step towards **developing an e-learning** that addresses the unique needs of each population, fostering a more supportive and responsive healthcare system for older adults.

Methodology of the needs assessment

In this needs assessment, both quantitative data (surveys) and qualitative data (focus groups and interviews) were collected to provide a comprehensive understanding of the needs of **professionals, students and older adults**.

The **surveys** revealed demographic information and background details on education, professional development, career and medical and psychiatric history for older adults. This quantitative data served as a basis for understanding the basic characteristics of the assessed population, ensuring a clear profile of the sample used in the needs assessment.

The questions for the **focus groups and interviews** were based on prior research and were refined through multiple iterations with consortium partners in work package 2 (WP2), the SACRED consortium and the advisory board of SACRED. This qualitative approach allowed for more profound answers regarding the perceptions, beliefs and experiences of the participants.

To ensure a comprehensive understanding of the needs of professionals, students, and older adults in the context of integrated care, a **mixed-methods approach** was adopted, combining both quantitative and qualitative data collection. Quantitative surveys provided essential demographic and background information, establishing a clear profile of the target populations and enabling structured comparisons across groups and pilot sites. Complementing this, qualitative data from focus groups and interviews offered deeper insights into participants' perceptions, experiences, and expectations, capturing the nuanced realities of care provision and reception.

This methodological integration was chosen to balance breadth and depth, allowing for both generalizable findings and rich, contextual understanding. The iterative development of qualitative instruments, grounded in prior research and refined through collaboration with consortium partners and advisory board members, further ensured the relevance and rigor of the data collected.

○ Population

Professionals, students and older adults were assessed separately to maintain homogeneity within each group.

Professionals, excluding volunteers and informal caregivers, with at least three years of experience in caring for older adults with dementia or multi-

morbidity/disabilities, including retired professionals, were included. Both junior and senior professionals were represented to ensure a more comprehensive outcome. Professionals were recruited from acute and residential care settings for older populations as well as from home care and semi-residential care settings such as day care centers.

Students in programs related to physical and mental health, social work, or welfare, with practical experience in caring for older adults with dementia or multi-morbidity/disabilities, were also included. This subset comprised both junior and senior students to capture a range of experiences. Students were recruited from the Universities (of Applied Sciences) included in this consortium, as well as from partner organisations of these universities (of Applied Sciences) that offer health and welfare educational programs.

Older adults aged 60+ years, or those with young onset dementia (<65 years), with a formal diagnosis of mild cognitive impairment or young onset dementia were assessed. Informal caregivers could join the older adults if needed to facilitate the conversation. Additionally, older adults with multi-morbidity/disabilities, such as ischemic heart disease, stroke, diabetes, chronic obstructive pulmonary disease and other chronic conditions, were included. Informal caregivers of older adults with severe cognitive impairment who could no longer participate directly were also part of the assessment. Both residential care and community-dwelling older adults were represented to ensure a mix of those with young onset dementia, multi-morbidity/disabilities and informal caregivers.

○ Data Collection and Analysis

The surveys collected demographic variables and background information from professionals, students and older adults. Focus groups and individual interviews provided deeper insights into the participants' perceptions, beliefs and experiences. The integration of both methods was necessary to ascertain a profound needs assessment.

Professionals were surveyed on general demographics, professional information and their familiarity with integrated care, shared decision-making, interdisciplinary collaboration and psychiatric symptoms and classifications in older adults. Focus group questions for professionals included their understanding of integrated care, challenges faced in providing care, addressing emotional and behavioral challenges and involving informal caregivers.

Students were surveyed on general demographics, their educational programs and their familiarity with integrated care, shared decision-making, interdisciplinary collaboration and psychiatric symptoms and classifications in older adults. Focus group questions for students included their understanding of integrated care, challenges faced in integrating theory into practice, addressing emotional and behavioral challenges and involving informal caregivers.

Older adults were surveyed on general demographics, health information, living situations and their satisfaction with current care. Focus group questions for older adults included their opinions on integrated care, challenges faced in their health and emotional well-being, resources and support needed for independence and their experiences with healthcare providers.

○ How to read the results?

First, the background information of professionals, students, and older adults across the six pilot sites is reported, followed by an overview of the familiarity with integrated care among professionals and students, and the current care situation of the assessed older adults.

Second, the results from the focus groups and interviews from each of the six pilot sites are integrated and reported using thematic analysis.

Third, the preferences for learning and suggestions for the e-learning are extracted from the summary of focus groups and interviews.

Finally, a full summary of the focus groups with professionals and students, as well as the summary of the interviews with older adults across the six pilot sites, can be consulted in the attachments of this report.

Detailed results per group

Out of the initially expected 30 professionals (5 per site), 30 students, and 30 older adults, a total of 57 professionals, 34 students, and 31 older adults from various pilot sites—Rotterdam (Netherlands), Syros (Greece), Flanders (Belgium), Treviso (Italy), Tenerife (Spain), and Valencia (Spain)—were ultimately included in this needs assessment.

