

Shifting Palliative Care Paradigm in Primary Care From Better Death to Better End-of-Life : A Swiss Pilot Study

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Research Article

Keywords: cancer care / oncology, death and dying, doctor-patient relationship, palliative care / end-of-life, primary care, quality of life

Posted Date: February 3rd, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-153919/v1>

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Abstract

Background: Patients suffering from advanced cancer often lose contact with their primary care physician (PCP) during oncologic treatment and palliative care is introduced very late.

The aim of this pilot study was to test the feasibility and procedures for a randomized trial of an intervention to teach PCPs a palliative care approach and communication skills to improve advanced cancer patients' quality of life.

Methods: Observational pilot study in 5 steps. 1) Recruitment of PCPs. 2) Intervention: training on palliative care competencies and communication skills addressing end-of-life issues. 3) Recruitment of advanced cancer patients by PCPs. 4) Patients follow-up by PCPs, and assessment of their quality of life by a research assistant. 5) Feedback from PCPs using a semi-structured focus group and three individual interviews with qualitative deductive theme analysis.

Results: 8 PCPs were trained. PCPs failed to recruit patients for fear of imposing additional loads on their patients. PCPs changed their approach of advanced cancer patients. They became more conscious of their role and responsibility during oncologic treatments and felt empowered to take a more active role picking up patient's cues and addressing advance directives. They developed interprofessional collaborations for advance care planning. Overall, they discovered the role to help patients to make decisions for a better end-of-life.

Conclusions: PCPs failed to recruit advanced cancer patients, but reported a change in paradigm about palliative care. They moved from a focus on helping patients to die better, to a new role helping patients to define the conditions for a better end-of-life.

Trial registration : The ethics committee of the canton of Geneva approved the study (2018-00077 Pilot Study) in accordance with the Declaration of Helsinki

1) Background

Cancer is one of the main causes of death in Switzerland. Each year nearly 17'000 people will die with cancer as main diagnosis. Primary care physicians (PCPs) mostly deliver the diagnosis, then patients are referred to oncologists for management and treatment planning (1). During this period there is often a loss of contact between patients and PCPs. When cancer becomes life-limiting and unlikely to be cured, oncological treatments may no longer be appropriate and a transition back to the PCP usually occurs (1).

However, this transition often occurs very late. A palliative care approach is introduced in the last weeks or days of life of patients, advanced directives are poorly defined, and spiritual needs are minimally supported (2, 3). This suggests PCPs could be involved much earlier to assess and manage the multidimensional needs of these patients. These needs include the management of pre-existing comorbidities, coordination of care between the different healthcare providers, detection of relapse,

management of treatments' side effects and symptoms due to cancer (4–6). PCPs need to regularly reassess patients' needs and to know their patients' wishes and preferences for end-of-life care. Furthermore, patients' spiritual needs have to be recognised and considered (7–9).

A systematic review identified barriers to the introduction of this palliative care approach: lack of time, lack of training, ambivalence towards discussing end-of-life issues and lack of communication skills. Swiss PCPs also expressed uncertainty and discomfort communicating about these subjects with patients (10). This highlighted a need for PCPs to access improved training in palliative care approaches and communication with advanced cancer patients and to receive support in end of life care (11, 12). PCPs need good communication skills for complex conversations with intense social, psychological and spiritual significance (5, 9, 12–17). They should feel comfortable to talk about end-of-life issues, as well as important values or personal goals for care, preferences for types of care, and preferred place of care or dying. They need to know how to initiate a shared decision-making process and advance care planning (18). Yet to date we lack evidence in relation to the effectiveness of training PCPs in palliative care on the quality of patients' end-of-life care.

The purpose of the present study was to assess the feasibility of an educational intervention for addressing end-of-life issues tailored for PCPs and to identify best strategies and barriers for the recruitment of outpatients with advanced cancer. The final aim of this study was to develop a randomised trial to test the effectiveness of a PCP tailored intervention to improve outpatient's quality of life with advanced cancer.

2) Methods

Our objectives relate to the assessment of the feasibility of the intervention, the proposed recruitment strategies and outcome assessment protocols:

1. Determine best strategies as well as recruitment and retention rates of PCPs
2. Determine the acceptability of the intervention for the PCPs (engagement and compliance with the intervention)
3. Identify best strategies for recruitment and retention of the patients with advanced cancer by their PCPs
4. Test procedures and outcome measurements for this randomised study to assess the effectiveness of a PCP tailored intervention.

