

PRoF Award abstract – Call 2018

Deadline for submission: Thursday March 1st 2018 (12 o'clock noon)

Please send to: PRoF-Award@uzgent.be.

<VZPAL Towards Advance Care Planning for all hospitalized patients. >**1. Research Outline**

Acronym	VZPAL
Project name in English	The development and implementation of practical strategies to facilitate advance care planning (ACP) in hospital.
Pitch (1 sentence)	In order to increase ACP conversations between hospital professionals and patients, based on PhD results, we will develop an evidence-based e-learning program and implement a validated communication tool for Advance Care Planning (“Mijn Wensen voor mijn gezondheidszorg.”).
Executive summary (max. 10 lines)	

2. Cause and context of the research**2.1 Challenges for palliative patients in the hospital**

The hospital is an important care setting for palliative patients. Despite national policies aimed at increasing home death and –in some countries- a tendency towards more out-of-hospital deaths, the proportion of people dying in a hospital setting remains persistently high (1–10). These figures contrast with patient preferences: the majority of patients in different countries prefer home death. (10–12) Next to dying in the hospital, palliative patients often reside in the hospital in the last period of their lives. (1,13,14) In these moments, palliative

patients receive treatments (e.g. radiotherapy) and forms of care (e.g. oxygen, ICU) that are more invasive than in other settings (15). Studies have shown shortcomings in meeting needs of palliative patients and relatives in the acute hospital (15–23). Two important shortcomings are inadequate communication (15–22,24–26) and a focus on unrealistic cure and life-prolongation in this setting, instead of quality of life (24,25,27). In a qualitative study of Reyniers et al (25), for example, relatives indicated that communication by physicians in the hospital setting is frequently rather poor and they had difficulties with the fact that tests and treatments are used routinely without questioning whether they are actually necessary. Advance Care Planning (ACP) communication might contribute to overcome these shortcomings in the hospital (24,28–31).

2.2 ACP in the hospital: necessary care for palliative patients

In a study on ongoing ACP communication in hospital, researchers state that avoiding discussions in hospitals about how aggressive measures will affect patients at the EOL, is a failure of caring for patients: a lack of ACP discussions may lead to patients feeling overly optimistic about their prognosis, thereby choosing aggressive medical care with a high treatment burden or a high likelihood of an undesirable outcome. (32) Failure to engage in ACP discussions in the hospital, has been associated with significantly greater risk of death. (33)

A study in oncology patients, shows that only 31% of patients with advanced cancer reported having baseline discussions about end-of-life care issues with oncologists. (34) However, in a study of 65 patients with cancer by Dow et al (35), 95% of patients admitted to an oncology service, believed that discussing advance directives (Ads) was very or somewhat important; in addition, 48% of the patients preferred the discussion be with their oncologist, 34% preferred their primary care physician, and 11% preferred their admitting physician. Although evidence demonstrates patients and families want to discuss ADs, they do not initiate discussions or topics of death and dying unless invited by their oncologist. (36) Family

caregivers stated the need for more explanation when decisions are being made about life-prolonging treatments in hospital. (37) Another study showed that patients and families want to discuss the transition to palliative care with their oncologist. (38)

2.3 Aims of the studies and research questions

The underlying aim of the studies was to facilitate implementation of ongoing Advance Care Planning discussions between hospitalized patients, their families, hospital physicians and nurses.

There were two assumptions and research questions that were studied:

1) Assumption I: The hospital setting holds specific challenges for the implementation of ACP by the populations dealing with ACP.

The first aim of the study is to get a better understanding of the experienced obstacles for hospitalized palliative patients, their families, physicians and nurses in starting ACP-discussions in the hospital practice.

Research question I: What are the experienced obstacles for hospitalized palliative patients, their families, physicians and nurses in starting ACP-discussions in the hospital practice?

2) Assumption II: If hospital professionals use a communication tool as an aid in ACP conversations, communication on current and future health care needs is experienced as easier. The second aim was to develop and validate a communication tool that focusses on overall healthcare needs and shared decision making. Research question II: What are the generic aspect of ACP that should be formalized in a comprehensive communication tool that can facilitate ACP in all healthcare settings and for disease staging?

2.4 Methods

The first research question was studied with multiple methods: grounded theory, a systematic review of the literature and a Delphi study from European experts. This triangulation of methods led to stronger results. The second research question was also studied with multiple methods: a literature study, a combination of a Delphi study and focus groups with Flemish experts in palliative care and a usability study in hospital setting using an ad hoc patient reported outcome measure.

2.5 Results

2.5.1 Results for research question 1

As an answer to our first research question, “What do hospital professionals see as obstacles for having ACP conversations?” we will present five fields of tension that our participants reported on. Our analysis showed five fields of tension that can help explain why ACP discussions are not being implemented in hospitals.