○ Professionals

Background information

Variable	Answers	N (Total= 57)
Pilot site	City of Rotterdam (Netherlands)	7
	Syros (Greece)	5
	Flanders (Belgium)	10
	Treviso (Italy)	10
	Tenerife (Spain)	20
	Valencia (Spain)	5
Age	Average	42,3 years
	Minimum-maximum range	23-66 years
Sex	Male	6
	Female	51
Educational level	Primary Education (ISCED 1)	0
	Lower Secondary Education (ISCED 2)	2
	Upper Secondary Education (ISCED 3)	7
	Post-secondary non-Tertiary Education (ISCED 4)	48
Language proficiency	Very poor	0
	Poor	0
	Average	1
	Good	12
	Very good	44
Profession	Psychologist-Psychotherapist	16
	Nurse	12
	Speech therapist	7
	Social worker-counsellor	6
	Nurse assistant/care assistant	4
	Care/service coordinator dementia	3
	Coach	3
	Head Nurse	1
	Occupational therapist	1
	Ortho pedagogue	1
	Physical therapist	1
	Physician (older adults)	1
	Reference person dementia	1
Years of experience	≤5 years	15

	6-10 year 11-15 years >15 years	17 5 20

Table 1: Demographics professionals

The assessment included **57 professionals** from various pilot sites: Rotterdam (Netherlands), Syros (Greece), Flanders (Belgium), Treviso (Italy), Tenerife (Spain) and Valencia (Spain). The average age of the professionals was 42,3 years, with a range from 23 to 66 years. The majority were female (89%). Most professionals had completed post-secondary non-tertiary education (ISCED 4). Language proficiency was generally high, with 44 professionals rating their proficiency as very good. The professionals held various roles, including care/service coordinators for dementia, nurses, occupational therapists and psychologists, with a significant number having over 15 years of experience. (See table 1)

Familiarity with integrated care

Variable	Answers	N
Effectiveness of training/education in handling emotional and psychosocial challenges in older adults with dementia or disabilities	Strongly disagree Not likely to agree Neither agree nor disagree Agree Strongly agree	1 7 15 28 6
Familiarity with integrated care for older adults	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	0 0 3 32 22
Familiarity with shared decision making with older adults	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	0 3 2 35 17
Familiarity with interdisciplinary collaboration in the care for older adults	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	1 0 4 22 30
Familiarity with psychiatric symptoms, classifications in older adults and basic psychotherapeutic treatment methods	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	1 2 13 22 19

Table 2: Familiarity with integrated care professionals

The effectiveness of training and education in **handling emotional and psychosocial challenges** in older adults with dementia or comorbidities/disabilities is also noteworthy. In total, 28 professionals (49%) agree that their training has been effective, while 15 professionals neither agree nor disagree (26%) and 7 professionals are not likely to agree (12%). This suggests that while many professionals feel adequately prepared, there is still room for improvement in training programs to better equip them with the necessary skills to handle these challenges.

The assessed professionals generally have a **high level of familiarity with integrated care for older adults**. Out of 57 respondents, 32 professionals reported being somewhat familiar (56%) and 22 very familiar with integrated care (39%). This indicates a strong familiarity of the holistic, multidisciplinary approach required to address the medical, psychological, social and spiritual needs of older adults. Similarly, familiarity with **shared decision-making** is high, with 35 professionals somewhat familiar (61%) and 17 very familiar (30%).

Interdisciplinary collaboration is another area where professionals show high familiarity, with 22 somewhat familiar (39%) and 30 very familiar (53%). This highlights the recognition of the need for effective teamwork among diverse healthcare providers to ensure comprehensive care. However, there are some gaps in familiarity with psychiatric symptoms, classifications and basic psychotherapeutic treatment methods. While 22 professionals are somewhat familiar (39%) and 19 very familiar (33%), 13 are neither familiar nor unfamiliar (23%), indicating a need for further training in this area. (See table 2 and figure 1)

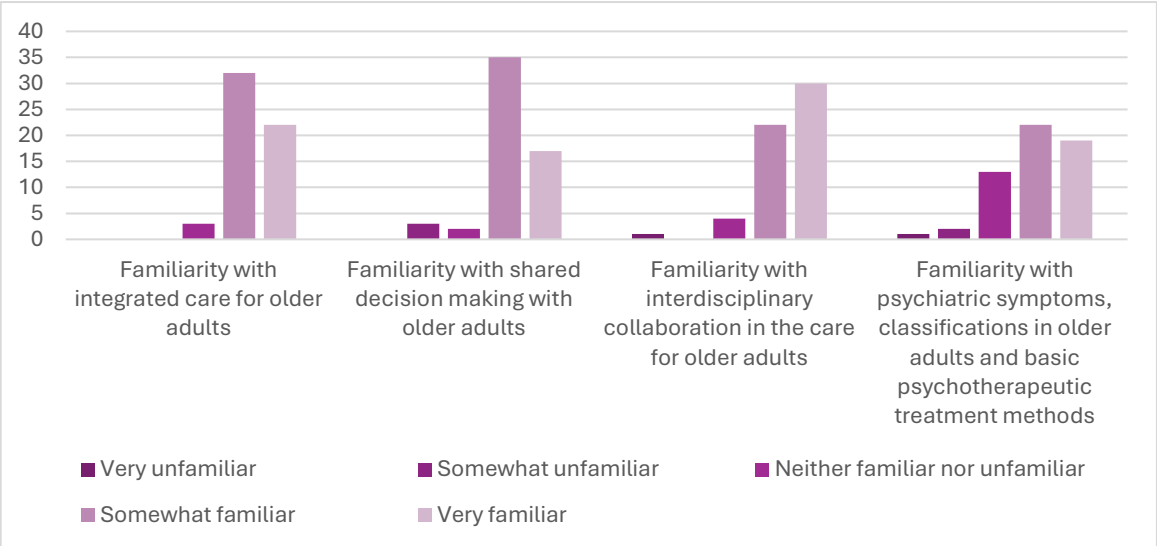

Figure 1: Familiarity of professionals with integrated care, shared decision making, interdisciplinary collaboration and psychiatric symptoms and treatment options