Study design:

The pilot study was divided in five parts:

- Recruitment of PCPs

- Training of PCPs with the tailored intervention
- Recruitment of the patients by the PCPs
- Patient follow-up by the PCPs and assessment of their quality of life by a research assistant
- Feedback from PCPs in relation to the training and the study procedures

2.1. Recruitment of the PCPs:

We recruited PCPs among a convenience sample of primary care medical teachers attached to our university in the French speaking part of Switzerland. Fifty emails were sent in April 2018 to invite PCPs to participate to this study. We planned that approximately 10 PCP would agree to participate.

2.2. The training of PCP:

Two half-day trainings were delivered (between June and August 2018) aiming to facilitate PCPs' active role in keeping contact with advanced cancer patients, daring to address with the patient a so-called "plan B": the treatment plan in addition to the oncologic treatment. The courses covered the following themes: advanced directives; communication about early palliative care, patient care preferences, and advance care planning; palliative care network presented by two nurses; and palliative care clinical care strategies (symptoms and pain assessment, pain treatment strategies, screening for severe symptoms). Possible themes that are important to be addressed with advanced cancer patients were presented and discussed (Table 1: Table 1: Possible important themes to address with advanced cancer patients). The workshops were delivered jointly by a palliative medicine consultant (SP); a senior PCP with expertise in palliative care and in postgraduate communication education for the role plays (JS); a junior PCP training in research (CC); two palliative care nurses; two trained simulated patients.

Effective ways of discussing end-of-life issues with patients were explored through an interactive role-play with simulated patients.

At the end of the training, participants completed a questionnaire assessing their perspective on the organisation; content; teaching methods; quality of teachers; extent to which the training met their expectations and global satisfaction, using a 5-point Likert scale. They also completed 4 open questions asking them about lessons learned; suggestions for improvement, unmet needs and overall satisfaction).

2.3. Recruitment of advanced cancer patients by the PCPs:

Inclusion criteria were: Patients with advanced cancer followed by the PCP; fluent in French.

Exclusion criteria: imminent death. The recruitment period was from September 2018 to December 2019.

We planned that each PCP would include 1-3 patients.

2.4. Follow-up of patients by the PCP

It consisted in four consultations with the PCP that were paid by the study over six months (content of the consultation could be defined by the patient and the PCP); in addition, patients were asked to complete a questionnaire submitted by telephone by a study assistant (MM). In addition to patients' personal data, the following data were collected (at time 0, + 3 months, + 6 months): symptom scale (Edmonton symptom assessment (19), quality of life scale (SF12v2) (20), anxiety and depression scale (hospital anxiety and depression scale) (21), spiritual and care values (FACIT SP) (22)).

2.5. PCPs' feedback in relation to the training and the study procedures

Focus groups were planned with the PCPs to collect their feed-back concerning the intervention, the recruitment and the follow-up of the patients and the strategies and barriers to participation in a randomised study. The method had to be adapted on-line because of the COVID-19 pandemic. The interviews were conducted by JS (MD), known by participants as PCP, colleague and clinical teacher at the university. A content analysis was done qualitatively by deductive theme analysis on an audio-recording of the session partly verbatim retranscribed (relistened more than 3 times) afterwards; themes were comparatively analysed by the two authors (JS and SP) until full agreement on themes. The Table 3 (Table 3: Guide for semi structured focus -group /interview) details the semi-structured interview guide (pilot-tested among clinical teachers of the teaching unit).

The primary care clinicians gave informed consent to group or individual interviews after the intervention, and also gave signed informed consent to participate in the workshops and the study, as well as for publication of results.

The patients provided an informed signed consent to participating in the study. The study was approved by the ethics committee of the canton of Geneva in accordance with the Declaration of Helsinki (2018-00077 Pilot Study: continuous follow-up by primary care physicians facilitating early palliative care for patients with advanced cancer disease).

3) Results

3.1. Recruitment of the PCP

Eight PCPs agreed to participate to the study (demographics Table 2: Table 2: demographics of participating PCPs). Two participants were relatively experienced in palliative care.

