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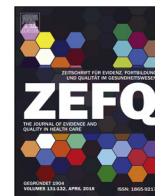
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## Advance Care Planning in the Netherlands



## Advance Care Planning in den Niederlanden

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## ABSTRACT

The Dutch health care system fosters a strong public health sector offering accessible generalist care including generalist palliative care. General practitioners are well positioned to conduct ACP, for example, to continue or initiate conversations after hospitalization. However, research shows that ACP conversations are often ad hoc and in frail patients, ACP is often only initiated when admitted to a nursing home by elderly care physicians who are on the staff. Tools that raise awareness of triggers to initiate ACP, screening tools, information brochures, checklists and training have been developed and implemented with funding by national programs which currently focus on implementation projects rather than or in addition to, research. The programs commonly require educational deliverables, patient and public involvement and addressing diversity in patient groups. A major challenge is how to implement ACP systematically and continuously across sectors and disciplines in a way that supports a proactive yet person-centered approach rather than an approach with an exclusive focus on medical procedures. Digital solutions can support continuity of care and communication about care plans. Solutions should fit a culture that prefers trust-based, informal deliberative approaches. This may be supported by involving disciplines other than medicine, such as nursing and spiritual caregiving, and public health approaches.

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## ZUSAMMENFASSUNG

Das niederländische Gesundheitssystem fördert einen starken öffentlichen Gesundheitssektor, der Zugang zu einer allgemeinmedizinischen Versorgung einschließlich einer allgemeinen Palliativversorgung bietet. Allgemeinmedizinerinnen und -mediziner sind gut aufgestellt, um ACP durchzuführen, also beispielsweise Gespräche nach einem Krankenhausaufenthalt fortzusetzen oder anzubahnen. Die Forschung zeigt jedoch, dass ACP-Gespräche häufig ad hoc geführt und bei gebrechlichen Patientinnen und Patienten oft erst bei der Aufnahme in ein Pflegeheim von den in der Altenpflegeeinrichtung tätigen Ärztinnen und Ärzten angestoßen werden. Mit finanzieller Unterstützung durch entsprechende nationale Programme wurden Instrumente zur Sensibilisierung für Anlässe zur Anbahnung von ACP, Screening-Instrumente, Informationsbroschüren, Checklisten und Schulungen entwickelt und implementiert, die aktuell eher Implementierungsprojekte in den Fokus nehmen anstatt Forschung zu fokussieren oder zu ergänzen. Üblicherweise verlangen diese nationalen Programme Aufklärungsmaßnahmen, die Einbeziehung von Patientinnen und Patienten sowie der

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Öffentlichkeit und die Berücksichtigung von Diversität in den Patientengruppen. Eine große Herausforderung besteht darin, ACP systematisch und kontinuierlich, sektoren- und fachgebietsübergreifend so umzusetzen, dass eine proaktive und zugleich personenzentrierte Herangehensweise gefördert wird und nicht ein Ansatz, der ausschließlich medizinische Maßnahmen in den Blick nimmt. Digitale Lösungen können die Versorgungskontinuität und die Kommunikation über Versorgungspläne unterstützen. Die Lösungen sollten zu einer Kultur passen, die vertrauensbasierte, informelle und beratende Ansätze bevorzugt. Unterstützend kann dabei wirken, wenn noch andere Fachgebiete als die Medizin wie etwa die Krankenpflege und die spirituelle oder seelsorgliche Betreuung einbezogen werden und auch Public-Health-Ansätze Berücksichtigung finden.

## Health care system and context in the Netherlands in relation to advance care planning (ACP)

Access to end-of-life care is relatively good in the Netherlands according to a recent Organisation for Economic Co-operation and Development (OECD) report [1]. Long-term care expenditures are covered mostly by the public sector that strongly supports social security. Expenditures on long-term care are substantial including on nursing home care, amounting 4% of the Netherlands' Gross domestic product (GDP) compared to 1.5% on average across OECD countries [2].

Almost all citizens are registered with a general practitioner (GP) and the Netherlands has more GPs than the European Union (EU) average (1.6 vs 1.0 per 1000 inhabitants) while fewer medical specialists (2.0 vs. 2.5) [3]. GPs adopt a gatekeeping role with respect to referral to specialist medical care, and they are in a position to coordinate care delivered by other professionals. While medical specialists may get to know patients well over the course of a long illness, GPs may know patients over the course of their lives and may also care for their family members. Further, not all patients are treated by specialists and therefore, GPs may engage in advance care planning (ACP) about future treatment preferences or what makes a good quality of life when people develop a chronic-progressive, potentially life-limiting disease. Preferably, they closely cooperate with the hospital medical specialists who also conduct ACP conversations during such disease trajectory. This is a challenge, however. Evidence of correspondence with other healthcare professionals was found in only about half of charts of patients who died in general practice with cancer, organ failure or multimorbidity [4]. Further, for only 45% of older people referred to a Dutch hospital for acute geriatric assessment, preferences of life-sustaining treatment were known, mostly regarding Cardiopulmonary resuscitation (CPR) [5]. Whereas only 53% of discharge summary letters after hospitalization reported information about limited life expectancy, that information was found on further review of the whole chart in 70% [6].

