Dia 1 Title

The importance and value of psychosocial care and support in dementia in historical perspective, with reflection and commentary

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Good morning! First of all, I would like to thank the organisers of the congress for inviting me and for giving me the opportunity to talk about a subject that has fascinated me for more than 40 years now, and that is the importance and value of psychosocial care and support for people living with dementia and their carers.

Thank you all for coming at this early hour.

1. Introduction

Last year I retired, which prompted me to look back and take stock of what we have achieved over the past 40 years with research on psychosocial care and support for people with dementia.

In my lecture, I would like to take you along the path I have walked, partly on the basis of a number of important insights that gradually emerged through practical experiences and research in the field of psychosocial care. At the end of that path, I want to look to the future: the further development of psychosocial care and support for people with dementia.

But first, I would like to share with you some quotes from people with dementia from the literature, in which they express their feelings about the changes in their lives due to dementia and how they deal with them:

Dia 2 Quotes from people with dementia

'I am trying to control it. (...) I try to write everything down in my diary and look at it. If I remember to look at it.' (Gillies 2000)

'I haven't told anyone. I think they will treat me differently (...).' (Langdon et al. 2007)

Yes, internally I do get angry then, but I try not to let it show. (De Boer et al., 2010)

'I think about dying a lot. There has to be a line drawn somewhere ... when it is time to go, when life is not quality anymore.' (Page & Keady, 2010)

Recognising and acknowledging emotions in others, including people with dementia, starts with recognising and acknowledging emotions in yourself. Understanding these emotions is a step further. Why does a situation make you sad, anxious, angry, rebellious or insecure? This is not always exactly clear and it requires self-reflection. Understanding other people's emotions also takes time and effort. And, not unimportant, interest and motivation.

As a young Human Movement Sciences student, doing an internship in a psychogeriatric nursing home in 1979, where I first met people with dementia, I could not accept that their emotions and behavioural expressions, such as apathy, agitation, aggression, depression and anxiety, were a direct result of brain degeneration, as was widely believed and proclaimed at the time. I was intrigued that there was so much variation between people with dementia, but also that people could vary so much from day to day and even from hour to hour and in a variety of situations, such as in the living room, during movement-activation sessions or when visited by a child or grandchild. Simply attributing that variation to brain degeneration amounts to a total denial of the person behind the disease, and the influence of – and the interaction with – the people around them.

This observation and this realisation, have been the basis of my further research into the psychosocial causes of behavioural and mood disruptions in dementia. But also into ways in which we can prevent or influence them in a positive way, and how we can integrate these effective methods into the interaction with, the care for, and psychosocial support of people with dementia, so they can benefit from it. That is, be more emotionally balanced and enjoy their lives because they feel supported, but most importantly, because they feel known and recognised.

Because that is what we generally aim to do in psychosocial care: guide and support people with dementia and informal carers to adjust psychologically and socially to the consequences of dementia, and living with dementia, with the ultimate goal of enhancing their well-being (Dröes, 1991).

2. Psychosocial care, key insights 1980-2023

OK, back to the field of psychosocial care research.

I promised to share with you some important insights that have emerged over the past 40 years.

Dia 3 Understimulation

The first one I want to mention is:

Understimulation in long-term care facilities can contribute to behavioural and mood disorders. These are partly preventable or positively influenced by activation.

I referred to this in my introduction. In the late 1970s, early 1980s when I did my internship as a master student in a nursing home, the potentially negative impact of under-stimulation on people with dementia was actually not well known in psychogeriatrics. Behavioural and mood disruptions were usually attributed to brain degeneration. But my own studies on the effect of movement activation as a form of psychomotor therapy in nursing homes, in the period 1983 to 1988, repeatedly showed that aggression, night-time restlessness, non-social behaviour and dissatisfaction were positively influenced when people actively participated in movement activation groups three times a week for 45 minutes (Dröes, 1997a,b; Dröes, 1991; Dröes & van Tilburg, 1996). To me this proved that behavioural and mood disruptions are not simply a consequence of brain degeneration, but are partly caused by other factors, such as understimulation.