3.2. Training of PCPs

Two sessions were organised (1st course 5th June and 7th June 2019; second course 19th June and 28th August 2019). All participated in both workshops.

Only half the participants completed the evaluation form: they reported a mean 10/10 global satisfaction with the training.

3.3. Recruitment of advanced cancer patients by the PCPs:

Though we sent five emails to remind PCPs to recruit patients, eight patients only were recruited by four PCPs and four patients could finally be included

3.4. Patients' follow-up

PCP's didn't have to notify patients' consultations.

Only one patient completed the baseline and two follow-up questionnaires, two patients completed both the baseline and first follow-up questionnaire whereas one patient only completed the baseline questions.

Two other patients could never be joined by phone, and two declined participation at the first phone call.

3.5. PCPs' feedback in relation to the training and the study procedures

Five PCPs participated in the focus group (90 minutes) by zoom in April 2020 (we avoided contact because of COVID-19 pandemic), and three answered the same semi-structured interview individually by phone (30 minutes).

The thematic deductive analysis revealed five different themes, data saturation was achieved after the focus group and the first individual interview.

3.4.1. PCPs' role:

PCPs felt **empowered and legitimated to take a more active role**, and to keep contact with their patients during oncologic treatments.

It is now clear for me that it is important to walk together on the same path with the patient and the oncologist so as to avoid this parallel path on which we feel losing contact with our cancer patients... They expressed being **more conscious of their role and responsibility** and more comfortable to discuss treatments with their advanced cancer patients, as well as to address their preferences, and anticipate for worsening situations.

to dare addressing difficult issues... of a possible negative issue...when patients sometimes prefer to hear that there is still another treatment that can be tried..., but having to address a plan B in case the treatment does not allow the expected outcome

3.4.2. Changes in practice

Participants reported being **more active to contact patients** by phone during their oncologic treatment.

I proactively called patients where I had lost contact (during their oncologic treatment), and I felt it legitimate ... before, I got some letters, reports...I felt before like embarrassed...but then every time I called,

patients were amazed... positively... and it ended on very important discussions

One participant expressed the way she listens differently to the patients and **actively picks up cues to address difficult issues.**

it is now easier for me, when the patient comes and speaks about his treatment telling: “oh my chemotherapy...” and leaves a silence, now it is easier for me to hear the unspoken and to react to it
The **interprofessional collaboration for advance care planning** became an evidence, aiming the best care for the patient.

I developed the thought of anticipation together with an interprofessional team, defining the advance care plan, and sharing it in a written form with all other concerned healthcare providers... this completely changed my relationship with my network, because everyone was reassured, to know everyone’s role, and knowing what to do next, this changed a lot in situations where sometimes everyone felt exhausted
Palliative care has changed its significance and definition, from what was considered end-of-life care, into a larger view of aiming for the best treatment for the patient and anticipating negative health issues. This means foreseeing the actions in case of worsening, for instance what can be done without hospitalisation and aggressive treatments, as well as adjusting care to patient’s preferences.

“I changed my definition of palliative care...it was the treatment for the 2–3 last days of life...I now try, with the interprofessional team, to adapt better to patient preferences of care”.

“It is not an alternative anymore between curative and palliative, but series of options... to find out with the patient “

Palliative care appeared not to be a science that can be learned and that defines the best way to treat patients, but it **teaches the way to find out what is the best treatment for one patient.**

“...and I realized that I probably think I know what is the best for the patient,...and that I had a way of thinking palliative care in a very narrow angle,.. and that patients might all need a more personal approach”.

It was reported that PCP learned to have a **broader vision of patient’s needs** and to screen for other subjective symptoms than just pain (for instance anxiety, loss of appetite, depression).

“It helped me to better support the emotions, and I feel better equipped to support patients when having emotional discomfort or other symptoms, ...and I feel less helpless”.

PCPs expressed feeling **more legitimate as patient’s advocate** in front of specialists or hospital caregivers, being conscious of knowing the patient well especially if advance care planning discussions had taken place.

3.4.3. About advance directives and advance care planning

Participants reported **thinking more actively to define advance directives and to pick up cues** from patients more easily and earlier to address the subject.

