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**ADVANCE CARE PLANNING AND
ITS PRACTICAL APPLICATION IN HUNGARY**

Doctoral (Ph.D.) thesis booklet

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**Pécs, Hungary,
2023**

INTRODUCTION

Since **chronic diseases** have become the leading causes of death, people are expected to undergo increasingly longer periods of terminal illness. During this terminal stage the patients' physical and mental condition declines, and they often experience severe symptoms. However, this period allows patients to prepare for the last period of their lives.

Advances in medical technology may prolong patients' lives, even when they can no longer provide an **acceptable quality of life for the patients**. In modern Western societies, people pay more attention to the last period of life and the preparation for their death than before.

Personal values play an increasing role in **decision-making** regarding end-of-life care, the accepted (or refused) type and length of medical treatments. Regulations in developed countries have responded to the population's needs regarding end-of-life care, therefore **patient autonomy** and **shared decision-making** have become core components of the patient-centred end-of-life care.

The importance of **studies in the general population** has increased in the last 20 years since people might be involved in end-of-life decision-making later on as patients themselves or as their relatives. Although the 'taboo' of **communicating about death and dying** has decreased, talking about end-of-life topics remains a challenge on a personal level amongst family and friends. Evidence has shown that most people find end-of-life discussions important but do not share their care preferences with their loved ones or healthcare providers (HCPs).

In addition to decisions based on medical expertise, the emergence of decisions based on the **patients' individual values** has challenged healthcare system, necessitating a new approach and new practices in end-of-life care. **Advance care planning (ACP)** is a widely used process to explore and document patients' treatment preferences regarding end-of-life care.

Current guidelines identify **primary care** as an ideal place for ACP and recommend that **general practitioners (GPs)** initiate ACP discussions.

In Hungary, advance care planning is almost **unknown** to healthcare providers and the general population; however, its widespread establishment would be important based on the demographic trend of population ageing.

In line with international recommendations, it would be advisable for **GPs** to conduct ACP discussions in Hungary, as stated in the Decree No. 28/2022 of the Ministry of the Interior issued on 25 August, which defines end-of-life discussions as a GP's competency.

AIMS OF THE THESIS

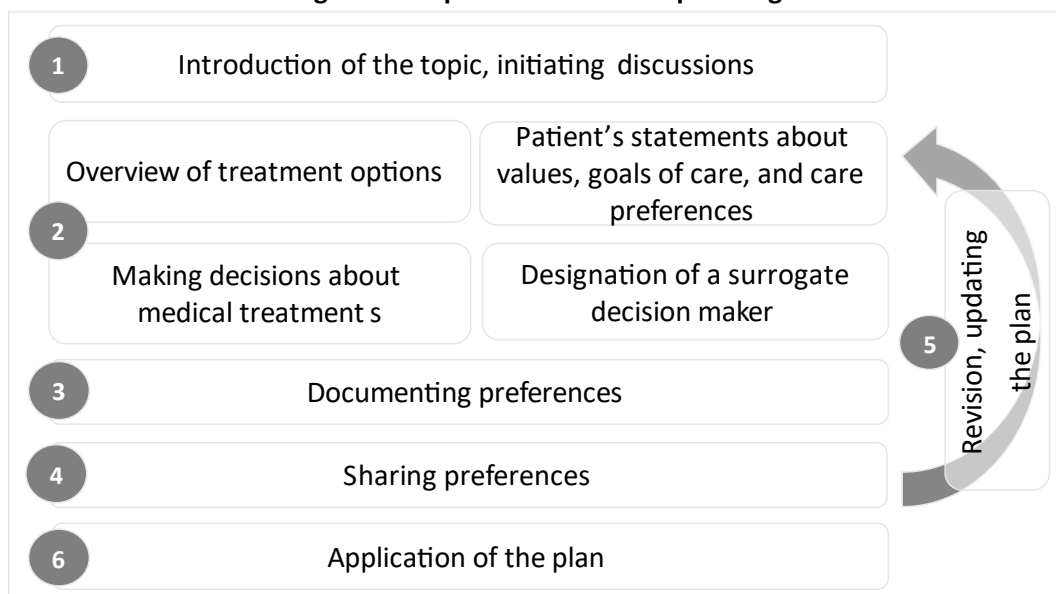
- To introduce the international practices of advance care planning and its applicability in Hungary.
- To explore the attitudes, needs, opportunities, and knowledge of the Hungarian general population regarding aspects of advance care planning and end-of-life decision-making.
- To explore the attitudes, views, and knowledge of the Hungarian general practitioners regarding the conditions of advance care planning and end-of-life decision-making and to investigate their willingness to discuss patients' end-of-life care preferences.
- To formulate recommendations on development opportunities related to advance care planning based on the study results.