Field of tension no.1: When exactly should ACP be initiated?

Participants reported that they were often confronted with feelings of powerlessness when caring for severely ill patients. Some participants reported that focusing on quality of life of patients and family helped them cope. As a psychologist said, “I cannot cure the patient, no one can. But I do can give him the best during the time that he is still around.” A nurse said, “I find more satisfaction in washing a patient’s hair than in providing difficult technical care. . . I think the patient should be considered a person and talked to as a person with personal wishes concerning care.” Other participants, however, felt more in control when they contributed to the prolongation of life. They were more focused on the technical and medical side of a disease trajectory and found quality and meaning through interventions. They were hesitant to have ACP discussions with patients, because they preferred to focus on fighting. As a physician said, “I don’t see the point of talking about ACP if there are still real treatment options.” In a hospital setting, these two groups of participants have to work together. Because of their strong beliefs on what constitutes the best to a patient’s life, tension may arise within a team on when to start ACP discussions.

Field of tension no. 2: Differences in ethical sensitivity.

Our results showed differences in ethical sensitivity among participants: Some participants tended to be more sensitive to the negative consequences of care- and treatment planning for the patient. They often described these situations with the antonyms “correct-incorrect”: “It is not correct that the patient gets a treatment against his will.” A psychologist said, “I really thought it was incorrect to let the patient believe he still had treatment chances, while actually he was dying.” Some participants reported not being easily touched by patient situations. One of them called it “indifference of colleagues.” Differences in ethical sensitivity within a team, but also among patients and families, create tension and conflict.

Field of tension no. 3: Should care be patient-centered? The basis for decision-making according to participants. Different criteria were reported being used to decide when the treatment and care policy should be changed. First, some participants believed that the wish of the patient should be central to treatment and care decision- making. A psychologist said, “I think we should follow what the patient wants, even if treatment chances are zero; we have to give treatment, if this is what the patient needs.” Second, other participants expressed the belief that the resilience of patients and their families should be taken into account: Sometimes patients should be protected against themselves (e.g., physical exhaustion following treatments). A head nurse said, “We always check whether the family is still capable of caring for the (chronic) patient. If not, we think this is an important reason to stop treatment.” A third group of participants considered the medical condition to be the most important factor in order to change treatment policy, regardless of the patient’s feelings. A physician said, “I think medical options determine whether we decide to stop treatments.” These differences led to tension within the team. *“I don’t want you to die!”* Results of this study showed that participants discriminated on which patients had the subjective right to ask for treatment to be stopped. Participants reported being more reluctant to respond to the request to stop treatment when the patient involved is young, has a family to live for, or still has a high quality of life. Requests from older patients or those who feel lonely or are clearly suffering were more easily taken seriously. Another reason for refusing to hear a patient’s request was sympathy: A nice person should not stop

trying. The participant's view on what is acceptable played an important role in ACP discussions.

Field of tension no. 4: Discussing death or not?

Participants reported having different opinions on whether or not to discuss death. Most participants felt that discussing imminent death with a patient helps to reduce fear. Some considered discussing death unhelpful as it may aggravate fear, or make patients unnecessarily anxious. A nurse said about this, "I was very afraid to talk about death, but I learned to see that it doesn't aggravate fear but relieves a patient." It caused friction in a team when some team members were not allowed to talk about dying, if they felt this would help the patient.

Field of tension no. 5: Conflicts of interest.

Participants were under the impression that being cared for in a university hospital postponed ACP discussions initiation, because physicians are able to treat longer because of the experimental study therapies. Participants also reported a conflict of interest between the economic pressure to ensure patients leave hospital as quickly as possible and the opportunity to explore patient wishes. A social worker said, "We don't have time to talk to the patient. We have to get the patient out of hospital: that is our core job."

2.5.2 Results for research question 2

As an answer to our second research question, we developed a communication tool for advance care planning: 'MIJN WENSEN voor mijn gezondheidszorg'. A group of 31 experts in palliative care scored each item on validity and clarity in two online Delphi rounds, alternated with live focus groups to find consensus on the desired improvements. The overall Content Validity Index (S-CVIAve) for the final version was 0,94 (cut off=0,90).

There are several items included in this tool that offer information: (a) on advance care planning, (b) on health care goals and limitations of treatment in a curative, chronic, palliative and terminal stage, (c) on euthanasia, (d) on patient rights and (e) on advance directives.

The other items are structured questions on actual and future health care needs and treatment preferences for different aspects and stages of disease. Most important principle was to focus on treatment goals, and not on specific medical interventions, so as the physician can translate the wishes of the patient into a balanced treatment plan.