○ Students

Background information

Variable	Answers	N (Total=34)
Pilot site	City of Rotterdam (Netherlands) Syros (Greece) Flanders (Belgium) Treviso (Italy) Tenerife (Spain) Valencia (Spain)	5 5 6 6 7 5
Age	Average Minimum-maximum range	25,5 years 20-47 years
Sex	Male Female	10 24
Educational level	Primary Education (ISCED 1) Lower Secondary Education (ISCED 2) Upper Secondary Education (ISCED 3) Post-secondary non-Tertiary Education (ISCED 4)	0 0 15 19
Language proficiency	Very poor Poor Average Good Very good	0 0 0 9 25
Education	Nursing (bachelor) Occupational therapy (bachelor) Psychology Medicine (master) Physical therapy Social work Neuropsychology (master) Neuroscience (master) Nursing (higher vocational education) Occupational therapy (master) Psychosocial gerontology Special education Speech therapist	7 6 6 3 3 2 1 1 1 1 1 1 1
Study year	First stage or first year Intermediate stage (in between first year and last year) Final stage or last year	6 9 19

Table 3: Demographics students

The assessment included **34 students** from the same pilot sites (i.e., City of Rotterdam (Netherlands), Syros (Greece), Flanders (Belgium), Treviso (Italy), Tenerife (Spain) and Valencia (Spain)). The average age of the students was 25,5 years, ranging from 20 to 47 years. The majority were female (71%). Most students had completed upper secondary education (ISCED 3) or post-secondary non-tertiary education (ISCED 4). The students were enrolled in various educational programs, amongst which predominantly nursing, occupational therapy, psychology, medicine and physical therapy. The majority of these students were in the final stage of their studies. Language proficiency was high, with 25 students rating their proficiency as very good. (See table 3)

Familiarity with integrated care

Variable	Answers	N
Effectiveness of training/education in handling emotional and psychosocial challenges in older adults with dementia or disabilities	Strongly disagree Not likely to agree Neither agree nor disagree Agree Strongly agree	0 7 11 14 2
Familiarity with integrated care for older adults	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	0 4 11 15 4
Familiarity with shared decision making with older adults	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	1 4 9 16 4
Familiarity with interdisciplinary collaboration in the care for older adults	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	0 4 8 16 6
Familiarity with psychiatric symptoms, classifications in older adults and basic psychotherapeutic treatment methods	Very unfamiliar Somewhat unfamiliar Neither familiar nor unfamiliar Somewhat familiar Very familiar	0 8 11 12 3

Table 4: Familiarity with integrated care students

The effectiveness of training and education in **handling emotional and psychosocial challenges** in older adults with dementia or disabilities is another area of concern. While 14 students agree that their training has been effective (41%), 11 neither agree nor disagree (32%) and 7 are not likely to agree (21%). This suggests that there is significant room for improvement in training programs to better equip students with the necessary skills to handle these challenges.

The 34 assessed students have varying levels of **familiarity with integrated care for older adults**. Out of 34 respondents, 15 students are somewhat familiar (44%) and 4 very familiar (12%), while 11 are neither familiar nor unfamiliar (32%). This indicates that while some students have a good understanding of integrated care, there is a need for more comprehensive education on this topic.

Familiarity with **shared decision-making** is also mixed, with 16 students (47%) somewhat familiar and 4 very familiar (12%), but 9 neither familiar nor unfamiliar (26%). This suggests that more emphasis on the importance of involving older adults in their care decisions is needed in student training programs.

Interdisciplinary collaboration is another area where students show varying levels of familiarity. While 16 students are somewhat familiar (47%) and 6 very familiar (18%), 8 are neither familiar nor unfamiliar (24%). This highlights the need for more education on the importance of teamwork among healthcare providers.

Familiarity with **psychiatric symptoms, classifications and basic psychotherapeutic treatment methods** is also varied, with 12 students somewhat familiar (35%) and 3 very familiar (9%), but 11 neither familiar nor unfamiliar (32%). This indicates a need for more training in this area to better prepare students for the complexities of caring for older adults with dementia or multi-morbidity. (See table 4 and figure 2)

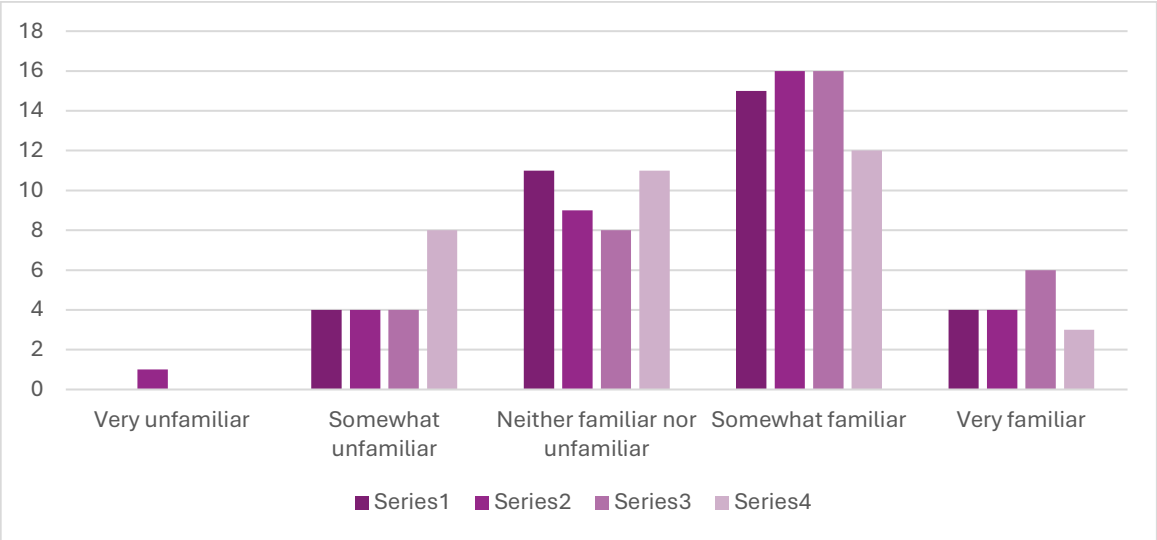

Figure 2: Familiarity of students with integrated care, shared decision making, interdisciplinary collaboration and psychiatric symptoms and treatment options