I. ADVANCE CARE PLANNING - AN INTERNATIONAL OVERVIEW AND ITS APPLICABILITY IN HUNGARY

Advance care planning: an international overview

Advance care planning is a process that supports patients in discussing and sharing their preferences and decisions regarding future medical care with their physicians (or other HCPs) and family members. A consensus-based Hungarian translation has not yet been formulated for the term *advance care planning*. The terminology used in the thesis is our own translation. ACP was originally applied in the context of palliative care in cancer patients. Nowadays, ACP is used in various contexts, patient populations and settings in practice. ACP is a proactive, continual process of formalized discussion. Its steps are presented in Figure 1.

Figure 1. Steps of advance care planning



Patients' wishes regarding end-of-life care expressed during the consultations are recorded in writing. Advance care plan is a document to serve as a guideline for the HCPs regarding the patient's physical, psychological, and spiritual needs. Advance directives are legal tools directing treatment decision-making and/or designating surrogate decision-makers.

Benefits of ACP

ACP improves the concordance between patients' preferences and the delivered care, even if the patients are unable to communicate for themselves. It helps to reduce stress, anxiety, and depression of family members (since decisions are not made in a crisis), and it defines the goals of care for healthcare providers and improves teamwork.

Roles of GPs in ACP

GPs encounter a large number of patients for whom ACP would be beneficial. GPs have a longstanding relationship with patients, and know the patients' medical history, family context and personal characteristics. These factors help them initiate ACP discussions.

Conditions for the application of ACP In Hungary

Legal background

The Health Care Act (1997. CLIV.) defines patients' rights, which are essential for ACP and allows patients to make an advance directive (though the term *advance directive* is not used in the text).

Healthcare and healthcare providers

End-of-life conversation has no formalized practice in the Hungarian healthcare system, and patients' end-of-life care preferences are not systematically assessed. Studies have explored paternalistic decision-making practices, and HCPs are unprepared for the difficult topics of doctor-patient communication. In line with international recommendations, Hungarian GPs would be in an ideal position to initiate ACP discussions. However, their attitudes, knowledge, and willingness are unknown.

Hungarian society

Public attitudes towards death and dying are changing in Hungarian society; however, most families still have difficulty openly discussing death-related topics. No comprehensive study has been conducted investigating the views, knowledge and needs of the general population regarding end-of-life issues.

Barriers and facilitators

The past decade has also seen a shift in the attitudes of healthcare professionals, with increasing numbers of education and training initiatives and scientific research on end-of-life issues being carried out. The main barriers are lack of information in generally, terminology problems, lack of an advance directive form and lack of a registry in Hungary.

II. A NATIONWIDE SURVEY OF THE HUNGARIAN POPULATION ON ADVANCE CARE PLANNING AND END-OF-LIFE DECISIONS

Aims of the study

This study aimed to explore the views of the Hungarian general population regarding ACP and end-of-life decision-making. The specific objectives were:

1. To explore the need for open doctor-patient communication and shared decision-making.
2. To analyse the needs, opportunities, and actions to communicate their end-of-life care preferences.
3. To investigate the knowledge about end-of-life decisions.
4. To explore personal preferences for end-of-life care.

