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Impacts of advance care planning on end of life management

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Title of the review article: Impact of advance care planning on end of life management

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Abstract:

Purpose of review

The aim of this review is to critically appraise the recent evidence on different aspects of impact of advance care planning in palliative care and to reflect on further implications on practice and research in the future.

Recent findings

Evidence about various ACP impact is rapidly growing and most common outcome measures are still AD completion, change in hospital admission rate and patients' and families' views and experiences with ACP. Mainly descriptive studies bring new information of ACP impact for specific groups of patients, their families, settings, countries, contexts, staff and health care system as such. It is not yet clear who and when would best conduct ACP, from GPs to specialist in the hospitals and even lay-navigators for cancer patients; from early ACP conversations to critical ACP in acute events at the

end-of-life. The needs for ACP impact high quality evidence is becoming more urgent due to unexpectedly high palliative care needs in future projections.

Summary

Recent studies on various ACP impacts reveal variety of outcomes for different patient groups and settings, and are contributing to a wider picture of ACP situation around the world. However, high quality evidence on ACP impact is still urgently expected in times of growing need for system-level changes for effective ACP implementation.

Keywords

Advance care planning, end of life conversations, impact, outcome

Introduction

Advance care planning is receiving very high attention in research in the last ten years (1*,2*). According to definition of the EACP taskforce (3), ACP consists of a gradual unfolding communication between patients, relatives and professional caregivers supporting patients to discuss and, if they wish, record and share their preferences, values and specific treatment choices to inform their future care.

The concept and practice of ACP is still evolving. More attention than earlier is paid to a structured process of ongoing communication. A process of in-depth interviews has been proposed as a method to facilitate self-revelation and relationship building based on openness and engagement in order to help patients identify their values and preferences for future care (4). This approach may be more effective than written documents alone (5).

Research reporting the impact of ACP is not consistent and clear which might be due to different types of ACP interventions and different outcome measures sought in different studies. However,

some sources demonstrated that comprehensive system-level effort of well-structured ACP interventions can empower patients and relatives facing the uncertain future in the context of life-shortening illness through developing a shared understanding and making informed health care treatments decisions for future care (4,6,7). As a result, it is much more likely that end of life care for patients will be consistent with their preferences and that patients' and their families' satisfaction with care will improve. Furthermore, ACP reduces stress, anxiety, and depression in surviving relatives (6). To achieve these outcomes, it was pointed to the importance of trained facilitators to offer in-depth ACP conversations (8,6,9).

In this paper we are looking at the evidence published from January 2016 to June 2017 on ACP impact in a broader sense.

What are the trends in ACP development?

Researchers on ACP impact often do not report in detail about the structure and content of ACP used in their studies. However, some well-known ACP models are sometimes presented and examples of new naming are noted, i.e. a facilitator-based ACP (10**), as a result of recognition of ineffectiveness of advance directives (AD) form alone and undefined ACP processes with open discussions. In contrast to AD which is focused on patient's medical treatments preferences, ACP process is person-centred by exploring person's psychosocial context and values through in-depth interview(s) (4). It is crucial for patients together with their surrogate, to explore and reflect on their values to be able to identify their preferences for future health care (11**).

In recent study by Epstein et al. (11**), a novel ACP paradigm has been proposed. The authors seek to sensitively address patient perspectives by creating a model, where in the first part patients are helped in revealing goals, experiences, concerns, fears, needs and supporting agents. In the second part they are offered the goals of care video which helps them to get acquainted with different options for decision-making.

What are the outcomes of ACP and for whom?

Systematic exploration of efficacy of ACP for older adults reveals a lack of randomized clinical trials (RCT) about the impact of ACP irrespectively of health care setting (12). A meta-synthesis of studies about older people experiences of ACP shows varied views. Older people's readiness for ACP is influenced by their views of life and death and it is important for them to get truthful information, and family and financial support to maintain dignity (13*). An exploration of Australian community older people awareness and experiences of ACP reveals their difficulties in planning for hypothetical health events, although they welcome ACP process (14).

Pediatric ACP (pACP) may be particularly challenging. Although parents find it difficult to participate, they recognize it as important. A sensitive and gradual approach, which emphasizes hope and quality of life issues, is important for them (15). A RCT studying adolescents with HIV/AIDS showed substantial immediate preferences agreement to limit future medical treatments for pACP dyads (adolescents/families) which decreased over time (16*).