Incidentally, I was not the only one looking into this. At the time, other researchers were also focusing on the effect of movement activation, cognitive stimulation, offering choices and stimulating interaction with the environment on people with dementia (Rodin & Langer, 1977; Hanley, 1981; Reeve & Ivison, 1985; Rodin, 1986; Carey & Hansen, 1985; Holden & Woods, 1988; Hopman-Rock et al., 1999; Heyn et al., 2004). Later studies have also demonstrated the benefits of activation

on overall functioning and well-being (Dröes et al., 2011; Dröes & Scherder, 2015). Examples include Cognitive Stimulation Therapy (CST; Orrell et al, 2014; Spector et al, 2003, 2010; Woods et al, 2006), occupational therapy at home (Gitlin et al, 2003; Graff, 2008) and recently, exergaming, a combination of 'exercise' and 'gaming' (Van der Molen-van Santen, 2021).

The mid-1980s also saw the rise of rehabilitation medicine (Bangma & Kap, 1988). Its focus was mainly on functional activation and reactivation: stimulating memory, orientation, action and communication, and not so much on regaining a psychological and emotional balance, learning to live with the disability or illness. This psychosocial perspective (Dröes, 2010) was relatively underappreciated in the reactivation and rehabilitation medicine of the time. Even in the International Classification of Impairments, Disabilities & Handicaps (ICIDH), the chapter on 'perceived disability' was not very comprehensive. The fact that this is also very important was not recognised until later, in the 1990s. It was the subject of my PhD thesis in 1991 (Dröes, 1991).

This development was related to the second insight I want to mention here:

Dia 4 Adaptation and Coping

Being confronted with dementia is intense, which consciously or unconsciously triggers all kinds of survival mechanisms (coping strategies) to maintain a psychological and emotional balance.

During my studies into the effect of movement activation in various Amsterdam nursing homes in the mid-1980s, when I personally led the movement sessions as a therapist and had regular discussions with participants before and after the sessions, I experienced that many people with dementia are aware of their own deterioration and its consequences in their daily lives: Being dependent on the people around you, being approached differently by family and friends, the suspicion this can create, the feeling of not being taken seriously, feeling worthless, experiencing sadness and disbelief due to the loss of your own home, neighbourhood, friends, not feeling accepted by fellow residents on the nursing home ward where you are staying.... These are some of the experiences people with dementia shared with me at the time. Most poignant was when a resident asked me if she could come home with me, because the nursing staff wanted to transfer her to a different ward because of her increased apraxia and aphasia. Her behaviour irritated her fellow residents to the point that they rejected her. She was very sad about that.

By the way, this was not talked about easily or candidly back then. It is more common nowadays. For example, I remember conversations between participants with dementia in Meeting Centres that I have witnessed regularly in recent years. The conversations in the nursing home at that time I conducted in confidence. People did not want to be seen as the 'bad patient', and certainly did not want any conflict with the nursing staff; those were different times. There was no 'Me too' movement yet, let alone emancipated nursing home residents with dementia. Everyone I spoke to, though, did have their own way of dealing with the dependency, sadness, suspicion, negative self-image and group dynamics. Some were cooperative when being helped, others were more rebellious; some sought distraction in an activity when they were sad, others retreated into themselves and sat in a chair with their eyes closed; some sought refuge elsewhere when they could not connect with their fellow residents, others did not accept this and went into battle swearing. We also see these observations in the PhD thesis of Jacomine de Lange (2004), who conducted qualitative research in the late 1990s in the Dutch Integrated Emotion-oriented Care in Nursing Homes project.

You will understand that I was shocked when, as recently as 1991, one of the older opponents at my PhD defense bluntly claimed that people with dementia are not aware of their disabilities and therefore logically do not use coping strategies. There was still a long way to go. Being suddenly confronted with an acute serious, or chronic, illness and experiencing deterioration in your functioning involves major changes that one has to cope with, in one way or another, to retain a psychological and emotional balance. Everyone does this in their own way, consciously or unconsciously. Coping strategies are strategies learned throughout life to cope with stress (Lazarus & Folkman, 1984). Often they work, sometimes they don't, and then people get upset, become dysregulated. This also applies to people with dementia (Dröes, 2007). And the people around them certainly <u>can</u> have an influence on this (Laybourne et al., 2019).