Methods

A cross-sectional survey was performed on a representative sample (n=1100) of the general population in Hungary. Questionnaires were completed face-to-face by professional interviewers. Statistical analysis was undertaken using IBM SPSS Statistics for Windows (version 24.0) software. Descriptive and multivariate statistical analysis (analysis of variance, cluster analysis) was performed.

Findings

Sociodemographic characteristics of the participants

The male to female ratio was 46.7% to 53.3%, and the mean age was 47.51 years. More than half (53.1%) had completed secondary school. Half of participants (51.8%) lived in a county seat or a town. 25.6% lived with their partner, and 22.3% with their partner and children.

Open communication and shared decision making

91.6% of participants considered it important to get truthful information from their doctor, even in case of having an incurable illness. Shared decision-making was important for 93.7%, and the involvement of family members for 86.5%. 77.3% of the surveyed adults find it reasonable if a person makes his or her own decisions in advance regarding end-of-life medical treatments in case of future incapacity.

End-of-life discussion: needs, opportunities, actions

71.6% of participants found it important to discuss their end-of-life care preferences with someone in advance, while they were still in good health. 75.3% believed that it was the family members' task to talk with the patient about his or her end-of-life care preferences, and 79.6% mentioned HCPs as carers whose task it was to talk with the patients about their choices. Six out of ten participants thought that the GP should talk with the patient about this topic. (Multiple choices were allowed.) 55.8% of participants reported that there was someone in

their family, and 36.0% among their HCPs with whom they could speak openly about end-of-life topics. The difference between needs and opportunities for end-of-life discussion with family members was 19.5 points. A 43.6-point disparity was found between the majority who thought that HCPs should talk with the patients and the minority who had the opportunity for this discussion. 12.6% of the participants had already discussed their end-of-life care preferences, almost without exception with a family member. The differences between needs and actions were even higher (62.9%, and 79.3%). (Figure 2)

Figure 2. Discussion of end-of-life care wishes: Needs - opportunities - actions

Total sample n=1100 (%)	Family members	Healthcare providers
	DIFFERENCE	DIFFERENCE
Needs	75.3	79.6
	19.5	43.6
Opportunities	55.8	36.0
	62.7	79.3
Actions	12.6	0.3

Knowledge about end-of-life decisions, willingness to complete advance directives

65.1% of the surveyed population knew that patients have a right to refuse medical treatments in Hungary; however, the details of the regulations were less known. 34.5% have heard about advance directives, and 90.3% of these participants believe it was possible to make a will in this form. 55.5% of Hungarians would be willing (14.8% definitely and 40.7% probably) to complete advance directives.

End-of-life care preferences

Two-Step cluster analysis divided participants into three groups according to the acceptance or rejection of life-prolonging treatments. 70.2% of the surveyed adults belonged to *Cluster 1*, grouped those participants who would only choose symptomatic treatment

- (1) if they were dying of old age,
- (2) if they were in the final stages of an incurable, fatal disease,
- (3) if they suffered irreversible brain damage, or
- (4) if they were incapable of caring for themselves due to dementia.

Respecting end-of-life care preferences – perceptions

77.1% of surveyed adults believed that their family members and 69.7% that HCPs would definitely or probably respect their end-of-life care preferences.

III. GENERAL PRACTITIONERS' VIEWS OF ADVANCE CARE PLANNING AND END-OF-LIFE DECISIONS IN HUNGARY

Aims of the study

This study aimed to explore the views of the Hungarian general practitioner regarding ACP end-of-life decision-making.

The specific objectives were:

1. To explore attitudes related to information giving and decision-making regarding end-of-life issues,
2. To analyse perceptions of their knowledge and skills to discuss end-of-life topics,
3. To investigate the knowledge about end-of-life decisions,
4. To explore the importance of open communication and shared decision-making,
5. To explore the importance of end-of-life discussions, and GPs' willingness to initiate such discussions.

The study was carried out in two phases: *Study 1* in 2016-17 and *Study 2* in 2022. The questionnaire of *Study 2* contained questions from *Study 1* and questions from the general population survey.