I realized that it is easier to speak about advance directives when patients are not feeling too bad, so I address the subject much earlier

The formal form does not really help and is too impersonal, the most important is the **rich discussion about personal values** that can be written in a personal way.

The paradigm about advance directives has changed becoming a **more positive role for the PCP to help patients to make decisions for a better life.**

"Before I thought that advance directives were the way of dying and felt uncomfortable addressing this subject, but now it is more helping a patient to decide personally for the choices of care and for his wishes for continuing life"

3.4.5. Difficulties recruiting patients

PCPs found it difficult to recruit patients **fearing to impose a too important load** with the questionnaires. They did not feel comfortable to let a foreign person (research assistant) "annoying" patients with the questionnaires.

Though they follow patients with metastatic cancer, they expressed it was difficult to consider them as "advance cancer patients", **like if they were condemning patients** if they recruited them into the study. Some situations crystallise the **difference of conception of the patient's health status**: patients often still have hope though the diagnosis of advance cancer has been shared, while the PCPs know that they are in an end-of-life stage: in these cases, PCPs are uncomfortable to be the "bad news announcer".

though we try to increase quality of life, we take the risk to take the hope away, when we speak about palliative care

It's difficult for us, ...maybe unconsciously we don't accept that it's the end. So it's hard to talk about it, we would like to give hope

They reported some patients not wanting to address end-of-life issues, making it impossible to recruit them.

One of my patients refused to address the subject of possible negative issue

PCPs expressed the **difficulty to express the word "palliative care"** with patients, because associated to death, and suggested to rename it: "*support treatment*" or, "*patient support*". Some PCPs found it very important to clarify the palliative attitude with the patients and families.

4) Discussion

This pilot study explored the feasibility of a study improving follow-up by PCPs of advanced cancer patients, including early palliative care and involvement in the definition of treatment care plan and

advance directives.

The project as such failed, as there were very few patients recruited; suggesting that it is very difficult for PCPs to recruit patients suffering from advanced cancer.

However, the two half-day workshops were much appreciated and had a positive effect on PCPs' attitudes and actions towards their advanced cancer patients. The qualitative analysis of the focus groups showed that PCPs felt empowered to take an active role in the follow-up of their patients during oncologic treatment. As described in the literature, PCPs felt responsible to initiate end-of-life discussions, arising from their role and expertise, and these conversations' benefits (23, 24). PCPs felt better equipped in communication skills, and picked up cues more easily to address advance directives or end-of-life discussions, having practiced in role plays and made their own experience with patients. Training and coaching of non-palliative care clinicians such as PCPs can increase the practice of palliative care for the patients. Trained PCPs identify more palliative patients than do untrained PCPs and the non-palliative care clinicians report increased comfort and skill at conducting goals of care conversations (25).

For patients and PCPs alike, palliative care has a negative image as it is related to death. In the literature, PCPs' barriers to communicating on these subjects were described as: concerns about patients' readiness for end-of-life discussions or their potential psychological impact (17); family conflict (26); cultural factors (27–29); prognostic uncertainty (14, 30); and inexperience (23, 26). This prevents PCPs from addressing these difficult subjects, and in our study, probably contributed to their difficulties recruiting patients. Very interestingly, the definition of palliative care changed during the study for the participating PCPs: they reported investing their role as facilitator for a better definition of patients' care preferences instead of having to address issues related to death. They felt able to avoid unnecessary treatments, and to allow respect of patients' choices regarding their plan and place of care. Early palliative care has effectively been shown to be a new paradigm of oncologic treatment and palliative care, improving QOL, depression, prognostic understanding, and health service use in patients with advanced cancer (31).

PCPs also reported having experienced the specificities of interprofessional teams in palliative care. The interprofessional nature of palliative care teamwork with a view to whole person care has been described before. This teamwork differs from traditional models where the team is led by physicians, which are primarily focused on a disease process (32).

Regarding the advance directives and advance care planning, PCPs reflected how the study made them conscious of their role in actively helping patients define their preferences. The study led them to shift from the "after you" position in which PCPs expect patients to address the subject, while patients expect PCPs to address it first (33).