Dia 5 Coping strategies

The fine qualitative interview studies by, among others, Els Steeman in Belgium (Steeman et al. 2006, 2007), Marieke de Boer in the Netherlands (De Boer et al., 2007) and Linda Clare (2003, 2004) and John Keady in England (Keady et al, 2001, 2010; Calvert et al, 2020), and the many testimonies of people with dementia in recent decades, including from participants of the European Working Group of People with Dementia of Alzheimer Europe (https://www.alzheimer-europe.org/european-working-group-peopledementia) and poignantly described in several books (e.g. Langdon et al., 2007; Bère Miesen (2000), and Anne Mei Thé (2017)) confirm the wide variety of perceptions and challenges experienced by people with dementia and the different strategies they use to deal with them.

This brings me to the third insight:

Dia 6 Adjustment mechanisms

The adjustment mechanisms, which we call 'adaptation', and in case of experienced stress, 'coping', differ from one individual to another. This is due to differences in personality and life history, but also to the specific limitations resulting from the dementia or other additional chronic conditions, and social and material circumstances.

To be effective, psychosocial support must therefore always be tailored to the individual and their interaction with the environment. This requires knowledge about the person, their illness and circumstances, and an understanding of what they are going through, their experience. The person must feel heard, understood and safe. Then, connection and trust can develop.

Searching for concepts and theoretical models that could explain the wide variation between people with dementia, and that went beyond the functional level and also considered the experience and behaviour -the perspective of psychosocial care- I had regular discussions in the second half of the 1980s with my supervisor Prof Willem Van Tilburg, then head of the Department of Psychiatry at the Vrije Universiteit in Amsterdam. Hé was the person who, in one of these conversations, suddenly suggested that I look into the concept of 'coping'. I had never heard the word before, but after his explanation, it certainly seemed interesting. At the time, Richard Lazarus and Susan Folkman (1984) had just published a voluminous book entitled Stress, Appraisal, Coping. It was an update of the book Stress and Coping, which Folkman had published 20 years earlier. So the difference was in the addition of the concept of Appraisal, which was defined as: the individual cognitive assessment of the situation. Whereas situations were previously thought to be stressful in themselves, it was now described how individuals can experience situations completely differently: what is stressful for one person may not be stressful at all for another. This is because the cognitive assessment of the difficulty of a situation is determined by your personality, past experiences, how you have learned to handle similar situations, for example, but also your functional capabilities to deal with the situation (when you have difficulty walking, live on the third floor and the supermarket is a few miles away, it takes a much bigger effort to do your shopping than when you live on the ground floor and around the corner). Also, personal and material circumstances can play a role. To stick with the example: if you have a son or daughter who does your shopping for you every week, it doesn't matter whether you live at a distance from the supermarket or around the corner.

I did not find any scientific literature specifically on coping with dementia. But there was a very interesting book by Verwoerd (1976) from the United States, entitled Clinical Geropsychiatry. This book described, from a psychodynamic perspective, some coping and defence mechanisms in senile dementia, such as strategies aimed at mastery and control (for example obsessive and compulsive behaviour, and overcompensation), and strategies to keep the threat away from consciousness, such as suppression and denial. In 1989, in the US, the book Psychiatric consequences of brain disease in the elderly by Conn, Grek and Sadavoy (1989) was published, which described similar coping strategies (Sadavoy and Robinson, 1989).

Finally, I found Rudolf Moos' (1977) book Coping with physical illness, in which he and Vivien Tsu wrote a chapter on the 'Crisis of physical illness'. They describe a number of basic adaptive tasks (nowadays we would say 'challenges'), which people generally face during serious illness and crisis. These include coping with one's own disabilities, maintaining an emotional balance, and preserving a positive self-image, but also coping with the uncertain future, maintaining social contact with family and friends, and dealing with care providers and treatments.

Dia 7 the Adaptation-Coping model and its applications

Based on all this information, I developed the integrated, interactive, psychodynamic Adaptation-Coping model, a conceptual model for understanding adaptation and coping in illness and crisis situations in general (Fig. 2). Central to the model are the concepts of individual cognitive appraisal of Lazarus & Folkman and the adaptive tasks of Moos & Tsu.