Methods

A cross-sectional survey was performed among Hungarian GPs. Respondents of *Study 1* filled out the questionnaire on paper at conferences and trainings. Respondents of *Study 2* were asked to fill out the questionnaire online at conferences and training, and it was sent to GPs' mailing lists.

Statistical analysis was undertaken using IBM SPSS Statistics for Windows (version 28.0) software. Descriptive analysis and analysis of variance were performed. P-value <0.05 was considered statistically significant.

Findings of Study 1

Characteristics of respondents

In *Study 1*, the number of respondents was 142. 43.0% of them were male, and 56.3% were female. The mean age was 50.90 years. 31.0% of surveyed GPs worked in towns, and the proportion of village practices was 27.5%.

GPs' attitudes toward end-of-life issues

85.2% of respondents fully agreed with the statement that "patients have the right to get truthful information even if their illness is incurable" and 72.3% fully agreed that "patients

have the right to make decisions about their treatment". The surveyed GPs moderately agreed that it is uncomfortable for doctors (the mean score was 3.34 on a 5-point scale and patients (mean score: 3.48) to talk about death and dying.

GPs' perceptions related to their preparedness, knowledge, and skills

Respondents felt moderately prepared to discuss *end-of-life* issues (the mean score was 3.63 on a 5-point scale) and rated their knowledge and skills essential for end-of-life discussion as moderate (mean scores: 2.88-3.66).

Knowledge of advance directives

70.4-83.1% of respondents knew it was possible to refuse medical treatments in advance directives and appoint a surrogate decision maker. However, only 14.8% have heard that making a will was not allowed in this form.

Discussion and documentation of end-of-life care preferences

85.9% of respondents believed that it was the family members', and 81.7% thought the GPs' task was to talk with the patients about their end-of-life care preferences. (Multiple choices were allowed.) 45.1% of surveyed GPs would be definitely willing, and 26.1% probably willing to discuss with the patient their choices and help document them.

Findings of Study 2.

Characteristics of respondents

178 GPs participated in *Study 2*. The male to female ratio was 36.0% to 64.0%, and the mean age was 55.5 years. 55.1% of them practised as a GP for more than twenty years, and 31.0% worked in towns.

GPs' attitudes toward end-of-life issues

83.6% of respondents fully agreed with patients' right to get truthful information even if their illness is incurable, and 82.5% with patients' right to make decisions regarding their medical care.

The surveyed GPs moderately agreed that it is uncomfortable for doctors (the mean score was 3.27 on a 5-point scale and patients (mean score: 3.54) to talk about death and dying. Respondents rated their discomfort as the lowest (mean score: 2.81).

87.4% find it reasonable if people make their own decisions in advance regarding end-of-life medical treatments in case of future incapacity.

GPs' perceptions related to their preparedness, knowledge, and skills

GPs' perception was that they were moderately prepared to discuss end-of-life topics with patients (the mean score was 3.53 on a 5-point scale). Respondents rated their

communication skills the highest (mean score: 3.44) and their practical knowledge of self-determination the lowest (mean score: 2.40).

Knowledge of end-of-life decisions

96.1% of the surveyed GPs knew that patients have a right to refuse medical treatments in Hungary; however, 43.3-80.3% had detailed knowledge of the regulation. 86.0% have heard about advance directives, and the vast majority (69.7%-79.8%) knew it was allowed to refuse medical treatments and appoint a surrogate decision maker in an advance directive. Only a fifth (20.8%) knew that inheritance issues could not be decided in this form.

Discussion and documentation of end-of-life care preferences

According to the respondents, discussing end-of-life care preferences with the patient was the task of trained facilitators (97.2%), family members (95.5%) and GPs (92.7%). (Multiple choices were allowed.)

98.9% of GPs found it important to give truthful information to patients even if their illness is incurable. 99.5% considered shared decision-making and 77.5% end-of-life discussion important.