Persons with dementia often forward ACP decisions to their relatives while capacitated (17). Recent RCT study, which tested goals of care (GOC) decision video-aid intervention to improve quality of communication and palliative care for nursing homes residents with advanced dementia, reported improvement in GOC communication, enhanced GOC plans and reduced hospital transfers (18).

Cancer patients who were enrolled in facilitator-based ACP program in a tertiary hospital were less likely admitted to the intensive care unit and more often died in hospice (10).

Research of ACP for patients with neuromuscular disease and patients with metastatic brain tumours, both with different specific needs, is very limited, with low rate of ACP discussions in both groups and lack of intervention studies (19,20).

Although the systematic literature review shows that due to scarce data it is not possible to conclude whether ACP can influence the number of hospital admissions, life-prolonging or curative treatment requirements, or willingness of healthcare professionals to follow end-stage kidney disease patients' preferences (21), a pre- and post-intervention study of facilitated ACP for haemodialysis patients

demonstrates a significant increase of documented patients' preferences to not be resuscitated and of completed AD (22).

According to two literature reviews (23,24), clinician-guided ACP group of homeless persons attained significantly higher AD completion rates and higher rates of surrogate decision-maker designation than self-guided groups. A majority of participants post intervention reported that they feel in peace, they think more about their health, own death, and family and friends. A cohort study shows that for homeless people, who completed AD through a clinician-guided process, it was significantly more likely for their AD to be available to health care professionals and to affect their health care in the case of hospitalization (25).

ACP impact on patients' relatives

Relatives of nursing homes' residents are reporting to be insecure and their views of residents' ACP preferences significantly differ (26*). Two qualitative studies of bereaved surrogates' perspectives on ACP reveal that it facilitates important family discussions (27) and helps strengthening relationships (18). It also helps surrogates to better understand patient's illness and end-of-life care, to feel prepared for end-of-life decision-making, and to have peace of mind during and after decision-making (27,18). Providing quality information to the families and including them in continued communication during the evolving situation of advanced diseased is crucial for their collaboration in ACP decision-making (28*).

Who is discussing ACP with patients and where?

According to Lopez (29**), ACP decision-making for transfer nursing home residents with advanced dementia to hospital is made with physicians and nurses together with the resident and their family. On the other hand, in an Irish long-term care setting nurses were the executors of ACP program (30*). A suggestion based on a systematic review is that all nursing home staff is educated and involved in ACP in order for its implementation to be successful (31**).

ACP discussion with general practitioners (GP) is strongly associated with better experience of primary care treatment in Japanese patient which is not the case with completion of AD solely (32*).

Dutch pulmonologists consider ACP as important aspect of palliative care, although they report about an ongoing problem in caring for patients with advanced COPD patients due to different criteria used for the introduction of palliative care (33*). For Australian patients with COPD and other chronic lung diseases, nurse-facilitated ACP was acceptable. It was also effective in increasing completion of ADs and awareness of symptom burden, although the inclusion rate was lower than expected (34).

In quality improvement project, two dedicated nephrology fellows conducted ACP discussions with haemodialysis patients with limited life expectancy during hemodialysis sessions, which led to increased documented patient preferences as reflection of patients' better understanding of their treatment options (22).

Even in case of lay navigator-led ACP intervention for cancer patients led to fewer hospitalizations in comparison to patients who declined ACP participation (35).

Why is it so difficult?

A Canadian exploratory study of health care providers' experiences from wide range of health care facilities noted the discomfort with death and dying as their most important barrier for end-of-life discussions and decision-making. They also noted confusion of role responsibilities in end-of-life communication and lack of coordinated care among settings. The interprofessional teamwork was found as the key facilitator (36). Patients often report discomfort with ACP conversation, although they found such conversations necessary and valuable (11).

Cost implications of ACP

The economic evaluation of ACP is necessary in order to adequately understand the impact of ACP programs in practice and to gain recognition by payers through appropriate reimbursement. In a recent systematic review, six out of seven reviewed studies detected the reduction in costs of care per patient,

however, it remains unclear which specific elements are essential for observed cost reductions since patient selection, costs measured and interventions varied among studies (37).

A study using a simulation model, demonstrates that in-hospital ACP and palliative care have the potential to result in estimated cost savings of 11% of all ICU costs and 25% of ICU costs for patients with chronic life-limiting illness. ACP early in the course of a treatment is estimated to have the greatest impact on cost savings (38).

In the United States ACP is recently a reimbursed service. Tips for health professionals on how to use them in practice are offered by Jones et al. (17) and by Dingfield et al. (39*).