In my PhD thesis, particularly in the study of the effect of psychomotor therapy, I elaborated and operationalised this model in detail for people with dementia (Dröes, 1991). Later studies by several of my PhD students further operationalised and validated the model (De lange 2004; Ettema, 2001,2007). The model formed the theoretical basis of the quality-of-life measurement instrument Qualidem (Ettema et al., 2007), which is now widely used in and outside the Netherlands. Several studies after 2000, in which people with dementia were interviewed about their experience and coping with dementia, confirmed the relevance of the concepts of adaptation and coping and adaptive tasks or challenges in dementia (e.g. Steeman et al.(2007); De Boer et al. (2007, 2010); Clare, 2003; Gilmour & Huntington, 2005; Macquarrie, 2005; Macrae, 2008; Keady 2001, 2010).

The model served as the basis for the development and evaluation of new interventions in the 1990s, such as psychomotor therapy for people with dementia (Dröes, 1991; Dröes & van Tilburg, 1996), integrated experience-oriented care in nursing homes (Finnema, 2000; Van der Kooij, 2003; De Lange, 2004), and the Meeting Centres Support Programme for community dwelling people living with dementia and their informal carers (Dröes et al., 2000, 2004, 2006).

Dia 8 Meeting Centres Support Programme

The combined Meeting Centres programme provides practical, emotional and social support within the context of a social day club and a carer programme. Support is provided on the basis of an individual psychosocial diagnosis, based on how people are able to deal with the adaptive tasks mentioned in the Adaptation-Coping model. In several national and international studies, this socially integrated, person-centred programme has shown to be more effective than the usual day care treatment in counteracting behavioural and mood disruptions and improving quality of life. And ... it is also more cost-effective (Dröes et al., 2000, 2004, 2006; Brooker et al., 2018; Henderson et al., 2021). This is also true of the recently researched complementary individual programme DemenTalent, in which staff of the Meeting Centres guide people with dementia to find volunteer work in organisations in their neighbourhood,

such as a sports club or schools and municipal maintenance of green spaces (Dröes et al., 2019).

Dia 9 MeetingDem Network of interest

The successful Meeting Centers intervention is now applied in more than 190 locations in the Netherlands and, following the European JPND-MeetingDem implementation project (Dröes et al., 2017; Brooker et al., 2018), also in about 180 locations abroad: in Europe (in Italy, Poland, Spain and UK), but also in Aruba, Australia, Japan, Singapore, Surinam and Zimbabwe.

And that brings me to the fourth insight I want to share with you today:

Dia 10 Quality of life

It is crucial to know what people find important in their lives when you want to help maintain or improve their quality of life. We know from research that this varies from individual to individual.

Being attentive to the changes a person goes through as a result of their dementia, the impact this has on them, what they struggle with and how they and those around them cope with it, is one thing. You can compensate for disabilities, support the person in the adaptation process in areas where he is struggling, and appeal to his strengths, his talents. But... that is not all.

To maintain or improve quality of life, which is the ultimate goal of care and psychosocial support in dementia, you will also need to know more about what a person finds important in their life. You need to get to know the person. From interviews conducted by the Dutch Leo Cahn Working Group on Quality of Life in Dementia with people with dementia in day care centres, Meeting Centres and nursing homes, published in 2006, a number of criteria for quality of life emerged.

Dia 11 Quality of life domains

Some of these were already known from the literature, such as having fun, enjoying the living environment (for example, a pleasant neighbourhood with green areas (Hendriks et al., 2016), but also having sufficient opportunities to engage in activities, such as playing sports, and visiting a museum or theatre (Mittelmann & Epstein, 2009; Hendriks et al., 2019; Boersma, 2017). But new domains were also mentioned, such as still being of use to others, being accepted as you are and being treated as equals, self-esteem, but also experiencing freedom and self-determination (Dröes et al., 2006; Gerritsen et al., 2010; Dröes & Gerritsen, 2018). -By the way, this is perfectly in line with current views on empowerment of people with dementia (Van Corven, 2022).- In this context, we conducted research on people with dementia doing volunteer work (DemenTalent), which I mentioned earlier. And this has been found to meet a clear need in a proportion of people with dementia and to lead to significantly less behavioural disruptions and a more positive mood (Dröes et al., 2019).

I would like to show you a video clip on this.

Dia 12 Short video DemenTalent (2.13 min)

(https://youtube.com/channel/UCI3kRVVTGHf4ZX0Ly-7s0Wg).