○ Older adults

Background information

Variable	Answers	N (Total=31)
Pilot site	City of Rotterdam (Netherlands) Syros (Greece) Flanders (Belgium) Treviso (Italy) Tenerife (Spain) Valencia (Spain)	5 5 5 5 6 5
Age	Average Minimum-maximum range Missing	81,5 years 60-94 years (2)
Sex	Male Female	12 19
Language proficiency	Very poor Poor Average Good Very good	0 0 5 17 9
Years since diagnosis	≤5 years 6-10 year81 11-15 years >15 years Missing	10 6 3 3 9

Table 5: Demographics older adults

The assessment included **31 older adults** from the same pilot sites (i.e., Rotterdam (Netherlands), Syros (Greece), Flanders (Belgium), Treviso (Italy), Tenerife (Spain) and Valencia (Spain)). The average age was 81,5 years, ranging from 60 to 94 years. The majority were female (61%). Language proficiency varied, with most rating their proficiency as good (n=17) or very good (n=9). The older adults had been diagnosed with dementia or multi-morbidity/disabilities for varying lengths of time, with 10 older adults having been diagnosed within the last 5 years and 6 older adults having been diagnosed between 6-10 years. There was one informal caregiver included and interviewed. (See table 5)

Current care situation

Variable	Answers	N
Living situation	Living together with a spouse or partner	13
	Living alone	7
	Living together with other family members	5
	Missing	6
Current main informal caregiver	(Grand)Children	10
	Only self-care	3
	Family and formal care	3
	Partner	2
	Partner and (grand)children	1
	Self-care and children	1
	Formal informal caregiver	1
	Home care services	1
	Missing	9
If not living at home, where is care received?	Day care center	1
	Nursing home	6
How do you rate your current care?	Very unsatisfied	0
	Somewhat unsatisfied	1
	Neither unsatisfied nor satisfied	1
	Satisfied	21
	Very satisfied	8

Table 6: Current care situation: older adults

Living situations of these 31 older adults in this assessment varied: 13 (42%) are living together with a spouse or partner, 7 (23%) are living alone, 5 (16%) are living together with other family members, and 6 responses (19%) are missing. The missing data are likely related to the fact that these older adults reside in nursing homes, where living arrangements may be less clearly defined or not individually reported.

For the current main informal caregiver of older adults, 10 (32%) have (grand)children as their main informal caregivers, 3 (10%) rely on only self-care, 3 (10%) have family and formal care, 2 (6%) have a partner as their main informal caregiver, 1 (3%) has both partner and (grand)children as informal caregivers, 1 (3%) relies on self-care and children, 1 (3%) has a formal informal caregiver, 1 (3%) relies on home care services, and 9 responses (29%) are missing. The missing data is likely due to at least six older adults residing in nursing homes, where they may be unable to identify a primary caregiver.

If not living at home, 1older adult (14%) receives care at a day care center, and 6 older adults (86%) receive their care at a nursing home.

In terms of rating their current care, 21 older adults (68%) are satisfied and 8 older adults (26%) are very satisfied. Only a minority of older adults rated their care with very unsatisfied (n=0), somewhat unsatisfied (n=1, 3%) or neither unsatisfied nor satisfied (n=1, 3%). (See table 6)

Integration of results

○ Understanding of integrated care

Professionals understand integrated care as a holistic, multidisciplinary approach that addresses medical, psychological, social and spiritual needs. It involves coordinated care among various professionals, including doctors, nurses, social workers, psychologists and therapists. The goal is to support both patients and informal caregivers, starting at home and continuing through various stages, ensuring a seamless care pathway that considers the patient's life history and preferences.

"Integrated care starts as soon as the diagnosis is made, often at home, involving the general practitioner or case managers. That is where care and integrated care begin and then additional disciplines are involved over time." (Professional from Rotterdam)

"Holistic, multidisciplinary approach addressing medical, psychological, social and spiritual needs. The keyword is empathy and understanding cognitive changes." (Professional from Greece)

Students view integrated care as personalized care that addresses all aspects of an older adult's life, requiring a multidisciplinary approach. The focus is on the individual's needs, maintaining dignity and quality of life through continuous communication and coordination among healthcare providers, patients and families.

"The care for someone with dementia would need to be adapted according to their diagnosis and their personal needs, with an understanding of both the patient's requirements and potential care opportunities." (Student from Rotterdam)

Older adults generally feel that integrated care is applied in their current care, addressing physical, emotional, cognitive and social needs. They appreciate personalized care and involvement in decision-making, though some feel that coordination among healthcare providers could be improved.

Based on the analysis of this assessment, professionals, students and older adults define integrated care for older adults as follows:

*"**Integrated care is a holistic, multidisciplinary approach** to healthcare that addresses the medical, psychological, social and emotional needs of older adults. It involves coordinated efforts among various healthcare professionals, including physicians, nurses, social workers, speech therapist, psychologists, occupational and physical therapists to ensure that care is personalized and tailored to the individual's preferences and priorities. Integrated care emphasizes the importance of involving patients and their families in decision-making processes, maintaining respect and empathy and supporting both physical and mental well-being through meaningful daily activities and continuous communication. The goal is to provide comprehensive, seamless care that enhances the quality of life and autonomy of older adults, enabling them to live fulfilling lives despite physical or mental challenges."*

- Ability to deliver integrated care

The ability to deliver integrated care varies among professionals. Some feel capable within their departments but recognize gaps outside of them, such as missing information upon client admission. Others face systemic gaps, resource shortages and lack of infrastructure. Successful implementation examples include the STIP method and interdisciplinary meetings, while failures often result from poor communication and coordination.