49.4% of surveyed GPs would be definitely, and 32.6% probably willing to discuss with the patient their end-of-life preferences and help document them. Those GPs who would be definitely willing to discuss patients' end-of-life preferences -compared to other respondents

- felt less uncomfortable talking about death and dying with patients ($p < 0,001$),
- considered truth-telling, shared decision-making and end-of-life discussion as more important ($p < 0.001$),
- felt more prepared to discuss end-of-life issues ($p < 0.001$), perceived their communication skills as better ($p = 0.014$) and considered themselves more informed about end-of-life patient rights and practical tasks of end-of-life decisions ($p < 0.001$),
- had more knowledge of advance directives ($p = 0,042$).

Respecting end-of-life care preferences

64.6% of surveyed GPs believed that HCPs would definitely or probably respect patients' end-of-life care preferences. 84.2% of respondents would definitely or probably respect their patient's end-of-life wishes even if they disagreed.

IV. SUMMARY OF THE MAIN FINDINGS, CONCLUSIONS

The summary presents the main results of the studies according to the steps of advance care planning (Figure 3).

Legal background

The Health Care Act defines patients' rights, which is essential for ACP and allows patients to make an advance directive.

Advance decisions regarding end-of-life care

More than three-quarters of the general population and nearly 90% of GPs find advance decisions regarding end-of-life care reasonable.

Truth-telling

Nine out of ten adults in Hungary think it is important for their physician to provide honest information, and almost all GPs think it is important to provide honest information in case of an incurable illness.

End-of-life discussion, shared decision-making (Steps 1 and 2)

The end-of-life discussion is considered important by seven out of ten Hungarian adults and shared decision-making by nine out of ten. Eight out of ten GPs find end-of-life discussion, and all of them find shared decision-making important.

End-of-life discussion as a task (Steps 1 and 2)

Eight out of ten Hungarians believe that HCPs and seven out of ten think that family members should talk with patients about their end-of-life care preferences. GPs unanimously consider end-of-life discussion to be the task of HCPs and family members. Among the general population, six out of ten adults and among GPs, nine out of ten, believe it is the GPs' task to discuss end-of-life care with the patients.

Knowledge of end-of-life decisions (Steps 2 and 3)

The right to refuse treatment is known to two-thirds of the general population and is well-known among GPs. One-third of Hungarians and more than four-fifths of GPs have heard of advance directives.

Advance directives (Step 3)

More than half of the Hungarian adults would be willing (14.8% definitely, and 40.7% probably) to complete advance directives and half (50%) of the GPs would be definitely, and one-third (33%) probably willing to discuss with the patient their end-of-life preferences and help document them.