ACP has been studied extensively in various patient groups in the Netherlands over the past decade. However, ACP is still rarely documented in GP health records [5,7–9]. Indeed, ad hoc rather than systematic ACP approaches, in particular informal conversations on future care preferences or with family only are common [10,11]. Yet most Dutch citizens would favor their physician to take a proactive approach regarding end-of-life issues and think ahead about future care in situations of dependence [12]. For example, they wanted to be invited to information meetings about end-of-life care to facilitate advance care planning by their own GP, rather than by other organizations [13]. Although they find palliative care an important and attractive part of their work, many GPs find starting ACP discussions challenging [9,14]. In practice, GPs tend to wait for multiple triggers to start ACP, or they neglect opportunities in particular for those with multimorbid conditions and frailty compared with those with cancer [15,16]. They may have limited communication skills to talk about future scenario's [14,17] and find it difficult to talk about deterioration and dying in a society

where death is not seen as a natural part of life anymore—as noted elsewhere too [18], and GPs felt this makes it difficult for them to start ACP discussions [9]. A trusting relationship between ACP conversations partners is preferred by Dutch older people with and without dementia, their family caregivers and physicians [16,19].

A quarter of citizens die in nursing homes (mostly of non-sudden deaths), and 10% in other residential care [20] including 70% of persons with dementia sampled from GP practices [21]. Nursing homes employ specialized elderly care physicians who provide generalist palliative care [22]. They consistently offer ACP for nursing home residents, mostly with their family caregivers within weeks from admission. They often strongly guide and influence (advance) decision-making [23,24]. Yet their approach to ACP varies. Some elderly care physicians adopt a proactive approach discussing scenarios in advance, while others limit to deciding on acute decisions in advance (CPR and hospitalization) and would continue conversations only after the resident declines [25]. Often, in the case of dementia, decisions may be revisited each half year, but are not being revised [23]. Nevertheless, there has been a trend of increased satisfaction with care at the end of life—including on feeling involved in decision making regarding nursing home residents with dementia from the perspective of bereaved family [26].

For patients who are treated actively or with curative intent in the hospital, the process of ACP can start in the hospital. Medical specialists then communicate or align care plans with the patient's GP or elderly care physician, and, if the disease progresses and active medical treatments are no longer desired, handover to them.

## A brief history of ACP in the Netherlands

The Netherlands has a history both of speaking explicitly about patient's wishes and of limiting medical care at the end of life when the care is perceived as not benefitting the patient anymore. Active ending of life at the explicit request of the patient (euthanasia) is legally possible in the Netherlands which may affect the physician-patient relationship. For example, physicians may feel pressured when it is raised as a topic in the context of ACP conversations [27]. However, euthanasia is still the exception; 5.1% of all deaths is the result of euthanasia [28]. Although the general public in the Netherlands is greatly in favor of the possibility (87%) [29], the actual explicit deliberation about one's wishes is burdensome psychologically. As for medical treatment, informed consent is required and medical treatment may be refused. Advance directives refusing treatment have legal status since 1997. Even so, still only a minority of people have actually written one and discussed it with their GP and relatives. Although the profession is greatly in favor of timely talking about end-of-life preferences [30], physicians struggle with the question who is to instigate ACP and how to plan it in comparison to the natural inclination to fight death as long as possible. Nevertheless, GPs as a profession have worked hard to improve expertise on palliative care, and they generally accept ACP and end-of-life decision making and care, as part of

their responsibility [17] which is consistent with the curriculum for GP trainees requiring they are able to hold a conversation about an approaching end of life [31].

### ACP definitions in use and under development

A European Association for Palliative Care (EAPC) task force that developed the definition of ACP and the recommendation for its application by Rietjens et al. [32] was led by researchers from the Netherlands. The abbreviated definition states the goal of ACP: “Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate.” The definition was translated into Dutch and published in a national GP journal [33]. Continued work on ACP in dementia, as commissioned by the EAPC, is being led by Netherlands as well (van der Steen, Korfaage et al. [34,35]).

Various Dutch terms for ACP are being used, such as one that translates to “early care planning.” However, also in Dutch, ACP is often referred to as “advance care planning” with the English expression or less often, it’s Dutch translation. In the Netherlands Quality Framework for palliative care [36], ACP is referred to as “proactive care planning” (in Dutch). It is being defined as a process of thinking ahead, planning and organizing. It also refers to shared decision making, continuity of conversations, and not just future care and treatment but also current care and treatment which is not typically included in international definitions.