"There is a lack of knowledge and expertise among informal caregivers. Workload is extremely high and there's a care gap. The complexity of the clients is increasing." (Professional from Rotterdam)

Students' experiences vary, with some observing effective implementation and others noting systemic constraints. Successful examples include small living units with dedicated nurses and personalized care routines, while failures often involve rigid, task-oriented care and inadequate family involvement.

"Care is not yet complete, with activities often failing to consider individual interests or capabilities." (Student from Greece)

Older adults generally believe their current care meets their needs and expectations. They feel well cared for by both family and professional informal caregivers, though experiences vary. Some participants noted that while their care is comprehensive, the coordination among different healthcare providers could be improved to ensure a more seamless experience.

○ Challenges in providing integrated care

Professionals face challenges such as lack of resources, time constraints and gaps in knowledge. High patient-to-staff ratios, inadequate training and geographic barriers limit access to specialists. Communication with older adults and their informal caregivers is hindered by sensory and cognitive impairments, informal caregiver stress and language barriers. Emotional and behavioral challenges are managed through non-pharmaceutical interventions, empathy and tailored care plans, but systemic issues persist.

"Challenges include time pressure, lack of resources and a big difference between the setting of a residential care center and an acute ward in a hospital." (Professional from Flanders)

Students face challenges in integrating theory into practice, such as high workloads, insufficient staffing and inadequate resources. Effective communication is hindered by cognitive impairments and the emotional burden on informal caregivers. Students need more training on communication strategies and techniques for building trust and rapport. Approaches to managing emotional and behavioral challenges include creating a calm environment, non-verbal communication and engaging in meaningful activities, though time constraints and high workloads limit effectiveness.

Older adults face challenges such as health issues impacting emotional well-being, occasional feelings of isolation and navigating between different care providers. Support from family and friends is crucial for living a meaningful life despite physical or mental challenges. Better coordination and communication among care providers are needed to address these issues.

"Continuing to live at home is the highest priority, if possible. It is important to keep in touch with family and the outside world." (Older adult from Flanders)

"Maintaining independence/autonomy, managing pain and managing emotions are important." (Older adult from Treviso)

○ Involving informal caregivers

Involving informal caregivers is challenging due to their lack of knowledge, emotional exhaustion and misconceptions about care tasks. Financial and time burdens lead to social isolation and there is a need for better support and training for informal caregivers.

"There are gaps in knowledge and skills, especially in the areas of reflection on one's own actions, person-centered care and the involvement of informal caregivers."
(Professional from Flanders)

Students face challenges including informal caregivers' lack of understanding of disease progression, emotional struggles and reluctance to be involved. Better communication and support systems are needed to engage informal caregivers effectively.

"Family members often have unrealistic expectations and it is difficult to compromise or explain that they will not be able to do everything they want."
(Student from Treviso)

Older adults appreciate the involvement of family members in their care, though experiences vary. Some participants feel actively involved in decisions about their care, while others experience decisions being made for them by the informal caregivers. Ensuring participants' autonomy and preferences are respected is important.

"There is a significant lack of information on what to do after a diagnosis. Many families don't know what steps to take or where to seek the help they may need."
(Professional from Tenerife)

Knowledge and experience Gaps

Professionals acknowledge gaps in their knowledge, skills and attitudes. Areas for growth include sensory processing, complementary care methods and relationship-based care. Continuous education through seminars, online courses and peer discussions is preferred.

“The emotional aspect in care is often neglected” (Professional from Tenerife)

Students feel unprepared for the emotional and behavioral complexities of dementia care. They express a desire to learn more about assessing needs, providing personalized care and engaging in meaningful activities. Preferred learning methods include practical, hands-on experiences such as role-playing and simulation exercises.

"Students know and understand diagnostic characteristics but struggle to apply them in practice with patients." (Student from Tenerife)

"Improve coordination, listen more to patients and better understand our daily reality. (Older adult from Valencia)

Older adults generally feel their current care addresses their needs and expectations, though some note occasional misunderstandings or gaps in communication. Older adults value living environments that support their independence, emotional well-being, and social connections. Key needs include accessible and safe housing, personalized care, better coordination among specialists, meaningful daily activities, and strong support networks involving family, neighbours, and professionals.

"The most important advice is that healthcare professionals and students should be willing to listen and show understanding." (older adult from Flanders)

- Differences per pilot site

Rotterdam: Key needs and suggestions for e-learning in Rotterdam focus on enhancing communication skills, especially for complex groups like older adults with dementia, and promoting interdisciplinary collaboration. Students and professionals alike emphasize the importance of practical, interactive content—such as real-life cases, videos, and reflection tools—over passive text-based modules. Older adults value autonomy and clear, empathetic communication, suggesting that e-learning should also foster awareness of patient perspectives. Motivation can be increased through certification, relevance to practice, and emotional engagement via storytelling. Tailoring content to different roles while maintaining a shared foundation is essential.

Syros: Key needs and suggestions for e-learning in Syros emphasize experiential, interactive, and human-centered learning, combining theory with real-world practice through simulations and case studies. There is strong demand for caregiver education, psycho-emotional support, and non-pharmaceutical interventions. Older adults and informal caregivers value empathetic, personalized care, multisensory stimulation, and active involvement in decisions. The emotional and financial toll of caregiving highlights the need for respite care, accessible infrastructure, and better coordination among professionals. E-learning should be multilingual, flexible, and inclusive, offering practical, emotional, and educational support for both formal and informal caregivers.