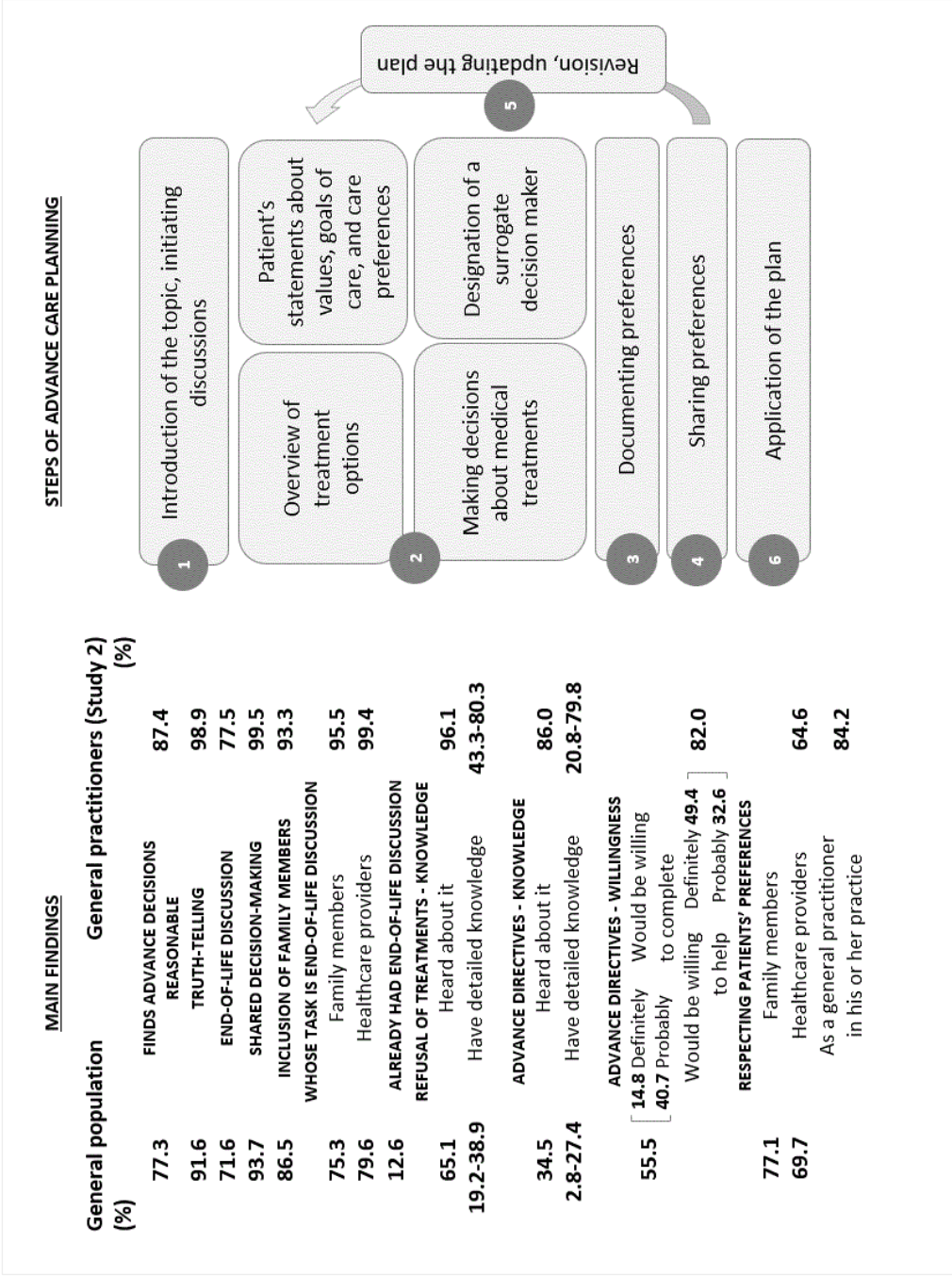
Sharing preferences (Step 4)

The formal requirements and lack of record-keeping make putting advance care planning difficult to put into practice.

Respecting end-of-life preferences (Step 6)

Eight out of ten Hungarians believe that their family members and seven out of ten believe that HCPs respect their end-of-life care preferences. Eight out of ten GPs would respect their patient's choices even if they disagree.

Figure 3. Summary of the results



Conclusions

Both the Hungarian general population and GPs believe that

- Patients have the right to make their own decisions regarding end-of-life medical treatments,
- Truth-telling and shared decision-making are important even in case of an incurable illness,
- There are high needs and willingness to discuss end-of-life care preferences, and family members and HCPs should also take an active role in the discussions,
- Patients' end-of-life preferences would be respected.

Despite the presented results, end-of-life discussions are rarely realized in Hungary. Compared to international results as well as compared to the needs, the general population's activity regarding end-of-life planning is low.

One reason for this is that opportunities for end-of-life discussions fall short of needs: *high needs* meet *limited opportunities*. This is particularly true for health care providers, where the *high importance* attached to end-of-life discussions is coupled with a *limited willingness* to carry out the task.

Another reason is the general lack of knowledge about end-of-life decisions among the Hungarian general population and the Hungarian GPs.

The third reason - despite the observed need and willingness- is the lack of 'tools' to facilitate end-of-life discussions, both within the family and in the health care system.