What also emerged from the study by the Quality of Life Working Group was that people differed in what they considered important for their quality of life, and that sometimes the person with dementia really does interpret needs and wishes differently, or in a more nuanced way, than the professionals around them (Gerritsen et al., 2010). To give an example: caregivers indicate that sufficient social contact is important for people with dementia, while people with dementia themselves are much more specific in this respect, stating, among other things, that they want to stay in touch with their children and grandchildren.

Measuring quality of life is thus more complicated than one might think, and the selection of measuring instruments is critical when it comes to evaluating interventions: Not only does the measurement instrument have to fit well with the domains targeted by the intervention (Schölzel et al., 2007), but it also has to measure what the individual person finds important for *their* quality of life. This has led to the development of methods to measure quality of life in a personalised way.

Dia 13 Artikel Hendriks et al

Iris Hendriks conducted research into this and developed reliable, personalised versions of existing quality-of-life measurement instruments (DQOL and QOL-AD), in which every individual can indicate how important they feel the different domains are (Hendriks et al., 2021). These are then taken into account as 'weights' in determining their quality of life. Further research will have to show whether these personalised measurements deliver more

nuanced results in intervention studies. It would be great if this allows us to take a step forward in the more accurate design and evaluation of personcentred care.

Dia 14 Informal carers

The fifth insight I want to share with you is:

Informal carers of people with dementia gradually feel more burdened and may develop psychosomatic complaints if they do not receive adequate information and support. On average, their health is worse compared to the health of their peers.

Dia 15 Aims and interventions of caregiver support

This insight, which was already known in the 1990s, has led to the development of many interventions to guide and support informal carers (Vernooij-Dassen, 1993; Van Mierlo et al., 2012a; De Clercq et al., 2022; Van der Lee, 2022), with a variety of aims, such as to decrease burden and stress and to improve their knowledge, caring skills, mood, mental health, self-efficacy, coping, sense of competence, resilience, well-being and quality of life. Some examples of interventions are shown on the slide (Alzheimer cafes, respite care, peer support groups, telephone support, case management, psychoeducational programmes for skills training and therapies like cognitive behavioural therapy (including cognitive reframing), internet-based support interventions and multicomponent combined interventions). From the international systematic reviews we have learned that especially interventions that are flexible and personalised, offer emotional and social support in addition to practical support and information, and provide support to both the person with dementia and the caregiver, are more effective in supporting them both than interventions which do not meet these characteristics (Smits et al., et al., 2007; Olazarán et al., 2010; Van 't Leven et al., 2013; Laver et al., 2017; Van der Lee et al., 2022).

With my own research group we have conducted several studies on the combined, multicomponent Meeting Centres support programme, in which informal carers can participate in information meetings on relevant topics regarding dementia and discussion groups with other informal carers, as well as receive individual counselling (Dröes et al., 2004, 2006). Because their loved one participates in the day club of the Meeting Centre several days a week, the informal carer also gets respite on those days.

Dia 16 Publications carer appreciation Meeting centers

The Meeting Centre programme is highly appreciated not only by the participants with dementia, but also by their informal carers: they feel less burdened and better able to take care of the person with dementia, and this leads to postponement of nursing home admission (Dröes et al., 2004, 2011; Szcześniak et al., 2019). We are therefore very happy that the centres are now included in the Dutch Ministry of Health, Welfare and Sport's National Dementia Strategy 2021–2030. And of course we hope that other countries will follow. Just a month ago we heard that the Meeting Centres are now also recommended in the Scottish Dementia Strategy, which was launched in late May of this year.

Dia 17 Other forms of carer support

Other forms of informal carer support we investigated are Into D'mentia, a virtual reality dementia simulator in which informal and professional caregivers can briefly stand in the shoes of the person with dementia; Dementelcoach, telephone coaching for carers; and the STAR online course on dealing with dementia. These interventions have been shown to lead to more empathy and a more person-centred attitude towards the person with dementia and a greater sense of competence among informal carers, who feel better able to take on their care responsibilities (Van Mierlo et al., 2012b; Hattink et al., 2015a; Jütten et al., 2018).

This has resulted in a pilot, linking both Dementelcoach and the STAR online course to existing Meeting Centres as additional, or alternative, offerings for informal carers in the so-called *individualised* Meeting Centres Support Program (iMCSP). And this proved to be successful! Over the past two years, we have therefore campaigned to further disseminate these new forms of support through Meeting Centres in the Netherlands.