Flanders: Key needs and suggestions for e-learning in Flanders include: enhancing knowledge on person-centered and psycho-emotional care, handling emotional and behavioral challenges, and involving informal caregivers effectively. Students and professionals emphasize the importance of practical, interactive content (e.g., case studies, simulations) and flexibility in learning formats. There is a strong call for reflection, real-world applicability, and support for communication skills. Older adults value empathy, autonomy, and meaningful activities, suggesting that training should also focus on these lived experiences.

Treviso: Key needs and suggestions for e-learning from the Treviso assessment include the importance of integrating theory with practice, especially through simulations, videos, and case studies. Professionals and students alike emphasize the need for tools that support emotional and communication skills, especially in dementia care. Older adults value empathy, patience, and personalized care, suggesting training should foster these qualities. All groups highlight the need for flexible, interactive, and up-to-date content tailored to real-world challenges. Finally,

the platform should support interdisciplinary understanding and offer guidance tools for navigating care systems.

Tenerife: Key needs and suggestions for e-learning in Tenerife include the demand for more practical, interactive, and emotionally engaging content tailored to real-life scenarios. Students, professionals, and older adults emphasize the importance of empathy, personalized care, and understanding emotional and psychological needs. There is a shared call for dynamic tools like simulations, case studies, and group-based learning to bridge theory and practice. E-learning should include caregiver guidance, emotional support strategies, and accessible, visually rich formats. All groups stress the need for better coordination, communication, and resources in integrated care.

Valencia: Key needs and suggestions for e-learning in Valencia include improving communication skills with older adults and caregivers, enhancing interdisciplinary teamwork, and addressing emotional and psycho-social care. Students and professionals highlight the need for practical, interactive content like case studies and simulations, while older adults emphasize personalized, coordinated care. E-learning should be modular, flexible, and combine individual and group learning to bridge theory and practice effectively.

○ Integration of care and interdisciplinary communication

Professionals emphasize the importance of a holistic and multidisciplinary approach to integrated care, addressing medical, psychological, social and spiritual needs. This involves coordinated efforts among doctors, nurses, social workers, psychologists and therapists to ensure that care is personalized and tailored to the patient's life history, preferences and needs. Tailored care includes adapting the environment and involving family members in the care process.

To enhance communication, professionals suggest improving clarity and ensuring that all team members are aware of each other's roles and responsibilities. This can be achieved through regular interdisciplinary meetings and clear documentation. Engaging family members in the care process and providing them with clear information about the patient's condition and care plan is crucial. Organizing family evenings and providing educational resources can help. In cases where patients have cognitive impairments, non-verbal communication techniques, such as body language and gestures, should be emphasized.

To enhance communication, **students** highlight the need for clear communication between healthcare providers and patients, as well as among different professionals. This includes adapting language to the cognitive level of older adults and ensuring that information is conveyed effectively. Engaging informal caregivers in the care process is crucial and students suggest providing informal caregivers with clear information about the patient's condition and care plan and involving them in decision-making processes.

Older adults appreciate when healthcare professionals take the time to understand their unique situations and provide care accordingly. Clear communication and better coordination among specialists are highlighted as areas needing improvement. They also emphasize the importance of listening to patients and involving them in decision-making processes.

Systemic improvements are necessary to enhance care delivery. Improving coordination among different healthcare services and professionals ensures seamless care delivery. This includes better integration of services and clear communication channels. Utilizing digital platforms and tools supports communication and participation among healthcare providers and informal caregivers, streamlining information sharing and improving care coordination.

○ Preferred learning methods

Professionals prefer in-person classroom training that is interactive and allows for deep learning through shared experiences. They value external trainers and voluntary participation, which enhances motivation and engagement. E-learning is appreciated for its flexibility but must be interactive and practical, incorporating videos, quizzes and assignments. Group learning is favored for its collaborative nature, fostering discussions and shared experiences.

Students also prefer hands-on workshops, seminars and simulations that provide practical experience. They suggest combining e-learning with face-to-face sessions to encourage interaction and deeper understanding. E-learning should be interactive, concise and relevant to real-world scenarios, including quizzes, case studies and practical examples. Group learning is preferred for its collaborative benefits, while individual learning allows for self-paced study.

- Suggestions for the e-learning based on the needs assessment

"E-learnings are fine and practical as long as they're interactive. Often, they are too 'dry'. A good e-learning should be engaging to make it stick." (Professional of Rotterdam)

Understanding Integrated Care

Integrated care involves a holistic, multidisciplinary approach that addresses the medical, psychological, social and emotional needs of older adults. It requires coordination among various healthcare professionals, including doctors, nurses, social workers, psychologists, speech therapist and therapists. The module should emphasize the importance of a patient-centered approach, where care is tailored to the individual's needs and preferences and the role of informal caregivers is recognized and supported.

Communication Skills

Effective communication is crucial in providing integrated care. The module should cover techniques for communicating with older adults who have cognitive impairments, such as dementia and their informal caregivers. This includes using simple language, non-verbal communication and creating a calm environment. It should also address the challenges of communicating with informal caregivers who may be stressed or in denial about the patient's condition.

"Two key topics that should be included are: communication skills (both with patients, family members and other professionals) and interdisciplinary teamwork skills." (Professional from Valencia)

Emotional and Behavioral Management

Prevention and treatment of the emotional and behavioral challenges of older adults with dementia or multi-morbidity is a key aspect of care. The module should provide strategies for understanding and addressing these challenges, such as identifying underlying causes of behavior, using non-pharmaceutical interventions and providing psycho-emotional support. It should also include techniques for

maintaining a calm and structured environment and engaging patients in meaningful activities.

Involving Informal caregivers

Informal caregivers play a crucial role in the care of older adults. The module should cover how to involve informal caregivers in the care process, provide them with the necessary support and education and address their emotional and practical needs. It should also highlight the importance of recognizing the expertise of informal caregivers and involving them in decision-making.