V. NOVEL FINDINGS

1. Creating the terminology for advance care planning in Hungarian.
2. Both the Hungarian population and GPs agree that everyone should be able to make their own decisions about end-of-life care.
3. There is a very high demand for honest information among the general public in the case of incurable illnesses, and a very high willingness among GPs to provide honest information.
4. Both Hungarian society and GPs assign great importance to discussing end-of-life care.
5. Participation in decisions relating to treatment is desired most by the general public and GPs are most willing to provide the opportunity.
6. There is a strong desire from the general population for active involvement of health care professionals in end-of-life discussions, but their opportunities for discussion are limited.
7. General physicians also consider end-of-life care discussions to be their own responsibility, feel moderately prepared to do so, and have a moderate willingness to take on this responsibility.
8. The proportion of end-of-life discussions among the Hungarian population is low, and these discussions are typically carried out with family members and relatives.
9. The possibility of refusing treatment is known by the general population and by GPs, but the exact details are less well known.
10. A third of the population and the vast majority of family doctors have already heard of advance directives. There is a common misconception among both the general public and GPs that it is possible to make a declaration on inheritance issues in this form.
11. In Hungary, there is a need and willingness to put end-of-life preferences in writing in the form of an advance directive.
12. The majority of the Hungarian population, in the terminal stage of an incurable disease, would only want to have their symptoms alleviated and would not want their lives prolonged by medical therapies.
13. Both the general public and family doctors believe that patients' end-of-life wishes should be respected.

VI. RECOMMENDATIONS

1. Training for HPCs

Theoretical and practical knowledge of ACP should be included in the training of doctors (especially GPs). Training should also include raising awareness and the development of communication skills.

2. Increasing the number of trained HCPs

Training programs for nurses, psychologists and social workers may increase the number of care providers prepared to participate in ACP discussions. In primary care, advanced practice nurses could be the professionals who, after necessary training, could perform this task in group practices in collaboration with GPs.

3. Drafting and publication of the Advance directives form as a legal annex

The practical applicability would be greatly assisted by the addition of a model advance directive form to the annex of the relevant government regulation. This would be a good opportunity to introduce advance care planning at the legislative level.

4. The registration of advance directives

The issue of the registration of advance directives (e.g., in the Electronic Health Service Space) should be addressed centrally and at the legislative level.

5. Providing funding

Providing funding and integration of ACP into family medicine indicators and group practice tasks would greatly facilitate the introduction and use of advance care planning in primary care.

6. Development and implementation of social awareness and information campaigns

Widespread public awareness and information campaigns should be launched to raise awareness regarding advance care planning, decision opportunities and advance directives.

7. Further studies

Longitudinal studies may support the practical application of advance care planning in Hungary.

PUBLICATIONS AND CONFERENCE PROCEEDINGS RELATED TO THE THESIS

Scientometrics

MTMT ID: 10028586 (Csilla Busa, Health Sciences)

Number of publications: 215

Independent citations: 245

Hirsch index: 7

Number of SJR articles: 22

- Q1: 11
- Q2: 2
- Q3: 6
- Q4: 3

Cumulative impact factor: **41.587**

ResearchGate: Csilla Busa, RG Score: 211.0

Awards:

- Excellent Author Award, University of Pécs Medical School, 2021
- Best review paper (with co-authors), Hungarian Cancer Society, 2017

Publications related to the thesis

- **Journal articles**

Csilla Busa, Eva Pozsgai, Judit Zeller, Agnes Csikos: Who should talk with patients about their end-of-life care wishes? A nationwide survey of the Hungarian population. *Scandinavian Journal of Primary Health Care* (40) 1 pp 157-164 (2022) **IF: 3.147**

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ACKNOWLEDGEMENTS

First and foremost, I would like to thank my supervisor, Dr Ágnes Csikós, for her invaluable help and advice throughout the research process.

I would also like to express my gratitude to my colleagues, Dr Judit Zeller, associate professor, and Dr Éva Pozsgai, senior lecturer, for their professional support in drafting and publishing our results.

Finally, I would like to give thanks to my family for their encouragement and patience.