### ACP tool development and dissemination

Tools that raise awareness of triggers to initiate ACP, screening tools, information brochures, checklists and training have been developed and implemented with funding by national programs. To help health care professionals in finding a moment to start ACP conversations, over the past two decades, basically two approaches have been used: starting based on triggers and based on screening tools. First, an acute medical situation is often the trigger to start ACP. For example, in patients with chronic obstructive pulmonary disease (COPD), starting ACP discussions during or shortly after a hospitalization for an acute exacerbation, was a clear point of reference to discuss future care according to patients and professionals [37,38]. The hospital lung team may start ACP, which also helps the GP, who only has limited experience with advanced COPD due to a small case load.

Internationally and in the Netherlands, the surprise question is a well-known tool to start palliative care [39]. The original question was “would I be surprised if this patient were to die in the next 6 months?” The Dutch Quality Framework palliative care [36] recommends using the surprise question as a screening tool, and further encourages clinicians to share prognosis and examine if the patient is open to an ACP conversation. Interestingly, no guidelines dictate when to apply the surprise question. The Quality Framework recommends its use earlier with a diagnosis of dementia. One problem is that when applied broadly, it identifies a group of patients ranging from frail older people, seriously ill patients with prognoses of months or years, to those with progressive terminal illnesses. It can be difficult to organize care for such a heterogenous group. The “double surprise question” appeared to be more specific in identifying patients with a prognosis of less than 12 months; it involves the original question, and if yes, followed by “would I be surprised if this patient was still alive after 12 months” [40].

Other tools have been developed and implemented to identify specific populations that are in need of palliative care more gener-

ally or may benefit from an ACP conversation. Thoonsen et al. [14] developed the RADboud university medical center indicators for Palliative Care needs (RADPAC) tool. It differentiates triggers for ACP for patients with cancer, COPD and congestive heart failure. It was developed in the same period as the Scottish Supportive and Palliative Care Indicators Tool (SPICT), which was translated to Dutch (SPICT-NL [41]). A few years later, a specific tool was developed to identify patients with COPD in need for palliative care, to be used during a hospitalization for an acute exacerbation, the PROPAL COPD tool [42,43]. These tools raise awareness as to risk of deterioration or end of life; however, professionals resist to use them in a systematic way [14,43].

A comprehensive toolkit has been developed to facilitate ACP in pediatrics, the IMplementing Advance Care planning Toolkit (IMPACT) [44,45]. IMPACT comprises materials to prepare clinicians, children with life-limiting or life-threatening conditions and their parents for ACP conversations [45]. It also includes conversation guides for healthcare professionals for ACP conversations with children and/or their parents, a format for documentation and a two-day IMPACT ACP communication training. The IMPACT materials are available in Dutch and English. They incorporate a holistic person-centered approach, considering the whole person, taking into account the physical, psychological, social and spiritual dimensions to arrive at care and treatment that facilitates a meaningful life [46]. In addition, IMPACT stimulates the exploration of the children’s voices and support a caring attitude towards children and their families, which helps envision the future in pediatric palliative care [47,48].

During the COVID-19 pandemic, for many GPs and patients, being confronted with a widespread life-threatening disease appeared an important trigger to start ACP discussions [49]. A national initiative resulted in a checklist to support healthcare professionals in documenting their ACP process concerning treatment goals and preferences with (frail) patients [50]. The authors recommend a non-tick box approach yet a list of treatment preferences is provided. The list was developed in a collaboration of national federations of GPs (NHG, the Dutch Federation of General Practitioners), medical specialists (FMS), physicians for people with intellectual disability (NVAVG), elderly care physicians (Verenso), nurses (V&VN) and patients (Patiëntenfederatie). Thuisarts.nl [51], a website for patients owned and created by NHG is widely used to retrieve information on health and illness. It contains an ACP module, as developed and evaluated by Erasmus MC [52], to support patients and relatives in taking the first steps of ACP, and encourages users to initiate conversations with their relatives and physician.

### ACP in pediatrics

In the Netherlands, pediatrics involves the medical care of infants, children and adolescents between zero and 21 years old. The population that qualifies for ACP includes the 6000 children diagnosed with a life-limiting or life-threatening condition.