And then we come to the sixth and final insight I want to share with you today:

The top 5 unmet needs in dementia relate to memory support, information, meaningful activities, social contact and safety. These can be met using assistive technology. To ensure user-friendliness and usability, 'user-participatory designing' is a prerequisite.

Dia 18 Top 5 of unmet needs and technology

The research by Henriëtte van der Roest among 230 community-dwelling people with dementia and 320 informal caregivers in the Netherlands, published in 2009, showed that these were the top five unmet needs (Van der Roest et al., 2009; Van der Roest, 2009). This has been confirmed in later studies, for example by Cohen-Mansfield (2015) in the USA and by Ferreira and colleagues (2016) in Portugal. Also, recent research by the Dutch Social Cultural Planning Agency has shown that in 2021, although care is generally rated positively, there are still relatively many *unmet* needs among people with dementia in nursing homes in the Netherlands in terms of activities/ having something to do, as well as social relationships (Verbee-Oudij and Koper, 2021).

Unmet needs in dementia are associated with behavioural and mood disruptions and increased mortality (Schwertner et al, 2021; Ballard et al, 2011; Kolanowski et al, 2011; Gaugler et al, 2005; Ferreira et al, 2016; Cohen-Mansfield et al, 2015; Van der Ploeg et al, 2013; Curnow et al, 2021). This was clearly demonstrated once again by the lockdowns during COVID (Gerritsen et al., 2022). Very recent research of Costanzo and colleagues (2022) has even shown the direct relationship between impaired social health -think of loneliness- and impaired functioning of specific parts of the brain in the elderly.

Dia 19 Promoting Social health

To promote social health in dementia (Dröes et al., 2017; De Vugt & Dröes, 2017; Vernooij-Dassen et al, 2021), we, and many of our colleagues, have conducted studies on social participation and meaningful activities for people with dementia in different settings over the past 15 years (Graff, 2008; Van Haeften-van Dijk, 2016; Boersma, 2017; Buist et al., 2018; Kerkhof, 2021; Van der Molen, 2021; Hendriks, 2022).

With the rise of assistive technology after 2000, several research groups around the world started to explore whether technology could contribute to fulfilling the unmet needs mentioned, especially in view of the expected increase in care staff shortages in the coming decades.

Dia 20 Technology projects with logos and user-participatory designing

With my own research group we were involved in about ten national and European projects from 2005 to date. You can see the logos on the slide: examples are DEM-DISC about a personalised interactive social chart (Van der Roest, 2009; Van Mierlo, 2015), COGKNOW and Rosetta to help people navigate through the day (Dröes et al., 2010; Hattink et al., 2016), with activity reminders and support for social contact and safety; the STAR online course for caregivers(Hattink et al, 2015b), Exergaming: a combination of exercise and gaming (Van der Molen-van Santen, 2021), the Marie-Curie INDUCT and DISTINCT-Innovative Training Networks, FindMyApps: helping people to find dementiafriendly apps (Kerkhof, 2021; Beentjes et al., 2020; Neal et al., 2021) and Known in the Nursing Home, which uses a digital Photo-Activity to promote personcentred social interaction between caregivers and people with dementia with the aim to make them feel more recognised for who they are (Tan et al., 2022).

What we learned from the studies conducted so far is that technology offers many opportunities, but that involving the future users, especially in the case of people with dementia, is a prerequisite for developing user-friendly and usable technology (Dröes et al., 2010; Span et al., 2013; Meiland et al., 2014; Kerkhof et al., 2019; Rai et al., 2020). Moreover, the research field is complex: It takes a lot of time to develop and properly evaluate well-functioning, personalised technology that seamlessly fits individual needs. This means there is a risk of the product being obsolete by the time it is ready for the market. Living Labs, collaborations with users, care and welfare institutions that immediately apply the technology in practice, and can therefore provide continuous feedback to the developers, are very important to speed up the development process, but also to better ensure usability and future implementation.