Discussion

This paper identified several impacts of evaluated ACP studies. AD completion, change in hospital admission rate and patients'/families' experiences are most common outcome measures in the recent ACP research. Researchers explore different characteristics of ACP for specific groups of patients and their families in various settings and with different health care providers. It is recognized that they differ significantly in various aspects, therefore, it is difficult to establish a consistent and reliable ACP model with clear structure and process for all patient groups in different health care settings. To provide a high level evidence of ACP impact it seems to be unreasonable to continue with studies on variety of non-defined ACP conversations. Furthermore, in this terms as for all palliative care complex interventions and especially for those interventions with behaviour change, there is recognized a need to report on the implementation fidelity in order to claim RCT findings (40**).

It is understandable that researchers and clinicians from different countries and cultures explore ACP from their specific interests and their stage of ACP activities to test their culture and sensitivities of

the system at their own pace. It is a remarkable achievement how wide internationally the ACP paradigm is spread in the newest research. From an early overview of the evidence at the beginning of Australian movement of ACP development in 2006 (41), when the majority of research came from USA and only few from Canada, UK, and some other European countries, twenty years later research on all kinds of ACP impact is spread nearly all over the world. If we look at the European situation, we can be worried that in this research realm Eastern European countries are currently not present.

In discussions about who should conduct ACP with patients and their families, it seems that GPs are well placed between ACP process and the patient's interpersonal context, and can contribute to continuity of care and long-term nature of relationships (2). GPs are aware of enhanced family relationships and resolution of conflicts between family and health care providers due to ACP conversations (42) and therefore might be motivated to be involved in ACP. However, lack of time and specific communication skills is recognized for physicians in all settings and it is therefore not surprising that they are often reluctant to initiate ACP conversations (39). Instead nurses are often the main ACP facilitators (30, 34).

On the other hand, Italian study of ACP for patients with advanced COPD shows difficulties of ACP proposed scenarios for this group of patients even when a pulmonologist is involved in such conversations. After pulmonologists facilitates ACP conversation with patients and proposes different treatment options, a repeated explanation is given in simple language on slides and on written material. A day after, patients remember what they have decided a day before in less than half cases. Topics are intubation and invasive mechanical ventilation, non-invasive mechanical ventilation, or palliation of symptoms alone (43). In the light of these findings, preparation for in-the-moment decision-making might be of greater importance for patients and their families (44) than thinking of very difficult and abstract situations which are difficult to comprehend. Patients' preferences often change at different stages of chronic illnesses (8, 45), therefore the main objective of ACP process to identify patient's values, treatment decisions and future care is ought to shift to

preparing patients and surrogates during early ACP process to be able to make best possible in-the-moment medical decisions as proposed by Sudore and Fried (44, 8). It is suggested, that redefining “planning” in ACP should aim at preparation of patients and their families for surrogate to be able to cooperate in-the-moment decisions which cannot be completely predicted.

More attention is needed to the fact, that patients’ relatives need continuous and exhaustive information through the process of advanced disease. It is shown that this is influencing their actions (28*) and their focus on care for patients (42).

In terms of cost reduction, it remains unclear which specific elements are contributing to observed cost reductions due to varied characteristics in ACP interventions. This adds to the frequently expressed need to establish consensus among wider research consortiums to establish common standards in ACP impact research designs.

It seems important to promote strategies to raise awareness and offer education for the whole society about end-of-life care and possible choices in order to alleviate neglect and discomfort in such conversations. High level evidence about effectiveness of a well-defined ACP is urgently needed to adapt health care policies and practice, because future projections show that palliative care need will grow far more than expected, if recent trends in cause of death continue (46). Mitchell suggests four urgent priorities to redesign health care system in the light of expansion of palliative care need in the future and ACP implementation is one of them (47).

Conclusion

Potential impact of ACP process in promoting end-of-life discussions and decisions in order for more patients to receive care according to their preferences is recently being explored more than in the past. For many years, researchers are working on the protocols and building international research consortiums to achieve stronger evidence of the impact of ACP process. However, even smaller studies are presenting several potential ACP impacts and learning points in different settings and

groups of patients with specific age, diagnosis or social state, their families, health care providers and also in the development of health care system.

Key points

- ACP conversations with AD completion, change in hospital admission rate and patients' and families' views and experiences are the most common outcome measures in recent ACP research.
- ACP impact for specific groups of patients, their families, settings, staff and countries are explored in recent mostly descriptive studies.
- It is not yet clear who and when should best conduct ACP.
- High quality evidence of ACP impact is becoming more urgent due to unexpectedly high palliative care needs in future projections.

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