Although broad consensus exists about the importance of aligning care and treatment to the child’s and families values, goals and preferences, pediatric ACP in practice is still in its infancy. In the past years, a substantial vanguard of healthcare professionals in pediatrics have been trained in pediatric ACP (IMPACT training [45]). Most of them were involved in specialized Pediatric Palliative Care (PPC) teams or were intrinsically motivated to develop their skills. Today, pediatric ACP is mostly provided by pediatric palliative care specialists using an end-of-life focused approach, including considering treatment limitations. However, in line with international developments, the Netherlands started with ACP earlier in the disease trajectory using a broader focus. This includes

supporting families in achieving good care for their child, including attention to the child's development, family balance and parenting during the different disease trajectories and palliative care stages. In parallel, ACP is increasingly seen as an overarching process of communication that informs and guides regular care. This results in a better understanding of the child and the family's values, goals and preferences, and facilitates alignment of care and connectedness between child, family and healthcare professionals. This view is adopted in the field of PPC and as such incorporated in the recently updated Dutch guideline "Palliative care for children" [53]. ACP is being integrated to facilitate appropriate pro-active care planning in a nationwide project aimed at improving and implementing an individual care plan in pediatric palliative care [54].

### ACP in ethnic minorities

The Netherlands is home to people from ethnic minorities such as from Turkey, Morocco, and former Dutch colonies. Thinking and speaking about end-of-life preferences is acceptable to many people from ethnic minorities [55], who value autonomy and wish to have a role in treatment decisions. This may apply to both first and second generation ethnic minorities. The favored role in the decision-making process, especially when applying the model of shared decision making, is however a subject in need of further study [56]. For example, it's not uncommon for people from ethnic minorities to differ from the Dutch medical culture of acknowledging the limits of medical possibilities (Touwen DP & de Ruiter M, thesis on decisions on intensive care in patients from an ethnic minority; personal communication, 2023). They also commonly differ in their attitudes towards euthanasia compared to the general Dutch population [57].

### Patient and Public Involvement (PPI) in development, research and implementation

Research and implementation programs from national research funders such as ZonMw commonly require diversity in patient groups, educational deliverables, and also patient and public involvement in the development of research and implementation activities. Patients or patient representatives are also commonly involved in ACP projects.

For example, the international mySupport study implemented a nurse-led ACP intervention with family caregivers of persons with dementia in six countries [58,59] and a PPI work package was part of it. Patient representatives participated in the project team and also gathered online internationally with representatives of other countries. In the Netherlands, the patient representatives helped practice ACP conversations during the training of nurses. Further, the Canadian Public and Patient Engagement Evaluation Tool (PPEET) PPI tool [60] was translated into Dutch and was published nationally for use with other patient groups [61].

### Education and training

The national funder ZonMw supports implementation of a training that includes ACP for healthcare professionals [62]. In 2020, the national educational project O<sup>2</sup>PZ ("Optimaliseren Onderwijs Palliatieve Zorg" [63]) created the Palliative Care Competence Framework for all health professionals working in various health care settings; nurse assistants, nurses, and physicians up to level 8 of the NQLF, the Dutch National Qualifications Framework [64], which is the level of the medical specialist after finishing

the residency. The framework provides a comprehensive set of core competences in palliative care.

For each of 28 medical disciplines in the Netherlands (e.g., gynecology, internal medicine), the necessary individual palliative care competences are being described in detail. These competences are now being included in the specific educational frameworks. Each of seven university medical teaching centres offer a Bachelor and Master program leading to the basic training for physicians (NQLF level 7). The educational Framework for Undergraduate Medical Education [65] describes the content and general final attainment targets that the program must achieve. The current educational framework entails preventive medicine, curative medicine, and palliative medicine. University medical centers are integrating these three areas in the curricula. ACP, shared decision making, good communication, holistic patient care are all themes that are relevant to palliative care but also important for the medical approach more generally.

### Challenges, barriers and further research

In 2022, the Dutch Ministry of Health initiated a research program on ACP, focused on implementation [66]. Therefore, implicitly, the question whether ACP is considered effective, has been answered by the Ministry with a yes, and tackling of barriers to implementation is being prioritized. For example, a bottleneck analysis in the context of development of the Quality Framework palliative care identified four of eight barriers related to information and communication including advance care planning [67].

We have described that the large GP sector in the Netherlands offers an opportunity to implement ACP, strengthening its continuity, yet approaches are often still ad hoc and reactive rather than proactive. Underuse of occasions and topics may be due to lack of knowledge of opportunities, occasions and topics and lack of time [11,15]. This results in ACP often newly started upon nursing home admission, while people rarely have a formal living will [25,68]. Further, of the four palliative domains, ACP less often addresses psychological and spiritual issues [69].

Digital solutions can support continuity of care and communication about care plans which was identified as a barrier in palliative care provision [67]. Solutions should fit a culture of preferring trust-based informal deliberative approaches. This may be supported by involving disciplines other than medicine, such as spiritual caregiving, empowering nurses, and use of public health approaches. This way, the Netherlands' ACP implementation and research effort can avoid burdening GPs. We should address implementing of ACP systematically and continuously across disciplines and sectors to support a proactive yet person-centered approach beyond an exclusive focus on medical aspects.

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### Conflict of interest

All authors declare that there is no conflict of interest.

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