The first group of questions concerns the health care wishes as a mentally competent patient, with preferences concerning:

1. the desired medical information (diagnosis, prognosis, symptom burden, treatment options)
2. the patient's desired involvement in shared decision making,
3. the desired involvement of informal caretakers in health care conversations,
4. what is important in the patient's life,
5. what would be too little quality of life,
6. how culture, religion or life philosophy influences the patient's take on appropriate health care
7. health care needs for different life domains: physical, emotional, social, financial, practical, legal, philosophical/religious.

The second group of questions concerns the patient preferences on possible treatment goals in a mentally competent (8.) curative, (9.) chronic, (10.) palliative and (11.) terminal stage of disease.

The third group of questions concerns the advance directives for future mentally incompetent situations: (12.) appointing a health care representative, (13.) treatment goals in case of acute mental incompetence like a cardiac arrest or cerebral infarct, (14.) treatment goals in case of temporary mental incompetence like a delirium, (15.) treatment goals in case of definite mental incompetence with ability of emotional interaction like dementia, (16.) treatment goals in case of definite mental incompetence with inability of emotional interaction like irreversible coma. The last item in this group is (17.) is an open question to address some remaining concerns.

The fourth group of questions deals with preferences after death: (18.) treatment of the remains (organ donation, relinquish body to science, desired transfer of body, faith regulations) , (19.) preferences concerning burial and (20.) preferences concerning funeral ceremony and. The last item in this group concerns (21.) messages for relatives.

The final question in this tool reflects on (22.) possible circumstances in which the given preferences should be reconsidered.

After the content validation, we performed a usability study in UZ Leuven. Health care professionals were asked to introduce the communication tool with patient who showed a need for advance care planning, and to discuss the clarified health care needs with patient, family and physician. The patients, family members and health care professionals filled out an ad hoc feedback questionnaire on the experienced impact of using the communication tool.

This questionnaire contains the following 5 point Likert scaled questions: Was the use of 'MIJN WENSEN ©' (1.) helpful, (2.) clarifying, (3.) time consuming, (4.) emotionally burdening? (5.) Do you want to use it more often in the future? (6.) Would you have liked to use it earlier? Does the use of 'MIJN WENSEN ©' have a positive impact on the quality of care, meaning: (7.) the quality of communication, (8.) the involvement of informal caregivers, (9.) the care for patient's needs, (10.) considering current treatment wishes, (11.) considering future treatment wishes, (12.) considering undesired treatments, (13.) follow up of health care planning? Does the use of 'MIJN WENSEN ©' have a positive impact on the peace of mind, meaning: (14.) the patient's level of anxiety, (15.) the patient's level of depressed feelings, (16.) the family members' level of stress, (17.) the experienced connection in care and (18.) the confidence in the treatment policy.

Of the 29 cases included, 81% of the patients and family members and 80% of the health care professionals reported that the use of 'MIJN WENSEN ©' was helpful (score 4 or 5), with 95% confidence interval (62.1%; 91.5%). Other figures show that in 60% to 80% of the cases the tool was also found to be clarifying, not time consuming and not emotionally burdening. The only exception here was that family members did find it emotionally

burdening in 47% of the cases. The impact on quality of care was in 70% to 100% of the cases experience as positive on all the respective items (question 7 to 13). The impact on the peace of mind was experienced as relatively positive: 52% of the patients felt less anxious, and 38% felt less depressed and 53% of the family members felt less stressed, which seems to make up for the emotional impact. Most patients, relatives and health care professionals experience more connection in care (respectively 57%, 60% and 53%) and more confidence in the treatment policy (67%, 71% and 60%).

2.6 Publications

Vanderhaeghen B, Bossuyt I, Opdebeeck S, Menten J, Rober, P. Toward Hospital Implementation of Advance Care Planning: should hospital professionals be involved?; 2017 Oct 23; 00(0):1-10.

Vanderhaeghen B, Bossuyt I, Menten J, Rober P. What do hospital professionals report as helping in overcoming obstacles for ACP decision-making? A qualitative study. Integr Clin Med. 2017.

Vanderhaeghen B, Bossuyt I, Menten J, Rober P. Vroegtijdige zorgplanning in het ziekenhuis. Aanbevelingen gebaseerd op interviews met hulpverleners uit deze setting. Tijdschr Geneeskd. 2017;1-9 [accepted for publication].

Heylen A, Vanderhaeghen B, Bossuyt I, Van Beek K, Rombouts W., De Pril M, Van Laeren A, Genbrugge E, Hageman E & Menten J. MIJN WENSEN voor mijn Gezondheidszorg. Leidraad bij vroegtijdige zorgplanning. UZ Leuven, 2017. [website UZLeuven] Available from:http://www.uzleuven.be/sites/default/files/vroegtijdige_zorgplanning_VZP_leidraad_patiënten.pdf

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Heylen A, Vanderhaeghen B, Bossuyt I, De Nys K, Menten J. 'MIJN WENSEN voor mijn Gezondheidszorg ©'. Ontwikkeling en inhoudsvalidering van een leidraad voor vroegtijdige zorgplanning. Tijdschrift voor Geneeskunde (in voorbereiding).