Personalized Care and Meaningful Activities

Providing personalized care that addresses the unique needs and preferences of each individual is essential. The module should include methods for assessing the needs of older adults, creating personalized care plans and engaging patients in meaningful daily activities that enhance their quality of life. This includes understanding the patient's life history and incorporating their interests and preferences into their care.

Psycho-Emotional prevention and treatment

The module should emphasize the importance of providing psycho-emotional support to both patients and informal caregivers. This includes techniques for managing stress, anxiety and depression and providing emotional support through active listening and empathy. It should also cover the importance of maintaining strong familial bonds and social connections.

"Empathy and psychosocial skills: How to manage emotional stress and the psycho-emotional needs of patients and their families." (Student of Valencia)

Training and Education

Continuous education and training are vital for healthcare professionals. The module should include various learning tools and resources, such as lectures, workshops, seminars, e-learning, role-playing and simulations. It should emphasize the

importance of practical, hands-on experiences and provide opportunities for interactive and engaging learning.

"Include AI, gamification, quizzes and collaborative platforms to enhance engagement." (Student from Greece)

Ethical and Legal Considerations

The module should cover the ethical and legal aspects of caring for older adults with dementia, disabilities and multi-morbidity. This includes understanding the rights and responsibilities of healthcare professionals, addressing issues of consent and capacity and navigating complex situations with professionalism and empathy.

Use of Technology in Care

The module should explore how technology can be used to enhance care for older adults. This includes the use of e-learning platforms for continuous education, telehealth for remote consultations and assistive technologies to support daily living and independence.

Case Studies and Real-World Applications

To make the learning practical and relevant, the module should include case studies and real-world examples that illustrate the challenges and solutions in providing integrated care. This will help learners understand how to apply theoretical knowledge in practical settings and improve their problem-solving skills.

"To be interactive, to transfer theory into practice through practical skills." (Student from Treviso)

Remarks and conclusions

This needs assessment report presents several methodological strengths that contribute to the depth and relevance of its findings. The use of a mixed-methods approach—combining quantitative surveys with qualitative focus groups and interviews—enabled a comprehensive exploration of the needs and experiences of professionals, students, and older adults. This triangulation allowed for both measurable insights and rich, contextual understanding of integrated care practices.

The inclusion of diverse participant groups across six European pilot sites (Rotterdam, Syros, Flanders, Treviso, Tenerife, and Valencia) added significant value to the assessment. By engaging professionals, students, and older adults, the study captured a wide range of perspectives and experiences, enhancing the applicability of its conclusions to a broader European context. The iterative development of qualitative instruments, grounded in prior research and refined through collaboration with consortium partners and advisory board members, further ensured the relevance and rigor of the data collected.

The focus on real-world application, particularly in relation to training needs and preferred learning methods, ensures that the findings are directly translatable into practical improvements, such as the development of targeted e-learning modules.

However, the assessment also presents several limitations. While the sample size exceeded initial expectations, it remains relatively small and may not be representative of the broader population. The voluntary nature of participation may have introduced selection bias, favoring individuals who are more engaged or available. Additionally, while the sample of professionals includes psychologists and professionals who address psychosocial aspects, it lacks representation from non-verbal therapeutic disciplines such as music therapy and psychomotor therapy. These professions offer complementary, non-verbal approaches that can have significant added value in dementia and integrated care. This limits the scope of the findings and suggests the need for broader inclusion in future assessments.

Additionally, some important topics were not explicitly assessed in the interviews. These include the use of clinical guidelines, scientifically validated interventions or methods, psychotherapeutic approaches, and creative or alternative therapies. The absence of these topics may have limited the depth of insight into evidence-based practices and the reliability of care delivery. Furthermore, the low implementation fidelity of certain care methods, meaning that interventions may not be consistently or correctly applied, was not explored. Including these elements could have yielded

different or more nuanced findings, especially regarding the effectiveness and consistency of integrated care.

Missing data, particularly among older adults, also poses a challenge. Responses related to living situations and caregiving arrangements were incomplete, likely due to institutional settings. This affects the completeness of the dataset and may obscure important trends. Among students, variability in familiarity with integrated care concepts and psychiatric symptoms reflects differences in educational curricula across institutions and countries, complicating cross-site comparisons.

Social desirability bias may have influenced responses in focus groups and interviews, especially regarding satisfaction with care or understanding of integrated care principles. Furthermore, the assessment provides a snapshot in time without longitudinal follow-up, limiting the ability to track changes in needs or perceptions over time.

The needs assessment for professionals, students, and older adults reveals important insights into improving integrated care for older adults with dementia, disabilities, and multi-morbidity. While professionals and students generally understand the principles of integrated care, there are notable gaps in training, particularly in psychiatric symptoms, psychotherapeutic methods, and managing emotional and behavioral challenges. Also, while the vision on integrated care is comprehensive and well-articulated, from the qualitative assessment it did not appear that integrated care explicitly referred to an inter- or transdisciplinary approach. Students often feel unprepared for the complexities of dementia care, highlighting the need for more comprehensive education. Older adults appreciate personalized care and involvement in decision-making, but they also report challenges with coordination among providers and occasional feelings of isolation. Professionals and students alike struggle to engage caregivers, pointing to a need for better communication and support systems. Barriers to delivering integrated care include systemic gaps, resource shortages, and poor interdepartmental coordination.

Based on the findings of this assessment the e-learning should incorporate real-world case studies, interactive tools, and guidance on dementia progression, communication strategies and caregiver involvement. It should also cover ethical and legal aspects of care, equipping learners to navigate complex situations with professionalism and empathy.