PCPs expressed how these rich discussions with their patients helped them to know them better, empowering them to become the patient's advocate while facing specialists or hospital caregivers. Again, it underlined the new experienced paradigm for participating PCPs, shifting from helping patients to better die to a new paradigm in which they improve the quality of end-of-life.

When coming to the analysis of the difficult patient recruitment with the participating PCPs, it showed that addressing end-of-life discussions remained difficult. The simple words “palliative care” were difficult to express to patients and some participants suggested to rename palliative care as “patient support” or “support treatment” so as to smoothen the discussion; as previously described (23). Similarly, as described in the literature, the participating PCPs expressed their fear of stealing patients’ hope (regarding their treatment and life expectancy) when trying to address end-of-life issues. It made them feel uncomfortable in the role of “announcer of bad news” (33). The fear of adding the load for their already frail and very sick patients of confronting a stranger asking a range of questions also contributed to caution while recruiting patients.

As suggested by participating PCPs, further research could concentrate on the PCPs attitudes and change of roles as indicators for the impact of the intervention, as well as the completion of advance directives or advance care planning. This would encourage more training of PCPs and allow further action research that could facilitate early palliative care and PCPs involvement for advanced cancer patients.

Strengths of our study include the qualitative approach of PCPs feedback that gives a very rich view of their thoughts, attitudes and roles. In addition to the low participation rate, another limitation is the possible selection of PCPs interested in palliative care, that may limit the generalisability of the intervention’s impact.

Conclusions

Primary care physicians find it very difficult to address end-of life subjects and failed recruiting patients suffering from severe cancer, despite the fact that the study aimed to improve quality of end-of-life. Though, PCPs benefit from interventions helping them to overcome barriers to address end-of-life issues, advance directives and advance care planning. It enhances interprofessional teamwork, palliative care and respect of patient preferences of care. PCPs described that it changed their paradigm of palliative care, investing their role to facilitate patients’ “better life for end-of-life instead of better dying”.

Future studies focusing on their changes of attitude and completion of advance directives and advance care planning as well as collaboration in interprofessional teamwork should contribute to the dissemination of better care for advanced cancer patients.

Abbreviations

PCP: primary care physician

Declarations

Ethical approval and consent: The ethics committee of the canton of Geneva approved the study (2018-00077 Pilot Study)

Consent for publication : no patient data, all PCP's consented for publication of data.

Availability of data and materials :

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests : The authors declare that they have no competing interests

Authors' contributions : All authors contributed to the design of the study protocol. Johanna Sommer and Sophie Pautex developed the intervention ; Christopher Chung was the study assistant helping at the implementation of the study. Dagmar Haller helped in the analysis of the data. First draft of the article was written by Johanna Sommer and completed/corrected by all the other authors.

Acknowledgements: we thank Mohamed Amir Moussa (study assistant)

Funding: Safra Private funds, Geneva

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Tables

Table 1: Possible important themes to address with advanced cancer patients

· Advance care planning (including emergency plan if worsening health status during nights or week-ends)
· Gravity of illness, fears, patient's representations
· Patient's needs, wishes, important life aims, projects to achieve in coming time
· Psychosocial needs
· Spiritual needs
· Relative's needs
· Financial aspects, worries
· Wished place of care and of end-of-life

Table 2: demographics of participating PCPs

Sex	Age (rank)	Years in practice	Home visits/week	Previous course in palliative care	Hours training palliative care	N of palliative care patients in last year as attending physician
F	55-59 years	12	5	Yes	>5 hours	2
M	50-54 years	12	7	Yes	>5 hours	12
M	50-54 years	14	4	No	none	2
F	45-49 years	4	2	Yes	10 hours	0
M	45-49 years	10	10	No	none	20
F	50-54 years	13	10	Yes	>5 hours	0
F	50-54 years	13	2	No	none	0
F	45-49 years	10	2	No	none	0

Table 3: Guide for semi structured focus -group /interview

1)	What lessons were learned from the project?
2)	What changed in your practice?
3)	What changed regarding the advanced directives (completed protocolled form)?
4)	What changed regarding an advanced care planning?
5)	What changed regarding your integration of palliative care into your practice?
6)	What changed in your way to integrate the family into the care of advanced cancer patients?
7)	What problems did you face during the project?
8)	What would you suggest as improvement for a next study?