Dia 21 Best Practice Guidance – two formats

Over the past few years, with the two Marie Curie Innovative Training Networks INDUCT and DISTINCT, in which 30 Early stage researchers worked on technology for people with dementia in 9 European countries, and of which I had the honour of being the research coordinator, we have developed a web-based Best Practice Guidance with more than 100 recommendations for the for use of technology people with dementia (www.dementiainduct.eu/guidance/ Dröes et al., 2023). These are relevant to the different target groups, such as people with dementia, informal carers, care and welfare professionals, as well as designers, researchers, and policy makers. Each target group can find specific recommendations relevant to them on this website by means of an easy to use search tool. I advise everyone involved in technology for people with dementia to take note of these recommendations and act accordingly. Of course I also invite you to visit our poster on the Best Practice Guidance at this conference.

Dia 22 Insights summarized: core concepts of psychosocial care

3. The future

So, these were some of the insights we have gained through research and continuous exchange with practitioners over the past forty years (Fig. 5). They have led to a greater understanding of the importance and value of psychosocial support, and to new, more effective, person-centred and relationship-centred forms of support (Nolan et al., 2004).

Some of the developed and evaluated interventions I have mentioned have been implemented on a larger scale and in several countries over the past 20 years. However, new interventions will still need to be further developed, evaluated and implemented. For example: the use of assistive technologies and artificial intelligence in dementia care, but also practical methods to personalise care – a recent systematic review of Gustavsson and colleagues in the British Medical Journal showed that care staff is happy to provide more person-centred care but that the task-oriented system and procedures make it very difficult for them to do so – (Gustavsson et al., 2023). And finally, further development of methods to personalise the evaluation of interventions is needed. So there is still a lot to do!

An important way to develop psychosocial care and support in dementia and increase the likelihood of successful further implementation of innovations, is, in my opinion, through the so-called Academic Workplaces: structural collaborations and continuous exchange between knowledge institutes (like universities and universities of applied sciences) and dementia care and welfare practice. In the Netherlands we have several Elderly Care academic workplaces, but most of them are focused mainly on long-term institutional or residential care.

Dia 23: Academic workplace figure

Recently, in October last year, we therefore started a new Academic Workplace on Post-diagnostic Care & Support in Dementia to promote scientific research and education in the field of care and support after the diagnosis.

Dia 24 Ambition of Academic Workplace

At present, in addition to the core group of two Universities, two care organisations and a Welfare organisation, all in the Amsterdam region, there are already quite a few collaboration partners who are actively working together in initial projects (as you can see on the slide). Students and postdocs play an important role in the Academic workplace.

Connections with basic medical and psychology education and with professional education in dementia care are crucial for professionals in training to experience the importance and value of psychosocial support and research. This will make them better professionals, who are better equipped for an integrative approach to dementia care (www.vumc.nl/AWHDD).

Dia 25: The MeetingDem Network

An international network that can also be seen as an academic workplace on post-diagnostic care and support, but on a European level, is the MeetingDem Network. This network stems from the JPND-MeetingDem project in which the Dutch model of Meeting Centres was adaptively implemented and positively evaluated in three countries in Europe: Italy, Poland and the United Kingdom. After this project the consortium decided to formally continue as the MeetingDem Network.

The main aims of the Network are shown on the slide:

- Further dissemination of the concept of Meeting Centers
- International knowledge exchange on effective post-diagnostic care and support for community-dwelling people with dementia and their carers
- Exchange of experiences and views
- International collaboration in applied research

Several countries in the Network have developed courses for the personnel of Meeting Centres, and recently we also developed an online Introductory course (in English and Spanish), together with two early stage researchers of the DISTINCT Network (Maurizio Molinari and David Neal), for pioneers who want to set up a Meeting Centre in their own country. If you are interested please visit the website of the MeetingDem Network (https://meetingdem.eu/).

I sincerely hope that such academic workplaces will lead to many new and fruitful collaborations, that will ensure innovative research, knowledge exchange and training, and the best quality of care and psychosocial support for the ever-growing group of people living with dementia and their carers, in line with the needs they experience. Coming to the end of my lecture, I would like to thank everyone with whom I have collaborated nationally and internationally within MeetingDem, Interdem, IPA, EAGP, Alzheimer Europe and ADI. These networks have been extremely important for the development of research on psychosocial care for people with dementia and I fully trust that they will continue to be so in the future.

Thank you so much for your attention!

Dia 26 Thank you with international photos older people

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