Attachments

Interview guide for the focus group professionals

Integrated care

- What is your understanding of integrated care in the care for older adults with dementia or multi-morbidity/disabilities?
- Do you feel you can deliver integrated care in your current practice according to your perspective?
- If so, can you please give an example how integrated care was implemented?
- If not, can you please give us an example how integrated care failed to be delivered?

Challenges

- What challenges or barriers do you anticipate or face when providing care for older adults with complex needs?
- What challenges do you face in communicating effectively with older adults and their informal caregivers?
- How do you currently address the emotional and behavioural challenges in older adults with dementia or multi-morbidity/disabilities?
- What challenges do you encounter in involving informal caregivers in the care you provide?

Knowledge and experience

- Do you experience gaps in your current knowledge/skills/attitudes in the care you provide for older adults with dementia or multi-morbidity/disabilities compared to integrated care?
- Are there any topics in caring for older adults with dementia or multi-morbidity/disabilities you want to know more about?

Learning methods

- What learning tools or resources could help you to increase your competences as a professional informal caregiver for older adults with dementia, disabilities and multi-morbidity?
- Do you have any experiences with learning new information and skills based on e-learnings?
- In your opinion, what strategies or approaches could make e-learning resources more accessible and practical for professional informal caregivers?

- Based on your experience, how can e-learnings complement and enhance other forms of learning in the field in terms of caring for older adults with dementia, disabilities and multi-morbidity?
- In your experience, do you prefer to learn new information by means of resources that are offered in groups (with peers) or individually?

Suggestions for the e-learning

- In this SACRED project, we aim to develop an e-learning for students and healthcare professionals to increase their competences on integrated care for older adults with dementia, disabilities and multi-morbidity. In your experience, what should definitely be included in this e-learning?

Interview guide for the focus group students

Integrated care

- What is your understanding of integrated care in the care for older adults with dementia or multi-morbidity/disabilities?
- Do you think integrated care is being offered for the older adults where you have received your training? Or where you have been doing an internship?
- If so, can you please give an example how integrated care was implemented?
- If not, can you please give us an example how integrated care failed to be delivered?

Challenges

- What specific challenges or barriers have you faced in integrating theory into practice, in terms caring for older adults with dementia or multi-morbidity/disabilities? (e.g. lack of resources, time constraints, or gaps in knowledge)
- What challenges do you face in communicating effectively with older adults and their informal caregivers?
- How do you currently address the emotional and behavioural challenges in older adults with dementia or multi-morbidity/disabilities?
- What challenges do you encounter in involving informal caregivers in the care you provide?

Knowledge/experience

- In your experience as a student, have you encountered situations or challenges where you felt your competences lacked in order to provide care to older adults with dementia or multi-morbidity/disabilities? If yes, can you give an example of such a situation or challenge?
- Are there any topics in caring for older adults with dementia or multi-morbidity/disabilities you want to know more about? (examples of topics can be: how to assess the needs of older adults, how to provide more personalized care, how to provide meaningful daily activities, how to provide psycho-emotional care, (basic) psychotherapeutic treatment, other topics,...)

Learning methods

- What learning tools or resources could help you to increase your competences as a student to provide care for older adults with dementia, disabilities and multi-morbidity? (e.g. lecture, workshop, seminar, e-learning, role-playing, simulation...)

- Do you have any experiences with learning new information and skills based on e-learnings?
- Do e-learnings play an important role in your current educational curriculum/training? (are they frequently offered in your current educational curriculum/training?)
- In your opinion, what strategies or approaches could make e-learning resources more accessible and practical for students?
- Based on your experience, how can e-learnings complement and enhance other forms of learning in your current education/training in terms of caring for older adults with dementia, disabilities and multi-morbidity?
- In your experience, do you prefer to learn new information by means of resources that are offered in groups (with peers) or individually?

Suggestions for the e-learning

- In this SACRED project, we aim to develop an e-learning for students and healthcare professionals to increase their competences on integrated care for older adults with dementia, disabilities and multi-morbidity. In your experience, what should definitely be included in this e-learning?

Interview guide for the focus group older adults

Integrated Care

- In your opinion, is this definition (or parts of it) applied in your current care?
- In your opinion, do you think the current care sufficiently addresses your needs and expectations in terms of your care?
- In your experience is your current care provided with respect/empathy?
- In your experience is your current care provided in a personalised way?
- In your experience is your current care involving meaningful activities on a daily basis?
- In your experience is your current care involving care for your psycho-emotional aspect?
- In your experience is your current care well-coordinated between different care professionals (such as medical doctors, nurses or other informal caregivers)?
- In your experience is your current care taking into account the aspects of life that are meaningful to you?
- In your experience is your current care taking into account your preferences and priorities?
- In your experience is your current care sufficiently involving you in decision making/decisions about your care?

Challenges

- How do your health challenges affect your emotional well-being? Can you explain?
- What enables you to live a meaningful life despite possible physical or mental challenges you might face?
- Do you feel comfortable talking to your doctors, nurses, or other care providers about your health concerns? Can you explain?
- Are there times when you felt misunderstood or that your concerns weren't fully addressed? Can you explain?
- Have there been any issues with communication or gaps in your current care? Can you explain?
- What resources or support would make you feel more independent or fulfilled? Can you explain?
- How easy is it for you to navigate between different care providers? Can you explain?

Experience and preferences

- In your experience, what is most important to you when it comes to your care? (e.g., staying at home, managing pain, maintaining autonomy or independence, managing emotions)
- How do you think healthcare providers could support these priorities?
- Are there times when you feel isolated or unsupported and what could help?
- Do you have people you can rely on for emotional or practical support?
- If so, who can you rely on?
- In times you feel unsupported, how do you cope with this lack of support?

Suggestions

- If you could change one thing about the healthcare you receive, what would it be?
- What advice would you like to give to healthcare professionals or students about caring for someone who faces the same health issues like you?

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