Heylen A, Vanderhaeghen B, Bossuyt I, De Nys K, Menten J. 'MIJN WENSEN voor mijn Gezondheidszorg ©'. Bruikbaarheidsstudie van een leidraad voor vroegtijdige zorgplanning. Tijdschrift voor Geneeskunde (in voorbereiding).

3. Innovation results achieved

The overall aim of this project is to help professionals who work in a hospital context, have ACP conversations. This project exists of two major parts that are both grounded in literature and in our own research (see point 2).

3.1 Project Part I: Development of an E-learning program for hospital professionals.

For this project, we would like to develop eight communication sessions of 20 minutes, based on the research results described above. Hospital professionals will be able to log in to the program for free. An advantage of using e-learning is the fact that professionals can see the sessions whenever they find the time to watch them and wherever they are. Professionals will have the possibility to ask questions by contacting the researcher of the palliative support team. Furthermore, they will have the option to send back feedback of each session on how helpful the session was. First, the program will be tested and evaluated in UZLeuven, but it will be made public later on for other hospitals.

3.2 Project Part II: Implementation of 'Mijn Wensen voor mijn gezondheidszorg' in hospital practice



Since the preliminary figures of the usability study show promising results on the potential benefit of using 'MIJN WENSEN © as a communication tool for ACP, we are now starting with structured implementation studies in some hospital wards of UZ Leuven (respiratory oncology, nephrology, chronic heart failure, chronic obstructive pulmonary disease, hematological oncology...), in home care and in geriatric nursing homes in the region of Louvain. In this process, we are developing a digital platform for registration of 'MIJN WENSEN ©' and other ACP information in the electronic patient file, as to stimulate continuity throughout different health care settings. Apart from further evaluating the impact of the communication tool, we will also conduct action research upon the different implementation processes, as to describe ways to enhance the effectivity of implementing ACP.

4. Link to the PRoF values

1 Awareness

This project is developed to contribute to empowerment of palliative patients who often reside in hospital. Patients are helped to express their views, values and wishes on care and treatment, which helps to adapt care better to their needs. Health care professionals are helped to explore this with patients and relatives, and to enhance the quality of shared decision making.

2 Comfort

Advance Care Planning contributes to an earlier introduction of care that is focused on physical and mental comfort, which is associated with longer living in palliative patients (39).

3 Safety

By having Advance Care Planning conversations, palliative patients report reduced anxiousness, because it allows them to have more control over the disease process.

4 Privacy

By focusing on highly personal values, ACP wishes are only reported in the electronic patient file of the hospital, which is highly secured.

5 Loneliness

Palliative patients that are alone, don't have partners to reflect upon treatment and care, like treatment burden. They need even more than other patients, professionals with whom they can have these kind of conversations. For them, our project is even more valuable.

6 Non-stigmatizing

The whole project is designed from the idea that every person, every patient is different and should get care and treatment that are adapted to their needs. Differentiation is in this context a concept that can only be put into practice if there is a culture with low stigmatization.

7 Intergenerational

This project contributes to helping hospital professionals start conversations which are essentially focused on connecting patients and families ((grand-)parents and children) in discussions about wishes about treatment and care. Studies indeed show that families are helped with early palliative care: it has effect on their social functioning and there are less symptoms of depression, less unnecessary treatments voor unconscious patients (40,41) and het creates the possibility for persons who are at risk for complicated grief disorder to get in contact with health professionals (42).

8 Flexibility

As studies report, Advance Care Planning conversations contribute to shorter hospital stays, because the necessity of treatments is evaluated faster and because patients can better pronounce what they need during hospital stays, which leads to faster and more qualitative solutions, e.g. the social worker can faster relocate a hospitalized patient to a palliative care unit or elderly home.

5. Applicable IPR rules

The study results, the e-learning program and the communication tool ‘Mijn Wensen voor mijn gezondheidszorg’, are intellectual property of UZLeuven. There are, however, no IPR rules for this project.

6. Information on the partners

This project was created and developed by the Palliative Support Team UZLeuven. This team aims to increase the quality of palliative care on acute hospital care units. The strategies to reach this goal are multiple: by coaching and intervision of teams, by education, spreading information and by research.

Note:

If your project is selected as laureate for the Award Symposium, a powerpoint presentation that reflects the project as suggested will be required (in advance), including a future plan how the funding will be used.

If your project is selected as the winner of the Award, you will be invited to present the results achieved thanks to the award during the Award Symposium of the next year.

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